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Caregiving for older adults within community settings

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Caregiving for older adults within community settings

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Editorial: Caregiving for older adults within community settings

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Editorial on the Research Topic
Caregiving for older adults within community settings

1 Why this Research Topic matters

Globally, there is a growing demand for caregivers to support older adults within community settings, driven primarily by increased longevity. Global life expectancy is currently 73.5 years, with countries such as Japan, Switzerland, and the United Kingdom already surpassing 80 years. By 2050, life expectancy is projected to increase to 78.2 years (1, 2). At the same time, the number of individuals 65 years and older will more than double in size, increasing from 761 million in 2021 to 1.6 billion in 2050, with the fastest growth occurring among individuals aged 80 years and older (3). Disease patterns are also shifting from communicable to non-communicable diseases (NCDs) such as cardiovascular disease, cancer, diabetes, and dementia, which contribute to functional limitations, substantially increasing the need for caregiver support (1, 2, 4–6). In parallel with these changes, smaller family sizes, shifting migration patterns, and direct care workforce shortages are reshaping the caregiving landscape, further straining natural caregiving support. These factors are contributing to the unprecedented global demand for care, which outpaces the availability of caregivers (3). With as much as 80% of care being provided by unpaid caregivers and given the shortage of direct care workers (3), it is critical to understand the unique challenges faced by both to design tailored services, community resources, and policies that can enhance caregiver wellbeing, quality of care, and promote equity.

In this context, we initiated the Research Topic (RT) *Caregiving for Older Adults within Community Settings* to advance knowledge in this critical area of research.

2 Summary of the contributions

This Research Topic represents a collection of 28 papers authored by 180 contributors. Contributors are affiliated with 77 institutions and represent research conducted in eight geographic regions: China, Italy, Kazakhstan, Korea, Singapore, Spain, the Netherlands, and the United States. The Research Topic contains a variety of manuscript types, including 20 original research papers, three brief research reports, and one for each of the following submission types: clinical trial paper, community case study, systematic review, methods paper, and study protocol. Most of the original research papers ($n = 18$) used a cross-sectional study design. Of the 20, 16 analyzed quantitative data, including two that conducted secondary data analyses using large national datasets: the Behavioral Risk Factor Surveillance System (BRFSS) (Cohen et al.), and the Health Information National Trends Survey (HINTS) (Ahn et al.). Qualitative ($n = 2$) and mixed methods ($n = 2$) approaches round out the remaining original research papers. Across the entire Research Topic, 20 papers reported receiving funding support, and four of those were supported by the National Institutes of Health (NIH) in the United States.

The research in this Research Topic was conducted primarily with family or unpaid caregivers, although some papers were framed from the perspective of older adults or field experts. Three of the 28 papers involved research conducted among paid caregivers (Hwang et al.; Rong et al.; Smith et al.). This signifies a gap that must be addressed. Without increasing the evidence base and attention on the paid caregiving workforce, particularly the need for broad policy support and investments in training, equitable wages, career growth pathways, and support needs, the supply-demand gap and quality of care provided to older adults will worsen. Noteworthy is the number of appellations for caregivers in the Research Topic's titles. "Family caregiver" ($n = 7$) was the most widely used form, followed by "informal caregiver" ($n = 5$), "unpaid" ($n = 3$), and "dementia caregiver" ($n = 3$), and a few other variations. "Primary caregiver" was only referenced once (Hu et al.), which may indicate it is out of vogue. Standardizing terminology in caregiving research could reduce confusion and enhance the synthesis of findings.

Additionally, the Research Topic areas can be divided into five buckets: (1) paid and unpaid caregivers for people living with dementia (PLWD), (2) caregiver burden/strain/overload, (3) caregiver physical and emotional health, (4) service demand/use/capacity (e.g., community-based support; hospice care; long-term care; technology); and (5) training, educational, and support needs of caregivers. While 10 papers in the Research Topic addressed the rural context in varying degrees, from a brief mention in the results to a focused analysis, only three of those had a specific emphasis on rural populations as indicated in the paper's title (Betegón et al.; Santoyo-Olsson et al.; Savla et al.). We originally conceptualized this Research Topic to focus exclusively on low-resource and rural contexts. However, due to the limited number of submissions initially, we expanded the focus. While it is heartening that one-third of the papers included some focus on rural settings, future research is needed on the unique policy, systems, and environmental changes required to support paid and unpaid caregivers in these contexts.

3 Significance and impact

This Research Topic reinforces that caregiving of older adults within community settings is important for those individuals receiving care and those providing care formally and informally. Additionally, it highlights that caregiving is important to society because it helps support dignity, independence, social connection, health, and reflects and builds on the social contract that values older people as full citizens. The emphasis on rural-urban differences and global diversity across the studies further underscores the need to account for critical cultural and contextual factors that contribute to a wide array of caregiver and care receiver outcomes.

4 Future directions

While the articles within this Research Topic advance critical knowledge in the field of caregiving, several areas warrant further exploration to address gaps, challenges, and opportunities within this evolving landscape. Potential avenues of future research inspired by this Research Topic include the following, alliterated with three Ps:

- Populations of interest

Efforts are needed to examine caregiving from heterogenous perspectives, a suggestion previously echoed by others (7), and expanded upon here. Distinct groups of unpaid caregivers have been historically under-represented in research including racial/ethnic minorities, LGBTQIA+ caregivers, and caregivers in low-resource and rural settings. Additionally, given the shift in family dynamics and the growing prevalence of multi-generational households globally, greater emphasis should be placed on the experiences of youth caregivers, including grandchildren, as well as long-distance and non-relative caregivers. Research could also center on the lived experiences of solo agers, Super Agers (90+), and Centenarians (one of the fastest growing age segments globally) to seek to gain a better understanding about how these individuals navigate the complex caregiving landscape and from whom they receive care and/or provide care to, such as a child (downward caregiving), given the rise of chronic conditions and disability at younger ages than in previous decades (8). As mentioned earlier in this editorial, there is also an opportunity to examine caregiving through the lens of the paid caregiving workforce in clinical and home or community settings. Finally, little attention has been given to the "caring triad" (i.e., the unpaid caregiver, paid caregiver, and care receiver team), despite the growth of home and community-based services that enable this experience.

- Potential topic areas

Community and clinical settings are feeling the strain of inadequate preparation for supporting older adults and their families. The global age-friendly ecosystem and development of multisector plans for aging in the U.S. (9, 10) represent an exciting opportunity to center caregivers within these frameworks. Moreover, research that highlights the importance of age-friendly employers and universities in supporting unpaid caregivers would be beneficial (11). Comparison of national policy frameworks, such as the National Strategy to Support Family Caregivers (12), offers an opportunity to promote transnational learning. Other topic areas include caregiver navigation services, integration of family caregiving within clinical care models (13), caregivers' technology use [(7), Smith et al.] in clinical and community settings, AI and generative AI to support families and agencies in the aging network, and experiential learning opportunities for health profession-motivated high school students designed to enhance the paid caregiving workforce pipeline. Lastly, most studies in the Research Topic focused on systems- and individual-level challenges related to caregiving. More emphasis should be placed on describing successful approaches or frameworks for supporting caregivers, protective traits that drive caregiver wellbeing, and caregiver-friendly community success models, particularly in low-resource and rural contexts.

- Programmatic and methodological approaches

Co-design principles should be used to ensure that programs and policies are relevant, accessible, and aligned with caregivers' needs and preferences, thereby fostering more equitable outcomes (6). In these approaches, it is important to leverage implementation science to integrate existing caregiver evidence-based strategies into community settings (6, 7). Conducting longitudinal studies is essential to evaluating the impact of national frameworks, community-centered interventions (7), and training and support on caregiver-related outcomes. These strategies can uncover the effectiveness, economic returns on investment (ROI), and scalability of current approaches.

5 Conclusion

This Research Topic reflects the interdisciplinary nature and diversity of thought, topics, and methodological approaches used in caregiving research today. It offers a glimpse into the future by highlighting salient issues impacting caregivers and care receivers in different settings across the globe. With the growing emphasis on caregiving as a social determinant of health (14), this Research Topic can help fuel advancements in caregiving research and practice. Browning et al. (6) recently published an editorial entitled "Grand Challenges: Addressing the Global Challenge of Healthy Aging" in the Aging and Public Health Section of *Frontiers Public Health*. In addition to the points they raised, this editorial adds caregiving to the list of grand challenges. Rosalynn Carter reminds us that caregivers are the cornerstone of society. Therefore, we believe this is a timely and relevant compendium of papers that will support researchers, practitioners, and communities in creating caregiver-friendly environments. This Research Topic and editorial share our insights and suggestions about future directions that can advance scholarship in this important area of research.

Author contributions

JS: Writing – original draft, Writing – review & editing. SC: Writing – original draft, Writing – review & editing. RO: Writing – original draft, Writing – review & editing. MS: Writing – original draft, Writing – review & editing.

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Conflict of interest

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A longitudinal qualitative study on the care needs journey map of primary caregivers of patients undergoing total knee arthroplasty

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Background: Total knee arthroplasty (TKA) is a common and effective treatment for advanced knee osteoarthritis, yet it imposes significant demands on primary caregivers throughout the perioperative and rehabilitation phases. Understanding caregivers' evolving needs is critical for optimizing patient outcomes and sustaining caregiver well-being. This study aimed to explore the dynamic care experiences and changing needs of primary caregivers of TKA patients across three distinct phases: the diagnosis period, discharge transition, and rehabilitation phase, and to construct a comprehensive journey map of caregiving needs.

Methods: A longitudinal qualitative study was conducted using purposive sampling. Sixteen primary caregivers of patients undergoing unilateral TKA were recruited from a tertiary hospital in Henan, China. Semi-structured interviews were conducted at three time points: preoperative (T1), pre-discharge (T2), and one month post-discharge (T3), resulting in 43 interviews. Data were analyzed using content analysis and synchronized temporal mapping to identify themes and subthemes along the caregiving timeline.

Results: Four major themes and 27 subthemes were identified: care tasks, emotional experiences, caregiving barriers, and support systems. Caregivers' responsibilities evolved from pre-surgical information gathering to intensive post-surgical care and long-term rehabilitation support. Emotional burdens shifted from anxiety and helplessness to fatigue and psychological strain. Major barriers included knowledge deficits, skill limitations, and inadequate systemic support. The caregiver support network transitioned from hospital-based to community and family-based systems over time. A visual journey map was developed to represent these findings.

Conclusion: Primary caregivers of TKA patients face complex and changing needs across different stages of care. A caregiver-centered, multidisciplinary, and phase-specific support framework is essential to improve the quality of postoperative care and reduce caregiver burden.

KEYWORDS

total knee arthroplasty (TKA), primary caregivers, longitudinal, qualitative research, caregiver burden

1 Introduction

Knee osteoarthritis (KOA) is among the most common degenerative joint diseases in middle-aged and older adults, characterized by progressive cartilage loss and osteophyte formation that lead to persistent pain, functional limitations, and poorer quality of life (1). In China and globally, demographic aging, obesity, and lifestyle-related risks have contributed to steady rise in KOA burden, with older women disproportionately affected (2, 3). These trajectories not only reflect disease prevalence but also foreshadow escalating care needs at the household level.

For patients with advanced KOA, conservative therapies are frequently inadequate, and total knee arthroplasty (TKA) is widely regarded as the standard intervention to relieve pain and restore mobility (4). The procedure's diffusion has been rapid—millions of TKAs are performed worldwide annually, and China has seen double-digit growth since 2010 with continued expansion expected (5). While these trends underscore TKA's clinical value, they also magnify the volume and complexity of postoperative support required after discharge, when patients transition to home-based rehabilitation and rely heavily on informal care (6).

Primary caregivers—most often spouses or adult children—sustain recovery across multiple stages, from preoperative preparation and inpatient rehabilitation to transitional discharge and ongoing home care (7). Their responsibilities span assistance with activities of daily living, symptom monitoring, complication surveillance, facilitation of prescribed exercises, and provision of emotional support. Yet caregivers' own needs—psychological coping, actionable information, and access to structured resources—are frequently under-recognized in routine care pathways (8).

A substantial body of work links caregiver burden and well-being with patient outcomes such as adherence, functional recovery, and readmission risk (9). However, much of this literature is cross-sectional, providing static snapshots that obscure how caregiving demands, stressors, and coping strategies evolve as patients move through distinct recovery phases. Limited longitudinal evidence illustrates marked temporal fluctuations—e.g., heightened strain in the first month and persistent information gaps thereafter—but the timing, intensity, and persistence of these patterns remain insufficiently resolved (10). Methodologically, heterogeneity in burden measures, follow-up intervals, and contextual factors further constrains synthesis, leaving uncertainty about when and how to intervene most effectively.

The "caregiving journey" framework addresses these limitations by foregrounding the staged, dynamic nature of informal care: responsibilities shift, emotions ebb and flow, and support needs reconfigure across perioperative and rehabilitation milestones (11). Building on this lens, journey mapping can make visible the "pressure points" where unmet needs cluster, thereby guiding the design and timing of targeted interventions and education (12). Nevertheless, systematic longitudinal applications of this approach in TKA remain scarce—particularly in China, where family-based caregiving is central—leaving gaps in culturally and system-specific guidance.

Accordingly, this study employs a longitudinal qualitative design to capture the evolving experience of primary caregivers for TKA patients (13). Repeated, in-depth interviews across preoperative, early postoperative, and home-rehabilitation stages allow us to trace temporal patterns in needs, stressors, and adaptive strategies beyond what cross-sectional snapshots can reveal. Guided by the gaps identified above, the objectives of this study are twofold: (1) to explore and interpret how caregivers' needs, challenges, and coping processes evolve across the perioperative and rehabilitation stages of TKA; and (2) to construct an in-depth understanding of the critical moments where informational, practical, and psychosocial support needs become most salient, thereby providing a nuanced foundation for context-sensitive, stage-specific interventions. By prioritizing caregivers' narratives and experiences, this study aims to generate empirically grounded insights for nursing practice, caregiver education, and health service planning.

2 Methods

2.1 Study design

This study adopted a longitudinal qualitative design grounded in the interpretivist paradigm, using the journey mapping method combined with conventional content analysis (14). This approach was selected to capture caregivers' evolving experiences and to interpret the contextual meanings of caregiving practices over time. The design was further informed by SRQR (Standards for Reporting Qualitative Research) and COREQ (Consolidated Criteria for Reporting Qualitative Research) guidelines, to enhance transparency and methodological rigor (15).

2.2 Participants and sampling

Participants were the primary caregivers of patients who underwent TKA at Henan Provincial Third People's Hospital. A purposive sampling method, guided by the principle of maximum variation, was used to ensure diversity in age, gender, educational background, and socio-economic status. Inclusion criteria for patients were: (1) first-time recipients of unilateral TKA; (2) a Tampa Scale of Kinesiophobia (TSK) score >37, indicating moderate to severe kinesiophobia; (3) clear consciousness, normal cognitive and hearing function, and the ability to communicate verbally or in writing; (4) provision of informed consent and willingness to participate in longitudinal follow-up. Exclusion criteria included: (1) severe dysfunction of vital organs such as the heart, liver, lungs, or kidneys; (2) diagnosed anxiety, depression, or current use of psychiatric medications; (3) mental illness or cognitive impairments impairing communication; (4) simultaneous participation in other similar studies.

Inclusion criteria for caregivers were: (1) the primary caregiver providing ≥4 h of daily care; (2) unpaid caregiving role; (3) adequate communication and comprehension ability. Exclusion criteria included: (1) caregivers with a professional healthcare background; (2) patients' death or caregiver withdrawal during the study. Sample size was determined according to the principle of data saturation, defined as the point at which no new codes or themes emerged during successive interviews (16). Saturation was reached after 16 caregivers were recruited, resulting in 43 interviews across three time points. The mean age of caregivers was 47.3 years (SD = 8.6). Ethical approval was granted by the Ethics Committee of Henan Provincial Third People's Hospital (Approval No. 2025-126).

2.3 Interview timing and guide

To reduce recall bias and ensure the authenticity of data, interviews were conducted at three key time points identified through literature review and clinical practice, and aligned with the structure of the caregiver journey map:

T1 (Preoperative phase): Within the first 2 days of hospitalization
T2 (Discharge transition phase): One day before discharge
T3 (Rehabilitation phase): One month post-discharge

Although these three time points may seem limited, they were chosen to balance participant burden with feasibility, and to capture phases shown by prior research to involve the most significant caregiving challenges. The relatively short interview duration (15–20 min) reflected participants' time constraints and fatigue during hospital stays, but repeated interviews allowed for cumulative depth.

A semi-structured interview guide was used consistently, refined iteratively during data collection to accommodate emerging themes. Sample questions included: "What is your biggest current difficulty as a caregiver?" and "How has this experience affected your own life and health?" A pilot interview with two caregivers was conducted to refine question wording and flow.

2.4 Data collection

All interviews were conducted by two researchers trained in qualitative methods. One served as interviewer and reflexive facilitator, while the second took observational notes on non-verbal cues. The researchers positioned themselves as clinical nurses with prior experience in perioperative care, which facilitated rapport but also necessitated reflexive journaling to manage potential bias.

T1 and T2 interviews were face-to-face in a private hospital room, while T3 interviews were conducted in person or by telephone, depending on caregiver preference. All interviews were audio-recorded and transcribed verbatim within 24 h. Participants were anonymized using codes (N1–N16).

2.5 Data analysis

All interviews were transcribed verbatim within 24 h and independently verified by two researchers. Data were analyzed using conventional content analysis (17), supported by NVivo 12 software for coding and data management. The analysis proceeded iteratively: transcripts were read repeatedly for immersion, and open coding was conducted to generate initial codes. Codes with similar meanings were then grouped into subthemes and further synthesized into broader themes. These themes were subsequently mapped onto a temporal framework corresponding to the caregiving journey (T1–T3), enabling both synchronic and longitudinal interpretation. To ensure credibility, coding decisions and theme development were discussed in regular peer debriefing sessions, and an audit trail was maintained throughout. The interview guide was refined iteratively to incorporate emerging insights, and data collection continued until thematic saturation, defined as the absence of new codes in successive interviews, was achieved.

2.6 Rigor and quality control

To ensure methodological rigor, multiple strategies were implemented throughout the study. First, trust was established between researchers and participants through long-term engagement in inpatient nursing care, fostering an environment conducive to open and honest dialogue. Second, reflexive journaling was used by all researchers to document potential biases, emotional reactions, and decision-making during data collection and analysis. This practice helped minimize the influence of subjectivity and maintained analytical transparency. Third, member checking was employed by revisiting selected participants to verify the accuracy of thematic interpretations and confirm that the findings reflected their lived experiences. Lastly, to ensure technical integrity, dual-device recording was used during telephone interviews—one for communication and the other for audio capture—to prevent data loss and maintain recording quality. These quality assurance measures collectively contributed to the credibility, dependability, and confirmability of the study findings.

3 Results

This longitudinal qualitative study traced caregivers' dynamic experiences across the preoperative (diagnosis), discharge transition, and rehabilitation phases (Table 1). The thematic analysis identified caregivers' experiences and captured both barriers and facilitators (Table 2). The analysis yielded four main themes—care tasks, emotional experiences, caregiving barriers, and support systems—and 27 subthemes, which were integrated into a comprehensive caregiving journey map. This map visually demonstrated how caregivers' roles evolved from performing basic organizational tasks to assuming a more

TABLE 1 Map of the care needs journey of the primary carer of a TKA patient over three periods.

Themes and Subthemes	Disease diagnosis period (1–3 days)	Transitional period from hospitalization (7–14 days)	Recovery period (months to years)
Caregiver tasks	Handle admission procedures, accompany the examination, understand the surgical process and notify other family members	Prepare the family environment, master basic nursing skills and displacement skills, and prepare for discharge	Long-term support for patient rehabilitation training, management of common complications (such as pressure sores, thrombosis, etc.) and emotional support
Emotional responses	Shock, anxiety, helplessness; tension about the risks of surgery and the role change in care	Concerns about the effectiveness of rehabilitation, care fatigue, lack of confidence, and possible sleep disorders	Hope coexists with stress, and anxiety and frustration are felt about the slow, repeated recovery and long-term care
Barriers to caregiving	There is a lack of knowledge about TKA surgery and nursing process, and communication barriers are significant	They cannot master the key points of rehabilitation care and lack social support and rehabilitation guidance	The care task is long-term, the economic pressure is great, and the family responsibility conflict is obvious
Coordination with healthcare staff and departments	Orthopedics, anesthesiology, radiology, outpatient nurses, admission coordinators, family members	Nursing staff, physicians, rehabilitation therapists, medical social workers, family members and other caregivers	Health care workers in rehabilitation institutions, psychological counselors, community workers, volunteers, family support networks

TABLE 2 Themes of care tasks in three periods for the primary caregivers of TKA patients.

Period	Theme	Sub-themes	Encoding	Representative statements
Preoperative	Information preparation	Lack of medical knowledge	There is insufficient knowledge of preoperative procedures and anesthesia for TKA	N1: “The doctor said I had to have surgery. I didn’t understand it very well, and I didn’t know what anesthesia or joint replacement was.”
	Coping	Anxiety and worry	There is an underestimation of the risks of surgery and the pressures of care	N3: “I heard that the operation is risky, and I’m afraid he will hurt, so I’m always worried.”
	Hospital affairs	The process is difficult	Not familiar with hospital procedures and the workings of the health system	N5: “When I first entered the big hospital, I didn’t know anything about the process. I had to run around to pay and get the bill.”
Hospital stay	Care participation	Assist with daily care	The patient is completely dependent on life in the early postoperative period, and the caregiver needs to be involved throughout	N7: “He can’t move his legs. I have to help him put on his pants, eat and go to the bathroom.”
	Communication and coordination	Communication between nurses and patients is difficult	Information asymmetry makes it difficult for caregivers to obtain clear rehabilitation guidance	N11: “The doctor said it was too fast, I couldn’t understand it, and I was afraid of asking too many questions and bothering him.”
	Emotional stress	Sleep and fatigue	Long-term care and mental stress lead to physical exhaustion	N9: “I can’t sleep well at the hospital and I’m worried about his condition. I’m very tired.”
Post-hospitalization	Family care	Environmental adaptation is difficult	The home space and facilities are not suitable for postoperative rehabilitation needs	N2: “The stairs at home are too steep for him to get downstairs. There are no handrails in the bathroom.”
	Skill requirements	Lack of rehabilitation guidance	Lack of guidance on postoperative functional training methods, frequency and precautions	N13: “The doctor said to exercise, but he didn’t teach me how to do it or how long to do it.”
	Role conflict	Time allocation pressure	Multiple role (work, family) conflicts increase the pressure of care	N6: “I have to go to work and take care of him. I don’t have enough time.”

complex “quasi-professional” function, accompanied by fluctuating emotions and shifting support needs.

3.1 Participant characteristics

A total of 16 dyads of TKA patients and their primary caregivers participated in this study. Caregivers ranged in age from 29 to 63 years, with a mean age of 47.3 years (SD = 8.6). The majority were female (68.8%), and most were either spouses (43.8%) or adult children (31.3%), with smaller proportions of in-laws (12.5%), siblings (12.5%), and parents of patients (6.3%). Educational attainment varied considerably, from illiteracy (12.5%) to postgraduate training (6.3%), though most caregivers had completed at least junior middle school (62.5%). Marital status was predominantly married (81.3%), with a minority unmarried (12.5%) or divorced (6.3%). Caregivers occupations were grouped into broader categories, including agriculture, healthcare and education, public service, technical or professional work, service and manual labor, and unemployed/retired, reflecting broad socio-economic heterogeneity.

Patients ranged in age from 52 to 74 years, with a mean age of 63.1 years (SD = 5.9), and an equal distribution of men and women. Educational attainment was generally lower than that of caregivers: nearly half (43.8%) had only primary schooling or were illiterate, while a minority reached junior middle school (37.5%) or higher education (18.7%). The majority were married (87.5%), and most were retiredd, agricultures, or manual workers. The primary causes of injury were falls from heights (31.3%), traffic accidents (25.0%), and slips (18.7%), with disease durations concentrated between one and three months (68.8%). Injury severity was most often classified as Grade B (31.3%) or Grade D (25.0%), while the remainder were Grade F as shown in Table 3.

TABLE 3 General information of TKA patients and their caregivers ($n = 16$).

Number	Relationship with patients	Sex	Age (years)	Educational status	Marital status	Occupation	Patient gender	Age of patient (years)	Educational level of patients	Marital status of the patient	Patient occupation	Disease duration (months)	Damage grading	T1	T2	T3
N1	Spouse	Woman	50	Junior college	Married	Healthcare/ education	Man	65	Senior middle school	Married	Unemployed/ other	2	3	F	F	F
N2	Sons and daughters	Man	32	Undergraduate course	Unmarried	Technical/ professional	Man	70	Junior middle school	Married	Retired	1	3	F	F	P
N3	Son's wife	Woman	38	Undergraduate course	Married	Finance	Man	72	Primary school	Married	Agriculture	3	3	F	F	F
N4	Spouse	Man	60	Special school	Married	Service/manual labor	Woman	62	Senior middle school	Married	Retired	2	3	F	F	P
N5	Spouse	Woman	55	Senior middle school	Married	Liberal professions	Man	60	Primary school	Married	Agriculture	1	3	F	F	F
N6	Spouse	Man	63	An illiterate person	Married	Agriculture	Woman	66	Junior middle school	Married	Service/manual labor	2	3	F	F	P
N7	Son-in-law	Man	43	Undergraduate course	Married	Public functionary	Woman	68	An illiterate person	Married	Unemployed/ other	3	3	F	F	P
N8	Brother and sister	Woman	47	Junior middle school	Divorced	Cleaning	Man	59	Junior middle school	Married	Service/manual labor	1	3	F	F	F
N9	Spouse	Man	58	Senior middle school	Married	Service/manual labor	Woman	64	An illiterate person	Married	Staff and workers	2	3	F	F	P
N10	Sons and daughters	Woman	35	Master	Unmarried	Healthcare/ education	Man	67	Primary school	Bereft of one's spouse	Retired	1	3	F	F	F
N11	Spouse	Man	61	Junior middle school	Married	Retired	Woman	63	Special school	Married	Dancer	1	3	F	F	P
N12	Brother and sister	Woman	45	Undergraduate course	Married	Healthcare/ education	Man	60	Junior middle school	Married	Service/manual labor	3	3	F	F	F
N13	Spouse	Woman	59	An illiterate person	Married	Unemployed/ other	Man	69	Primary school	Married	Unemployed/ other	2	3	F	F	F
N14	Sons and daughters	Man	29	Undergraduate course	Unmarried	Technical/ professional	Woman	58	Senior middle school	Married	Staff and workers	1	3	F	F	P
N15	Father and daughter	Woman	36	Junior college	Married	Clerical staff	Man	74	An illiterate person	Married	Retired	2	3	F	F	F
N16	Mother and son	Man	40	Undergraduate course	Divorced	Constructor	Woman	62	Special school	Married	Staff and workers	1	3	F	F	P

T1 after admission, T2 before discharge, T3 one month after discharge. Interview form: F face to face, P telephone.

Damage grading: Grade 0 indicates a normal joint space without osteophytes or cartilage damage. Grade I refers to mild joint space narrowing with possible tiny osteophytes, usually accompanied by occasional mild pain that worsens after activity. Grade II is characterized by definite osteophyte formation and moderate joint space narrowing (less than 50%), with noticeable pain during stair climbing or after prolonged sitting. Grade III represents significant joint space narrowing (greater than 50%) and subchondral bone sclerosis, with daily activities becoming restricted and possible joint swelling. Grade IV describes complete joint space obliteration with extensive osteophyte formation and bone deformity, leading to persistent pain, stiffness, and difficulty or even inability to walk.

3.2 Theme 1: care tasks

Caregiving tasks expanded over time from logistical coordination to complex, quasi-clinical responsibilities. In the diagnosis stage, caregivers focused on obtaining medical information, organizing hospital admission, and negotiating treatment decisions. During discharge transition, tasks shifted toward facilitating functional training, modifying the home environment, and acquiring practical caregiving skills. In rehabilitation, responsibilities included preventing complications, managing long-term functional recovery, and sustaining patients' psychological adaptation. Differences between subgroups emerged: spouses more often engaged in continuous physical assistance, whereas adult children were more likely to coordinate external resources and financial support. This transition illustrates a trajectory of increasing technical and psychosocial complexity (Table 2).

3.3 Theme 2: emotional experiences

Emotional states varied across phases, with acute anxiety and helplessness dominating the diagnosis stage. During discharge transition, caregivers reported fatigue, tension, and insecurity regarding recovery. By the rehabilitation phase, emotions became ambivalent, combining hope with frustration at slow progress, and in some cases, role-related self-sacrifice. Female caregivers more frequently expressed emotional exhaustion and feelings of isolation, whereas male caregivers emphasized financial pressure and role strain. This heterogeneity underscores how caregiver identity shapes psychological vulnerability and coping strategies (Table 4).

3.4 Theme 3: caregiving barriers

Three categories of barriers were identified: (1) knowledge barriers, such as limited understanding of perioperative information; (2) skill barriers, including difficulties with mobility support, wound care, and complication prevention; and (3) systemic barriers, encompassing financial stress, fragmented care coordination, and insufficient community resources. These barriers intensified in rehabilitation, when institutional support diminished while care demands persisted. The findings reflect the uniqueness of the post-TKA context in China, where the family remains the primary care provider in the absence of structured community-based rehabilitation pathways (Table 5).

3.5 Theme 4: support systems

Support sources shifted from hospital-based professionals (orthopedics, anesthesiology, inpatient nurses) during the diagnosis and hospitalization phases to rehabilitation therapists and discharge planners in the transition phase, and finally to community services, counselors, and family networks in the rehabilitation phase. However, this transition also revealed fragmentation between hospital and community care, leaving caregivers without continuous professional guidance (Table 1).

4 Discussion

4.1 Dynamic evolution of care tasks and role transformation

This study used longitudinal qualitative interviews to systematically depict how caregiving tasks for TKA patients evolved across the diagnosis, discharge transition, and rehabilitation stages. The findings confirm that caregiving is not static but develops in a staged and accumulative manner. Caregivers began as logistical coordinators—responsible for admission, paperwork, and information gathering—and then shifted toward performing quasi-clinical duties, such as monitoring rehabilitation training, preventing complications, and supporting psychological recovery. By the rehabilitation phase, their roles increasingly resembled those of paraprofessionals, combining physical, technical, and emotional responsibilities.

This trajectory can be interpreted through role adaptation theory, which posits that individuals gradually reconstruct their roles in response to prolonged exposure to stressors and expectations. The evidence from this study enriches existing cross-sectional findings (18, 19) by demonstrating how caregivers actively adapt their roles over time. In particular, spousal caregivers were more consistently engaged in hands-on tasks, whereas adult children often took on resource coordination and financial responsibilities, illustrating how family role structures influence caregiving dynamics.

4.2 Stage-based emotional fluctuations interpreted through stress–coping models

Caregivers' emotional responses shifted significantly across the three phases, reflecting the appraisal and coping processes described in Lazarus and Folkman's stress–coping model. In the diagnosis stage, anxiety and helplessness reflected primary appraisal of uncertain events, while the discharge transition period was characterized by secondary appraisal under conditions of insufficient coping resources, leading to fatigue and diminished confidence. By the rehabilitation stage, caregivers reported ambivalent emotions: hope and optimism about patient recovery, but also frustration with slow progress, psychological suppression, and even self-sacrifice.

The gender differences observed add cultural nuance. Female caregivers frequently emphasized emotional exhaustion and loneliness, while male caregivers reported financial pressure and role strain. Such differences are consistent with gendered expectations in Chinese families, where women are often expected to engage in emotional labor and men in financial support. Compared with Western studies (20, 21), our participants reported more emotional suppression and acceptance of sacrifice,

TABLE 4 Emotional themes of the primary caregivers of TKA patients at 3 periods.

Period	Theme	Sub-themes	Encoding	Representative statements
Preoperative	Psychological fluctuations	Anxiety and worry	Fear of intraoperative risk and poor postoperative recovery	N2: "I can't sleep at night because I heard that others don't recover well after this operation."
	Character shock	A sudden sense of responsibility	Responsibility for sudden medical decisions has increased dramatically	N6: "I don't even know how to start with all this."
	Feeling of helplessness	Lack of support	The sense of powerlessness due to lack of information and lack of system support	N1: "No one told me what to do next. I was very confused."
Hospital stay	Emotional exhaustion	Both physically and mentally exhausted	Long-term care and anxiety coexist, resulting in low mood	N16: "Running up and down the hospital every day is tiring for both my body and mind."
	sense of guilt	I feel powerless	The guilt of not being able to alleviate the patient's suffering	N10: "I feel useless when he hurts me but can't help him."
	Struggle to adapt	Character maladjustment	Adaptation to the transition of caregiving status	N9: "It was really hard for me to accept the transition from family member to caregiver."
Post-hospitalization	Aloneness	Lack of social support	Lack of outside understanding and help	N4: "It would be nice if everyone went out of the hospital, but it's harder for me to take care of myself at home."
	Persistent anxiety	Uncertainty about rehabilitation	Worried about the postoperative recovery effect and future independence	N8: "The doctor said it depends on the situation, and I'm scared every day."
	Emotional repression	Sacrifice oneself	Neglect your own emotions and needs	N13: "I only think about whether he is well or not every day, and I don't care whether I am tired or not."

TABLE 5 Themes of care barriers in three periods for the primary caregivers of TKA patients.

Period	Theme	Sub-themes	Encoding	Representative statements
Preoperative	Knowledge barriers	Lack of knowledge about surgery	Lack of understanding of TKA procedures, postoperative risks and nursing requirements	N1: "The doctor spoke too fast for me to remember how to prepare."
	Communication barriers	Poor communication with medical staff	I am afraid that my questions will be annoying, so I dare not communicate actively	N3: "He gets a little impatient when I ask the doctor a few questions, so I dare not ask more."
	Lack of external support	Limited use of social resources	They do not understand the policy, medical treatment process and nursing resources	N6: "I don't know how to report medical insurance or how to hire a nurse. No one says anything."
Hospital stay	Skill barriers	Lack of nursing skills	Do not know how to assist patients to turn over, go to the toilet, rehabilitation training	N5: "He can't move, and I dare not move him for fear of hurting him."
	Resource barriers	Room conditions are limited	The care space is small and inconvenient	N8: "I sleep on a chair at night and it's not convenient to take a shower."
	Time conflict	It's hard to balance family and work	It's impossible to take care of the patient and work	N10: "The unit has to go, the hospital has to come, it's really tiring to run back and forth."
Post-hospitalization	Care skills impairment	Lack of home rehabilitation guidance	They do not know about home exercise and medication	N7: "I don't know how to help him exercise. I'm afraid I'll make a mistake."
	Economic pressures	Rehabilitation is expensive	It is necessary to buy auxiliary appliances and nutritional products, which is costly	N4: "The wheelchair and rehabilitation equipment alone cost thousands."
	Lack of support systems	Family support is inadequate	Other family members are less involved in care and responsibilities are concentrated	N13: "I'm the only one who can do it. The rest of the family can't help."

suggesting the influence of filial piety and spousal duty in shaping emotional coping strategies in the Chinese context.

4.3 Theoretical and analytical considerations: framing caregiver burden

Beyond descriptive findings, the analysis benefits from a theoretical integration of the caregiver burden framework. This framework conceptualizes stress across informational, physical, and systemic domains, and our data highlight how these burdens accumulate longitudinally. Early deficits in medical information limited caregivers' ability to make informed decisions. Skill-related challenges in patient transfer and complication prevention became most salient during discharge and early rehabilitation, when institutional guidance diminished. Systemic barriers—financial strain, lack of community rehabilitation services, and fragmented continuity of care—were most pronounced during long-term recovery.

These findings extend prior work (22, 23) by showing that caregiver burden is not simply a static condition but an escalating process tied to the temporal trajectory of recovery. Importantly, the theoretical framing underscores the need for stage-specific interventions. Structured preoperative education could address informational gaps, while community-based rehabilitation services and caregiver training programs could alleviate long-term skill deficits.

4.4 Evolution of support networks and cultural specificity

Support networks shifted from professional, hospital-based providers during admission and hospitalization to family and community resources during rehabilitation. This transition revealed fragmentation in the healthcare–community–home continuum, with caregivers often left unsupported after discharge. While similar patterns of fragmentation have been described internationally (24), the findings in this study reflect the particular reliance on family caregiving in China, where community rehabilitation and formal long-term care systems remain underdeveloped.

This cultural specificity is crucial: in China, caregiving remains deeply embedded in family structures, guided by norms of filial piety and collective responsibility. Unlike in some Western contexts where professional caregivers supplement family roles, Chinese families are often the sole source of support. This reliance underscores the importance of building multidisciplinary and community-integrated support systems that can bridge hospital discharge with ongoing rehabilitation.

4.5 The novelty of this study

An important contribution of this study lies in its methodological design. Previous research on TKA caregiving has been largely cross-sectional, providing valuable but static insights into caregiver burden, emotional distress, or support needs. By adopting a longitudinal design, this study captured temporal trajectories of caregiving tasks, emotional states, and barriers, revealing not only what caregivers experience but also when these challenges emerge and how they evolve.

For example, anxiety peaked during the diagnosis and discharge phases, while frustration and fatigue accumulated during rehabilitation. Similarly, systemic barriers were less visible during hospitalization but became acute once institutional support receded. Such insights are possible only with longitudinal observation, highlighting the added value of this approach for developing time-sensitive interventions.

4.6 Study limitations and future directions

This study has several limitations. First, participants were recruited from a single hospital, limiting generalizability to other regions. Second, although purposive sampling with maximum variation was employed, selection bias cannot be excluded; caregivers under extreme burden may have declined participation. Third, data were self-reported, and despite triangulation with non-verbal observations, recall and desirability bias may still have influenced findings. Fourth, the positionality of the researchers as clinical nurses may have affected interview dynamics, despite the use of reflexive journaling and peer debriefing to mitigate this risk. Fifth, the interview duration was relatively short (15–20 min) due to time constraints in clinical environments, which may have limited narrative depth.

Future studies should expand to multiple sites and diverse cultural settings, adopt mixed-methods approaches to triangulate qualitative findings with quantitative measures of caregiver burden, and extend follow-up periods to capture long-term trajectories beyond the first month of rehabilitation.

5 Conclusion

This longitudinal qualitative study mapped the evolving care journey of primary caregivers of TKA patients across the diagnosis, discharge transition, and rehabilitation stages. The findings revealed that caregivers encountered cumulative burdens, emotional fluctuations, knowledge and skill gaps, and insufficient systemic support at each stage, with their roles continuously shifting and intensifying. These insights underscore the need for stage-specific interventions. In the preoperative phase, structured caregiver education programs should be established to provide accurate medical knowledge, set realistic expectations, and prepare caregivers for their roles. During the discharge transition, multidisciplinary discharge planning combined with short-term psychological counseling is critical to reduce anxiety, enhance confidence, and ensure effective continuity of care. In the rehabilitation stage, caregivers would benefit most from community-based rehabilitation services, peer-support groups, and digital training platforms, which can sustain skill development, alleviate long-term burden, and prevent social isolation. Overall, a caregiver-centered, culturally sensitive, and multidisciplinary continuum of care should be prioritized to strengthen caregiving quality and mitigate both the physical and emotional strain on TKA caregivers.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Ethics Committee of the Third People's Hospital of Henan Province, Approval No. 2025-126. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

JH: Writing – original draft, Writing – review & editing, Investigation, Methodology, Conceptualization. GD: Writing – review & editing, Investigation. DL: Investigation, Data curation. DW: Data curation, Writing – original draft, Investigation, Conceptualization, Supervision, Project administration, Validation, Writing – review & editing, Funding acquisition, Software, Formal analysis, Methodology.

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An analysis of factors influencing the demand for community-based integrated health and social care in Southwestern China

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Objective: This cross-sectional study investigates the demand for CB-IHSC among older adults in Chengdu and identifies the factors influencing this demand, thereby providing a reference for developing and optimizing such services.

Methods: From August to December 2023, 511 eligible older adults residing in the central districts of Chengdu were selected through convenience sampling. Guided by the Andersen Health Service Utilization Behavior Model, the study categorized influencing factors into three dimensions: predisposing factors, enabling factors and need factors. Chi-square tests were first used to identify statistically significant variables within each dimension. These variables were then included in a binary logistic regression model to assess their association with service demand. Model calibration was assessed using the Hosmer–Lemeshow test.

Results: Demand for CB-IHSC was high (87.08%). Independent predictors included number of children (OR = 2.12), living with spouse (vs alone, Ref; OR = 0.48), lower income (OR = 0.40), convenient community medical access (OR = 1.75), children's support (OR = 3.71), lower self-care ability (OR = 0.18), poorer self-rated health, and higher awareness. Policies should improve accessibility, financing, and public awareness to increase uptake.

Conclusion: To support the sustainable development of CB-IHSC, Chengdu should continue strengthening capacity building in this sector. Efforts should be directed toward establishing diversified financing and support mechanisms, improving the accessibility and convenience of service delivery, and enhancing public awareness and education regarding CB-IHSC.

KEYWORDS

Andersen Health Service Utilization Behavior Model, CB-IHSC, long-term care, older adults, demand

1 Introduction

With the global trend of an aging population, China is facing increasingly severe demographic and healthcare challenges. According to the National Bureau of Statistics, by the end of 2024, over 310 million people in China will be aged 60 and above, representing 22% of the total population. Among them, approximately 78% suffer from at least one chronic disease (1). Despite the growing demand for care services for older adults, the availability remains inadequate, with only 406,000 care institutions and 7.99 million beds nationwide (1). This imbalance between demand and supply underscores the urgent need to develop efficient long-term care system in China.

In response, the Chinese government has implemented policies to develop long-term care services and foster a supportive environment for older adults. Since the release of the Opinions on Accelerating the Development of the Care-for-older-adults in 2013, various models have emerged, including integrated health and care institutions for older adults, community-based integrated health and social care (CB-IHSC), and home-based integrated care. However, while these models have proliferated, gaps remain in their accessibility, quality, and integration.

The developed countries have already established comprehensive care system for older adults, such as the U.S. Program of All-Inclusive Care for the Elder Adults (PACE), the UK's community-based older adults care framework, and Japan's Kaigo Hoken (Long-Term Care Insurance) system. However, China's care-for-older-adults industry is still in its early stages, with limited empirical research on CB-IHSC. Existing studies are primarily theoretical, focusing on framework development and public awareness, particularly in large cities. For instance, a study by Liu Xiaochu et al. reported a 66.3% demand for CB-IHSC in Luzhou (2), whereas a survey in Guangzhou indicated a higher demand of 86.26% (3). In Chengdu, older residents mainly require health management, smart care, medical consultations, psychological care, and rehabilitation nursing (4).

Further research across other megacities in China, such as Nanchang, Changsha, and Guangzhou, has identified multiple factors influencing demand for CB-IHSC, including health status, family support, and community environment (5, 6). For example, a survey in Guangzhou found a strong correlation between demand and factors such as health conditions, number of children, and self-rated health (3). Similarly, studies in Changsha highlighted the importance of family support, income levels, and the availability of medical resources in determining the use of community-based integrated care services (6). These findings underscore the need to understand how similar mechanisms operate in Chengdu.

The Andersen Health Service Utilization Behavior Model, proposed by Ronald M. Anderson in 1968, provides a robust theoretical framework for analyzing healthcare-seeking behavior. It posits that service utilization is jointly influenced by three categories of factors: Predisposing Characteristics (e.g., age, education), Enabling Resources (e.g., accessibility, family support), and Need (e.g., self-rated health, disease burden). This model's relevance for understanding the demand for CB-IHSC is well-supported, as existing studies indicate that such demand arises from a complex interaction of individual health conditions, socio-economic factors, and service availability (7–9). Furthermore, the model's applicability in the Chinese context has been extensively demonstrated in long-term care research conducted in settings such as Shaanxi, Suzhou, and Beijing (10–14). While alternative frameworks exist (e.g., the WHO's ICOPE model), the Andersen model's comprehensive and behavioral-focused structure makes it the most appropriate choice for systematically investigating the factors influencing demand for integrated care in this study.

1.1 The case of Chengdu

Chengdu, located in the southwest of China and as a national pilot for CB-IHSC, faces rapid population aging. Despite establishing 28 CB-IHSC complexes, challenges such as limited service scope and low public awareness persists (15, 16). Most studies on Chengdu focus on demand descriptions but lack a unified theoretical framework to explain the underlying drivers.

This study aims to fill this gap by applying the Andersen Health Service Utilization Behavior Model to identify key factors driving CB-IHSC demand in Chengdu. The following hypotheses are proposed, based on the model and prior literature:

> *H1* (Need): Poorer self-rated health and lower self-care ability are associated with higher demand for CB-IHSC.
>
> *H2* (Enabling—Access): Greater convenience of community medical care would be associated with higher odds of demand.
>
> *H3* (Enabling—Resources): Higher income is positively associated with demand for CB-IHSC.
>
> *H4* (Enabling—Family): Support from children positively influences demand. The more children an individual has, the lower the demand for services.
>
> *H5* (Predisposing—Co-residence): Compared with living alone, co-residence with a spouse/children would be associated with lower odds due to informal care.
>
> *H6* (Awareness): Higher awareness of CB-IHSC would be associated with higher odds of demand.

These hypotheses guide the model specification and analysis in the following sections.

Terminology: We use the term Community-Based Integrated Health and Social Care (CB-IHSC) throughout. Terms such as "integrated medical and social care" are treated as synonyms and, after first mention, replaced by CB-IHSC.

2 Materials and methods

2.1 Study design and participants

A cross-sectional survey was conducted among older residents aged 60 years and above in the main urban areas of Chengdu. The inclusion criteria were as follows: individuals who had resided for at least 6 months in one of the following districts—Jinjiang, Qingyang, Wuhou, Chenghua, Jinniu, Gaoxin, or Tianfu New District; individuals who regularly visited a designated community health service center for medical care; those aged 60 or older; and individuals capable of clear and logical communication. Exclusion criteria included: individuals with communication or expression impairments; individuals who refused to participate in the survey; respondents who completed the questionnaire in less than 3 minutes; those who selected the same response option throughout the questionnaire; individuals whose answers were internally inconsistent or logically contradictory. A total of 530 questionnaires were distributed, with 511 valid responses retained (effective response rate: 96.41%).

2.2 Data collection

Data were collected from August to December 2023 using electronic questionnaires administered at various community health service centers and nearby residential areas. Trained research assistants approached potential participants in waiting areas or common spaces of these centers, as well as in public areas of residential communities. They introduced themselves and the study purpose, explaining that the survey aimed to understand the needs and preferences of the CB-IHSC. Participation was voluntary, anonymous, and could be withdrawn at any time. Upon obtaining informed consent from the older participants or their accompanying family members, data were completed either by self-administration or with interviewer assistance as needed. Each survey session lasted approximately 5–10 min.

2.3 Questionnaire and measures

The questionnaire was designed based on the Andersen Health Service Utilization Behavior Model, which categorizes influencing factors into three dimensions: predisposing characteristics, enabling resources, and need factors. The following key factors were assessed:

Predisposing characteristics: Demographic characteristics: Age, gender, marital status, education level; Social structure variables: Occupation, living arrangements and number of children; Health beliefs: Factors such as attitudes toward health care and health-seeking behaviors.

Enabling resources: Financial resources: Monthly income, pension, monthly medical expenses and insurance coverage; Social support: Support from children, caregivers, or other family members (life care and financial support); Access to services: The proximity of healthcare facilities and the availability of medical resources in the community (ease of accessing medical services).

Need factors: Self-care ability: the ability to perform activities of daily living independently; Chronic conditions: Number of chronic illnesses the individual is managing; Health status: Self-reported health condition (e.g., good, fair, or poor); Awareness of services: awareness of CB-IHSC and actual demand for such services.

Outcome variable: Demand for CB-IHSC.

Demand, as a key concept in this study, is defined as the actual need or desire for CB-IHSC. It was operationalized in the questionnaire by asking participants the following question: “Do you currently have a need for community-based integrated health and social care services?” The response options were “Yes” or “No.” This was captured as a binary variable: “1” for respondents expressing a need (demand) for the services, and “0” for those indicating no demand.

2.4 Statistical methods

Data were processed and analyzed using SPSS 22.0 software. After assigning values to variables, both univariate and multivariate analyses were conducted. Univariate analysis was conducted using chi-square tests to identify significant variables associated with service demand. Multivariate analysis was performed using binary logistic regression. The model fit was evaluated by the Hosmer–Lemeshow test. The dependent variable was demand for CB-IHSC, coded as a binary variable: “0” representing no demand and “1” representing demand. In the binary logistic regression model, the relationship between the independent variables and the log-odds of demand is modeled. Let P represent the model-estimated probability that an individual has a demand for the services (i.e., Prob(Y = 1)). The odds of demand is then defined as P / (1 − P). The odds ratio (OR) for each independent variable, as reported in the results, represents the factor by which the odds of demand multiply for a one-unit change in the predictor variable, while holding other variables constant. An OR greater than 1 indicates that the predictor variable is associated with an increased likelihood of demand for the services, while an OR less than 1 suggests a decreased likelihood. Ordered categorical variables (e.g., income, satisfaction, self-rated health, convenience) were treated as ordinal predictors in the regression; dichotomous variables were binary-coded; nominal multi-level variables used the reference categories specified in Table 1 and Appendix Table A1.

The hierarchical modeling approach was applied to assess how much additional variance in demand was explained by adding successive sets of factors. Three logistic regression models were constructed accordingly: Model 1 included statistically significant variables from the predisposing characteristics. Model 2 included significant variables from both predisposing and enabling factors. Model 3 included significant variables from all three dimensions: predisposing, enabling, and needs. Each model followed the general form. Changes in Cox & Snell R^2 and Nagelkerke R^2 were used to evaluate improvements in model fit, indicating how each block of variables contributed to explaining demand.

$$\text{Model1}: \text{logit}\left(p\right) = \alpha_1 + \beta_1 X_{\text{predisposing characteristics}} + \varepsilon_1$$

$$\text{Model2}: \text{logit}\left(p\right) = \alpha_2 + \beta_{21} X_{\text{predisposing characteristics}} + \beta_{22} X_{\text{enabling resources}} + \varepsilon_2$$

$$\text{Model3}: \text{logit}\left(p\right) = \alpha_3 + \beta_{31} X_{\text{predisposing characteristics}} + \beta_{32} X_{\text{enabling resources}} + \beta_{33} X_{\text{needs}} + \varepsilon_3$$

Where α is the intercept, β denotes the partial regression coefficients, X represents the independent variables, and ε is the residual error term not explained by the model.

2.5 Quality control

Before the formal survey, all research personnel underwent standardized training to ensure familiarity with the questionnaire

TABLE 1 Analysis of factors influencing the demand for CB-IHSC among older participants with different characteristics.

Blocks	Independent variable	Category	N	Demand for the services		p	Chi-square
				No	Yes		
Predisposing characteristics	Education (Ref: Junior high and below)	Junior high school and below	261	20	241	$p<0.001$	18.625
		Bachelor degree	74	8	66		
		Junior college	59	12	47		
		Senior school	100	22	78		
		Master degree and above	17	4	13		
	Number of children (Ref: 0)	0	98	24	74	$p<0.001$	17.044
		1	161	16	145		
		2	133	18	115		
		≥3	119	8	111		
	Living arrangement (Ref: Alone)	Alone	80	9	71	$p<0.001$	33.561
		Nursing institution or other	7	6	1		
		Living with spouse	274	32	242		
		Living with children	150	19	131		
	Pre-retirement occupation (Ref: Public institution personnel)	Public institution personnel	100	15	85	$p = 0.020$	11.687
		Farmer	163	10	153		
		Other	72	10	62		
		Enterprise staff	104	16	88		
		no job	72	15	57		

(Continued)

TABLE 1 (Continued)

Blocks	Independent variable	Category	*N*	Demand for the services		*p*	Chi-square
				No	Yes		
Enabling resources	Income per month (RMB) (Ref: <3,000)	3,000–5,000	149	26	123	*p*<0.001	17.533
		<3,000	273	20	253		
		>5,000	89	20	69		
	Acceptable cost of medicine (RMB) (Ref:<1,000)	1,000–2000	109	16	93	*p*<0.001	21.454
		<1,000	352	34	318		
		2000–3,000	33	12	21		
		≥3,000	17	4	13		
	Convenience of community medical care (Ref: Inconvenience)	Inconvenience	48	11	37	*p* = 0.015	8.385
		Convenience	284	27	257		
		General	179	28	151		
	Source of care at the time of consultation/hospitalization (Ref: None)	Partner care only	98	17	81	*p* = 0.032	10.558
		One other source of care only	20	0	20		
		Child and child's spouse care only	201	25	176		
		Two or more other sources of care	123	10	113		
		None	69	14	55		
	Sources of financial help in case of medical consultation/hospitalization (Ref: None)	Partner financial help only	70	13	57	*p* = 0.003	16.040
		One other kind of financial help only	29	8	21		
		Children and children's spouses' help only	186	17	169		
		Two and more kinds of other financial help	145	12	133		
		None	81	16	65		
	Children's support (Ref: Do not support)	Do not support	101	19	82	*p* = 0.049	3.891
		Support	410	47	363		
Need factors	Self-care ability (Ref: No self-care ability)	Need help from others	104	34	70	*p*<0.001	45.739
		No self-care ability	6	0	6		
		Have self-care ability	401	32	369		
	Self-rated health (Ref: poor)	Poor	52	13	39	*p*<0.001	12.102
		Good	149	10	139		
		Fair	310	43	267		
	Awareness of the CB-IHSC (Ref: Never heard)	Know well	28	8	20	*p* = 0.003	11.331
		Never heard	200	16	184		
		Heard but not understand	283	42	241		

Pearson chi-square tests are computed within each variable using the No/Yes counts. Ref = reference category used in regression. Degrees of freedom (df) by variable — Education: df = 4; Number of children: df = 3; Living arrangement: df = 3; Pre-retirement occupation: df = 4; Income per month (RMB): df = 2; Acceptable cost of medicine(RMB): df = 3; Convenience of community medical care: df = 2; Source of care at the time of consultation/hospitalization: df = 4; Sources of financial help in case of medical consultation/hospitalization: df = 4; children's support: df = 1; Self-care ability: df = 2; Self-rated health: df = 2; Awareness of the CB-IHSC: df = 2; Satisfaction with the CB-IHSC: df = 4. Ref as labeled; order does not imply reference status.

content and mastery of appropriate survey techniques. A pilot study was conducted to test the survey procedures, identify potential issues, and refine the questionnaire and the overall research plan. Based on feedback, adjustments were made to ensure the reliability and validity of the survey instrument and methodology.

3 Results

3.1 Basic characteristics of the respondents

3.1.1 Predisposing factors

A total of 511 older participants participated in the survey, comprising 154 males (30.14%) and 357 females (69.86%). The respondents ranged in age from 60 to 100 years, with the majority aged between 60 and 70 years(68.49%), followed by those aged 71–80 (18.20%), 81–90 (9.39%) and above 90 (3.91%). Regarding educational attainment, 261 respondents (51.08%) had completed junior high school or below, while 250 (48.92%) had received a high school education or higher, including college, university, and postgraduate degrees. In terms of marital status, 78.67% of the respondents were married or living with a spouse. Concerning the number of children, 98 individuals (19.18%) were childless; 161 (31.51%) had one child; 133 (26.03%) had two children; and 119 (23.29%) had three or more children. Regarding living arrangements, 80 respondents (15.66%) lived alone, 274 (53.62%) lived with a spouse, 150 (29.35%) lived with their children, and 7 individuals (1.37%) resided in nursing homes or other care facilities. As for occupational background prior to retirement, 100 respondents (19.57%) were public sector employees, 104 (20.35%) worked in enterprises, and 163 (31.90%) were farmers. In addition, 72 individuals (14.09%) were unemployed, while another 72 (14.09%) were engaged in various other occupations (see Table 2).

3.1.2 Enabling factors

Regarding monthly income, 29.16% of respondents reported earning between 3,000 and 5,000 RMB, 53.42% earning less than 3,000 RMB, and 17.42% earning more than 5,000 RMB. The primary source of income was retirement pensions (56.56%), followed by financial support from children (19.57%). Pension insurance coverage was high, with 95.50% of the respondents indicating they had it, and 71.62% of them also possessing medical insurance. Monthly medical expenses varied: 352 individuals (68.88%) spent less than 1,000 RMB, 109 (21.33%) spent between 1,000 and 2,000 RMB, 33 (6.46%) spent between 2,000 and 3,000 RMB, and 17 (3.33%) reported spending over 3,000 RMB. While the majority of respondents reported relatively easy access to medical care, 9.39% experienced difficulties in accessing treatment. In terms of care-giving support during outpatient visits or hospitalization, 201 individuals (39.33%) relied solely on their children or spouses; 123 (24.07%) had two or more sources of care; 98 (19.18%) were cared for only by a spouse; 20 (3.91%) relied on a single other caregiver, and 69 (13.50%) reported having no care-giving support. Regarding financial support for medical expenses, 186 respondents (36.40%) received assistance exclusively from their children or spouse; 145 (28.38%) had multiple financial support sources; 70 (13.70%) relied solely on their spouse; 29 (5.68%) relied on one other person, and 81 (15.85%) had no support from others in any form. When asked whether their children supported their participation in CB-IHSC, 410 individuals (80.23%) responded affirmatively, while 101 (19.77%) indicated a lack of support (see Table 2).

3.1.3 Need factors

About the Self-care ability, 401 respondents (78.47%) were entirely self-sufficient, 104 (20.35%) partially dependent, and 6 (1.17%) entirely dependent. Concerning chronic disease status, most respondents reported having at least one chronic condition, while only 26.03% of them reported having no chronic illnesses. In terms of self-rated health status, 310 respondents (60.67%) considered their health to be good, 149 (29.16%) rated it as fair, and 52 (10.18%) assessed their health as poor. s of CB-IHSC was generally low: 283 individuals (55.38%) had heard of the model but lacked a clear understanding; 200 (39.14%) had never heard of it; and only 28 (5.48%) reported being very familiar with it. When asked about their need for CB-IHSC, 445 respondents (87.08%) expressed a clear demand, while 66 (12.92%) indicated no current need.

3.2 Analysis of factors influencing the demand for CB-IHSC with different characteristics

To identify variables significantly associated with the demand for CB-IHSC, bivariate analyses were performed using Chi-square tests for all predisposing, enabling, and need factors. As an example, Appendix Table A2 presents the cross-tabulation and Chi-square analysis between the convenience of community medical care and service demand. The analysis revealed a statistically significant association between these two variables ($\chi^2 = 8.385$, $p = 0.015$). The demand for CB-IHSC was highest (90.5%) among older adults who reported "Convenience" in accessing community medical care, followed by those reporting "General" convenience (87.3%). In contrast, the group reporting "Inconvenience" showed a comparatively lower demand rate (77.1%). This gradient suggests that better accessibility to local medical care is positively associated with a higher demand for integrated health and social care services. Following this approach, significant variables ($p < 0.05$) identified from the comprehensive bivariate screening are summarized in Table 1 below.

Among the predisposing factors, significant variables such as education, number of children, living arrangements, and occupation were found to have a statistically significant impact on the demand for CB-IHSC ($p < 0.05$). In terms of enabling factors, variables including income per month, acceptable cost of medicine, convenience of community care, sources of daily care and financial assistance during outpatient visits or hospitalization, as well as children's support for CB-IHSC, were identified as significant factors ($p < 0.05$). For need factors, self-care ability, self-rated health, awareness of CB-IHSC were all statistically significant ($p < 0.05$), as seen in Table 1.

3.3 Logistic regression analysis

As demonstrated in Table 3, Model 3 (269.736) exhibited the lowest −2 log-likelihood value compared to Models 1 (348.491) and 2 (323.742). The smaller the −2 Log Likelihood, the better the model fit, indicating lower model error and better overall performance. The Cox & Snell R^2 value for Model 3 was 0.215, which was higher than the values for Model 1 (0.084) and Model 2 (0.138). The Nagelkerke R^2 value for Model 3 was 0.400, also surpassing that of Model 1

TABLE 2 Sample characteristics.

Variable	Category	*N*	Proportion (%)
Gender	Male	154	30.14%
	Female	357	69.86%
Age	60–70	350	68.49%
	71–80	93	18.20%
	81–90	48	9.39%
	>90	20	3.91%
Education	Junior high school and below	261	51.08%
	Senior school	100	19.57%
	Junior college	59	11.55%
	Bachelor degree	74	14.48%
	Master degree and above	17	3.33%
Marital status	No partner	109	21.33%
	Partnered	402	78.67%
Number of children	0	98	19.18%
	1	161	31.51%
	2	133	26.03%
	≥3	119	23.29%
Living arrangement	Alone	80	15.66%
	Nursing institution or other	7	1.37%
	Living with spouse	274	53.62%
	Living with children	150	29.35%
Pre-retirement occupation	Public institution personnel	100	19.57%
	Farmer	163	31.90%
	Other	72	14.09%
	Enterprise staff	104	20.35%
	No job	72	14.09%
Income per month (RMB)	3,000–5,000	149	29.16%
	<3,000	273	53.42%
	>5,000	89	17.42%
Source of Income	Other	61	11.94%
	Retirement pension	289	56.56%
	Business income	51	9.98%
	Government Aid	10	1.96%
	Children's Provision	100	19.57%
Pension insurance	No	23	4.50%
	Yes	488	95.50%
Medical insurance	No	145	28.38%
	Yes	366	71.62%
Acceptable cost of medicine (RMB)	<1,000	352	68.88%
	1,000–2000	109	21.33%
	2000–3,000	33	6.46%
	≥3,000	17	3.33%

(Continued)

TABLE 2 (Continued)

Variable	Category	*N*	Proportion (%)
Convenience of community medical care	Inconvenience	48	9.39%
	Convenience	284	55.58%
	General	179	35.03%
Source of care at the time of consultation/hospitalization	Partner care only	98	19.18%
	One other source of care only	20	3.91%
	Child and child's spouse care only	201	39.33%
	Two or more other sources of care	123	24.07%
	None	69	13.50%
Sources of financial help in case of medical consultation/hospitalization	Partner financial help only	70	13.70%
	One other kind of financial help only	29	5.68%
	Children and children's spouses' help only	186	36.40%
	Two and more kinds of other Financial help	145	28.38%
	None	81	15.85%
Children's support	Do not support	101	19.77%
	Support	410	80.23%
Self-care ability	Need help from others	104	20.35%
	No self-care ability	6	1.17%
	Have self-care ability	401	78.47%
Have chronic disease	0	133	26.03%
	1	180	35.23%
	2	135	26.42%
	≥3	63	12.33%
Self-rated health	poor	52	10.18%
	Good	149	29.16%
	Fair	310	60.67%
Awareness of the CB-IHSC	Know well	28	5.48%
	Never heard	200	39.14%
	Heard but not understand	283	55.38%
Satisfaction with CB-IHSC	Comparatively satisfied	96	18.79%
	Not very satisfied	60	11.74%
	Very dissatisfied	28	5.48%
	Very satisfied	20	3.91%
	General	307	60.08%
Demand for the services	Yes	445	87.08%
	No	66	12.92%

Percentages are of the total sample; rounding may cause totals to differ from 100%.

TABLE 3 Model fit statistics.

Model	−2 Log Likelihood	Cox & Snell R^2	Nagelkerke R^2
Model 1	348.491	0.084	0.156
Model 2	323.742	0.138	0.257
Model 3	269.736	0.215	0.400

(0.156) and Model 2 (0.257). The Nagelkerke R^2 increased from 0.156 (Model 1) to 0.257 (Model 2) and 0.400 (Model 3), indicating a progressive improvement in explanatory power as additional factors were included. The larger the Cox & Snell R^2 and Nagelkerke R^2 values, the better, as they represent a higher proportion of variance explained by the model. Model 3 has the lowest −2 Log

Likelihood, and both the Cox & Snell R^2 and Nagelkerke R^2 are the highest, indicating the best fit. Additionally, from Model 1 to Model 2, the Nagelkerke R^2increased by 0.101. From Model 2 to Model 3, the Nagelkerke R^2 increased by 0.143, which is the largest improvement, confirming the most significant contribution of need-related variables and suggesting that these factors have the strongest influence in explaining the dependent variable. Therefore, Model 3 is the optimal model.

As shown in Table 4, the *p*-values for Model 1 ($p = 0.085$), Model 2 ($p = 0.135$), and Model 3 ($p = 0.413$) were all greater than 0.05. Furthermore, the Hosmer-Lemeshow test also yielded p-values above 0.05, suggesting that the data extraction process was sufficient and that the model specification was appropriate. Among the models, Model 3 demonstrated the highest level of significance and the best overall fit. Therefore, Model 3 was selected for binary logistic regression analysis to examine how much each factor influences the demand for CB-IHSC among older participants.

Based on the results from Model 3, variables including the number of children, living arrangements, income per month, convenience of community care, support's children, self-care ability, self-rated health, and awareness of the CB-IHSC were all found to be statistically significant ($p < 0.05$). These factors were identified as significantly impacting older participants' demand for CB-IHSC. Detailed results are presented in Table 5.

TABLE 4 Hosmer–Lemeshow goodness-of-fit test.

Model	χ^2	df	Sig.
Model1	13.893	8	0.085
Model2	12.377	8	0.135
Model3	15.988	8	0.413

4 Discussion

4.1 The demand for the CB-IHSC

The results of this study indicate a strong demand for CB-IHSC among older adults in Chengdu. Specifically, 87.08% of the respondents reported a need for such services, which is comparable to the demand level in Guangzhou (86.2%) (3) and slightly higher than that in Luzhou (66.3%) (2).

This elevated demand in Chengdu can be effectively interpreted through the Andersen Health Service Utilization Behavior Model. The city's proactive policy support and investment in CB-IHSC complexes and creating a "15-min convenient living circle" have directly enhanced Enabling Resources by improving the accessibility and availability. Our findings confirm that convenient of community medical is a significant positive predictor of demand (OR = 1.747). Simultaneously, these government-led initiatives have shaped Predisposing Characteristics, particularly health beliefs, by raising public awareness and fostering a more positive attitude toward integrated care models. This is corroborated by our regression results, which identified awareness of CB-IHSC as a key driver of demand (OR = 2.155). Therefore, the high demand in Chengdu is not merely an external phenomenon but is likely mediated by the model's core components: policy efforts improve enabling resources and shape predisposing characteristics, which in turn, as our model demonstrates, significantly influence the expressed demand for CB-IHSC.

TABLE 5 Logistic regression analysis including variables associated with CB-IHSC demand for the old adults.

Independent variable	B	*p*	OR	95% CI (Lower)	95% CI (Upper)
Education (Ref: Junior high and below)	0.090	0.608	1.09	0.78	1.55
Number of children (Ref: 0)	0.752	0.001	2.12	1.34	3.35
Living arrangement (Ref: Alone)	−0.741	0.011	0.48	0.27	0.85
Pre-retirement occupation (Ref: Public institution personnel)	−0.075	0.607	0.93	0.70	1.23
Income per month (RMB) (Ref: ><3,000)	−0.915	0.001	0.40	0.23	0.70
Acceptable cost of medicine (RMB) (Ref:<1,000)	−0.408	0.057	0.67	0.44	1.01
Convenience of community medical care (Ref: Inconvenience)	0.558	0.041	1.75	1.02	2.98
Source of care at the time of consultation/hospitalization (Ref: None)	0.073	0.611	1.08	0.81	1.42
Sources of financial help in case of medical consultation/hospitalization (Ref: None)	−0.145	0.290	0.87	0.66	1.13
Children's support (Ref: Do not support)	1.310	0.003	3.71	1.55	8.85
Self-care ability	−1.745	0.001	0.18	0.08	0.38
Self-rated health (Ref: No self-care ability)	−1.089	0.002	0.34	0.17	0.67
Awareness of CB-IHSC (Ref: Never heard)	0.767	0.022	2.16	1.12	4.14
Satisfaction with CB-IHSC (Ref: Very dissatisfied)	0.013	0.948	1.01	0.68	1.51

OR, odds ratio; CI, confidence interval. Precision standardized (B: 3 decimals; OR/CI: 2 decimals; p: 3 decimals or "<0.001").

4.2 Factors influencing demand

A key strength of this study is the hierarchical regression grounded in the Andersen Health Service Utilization Behavior Model, which allowed us to assess pre-specified hypotheses about the relative importance of factor domains. The results largely supported our hypotheses, yet several findings provided new insights. The data suggest that multiple factors—predisposing, enabling, and need factors—affect the demand for CB-IHSC among older adults in Chengdu. Specifically, the number of children and living arrangements were identified as significant predisposing factors; income, convenience of community medical care, and children's support as enabling factors; and self-care ability, self-rated health, and awareness of CB-IHSC as key need factors. Each of these is discussed below.

4.2.1 The composite role of children: quantity and support

Among the predisposing characteristics, the association between the number of children and higher demand for CB-IHSC (OR = 2.12) is one of our most surprising yet insightful findings. This is contrary to our H4 regarding the number of children. This positive relationship contrasts with the initial intuition that more children would substitute for formal services, as well as with the results of Xu Haijiao, who reported an inverse relationship between the number of children and demand for CB-IHSC suggesting that fewer children correlate with higher demand (17). Similarly, Li Qiang found that an increased number of children was associated with lower life satisfaction and higher levels of depression among their parents, indicating that more children do not necessarily bring more happiness (18). In families with multiple children, care responsibilities may be neglected or deferred, leaving older adults' care needs unmet and prompting them to seek alternative models such as CB-IHSC.

As hypothesized in H4, regarding the support from children, it appears to be a significant positive factor influencing demand (OR = 3.71), aligning with the findings of Tan Mei and colleagues (19). When children express understanding and support for CB-IHSC, older adults' confidence and demand for these services increase. Material and emotional support from children not only eases financial burdens but also reinforces the psychological readiness of older adults to adopt new care models.

This divergence finding underscores that the decision to utilize CB-IHSC is not solely determined by the structural aspect of family size (number of children), but is more significantly influenced by the functional aspect—the quality and nature of the support those children provide. A plausible explanation is that structural family size (quantity) does not translate into functional support unless accompanied by children's active support (an enabling resource). Our analysis suggests the enabling dimension—children's support for participation—shows a strong positive association with demand, indicating that who helps and how may matter more than how many children one has.

4.2.2 Living arrangements

Living arrangements may influence the demand for the CB-IHSC with solitary living potentially linked to higher demand. Studies have shown that empty-nest older adults exhibit a hierarchical needs structure, prioritizing medical care, emotional support, and basic life assistance (20). Due to declining physical functions, older adults often require greater medical support and daily care. The CB-IHSC provide continuous support, such as health check-ups, rehabilitation, in-home care, and life assistance, which help meet these needs. Additionally, older adults living alone are more likely to experience loneliness and insecurity, increasing their reliance on CB-IHSC for social interaction and emotional support. Thus, as the number of cohabitants decreases, the demand for CB-IHSC tends to increase. This finding partially supports H5, which hypothesized that co-residence with family reduces demand due to informal care. However, the quality of family support is crucial; older individuals with limited or no caregiving capacity from family may still require formal care. Therefore, while co-residence often reduces demand, the need for CB-IHSC remains higher among those living alone, where informal care is insufficient.

4.2.3 Monthly income

Contrary to hypothesis H3, monthly income was negatively associated with the demand for integrated care services. As income increases, the likelihood of choosing CB-IHSC decreases. This contradicts the findings of Nie Jie, who suggested that individuals with higher socioeconomic status were more likely to choose such services (21). However, the current results align with Zhi Mengjia and Xue Yuan, who found that higher-income individuals were more inclined to choose institutional care, while those with lower incomes preferred community or home-based care models (22, 23). This may be because traditional institutional care facilities have undergone years of development and offer better amenities and more comprehensive services, attracting wealthier older adults. In contrast, community-based care, which is more affordable, tends to appeal to those with lower incomes. The CB-IHSC is still relatively new and under development, so high-income individuals may remain cautious or hesitant to adopt it.

4.2.4 Convenience of community medical care

As predicted by H2, the ease of accessing medical services within the community may influence demand, with more convenient access potentially linked to greater demand. This finding is consistent with the results of Lü Xinrui (24). When nearby medical institutions are available, frequent needs such as medication, follow-up visits, and basic nursing care can be addressed locally, thereby reducing travel time, financial costs, and physical risks (such as falls) associated with hospital visits. The convenient of community medical care enhances older adults' trust in and reliance on CB-IHSC, thus increasing their willingness to use these services.

4.2.5 Self-care ability and self-rated health

Self-care ability and health condition were strongly associated with demand for CB-IHSC. Poorer self-rated health may be associated with an increase in demand, consistent with H1. Physical function typically declines as people age, resulting in reduced self-care ability. Older adults with poorer health and lower levels of independence—particularly those who are semi-dependent or disabled—tend to have a higher demand for integrated care services compared to those who are self-sufficient. These findings are consistent with the study by Lin Qin (25). The CB-IHSC offers personalized care plans according to varying levels of dependency, covering both basic daily needs and professional medical care. This model remains applicable even as the health status of older adult's changes, ensuring that their evolving care needs are effectively met.

4.2.6 Awareness of the CB-IHSC

As expected and in support of H6, a positive correlation was observed between the level of awareness of the CB-IHSC and the demand for the services. Higher awareness may be linked to a greater intent to participate (26), aligning with the research of Zhang Yujie (27). In this study, only 28 respondents reported a comprehensive understanding of CB-IHSC; 283 had heard of it but did not understand it, and 200 reported never having heard of it. These findings indicate limited dissemination and awareness of CB-IHSC.

4.3 Limitations

This study has several limitations that should be considered when interpreting the results. First, the use of convenience sampling in main urban areas, while practical, means that our sample may not be fully representative of all older adults in Chengdu, particularly those in suburban or rural districts, or those who are completely home-bound and do not access community health services. Consequently, the applicability of our findings to the entire older population of Chengdu or other regions of China may be limited. Second, the cross-sectional design captures a snapshot in time and cannot establish causal relationships between the factors and service demand.

5 Conclusion and policy recommendations

This study identifies the factors influencing the demand for CB-IHSC among older adults in Chengdu. With the aging population and rising demand for CB-IHSC, it is critical to bridge gaps in service availability, accessibility, and awareness. Based on these findings, the following policy recommendations are proposed.

5.1 Improve service accessibility and quality

Efforts could be directed toward enhancing the accessibility and quality of CB-IHSC. Expanding and upgrading community-based facilities may contribute to equitable distribution and comprehensive coverage. CB-IHSC might be further developed by strengthening cooperation between community health centers and care institutions for older adults. Standardized protocols for service delivery, health management, and emergency response should be established to ensure continuity, safety, and effectiveness of care. Professional staff training could also be prioritized to improve service capacity.

5.2 Tailor services to individual needs

Given the varying health conditions, economic statuses, and family support structures of older adults, it is crucial to provide personalized and differentiated services. For instance, semi-dependent or disabled older adults may require more intensive medical and nursing support. At the same time, independent individuals may benefit more from health education, regular check-ups, and social activities. By implementing needs-based stratification and care planning, service efficiency and user satisfaction can be significantly improved.

5.3 Enhance family and social support systems

Family support remains a key enabling factor in older adults' decisions to utilize integrated care services. Therefore, it is essential to strengthen the role of families in eldercare through policy incentives such as tax benefits, subsidies, or caregiver training programs. At the same time, community-based support networks could be developed to provide supplemental care and companionship, particularly for solitary or empty-nest older adults. Volunteer programs, inter-generational activities, and mutual-aid models may effectively complement formal care services.

5.4 Promote policy innovation and support

Local governments may continue to play a leading role by formulating long-term strategic plans and introducing targeted policies to support the development of CB-IHSC. It is crucial to increase financial investment, expand pilot programs, and disseminate best practices across communities. Furthermore, enhancing cross-sectoral coordination among departments such as health, civil affairs, and housing could support the sustainable development of these services. Additionally, promotional efforts should be enhanced using community bulletin boards, cultural events, and digital platforms (such as official WeChat accounts) to raise awareness and provide detailed information on available services. Increasing public understanding is essential to improving participation and ensuring that more older adults benefit from integrated care.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

HZ: Funding acquisition, Writing – original draft, Writing – review & editing. MY: Data curation, Formal analysis, Writing – review & editing. QZ: Investigation, Resources, Writing – review & editing. SL: Validation, Visualization, Writing – review & editing. PL: Funding acquisition, Methodology, Writing – review & editing, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Analysis of factors influencing the burden on family caregivers of disabled older adults in Guangzhou

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Objective: This study aims to investigate the current status of disability among older adults and analyze factors influencing the burden on their family caregivers in southern China.
Methods: A cross-sectional survey was conducted among 334 pairs of disabled older adults (≥65 years) and their primary family caregivers across three districts in Guangzhou. Face-to-face interviews using standardized questionnaires assessed disability levels via the "Long-term Care Disability Level Assessment" scale and caregiver burden via the Zarit Burden Interview (ZBI) scale. For ordinal variables, the Kruskal-Wallis H test was applied for multi-group comparisons, while the Mann–Whitney U test was used for two-group analyses. Statistical significance was set at $p < 0.05$. Ordinal logistic regression identified factors associated with caregiver burden.
Results: Among 334 disabled older adults in Guangzhou, the mean age was 82 years. Of these, 55.7% were married, 43.4% were male, 43.4% had an educational attainment of primary school or below. For the 334 family caregivers, 62.3% were female, 36.8% had completed high school or vocational education. The median years of caregiving experience was 5 years, with a median weekly caregiving time of 70 h. Caregiver burden distribution was as follows: 16.2% no burden, 41.0% mild burden, 28.7% moderate burden, and 14.1% severe burden. Statistically significant differences in caregiver burden were observed across the following variables ($p < 0.05$): disabled old adults' activities of daily living (ADL), caregivers' gender, child in school, physical disease, years of caregiving experience, weekly caregiving time, social interaction frequency, life satisfaction, and social support network size. Higher caregiver life satisfaction and elevated ADL scores in care recipients emerged as protective factors. Conversely, longer weekly caregiving hours and caregivers' physical illness were identified as risk factors.
Conclusion: This study identifies weekly caregiving time, caregivers' physical disease, disabled older adults' ADL capacity, and caregivers' life satisfaction as critical determinants of burden severity in aging China, advocating multilevel interventions.

KEYWORDS

old adult, disability, family caregivers, caregiving burden, influencing factors

1 Introduction

In 2011, the World Health Organization (WHO) defined disability as an umbrella term encompassing impairments, activity limitations, and participation restrictions (1). According to the Seventh National Population Census, individuals aged 60 and above account for 18.7% of China's total population, reflecting a 5.44% increase compared to the Sixth National Population Census. Within this aging population, a significant proportion of older adults experience disability due to aging, chronic diseases, or other factors.

In traditional Chinese culture, filial piety encourages older adults to age at home rather than in institutional care settings. Research based on the China Health and Retirement Longitudinal Study dataset indicates that family-based care remains predominant in China (2). A research shows that 5.9% of disabled old adults in rural China report receiving formal care, while the proportion in urban areas is 36.9% (3). Disability restricts mobility, narrows social interactions, and exacerbates psychological issues such as anxiety and depression among older adults (4). However, disability not only severely impacts the quality of life of older adults but also imposes substantial burdens on their family caregivers. In 1986, Zarit et al. (5) defined caregiver burden as the perceived deterioration of caregivers' emotional or physical health, social life, and financial status resulting from providing care to relatives.

A review on caregiver support highlights that caregiving adversely affects caregivers' physical and mental health, exposing them to risks such as reduced quality of life and heightened isolation (6). Furthermore, disabled older adults often require long-term medical and daily care, leading to high healthcare costs, rehabilitation expenses, and family caregiving expenditures, which significantly strain household finances. Prolonged caregiving may also trigger familial conflicts and strain interpersonal relationships. At the societal level, the growing aging population and rising prevalence of disability among older adults intensify pressure on healthcare systems. Long-term care, rehabilitation, and management of disability-related complications demand substantial medical resources, increasing service demands and exacerbating resource allocation challenges. Direct and indirect economic costs associated with disability—including household and national medical expenditures, long-term care costs, and investments in aging-related infrastructure—amplify the burden on social security systems. Andrew Kingston et al. (7) found that increased survival years among older populations impose significant strains on public health systems.

As the capital of Guangdong Province, Guangzhou is a core metropolis in this populous region, hosting a large aging population. The Seventh National Population Census reports that 2,130,600 individuals in Guangzhou (11.41% of its population) are aged 60 or older, marking a 1.67 percentage-point increase compared to the 2010 census. The old urban areas of Guangzhou have entered a phase of deep aging. With accelerating population aging, the number of disabled older adults continues to rise annually. Comorbidities such as hypertension and diabetes among disabled older adults further escalate medical demands, posing significant challenges to the city's healthcare system and necessitating more equitable resource allocation. By the end of 2022, Guangzhou had 195,700 healthcare professionals (a 4.26% increase) and 110,500 hospital beds (a 3.75% increase). Despite these improvements in healthcare resources, persistent issues such as uneven resource distribution, shortages of specialized care professionals, and gaps in long-term care insurance systems hinder Guangzhou's capacity to fully address the growing disabled population. As a major economically developed and densely populated city in China, Guangzhou's challenges in managing the burden on disabled older adults and their family caregivers exemplify the broader societal struggles posed by aging populations.

2 Method

2.1 Sample size calculating

The formula for sample size calculation is: $n = \frac{Z^2_{\frac{\alpha}{2}} P(1-P)}{d^2} \times \text{deff}$. p = 20.8% (8), $\alpha = 0.05$, $d = 0.05$, Deff = 1.3. The sample size was calculated to be 320, meaning that at least 320 pairs of disabled old adults and their family caregivers need to participate in the study.

2.2 Participant recruitment

Guangzhou's acknowledged regional development hierarchy comprises established downtown, new urban districts, inner suburbs and outer suburbs. Considering sample representativeness and research resources (time, funding, personnel), we randomly selected one district each from established downtown, new urban districts, and inner suburbs. From each district, 100–150 disabled older adults and their family caregivers were randomly selected for surveying. 343 pairs of disabled old adults and their family caregivers were invited to participate in the study. 9 pairs subsequently withdrew from the study. The final analytical sample thus comprised 334 pairs who completed the full study protocol. Through collaboration with community health service centers in the sampled areas, initial telephone contact was made with households containing adults aged ≥65 years. After explaining the study's purpose and significance, preliminary eligibility screening was conducted with both older adults and their caregivers. Those meeting all inclusion/exclusion criteria were formally invited to participate in this study. Data collection involved two-person interviewer teams conducting in-home, face-to-face interviews using paper-based questionnaires.

The inclusion criteria for disabled old adults were as follows: aged 65 years or older and assessed as disabled. The exclusion criteria included congenital disability or disability resulting from accidental injuries. For participants who met any of the following conditions, part of the questionnaire was completed by a family caregiver familiar with their situation: those with acute illnesses or chronic diseases in acute exacerbation; those with severe or terminal illnesses; those with severe cognitive impairments (e.g., Alzheimer's disease, mental illnesses); and those with hearing impairments or other conditions that prevented effective communication.

The inclusion criteria for family caregivers were as follows: being a family member and the primary caregiver of the disabled old adults. The exclusion criteria included inability to complete the survey or unwillingness to cooperate fully during the survey process.

This study was reviewed and approved by the Ethics Committee of the Guangzhou Center for Disease Control and Prevention (Approval Number: GZCDC-ECHR-2023P0081). Informed consent was obtained from all participants.

2.3 Assessment of disability

This study employed the Long-term Care Disability Level Assessment standard issued by the China Healthcare Security Administration to comprehensively evaluate the disability status and severity of older adults individuals across three domains: activities of daily living (ADL), cognitive ability, and sensory and communication abilities.

Activities of Daily Living (ADL): The ADL assessment evaluates 10 daily activities: facial and oral hygiene, bathing, eating, dressing, bowel control, bladder control, toileting, stair climbing, walking on flat ground, and transferring between bed and chair. Based on the total score, the ability to perform daily activities is categorized into three levels: severe impairment (0–40 points), moderate impairment (45–60 points), and mild impairment (65–95 points).

Cognitive Ability: Cognitive function was evaluated across four dimensions: time orientation, spatial orientation, person orientation, and memory. Each dimension was scored on a 0–4 scale, with lower scores reflecting poorer performance. Total scores classified cognitive ability into four levels: severe impairment (0–1 points), moderate impairment (2–3 points), mild impairment (4–15 points), and no impairment (16 points).

Sensory and Communication Abilities: This domain assessed vision, hearing, and communication ability, with each aspect scored on a 0–4 scale (lower scores indicating poorer ability). Total scores categorized sensory and communication abilities into four levels: severe impairment (0–1 points), moderate impairment (2–3 points), mild impairment (4–11 points), and no impairment (12 points).

The Long-term Care Disability Level Assessment categorizes disability into six grades based on scores in activities of daily living (ADL), cognitive ability, and sensory and communication abilities: mild, moderate, and severe (with severe disability further divided into Grades 1, 2, and 3). In this study, disability severity was consolidated into three levels: mild, moderate, and severe, with all severe subgrades (Grades 1–3) classified uniformly as severe disability.

2.4 Assessment of caregiver burden

Caregiver burden was evaluated using the Zarit Burden Interview (ZBI) scale (9), a psychometric instrument developed by Zarit et al. in the early 1980s to assess the multidimensional burden experienced by long-term caregivers of individuals with chronic illnesses. The ZBI quantifies physiological, psychological, social, and economic burdens arising from caregiving responsibilities.

This scale comprehensively addresses critical aspects of caregiver burden, including physical and mental health, social engagement, and financial strain. Each item is rated on a 5-point Likert scale: Never (0), Rarely (1), Sometimes (2), Often (3), and Always (4). Caregivers self-report their experiences based on subjective perceptions, with higher scores indicating greater burden severity. Total scores range from 0 to 88, categorized as follows: No burden(0–19points), Mild burden (20–39points), Moderate burden(40–59points), Severe burden (60–88points).

2.5 Survey content

This study collected the following characteristics of disabled old adults: age, gender, marital status, educational attainment, monthly household income per capita, the number of diseases, activities of daily living (ADL), cognitive ability, sensory and communication abilities, long-term care insurance, disability certificate. For family caregivers, variables included age, gender, marital status, educational attainment, occupation, child in school, relationship to the disabled old adults, physical diseases, hired nurse, acquisition of caregiving knowledge/skills, years of caregiving experience, weekly caregiving time, social interaction frequency, life satisfaction, and social support network size.

2.5.1 Variable classifications

Gender: Male or female.

Marital status: Married, widowed, or others.

Educational attainment: Primary school or below, junior high school, senior high school/technical secondary school, or college degree and above.

Monthly household income per capita: <¥1,000; ¥1,000–2,999; ¥3,000–4,999; ¥5,000–9,999; ≥¥10,000.

The number of diseases: 0 ~ 2, 3 ~ 6, ≥7.

Activities of daily living (ADL): mild impairment, moderate impairment, severe impairment.

Cognitive ability: no impairment, mild impairment, moderate impairment, severe impairment.

Sensory and communication abilities: no impairment, mild impairment, moderate impairment, severe impairment.

Long-term care insurance: yes, no.

Disability certificate: yes, no.

Occupation: Retired, laborer/farmer/part-time worker, unemployed, or others.

Child in school: yes, no.

Relationship to care recipient: Spouse, child/grandchild, or others.

Physical disease: yes, no. (Family caregivers experiencing physical disease in this study reported no limitations in their daily activities due to their disease.)

Hired nurse: yes, no.

Acquisition of caregiving knowledge/skills: yes, no.

Years of caregiving experience: 0–5 years; >5 years.

Weekly caregiving time: 0–30 h; 31–60 h; >60 h.

Social interaction frequency: Daily or 1–6 times weekly; 1–3 times monthly; 1–11 times annually; never.

Life satisfaction: Very satisfied, mostly satisfied, neutral, dissatisfied, or very dissatisfied.

Social support network size: 0 individuals; 1–2 individuals; 3–5 individuals; ≥6 individuals.

2.6 Data analysis

This study utilized the EPiData software for parallel double-entry data management, converting paper-based questionnaires into electronic formats. Discrepancies between the two data entries were systematically compared and rectified through verification to ensure data accuracy and completeness. Personal identifiers (e.g., names and ID numbers) were replaced with anonymous codes during data entry to uphold privacy protection and confidentiality principles.

The dataset underwent rigorous logical consistency checks to identify contradictions or implausible values. Missing data were addressed via multiple imputation or median substitution, with explicit documentation of imputation status. Outliers were identified and processed by consulting field investigators to verify authenticity, followed by corrections to maintain data validity and reliability.

Categorical variables were summarized as frequencies and percentages. For ordinal variables, the Kruskal-Wallis H test was applied for multi-group comparisons, while the Mann–Whitney U test was used for two-group analyses. Statistical significance was set at $p < 0.05$. Multivariable ordered logistic regression was employed to assess associations. All statistical analyses were performed using IBM SPSS Statistics 26.

2.7 Quality control protocol

Questionnaire Design Phase: Scientific content validity was ensured through unambiguous items with exhaustive response options; iterative refinement occurred post-pilot testing.

Sampling Phase: Randomized sampling procedures were strictly implemented, with rigorous application of inclusion/exclusion criteria.

Training Phase: Surveyors responsible for scheduling mastered: (1) appointment protocols, (2) functional disability assessment methods. Field interviewers demonstrated competency in: (1) communication techniques, (2) standardized assessment, (3) instrument administration, (4) sensitive issue handling, and (5) professional etiquette. Certification through competency assessment was mandatory prior to fieldwork. Burden assessments required caregiver evaluation in the absence of care recipients to minimize response bias.

Field Implementation: Dyadic interviewer teams conducted home visits, performing real-time cross-verification to ensure data fidelity.

Data Management: (1) Daily completeness audits with immediate remediation of missing data; (2) Double-blind electronic data entry with consistency reconciliation; (3) Logic checks, outlier handling, and error correction protocols.

3 Results

Among the 334 disabled old adults, the mean age was 82 years. Disability severity was distributed as follows: mild disability (106 cases, 31.7%), moderate disability (67 cases, 20.6%), and severe disability (161 cases, 48.2%). Among their family caregivers, the mean age was 64 years, with caregiver burden levels categorized as no burden (54 cases, 16.2%), mild burden (137 cases, 41.0%), moderate burden (96 cases, 28.7%), and severe burden (47 cases, 14.1%).

As shown in Table 1, caregiver burden significantly differed across activities of daily living (ADL) levels among disabled older adults individuals ($p < 0.05$). Similarly, Table 2 demonstrates statistically significant variations in caregiver burden among family caregivers based on gender, years of caregiving experience, weekly caregiving hours, physical disease, social interaction frequency, life satisfaction, and social support network size (all $p < 0.05$).

An ordinal logistic regression analysis was conducted with caregiver burden in Guangzhou City as the dependent variable (0 = no burden, 1 = mild burden, 2 = moderate burden, 3 = severe burden) and nine independent variables: activities of daily living (ADL) of disabled old adults, caregivers' gender, presence of school-aged children, caregiving duration (years), daily care hours, physical health conditions, social engagement frequency, life satisfaction, and social support. The parallel lines test demonstrated model adequacy ($\chi^2 = 35.782$, $p = 0.572$). As shown in Table 3, better ADL(OR = 0.992, 95% CI = 0.984–0.999) in old adults and caregivers' better life satisfaction(very satisfied: OR = 0.063, 95% CI = 0.018–0.213; mostly satisfied: OR = 0.179, 95% CI = 0.068–0.0469; neutral: OR = 0.266, 95% CI = 0.102–0.695) emerged as protective factors against caregiver burden. Conversely, longer daily caregiving time(OR = 1.009, 95% CI = 1.002–1.015) and caregivers' physical illnesses(OR = 1.642, 95% CI = 1.057–2.552) were identified as significant risk factors for elevated burden levels.

4 Discussion

This survey revealed that 47.9% of older adults with disabilities in Guangzhou exhibited severe limitations in activities of daily living (ADL). Comparatively, a study of community-dwelling older adults aged 70 and above in the United States reported a higher severe disability rate of 65.2% (10). The proportion of family caregivers experiencing moderate-to-severe burden in Guangzhou reached 42.8%, contrasting with findings from Shanghai, where a study of disabled older adults and their family caregivers documented a 24.95% prevalence of moderate-to-severe caregiver burden (11), indicating regional disparities in caregiver burden intensity. In this study, female family caregivers accounted for 62.3% of the total. Another survey on older adults individuals with disabilities conducted in communities in eastern China revealed a similar pattern, with female family caregivers comprising 66.7% of the sample (12).

Multivariate ordered logistic regression analysis identified longer weekly caregiving time as a significant risk factor. A Taiwan-based study of 2,439 caregivers demonstrated that those utilizing respite services (defined as structured programs providing caregivers with scheduled rest and recreational time) for over 14 days experienced substantially reduced caregiving burden compared to non-users (13). A study conducted in Japan targeting 82 family caregivers of older adults individuals with disabilities demonstrated that family caregiving services contributed to reducing the burden on caregivers (14). These findings underscore the necessity for governmental coordination of community resources, including neighborhood committees, volunteer networks, senior care service centers, and older adults associations, to establish comprehensive service systems. Implementation of daytime care services and structured respite programs could effectively reduce caregivers' daily time commitment, enabling temporary relief from continuous caregiving responsibilities.

ADL capacity emerged as a protective factor against caregiver burden, aligning with findings from Nardi et al. (15). Strategic interventions should prioritize enhancing disabled older adults' functional independence through rehabilitation training and assistive device implementation. Concurrent measures to prevent disability progression include regular health screenings for early detection of treatable conditions, coupled with encouragement of

TABLE 1 Comparison of caregiver burden of disabled older adults with different characteristics in Guangzhou.

Variables	Classification	Number of Participants	No Burden (n = 54) %		Mild Burden (n = 137) %		Moderate Burden (n = 96) %		Severe Burden (n = 47) %		*Z/H*	*p*值
Gender	Male	145	17	11.7	58	40.0	49	33.8	21	14.5	−1.556	0.120
	Female	189	37	19.6	79	41.8	47	24.9	26	13.8		
Age	65 ~ 80 years	154	22	14.3	57	37.0	46	29.9	24	15.6	−1.255	0.210
	≥81 years	180	32	17.8	80	44.4	50	27.8	23	12.8		
Marital status	Married	186	28	15.1	75	40.3	57	30.6	26	14.0	0.248	0.884
	Widowed	136	25	18.4	55	40.4	36	26.5	20	14.7		
	Others	12	1	8.3	7	58.3	3	25.0	1	8.3		
Educational attainment	Primary school or below	145	32	22.1	56	38.6	37	25.5	20	13.8	3.368	0.643
	Junior high school	80	6	7.5	38	47.5	27	33.8	9	11.3		
	Senior high school/ technical secondary school	69	12	17.4	26	37.7	16	23.2	15	21.7		
	College degree and above	40	4	10.0	17	42.5	16	40.0	3	7.5		
Monthly household income per capita	<¥1,000	16	2	12.5	9	56.3	4	25.0	1	6.3	1.180	0.881
	¥1,000–2,999	62	12	19.4	22	35.5	15	24.2	13	21.0		
	¥3,000–4,999	153	23	15.0	66	43.1	44	28.8	20	13.1		
	¥5,000–9,999	82	14	17.1	28	34.1	27	32.9	13	15.9		
	≥¥10,000	21	3	14.3	12	57.1	6	28.6	0	0.0		
The number of diseases	0 ~ 2	57	10	17.5	24	42.1	18	31.6	5	8.8	1.484	0.476
	3 ~ 6	245	39	15.9	105	42.9	65	26.5	36	14.7		
	≥7	32	5	15.6	8	25.0	13	40.6	6	18.8		
Long-term care insurance	Yes	129	39	19.0	80	39.0	55	26.8	31	15.1	−1.463	0.143
	No	205	14	15.6	40	44.4	26	28.9	10	11.1		
Disability Certificate	Yes	90	40	16.4	97	39.8	70	28.7	37	15.2	−0.086	0.932
	No	244	25	15.9	48	30.6	22	14.0	12	7.6		
Activities of Daily Living	Mild impairment	157	9	14.1	26	40.6	25	39.1	7	10.9	12.473	0.002
	Moderate impairment	64	20	12.5	63	39.4	49	30.6	28	17.5		
	Severe impairment	160	7	24.1	12	41.4	3	10.3	7	24.1		
Cognitive Ability	No impairment	29	39	15.2	102	39.7	84	32.7	32	12.5	2.901	0.407
	Mild impairment	257	5	19.2	13	50.0	3	11.5	5	19.2		
	Moderate impairment	26	3	13.6	10	45.5	6	27.3	3	13.6		
	Severe impairment	22	8	25.8	11	35.5	8	25.8	4	12.9		
Sensory and Communication Abilities	No impairment	31	44	15.2	120	41.4	86	29.7	40	13.8	4.325	0.228
	Mild impairment	290	2	20.0	5	50.0	2	20.0	1	10.0		
	Moderate impairment	10	0	0.0	1	33.3	0	0.0	2	66.7		
	Severe impairment	3	17	11.7	58	40.0	49	33.8	21	14.5		

TABLE 2 **Comparison of caregiver burden of family caregivers with different characteristics in Guangzhou.**

Variables	Classification	Number of Participants	No Burden (n = 54) %		Mild Burden (n = 137) %		Moderate Burden (n = 96) %		Severe Burden (n = 47) %		*Z/H*	*p*值
Gender	Male	126	29	23.0	50	39.7	31	24.6	16	12.7	−2.625	0.009
	Female	208	25	12.0	87	41.8	65	31.3	31	14.9		
Age	0–50 years	184	31	16.8	82	44.6	44	23.9	27	14.7	9.806	0.347
	>50 years	150	23	15.3	55	36.7	52	34.7	20	13.3		
Marital status	Married	297	48	16.2	126	42.4	85	28.6	38	12.8	−0.739	0.460
	Others	37	6	16.2	11	29.7	11	29.7	9	24.3		
Educational attainment	Primary school or below	42	8	19.0	19	45.2	12	28.6	3	7.1	1.376	0.711
	Junior high school	80	11	13.8	34	42.5	22	27.5	13	16.3		
	Senior high school/ technical secondary school	123	23	18.7	44	35.8	40	32.5	16	13.0		
	College degree and above	89	12	13.5	40	44.9	22	24.7	15	16.9		
Occupation	Retired	246	35	14.2	100	40.7	78	31.7	33	13.4	4.959	0.175
	Laborer/farmer/ part-time worker	18	2	11.1	7	38.9	7	38.9	2	11.1		
	Unemployed	39	7	17.9	17	43.6	3	7.7	4	10.3		
	Others	31	10	32.3	13	41.9	8	25.8	8	25.8		
Child in school	Yes	49	42	85.7	116	236.7	84	171.4	43	87.8	−2.121	0.034
	No	285	12	4.2	21	7.4	12	4.2	4	1.4		
Hired nurse	Yes	54	7	13.0	26	48.1	13	24.1	8	14.8	−0.321	0.748
	No	280	47	16.8	111	39.6	83	29.6	39	13.9		
Learn caregiving knowledge and skills	Yes	171	32	18.7	65	38.0	49	28.7	17	9.9	−0.078	0.938
	No	163	22	13.5	72	44.2	47	28.8	30	18.4		
Years of caregiving experience	0–5 years	179	35	19.6	78	43.6	52	29.1	14	7.8	−3.111	0.002
	>5 years	155	19	12.3	59.0	38.1	44	28.4	33	21.3		
Weekly caregiving time	0–30 h	70	18	25.7	36	51.4	11	15.7	5	7.1	18.932	<0.001
	31–60 h	79	11	13.9	35	44.3	22	27.8	11	13.9		
	>60 h	185	25	13.5	66	35.7	63	34.1	31	16.8		
Physical disease	Yes	219	27	12.3	94	42.9	63	28.8	35	16.0	−2.184	0.029
	No	115	27	23.5	43	37.4	33	28.7	12	10.4		
Social interaction frequency	Daily or 1–6 times weekly	90	20	22.2	41	45.6	21	23.3	8	8.9	9.528	0.023
	1–3 times monthly	122	19	15.6	43	35.2	38	31.1	22	18.0		
	1–11 times annually	101	12	11.9	46	45.5	29	28.7	14	13.9		
	Never	21	3	14.3	7	33.3	8	38.1	3	14.3		

(Continued)

TABLE 2 (Continued)

Variables	Classification	Number of Participants	No Burden (n = 54) %		Mild Burden (n = 137) %		Moderate Burden (n = 96) %		Severe Burden (n = 47) %		Z/H	p值
Life satisfaction	Very satisfied	25	10	40.0	10	40.0	3	12.0	2	8.0	42.376	<0.001
	Mostly satisfied	140	24	17.1	68	48.6	40	28.6	8	5.7		
	Neutral	105	17	16.2	39	37.1	36	34.3	13	12.4		
	Dissatisfied	46	2	4.3	16	34.8	12	26.1	16	34.8		
	Very dissatisfied	18	1	5.6	4	22.2	5	27.8	8	44.4		
Social support network size	0 individuals	153	18	11.8	62	40.5	48	31.4	25	16.3	12.734	0.005
	1–2 individuals	89	11	12.4	19	21.3	11	12.4	4	4.5		
	3–5 individuals	45	17	37.8	41	91.1	20	44.4	11	24.4		
	≥6 individuals.	47	8	17.0	15	31.9	17	36.2	7	14.9		

TABLE 3 An ordered logistic regression analysis of factors influencing the burden on family caregivers of disabled older adults individuals in Guangzhou.

Variables	Classification	β	$s_{\bar{x}}$	Wald x^2值	p值	OR值	95%CI
Caregivers' gender	Male	−0.315	0.222	2.016	0.156	0.730	0.472 ~ 1.127
	Female	0	.	.	.	1.000	
Child in school	Yes	0.296	0.308	0.921	0.337	1.344	0.735 ~ 2.457
	No	0	.	.	.	1.000	
Caregivers' physical disease	Yes	0.496	0.225	4.86	0.027	1.642	1.057 ~ 2.552
	No	0	.	.	.	1.000	
Social interaction frequency	Daily or 1–6 times weekly	−0.466	0.464	1.008	0.315	0.628	0.253 ~ 1.559
	1–3 times monthly	−0.051	0.45	0.013	0.91	0.950	0.393 ~ 2.296
	1–11 times annually	−0.381	0.456	0.698	0.403	0.683	0.28 ~ 1.669
	Never	0	.	.	.	1.000	
Life satisfaction	Very satisfied	−2.768	0.624	19.655	0	0.063	0.018 ~ 0.213
	Mostly satisfied	−1.721	0.491	12.272	0	0.179	0.068 ~ 0.469
	Neutral	−1.325	0.49	7.31	0.007	0.266	0.102 ~ 0.695
	Dissatisfied	−0.218	0.528	0.17	0.68	0.804	0.285 ~ 2.266
	Very dissatisfied	0	.	.	.	1.000	
Social support	0 individuals	0.572	0.339	2.85	0.091	1.772	0.912 ~ 3.438
	1–2 individuals	−0.01	0.261	0.001	0.971	0.990	0.594 ~ 1.65
	3–5 individuals	−0.323	0.336	0.92	0.337	0.724	0.375 ~ 1.399
	≥6 individuals.	0	.	.	.	1.000	
Activities of daily living (ADL)		−0.008	0.004	4.688	0.03	0.992	0.984 ~ 0.999
Years of caregiving experience		0.021	0.018	1.353	0.245	1.021	0.986 ~ 1.057
Weekly caregiving time		0.009	0.003	6.539	0.011	1.009	1.002 ~ 1.015

self-care activities within older adults' physical capabilities to reduce caregiver dependency. The analysis further identified caregivers' physical diseases as a significant risk factor, with caregivers' mean age being 63.2 ± 12.0 years. Advanced age correlates with diminished physical stamina and increased health vulnerability, while caregiving itself exacerbates health deterioration (16, 17). A study investigating spousal caregiving for older adults individuals with disabilities found that regardless of caregivers' willingness to provide care, negative experiences predominated in the caregiving process, particularly when caring for older adults spouses with particularly severe disabilities (18). This study found that 65.6% of the caregivers suffered from physical diseases. These results necessitate dual-focused health interventions: regular health monitoring, exercise promotion, sleep hygiene optimization, and nutritional guidance for caregivers, complemented by health education programs to enhance self-management competencies.

Higher life satisfaction ("very satisfied," "mostly satisfied" or "neutral") demonstrated statistically significant protective effects against caregiver burden, with threshold effects observed only at or above the "neutral" level ($p < 0.05$). Despite demonstrating a statistically significant association between life satisfaction and caregiver burden in our cross-sectional analysis, these findings cannot confirm causal directionality or reciprocal relationships. If causal precedence or reciprocal effects are substantiated, in-depth examination of the mediating pathways by which life satisfaction modulates caregiver burden becomes methodologically imperative.

Notably, 45.8% of caregivers reported no social interactions, and 6.3% lacked social support entirely. The effects of available social support networks and social frequency on family caregiver burden demonstrated no statistically significant difference. This suggests that caregivers' social resources and engagement frequency may not effectively translate into protective factors for burden mitigation. Findings from a study involving 115 informal caregivers in Slovakia indicated an inverse correlation between caregiving burden and the degree of social support (19). A study utilizing data from the Ohsaki Cohort 2006 Study demonstrated that social support mitigates the risk of functional disability among caregivers (20). Another study indicates that participation in support groups can significantly alleviate stress levels among family caregivers (21).

Focusing on disabled older adults and their family caregivers within the megacity context of Guangzhou, this study provides direct evidence to inform differentiated health resource allocation policies for major urban centers. This study additionally incorporated long-term care insurance status as a variable. Notably, no statistically significant effect of long-term care insurance coverage on caregiver burden was observed. This underscores the imperative for developing more effective, multidimensional support strategies to alleviate caregiver burden, highlighting the persistent complexity of this public health challenge.

Intervention strategies may focus on multidimensional approaches to enhance caregiver well-being: establishing mutual support groups for experience-sharing among caregivers, enhancing community outreach programs through neighborhood committees and social workers to address practical challenges, and developing dedicated psychological counseling platforms for stress management. Policy initiatives should integrate these psychosocial components into municipal caregiver support frameworks while allocating resources for community-based implementation.

5 Limitations and prospects

Caregivers experiencing extreme exhaustion, severe time constraints, or resistance to participation had lower inclusion likelihood. Our sample likely underestimates the proportion of the most overwhelmed and time-pressured caregivers, potentially leading to underestimated burden levels. This study selected districts representing established downtown, new urban areas, and inner suburbs—three categories constituting an intra-urban core-periphery development continuum. However, outer suburban populations were not covered. It is suggested that comparative studies be carried out in the outer suburbs in the future.

Different types of illnesses experienced by family caregivers may exert differential effects on caregiver burden. Given the highly dispersed disease spectrum and the limited sample size for any single diagnostic category within the present study, stratifying caregivers by specific disease types would create numerous subgroups with insufficient statistical power for comparative analysis. It is recommended that future studies be designed to facilitate adequately powered comparisons across caregiver disease subgroups.

Filial piety culture may contribute to underestimation of caregiver burden. To more accurately capture the full panorama of caregiving burden within Chinese cultural contexts, future studies should incorporate validated scales specifically measuring filial stress and social desirability bias.

This study primarily investigated the intensity of caregiver burden, with particular focus on burden-exacerbating factors. However, integrating both positive and negative dimensions of the caregiving experience represents a critical future research direction. We recommend that subsequent investigations incorporate standardized scales measuring positive caregiving experiences alongside burden assessments, enabling comprehensive evaluation of caregiving.

6 Conclusion

Against the backdrop of population aging in China, caregiver burden among family members supporting disabled older adults warrants urgent attention. This study reveals a pervasive burden experienced by caregivers of the disabled old adults in Guangzhou. Empirical evidence confirms that caregiving time, caregivers' physical diseases, disabled old adults' activities of daily living (ADL) capacity, and caregivers' life satisfaction constitute critical influence factors of burden severity. To address these challenges, targeted multi-level interventions are imperative. At the individual level, implementing ADL rehabilitation programs for care recipients is essential to enhance functional independence. Community-level strategies should prioritize establishing social support networks to improve caregivers' psychosocial well-being. Institutionally, integrating caregiver health monitoring into the public health service system represents a vital policy direction.

While this study employed a methodologically sound design and implemented rigorous quality control measures—providing valuable reference evidence for alleviating family caregiver burden among disabled older adults—its cross-sectional nature precludes causal inference. Future cohort studies are warranted to validate the current findings.

Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found in the article/supplementary material.

Ethics statement

Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

DL: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Validation, Visualization, Writing – original draft, Writing – review & editing. JL: Conceptualization, Data curation, Investigation, Writing – review & editing. YaL: Investigation, Writing – review & editing. YZ: Investigation, Writing – review & editing. JP: Investigation, Writing – review & editing. HF: Investigation, Writing – review & editing. YuL: Investigation, Writing – review & editing. YY: Investigation, Writing – review & editing. JS: Investigation, Writing – review & editing. BH: Conceptualization, Resources, Supervision, Writing – review & editing. WZ: Conceptualization, Funding acquisition, Project administration, Resources, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Associated factors of home hospice care utilization by the terminally ill older adults: a mixed-methods study

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Objective: Given the discrepancy between the low utilization rate of hospice care services and the high willingness to choose hospice care, this study aims to identify the factors influencing the utilization among older adults. The findings will provide a foundation for interventions designed to enhance the growth of this service.

Design: A mixed-methods study of convergent parallel designs.

Methods: In the quantitative research phase, in January 2024, a convenience sampling method was used to recruit 350 terminally ill older individuals from three hospitals and three communities in Guangxi, China. Face-to-face surveys were conducted using a general information questionnaire, a Home Hospice Care Service Needs Questionnaire, and a Home Hospice Care Service Knowledge, Attitude, and Practice Scale. In the qualitative research phase, semi-structured interviews were conducted with 16 terminally ill older individuals to explore the barriers and facilitators to the utilization of home hospice care services.

Results: A total of 332 (94.86%) older individuals completed the survey, and 45 (13.55%) accepted home hospice care. The identified barriers to utilization included high physiological, psychological, and spiritual needs, as well as families' feelings of guilt. The facilitators included being of advanced age (≥80 years), having chronic diseases, not needing a caregiver, having high social needs and knowledge scores, and perceiving a significant economic burden.

Conclusion: The utilization of home hospice care services by older adults is lower, which is influenced by both subjective and objective factors. The novel identification of 'families' guilty' as a barrier underscores the need for targeted interventions that address emotional and psychological barriers within families. Policymakers should consider these factors when developing strategies to promote the development of home hospice care for older adults, ensuring that interventions are culturally sensitive and economically feasible.

KEYWORDS

home hospice care, associated factors, Andersen model, terminally ill, older adults

1 Introduction

China's aging process is accelerating, with the aged population expected to increase from 250 to 400 million by 2050, resulting in an aging rate exceeding 30% (1). As age increases, the risk of death increases and the ability to take care of themselves declines (2, 3). Among the older adults, 6.18 million were disabled, 82.34% were unable to look after themselves before they died (4, 5). Therefore, the quality of life for the older adult at the end of life is in urgent need of attention.

According to the report of the World Health Organization (6), globally, 25.7 million people need hospice care in the last year of life, with older adults accounting for over 69%. Due to the traditional Chinese cultural concept of 'returning to one's roots' among Chinese older adults, approximately 87–89% of them pass away at home (7, 8). Home hospice care can improve the quality of life for older adults who die at home and their family members (9), reducing unnecessary hospitalizations and medical costs (10, 11). Therefore, studying home hospice care services for older adults is of great significance for improving the quality of life of older adults at the end of life.

According to the location of service, China's hospice care service models include home hospice care and inpatient hospice care. Home hospice care mainly refers to terminally ill patients living at home, receiving basic life care from family members, and obtaining medical services or consultations from general practitioners and hospice care institutions to meet the needs of patients and their families (12). China has developed hospice care into a basic medical service, but its development started relatively late, with pilot programs beginning in 2017, and home hospice care services started even later (13). At present, China's home hospice care service system is not mature and is unable to meet the needs of terminally ill older adults. Therefore, it is necessary to conduct more research. The willingness to utilize hospice care can promote its development (14). In South Korea, 88.9% of older adults at the end of life are willing to choose home hospice care (15); however, in China, 38.5% only (14). Compared with the global average, China's utilization rate of hospice care services is even lower. Globally, 14% of people who need hospice care are able to receive such services, while in China, only 0.3% (15). In order to meet the needs of China's large older population, it is necessary to explore the facilitators and barriers for older adults to utilize home hospice care services to promote the development of hospice care.

The development of hospice care in China is caught in a dilemma where there is a relatively high willingness but a low utilization rate of services (16). The reason for this dilemma is not just due to a lack of supply. In fact, the occupancy rate of hospice care beds is not high (15). Therefore, a systematic understanding of the factors influencing the utilization of home hospice care for terminally ill older adults could better facilitate its development. Existing research indicates that demographic characteristics, such as age (17, 18), health beliefs (19), economic income (20), perceived risk of illness (21), and attitudes toward death (22), influence the willingness or acceptance of hospice care services. It is evident that the factors influencing the utilization of hospice care encompass both objective and subjective elements. However, current research predominantly focuses on intentions, often employing either solely quantitative or qualitative methods, resulting in the study of factors influencing home hospice care utilization being somewhat limited. To comprehensively explore these factors and consider both objective conditions and subjective perceptions, it is essential to adopt a mixed-methods research approach.

The Andersen Model, a robust theoretical framework for analyzing the factors influencing the utilization of healthcare services, was proposed by American scholar Ronald Andersen (23). Therefore, guided by the Andersen Model, we employed a mixed-methods approach with a convergent parallel design to thoroughly investigate the associated factors of terminally ill older adults toward the utilization of home hospice care. This research aims to make up for the insufficiency of mixed-methods evidence in the research on factors influencing the utilization of home hospice care and provide actionable entry points to promote the development of home hospice care.

2 Theoretical framework

The Andersen Model posits that individual's utilization healthcare services decided by the following three dimensions: predisposing factors, enabling factors, and need factors (23). Predisposing factors are characteristics that exist before an individual encounters a health problem, including demographic characteristics, social structure, health beliefs, and attitudes. Enabling factors are resources that facilitate or hinder access to healthcare services, including personal, family, and community resources. Need factors reflect the actual or perceived need for health services. Predisposing factors include demographic, social structure, and health belief variables. Enabling factors encompass personal, family, and social resources. Need factors involve the perception and evaluation of health status. After five revisions, the model can comprehensively explain health service utilization behavior (24).

3 Methods

3.1 Design

Our research team consists of 15 members, including two deputy chief physicians and five deputy chief nurses in the field of hospice care, seven graduate students, and one graduate advisor. Our research team was responsible for the design and implementation of the entire study. Due to the cultural background of taboo death in China (in Chinese culture, death is often considered a taboo topic, primarily due to the belief that discussing death brings bad luck or misfortune), this study adopted a mixed method of quantitative and qualitative research, which results can complement each other, enhancing the depth and breadth of the research on the associated factors of home hospice care for older adults. We conducted a convergent parallel design, meaning that both types of research were employed independently and simultaneously (25). The quantitative research was conducted using Paper-version questionnaires through one-on-one interviews, and the qualitative research was completed using semi-structured interviews. This study's report refers to the Good Report of a Mixed-Methods Study (GRAMMS) (26).

3.2 Participants

In January 2024, a convenience sampling method was used to select 350 terminally ill older individuals from three hospitals and three communities in Guangxi, China, for the study. The surveyed hospitals and communities are all pilot sites for hospice care. For the qualitative study, the participants were recruited as follows: inclusion criteria included (1) older adult terminal patients (aged ≥60) or their primary caregivers who were deemed eligible for home hospice care by a physician and (2) those who provided informed consent to participate in the survey, and the exclusion criterion was individuals with communication difficulties. The inclusion criterion for the qualitative study was those who had completed the questionnaire and were willing to undergo a 20–30-min interview. According to logistic regression for sample size, at least 5–10 times the number of independent variables surveyed for the quantitative study is required and considered for a 10% sample loss (27). With 21 independent variables, the required sample size for the quantitative study was calculated to be 117–234 cases. The sample size for the qualitative study was based on the principle of saturation (28). Ultimately, a total of 332 (94.86%) terminally ill older individuals completed the questionnaire survey; 18 who failed to complete it were excluded, and 16 of them participated in qualitative interviews.

3.3 Research instruments

3.3.1 General information

Our research team designed a survey questionnaire to collect general information about terminally ill older individuals after a comprehensive literature review and group discussions. Guided by the Andersen Model, general data are divided into the following three categories with detailed content as follows: (1) predisposing factors, including gender, age, ethnicity, whether suffering from chronic diseases, and awareness of home-based hospice care; (2) Enabling factors, including marital status, place of residence, education level, monthly personal income (Chinese Yuan), method of medical payment, living arrangement, and type of primary caregiver; (3) need factors include the activities of daily living (ADL) score. The Barthel Index Scoring Scale is used for scoring. The Barthel Index, designed by American Florence Mahoney and Dorothy Barthel (29), is applied clinically and is a widely used tool internationally. The total score is 100 points, with higher scores indicating greater self-care ability and less dependency; a score of 100 means no dependency, 61–99 points indicate mild dependency, 41–60 points indicate moderate dependency, and ≤40 points indicate severe dependency. The nutritional risk of older adults was measured using nutritional risk screening (NRS 2002), which was proposed by Danish scholar Kondrup in 2002 (30). The total score of NRS 2002 consists of three parts: nutritional status impairment score, disease severity score, and age score (over 70 years old plus 1 point). The total score is 0–7 points. If the patient's score reaches or exceeds 3 points, it is considered that there is a nutritional risk, and nutritional support is required.

3.3.2 Home hospice care service need scale

This scale was designed by our team, referring to China's hospice care practice guidelines (31) and humanistic theories. The scale is divided into four dimensions: physiological needs (related to relieving symptoms, six items), psychological needs (related to helping patients cope with adverse emotional reactions, four items), social needs (related to individual social relations and support, seven items), and spiritual needs (related to patient's beliefs, values and the pursuit of the meaning of life, four items), with a total of 21 items. The scoring uses a Likert 5-point scale as follows: Completely do not need (1 point), Occasionally need (2 points), Moderately need (3 points), Very much need (4 points), and Completely need (5 points). The total score is 21–105 points. The higher the total score, the greater the demand for home hospice care services. In our study, we confirmed that the scale has good reliability and validity when applied to terminally ill older adult individuals. Cronbach's alpha is 0.949, and Scale-level Content Validity Index (S-CVI) is 0.923. See Appendix 1 for the scale.

3.3.3 Knowledge, attitude, and behavior of home hospice care scale

Before the survey, our team developed the scale guided by the knowledge theory, belief theory, and action theory of the Behavioral Change Wheel (BCW) (32). The scale uses a Likert 5-point scoring system as follows: Strongly agree (5 points), Agree (4 points), Uncertain (3 points), Disagree (2 points), and Strongly disagree (1 point). To enhance the reliability of the survey results, seven items were reverse-scored. The total score is 29–145 points. The higher the total score, the better understanding of home hospice care. This scale has good reliability and validity, too, with a Cronbach's alpha of 0.947 and an S-CVI of 0.941. See Appendix 2 for the scale.

3.3.4 Interview outline

The interview outline was designed to focus on the psychological processes and associated factors involved in the use of home hospice care by older adults or their families, and it referenced relevant literature (33). The final version of the interview outline was modified and confirmed after conducting pre-interviews with two terminally ill older individuals to ensure the understandability and accessibility of the guide. The details are as follows: (1) How did you learn about home hospice care? What are your thoughts on it? (2) Why did you accept/refuse home hospice care services? (3) What barriers or difficulties have you encountered when receiving home hospice care services? (4) What are your needs for home hospice care services? (5) What suggestions do you have for the provision of home hospice care services?

4 Data collection

4.1 Quantitative data collection

Before the survey, uniform training was provided to the members of the research team. During the research process, the purpose and significance of the study were first introduced to the respondents. After obtaining their consent, the research team members conducted one-on-one interviews with each respondent using the questionnaire. After the interview, two researchers checked all the questionnaires, eliminated the questionnaires that were not completed and the answer rules, and then entered the data into the Excel table. Of them, 18 (5.14%) questionnaires were incomplete.

4.2 Qualitative data collection

Before the interview, staff from the hospice care institutions or hospitals communicated with the interviewees in advance. After the interviewees' consent, two members of the research team conducted semi-structured interviews (one was responsible for the main interview, and the other was responsible for recording the interview dialogue, the interviewee's expressions, and body language). The two members had received training in qualitative interviewing and participated in the collection and analysis of quantitative data. Hospitalized patients were interviewed in the hospital, while home-based patients were interviewed at their homes under the guidance of hospice care personnel. The interview environment was quiet and relaxed, with each interview lasting approximately 20–30 min. The interviewers asked questions according to the interview guide, listened carefully, refrained from making suggestions or leading the interviewee, and used reflective questions to allow the interviewee to express their feelings. If necessary, the interviewers provided supplementary descriptions of the concept of home hospice care and repeated and summarized the interviewee's statements. Within 24 h of the interviews, the recording was converted into text, and the text data were returned to the interviewee for reading to ensure the accuracy of the data.

5 Data analysis

5.1 Quantitative data analysis

The SPSS version 27.0 was used for descriptive statistics and difference comparisons. Categorical data are represented by frequency (n) and percentage (%). Continuous data are expressed as mean ($\overline{x}$) and standard deviation (SD). In univariate analysis, comparisons of rates are made using the Chi-square test, and comparisons of means are made using the t-test. Multivariate analysis is conducted using logistic regression. Considering that the variable of education has a great OR value in the model, and it is reclassified or removed, primary school and below and junior high school are combined, and the sensitivity analysis is repeated by binary logistic regression. The significance level is set at $\alpha = 0.05$ (two-tailed).

5.2 Qualitative data analysis and result integration

Directed content analysis was employed for data analysis. After importing the text into the Nvivo 14.0 software, the Anderson Model was used as the coding framework, and the coding process was carried out in the following steps: (1) repeatedly listening to the recordings and reading the transcribed texts to gain an overall sense; (2) identifying factors influencing the utilization of home hospice care by older adults, which is the open coding; (3) aggregating all codes and, through repeated comparison and categorization, grouping codes with the same attributes into the same category, which is the axial coding; (4) classifying themes into three dimensions: predisposing factors, enabling factors, and need factors, which is the selective coding. Finally, the results were integrated using the parallel data comparison method (34). First, quantitative and qualitative data were placed side by side for direct comparison of their consistencies and differences. The integrated results were then jointly presented in tables to illustrate the findings and meta-inferences. All the processes were performed independently and simultaneously by two researchers. In case of disagreement, our research team held a collective discussion and finally reached a conclusion, which ensured the logic and reliability of each topic.

6 Results

6.1 Common method bias

Harman single-factor method was used to test the common method bias (35). The results showed that the characteristic roots of the 9 factors were greater than 1, and the explained variation of the first factor was 30.06%, which was lower than the critical value of 40.00%. Therefore, it shows that there is no obvious common method bias in this study.

6.2 Quantitative results

The average age of older adults was 70.73 years ($SD = 10.12$), ranging from 60 to 96 years old. A total of 45 (13.55%) older adults utilized home hospice care services. The Home Hospice Care Service Need Scale score was 24–100 (60.67 ± 19.91). The Knowledge, Attitude, and Behavior of Home Hospice Care Scale score was 32–124 (62.37 ± 17.80). Univariate analysis results showed that the utilization of home hospice care by older adults differed significantly in terms of age ($F = 6.971$, $p = 0.008$), type of caregiver ($F = 30.981$, $p < 0.001$), physiological needs scores ($t = 9.995$, $p < 0.001$), psychological needs scores ($t = 12.901$, $p < 0.001$), social needs scores ($t = 4.069$, $p < 0.001$), spiritual needs scores ($t = 8.971$, $p < 0.001$), knowledge scores ($t = -9.442$, $p < 0.001$), belief scores ($t = -4.315$, $p < 0.001$), and attitude scores ($t = -10.418$, $p < 0.001$). The general characteristics of older adults and the results of univariate analysis are presented in Table 1. Furthermore, binary logistic regression analysis was used to examine the associated factors of home hospice care service utilization, with detailed results shown in Table 2.

6.3 Sensitivity analysis

After merging the variable of education, the analysis showed that age, education, chronic disease, caregiver, physiological needs, psychological needs, social needs, spiritual needs, and knowledge, attitude, and practice are factors associated with utilization ($P<0.05$). When removed, the same results are shown, indicating that the results are robust (see Table 3).

6.4 Qualitative research results

A total of 16 individuals participated in semi-structured interviews, with 13 (81.25%) utilizing home hospice care and three receiving treatment in the hospital, with an average age of 68.50 years ($SD = 6.36$). All were cancer patients, and their detailed characteristics are shown in Table 4. From the interviews, 29 factors influencing the utilization of home hospice care by terminally ill older individuals were identified. These associated factors were first categorized into physiological needs, psychological needs, social needs, knowledge, beliefs, and attitudes, and then all categories were grouped into the themes of predisposing factors, enabling factors, and need factors

TABLE 1 Characteristics of participants and analysis of differences in home hospice care acceptance.

Variables	Accept		χ^2/t/F	P
	Yes (n(%))	No (n(%))		
Gender				
Male	24(18.05)	109(81.95)	3.819	0.051
Female	21(10.55)	178(89.45)		
Age (years)				
60–69	14(8.14)	158(91.86)	9.543	0.008
70–79	17(21.52)	62(78.48)		
80+	14(17.28)	67(82.72)		
Nationality				
Han	29(12.83)	197(87.17)	0.315	0.574
Minority	16(15.09)	90(84.91)		
Marital status				
Married	33(15.28)	183(84.72)	1.628	0.443
Unmarried/divorced	1(10.00)	9(90.00)		
Widowed	11(10.38)	95(89.62)		
Education				
Primary school and below	6(4.65)	123(95.35)	14.586	<0.001
Middle school	19(17.92)	87(82.08)		
High school and above	20(20.62)	77(79.38)		
Resident				
Rural	11(13.1)	73(86.9)	0.020	0.887
Urban	34(13.71)	214(86.29)		
Monthly income (Yuan)				
<1,000	21(17.36)	100(82.64)	2.352	0.308
1,000–3,000	12(11.54)	92(88.46)		
>3,001	12(11.21)	95(88.79)		
Payment				
Health insurance	42(13.68)	265(86.32)	0.095	0.758
Self-paying	3(20.00)	12(80.00)		
Living form				
With families	36(13.64)	228(86.36)	0.007	0.931
Alone	9(13.24)	59(86.76)		
ADL				
100	30(13.23)	180(86.77)	3.315	0.346
61–99	11(18.64)	55(81.36)		
41–60	3(4.92)	31(95.08)		
≤40	1(26.09)	21(73.91)		
Chronic disease				
No	20(21.51)	73(78.49)	6.971	0.008
Yes	25(10.46)	214(93.45)		
Caregiver				
Family members	32(25.40)	94(74.60)	30.981	<0.001
Nursing workers	11(14.28)	66(85.72)		
Not need	2(1.55)	127(98.45)		
NRS scores	1.09 ± 1.535	1.35 ± 1.507	1.072	0.285
Needs				
Physiological	11.89 ± 4.92	20.35 ± 7.14	−9.995	<0.001
Psychology	5.84 ± 2.70	12.39 ± 5.35	−12.901	<0.001
Society	13.56 ± 4.42	16.76 ± 7.26	−4.069	<0.001
Spiritual	9.84 ± 2.76	14.24 ± 4.49	−8.971	<0.001
K-A-P				
Knowledge	23.56 ± 5.38	16.01 ± 4.92	9.442	<0.001
Attitude	32.11 ± 10.40	25.17 ± 7.27	4.315	<0.001
Practice	26.78 ± 6.59	18.05 ± 5.70	10.418	<0.001

ADL, the activities of daily living (ADL) score; NRS, score of NRS 2002.

within the Andersen Model. Detailed information is presented in Table 5. The integrated results are detailed in Table 6.

7 Discussion

7.1 Predisposing factors associated with the utilization of home hospice care by the older adults

When exploring the predisposing factors for the utilization of home hospice care services among older adults, first, age is a factor that influences the use of home hospice care, which is similar to the findings of Kumar et al. (18). In our study, older people are more likely to choose home-based hospice care services, which may be related to their more ingrained 'bottom-up' concept and greater acceptance of death. Some researches also show that the proportion of older adults who chose to die at home is the highest (14.5 times that of hospitals, 3.4 times that of nursing institutions) (36), and their acceptance of death scores are also higher (37). Second, older adults with chronic diseases are also more inclined to utilize home hospice care services. This might be because these individuals have endured economic burdens for a long time, and home care is usually less expensive than hospitalization (38). However, qualitative research indicates that the factors are complex, including self-care ability and the pursuit of quality of life, which are relatively consistent with the existing research results (39, 40). In the future, methods such as longitudinal studies should be adopted to conduct more in-depth research on the utilization of palliative care services by older people in order to better understand the interaction of these factors and their impact on the utilization of services. More importantly, both quantitative and qualitative studies indicated that awareness and knowledge about home hospice care services were key factors in utilization. This factor positively influences the utilization behavior of older adults, which fully demonstrates the particular importance of doing well in promoting home hospice care. The qualitative study results supplement that older adults learn about home hospice care through doctors or families, with

TABLE 2 Factors of influencing accepting home hospice care among the terminally older adults.

Variables	*B*	*SE*	Wald χ^2	*P*	*OR*	95%CI	
						LLC	ULC
Age (years)			7.278	0.026			
70–79	2.332	1.161	4.035	0.045	10.297	1.058	100.193
80+	2.829	1.098	6.638	0.010	16.920	1.968	145.503
Education			7.697	0.021			
Middle	4.016	1.511	7.061	0.008	55.455	2.869	1,072.056
Senior and above	2.043	1.429	2.043	0.153	7.716	0.468	127.079
Chronic disease	−2.720	1.029	6.993	0.008	0.066	0.009	0.495
Caregiver			11.735	0.003			
Nursing worker	0.398	0.990	0.162	0.688	1.489	0.214	10.356
Not need	−5.723	1.675	11.676	0.001	0.003	0.001	0.087
Needs							
Physiological	−0.236	0.097	5.968	0.015	0.790	0.654	0.954
Psychology	−0.999	0.267	13.994	<0.001	0.368	0.218	0.622
Society	0.532	0.162	10.812	0.001	1.703	1.240	2.339
Spiritual	−0.408	0.142	8.234	0.004	0.665	0.503	0.879
K-A-P							
Knowledge	0.439	0.130	11.454	0.001	1.551	1.203	2.000
Attitude	−0.155	0.077	4.069	0.054	0.857	0.737	0.996
Practice	0.148	0.099	2.258	0.133	1.160	0.956	1.407
Constant	−2.627	2.347	1.253	0.263	0.072		

$R^2 = 0.479$, $\chi^2 = 47.316$, $p = 0.874$. Variables coding: age: 60–69 = 1, 70–79 = 2, 80+ = 3; education: primary school and below = 1, middle school = 2, high school and above = 3; chronic disease: no = 0, yes = 1; caregivers: family members = 1, nursing workers = 2, not need = 3.
SE, standard error; K-A-P, Knowledge, Attitude, and Practice scores; LLC, lower limit of confidence interval; ULC, upper limit of confidence interval.

the role of doctors' notification being more prominent, which is consistent with the research results of Lane et al. (41). Therefore, in the background of the cultural of taboos around death, promoting hospice care through doctors or families might be more significantly effective. In addition, the level of knowledge about home hospice care services (score status) also positively affects utilization behavior. The integrated results indicated that, in terms of knowledge about home hospice care, the subjective factors for older adults to utilize it were mainly recognizing that it can improve the quality of life and save medical resources. This finding reflects the terminally ill older adults' pursuit of quality of life and less economic burden. However, old adults in the UK and the US are more aware of hospice care at home than in China, as they have raised public awareness of hospice care through extensive publicity and education (42). Therefore, to improve the acceptance of the service, enhance the awareness of home-based palliative care among the old adults and their families through community education, emphasize its advantages and economy would be advice in the future.

7.2 Enabling factors associated with the utilization of home hospice care by the older adults

First, who do not require caregivers is the enabling factor for older adults to use home-based hospice services, which is slightly different from the results in western countries where family caregivers are more willing to choose home-based services (43). The reason might be that the supply is insufficient in China, and most of the pressure of daily care is still borne by family caregivers, which is a huge caring burden when terminally ill older adults stay at home (44). Generally, the terminally older are also concerned about the quality and safety of care services (45). Therefore, it is necessary to strengthen the training of nursing staff, enrich nursing human resources, such as collaborative training between medical institutions and society, and increase efforts to train medical caregivers and older adult caregivers. In fact, the decision-making of families and the dying older is a complex issue that might be emotionally contradictory (46). Qualitative research shows that when families feel guilty due to lack of care, they tend to choose hospitalization with the intention of making up for the sense of guilt, as they might think that choosing hospice care is equivalent to giving up treatment (47). Therefore, it is also necessary to improve the understanding of relatives on death and hospice care. In the future, various forms of community education activities should be carried out, such as lectures, workshops, and brochures, to improve the awareness of the population. Third, a huge economic burden is an incentive, and evidence also shows that hospice services can reduce the cost of treatment (48). It is worth noting that assessing the specific income does not accurately predict the motivation for utilization. In the future, the subjective economic burden and objective income of the older and their families should be assessed at the same time. It is necessary to learn from some developed countries, such as South Korea and the UK, which provide financial support for the health services of hospice care and clarify the medical insurance reimbursement system (49). Additionally, home-based hospice care resources are an important motivational factor. In qualitative studies,

TABLE 3 Factors of influencing accepting home hospice care among the terminally older adults.

Variables	*B*	*SE*	Wald χ^2	*P*	*OR*	95%CI	
						LLC	*ULC*
Age (years)			6.84	0.033			
70–79	2.817	1.137	6.136	0.013	16.721	1.8	155.307
80+	2.232	1.06	4.436	0.035	9.32	1.168	74.394
Education							
Senior and above	−0.419	0.881	0.226	0.635	0.658	0.117	3.7
Chronic disease	−1.876	0.905	4.3	0.038	0.153	0.026	0.902
Caregiver			8.761	0.013			
Nursing worker	−0.131	0.981	0.018	0.894	0.877	0.128	6.003
Not need	−4.5	1.526	8.699	0.003	0.011	0.001	0.221
Needs							
Physiological	−0.213	0.093	5.223	0.022	0.808	0.673	0.97
Psychology	−0.854	0.22	15.093	0	0.426	0.277	0.655
Society	0.505	0.146	11.98	0.001	1.657	1.245	2.205
Spiritual	−0.408	0.145	7.969	0.005	0.665	0.501	0.883
K-A-P							
Knowledge	0.316	0.104	9.226	0.002	1.371	1.119	1.681
Attitude	−0.216	0.075	8.255	0.004	0.806	0.695	0.934
Practice	0.264	0.107	6.045	0.014	1.302	1.055	1.607
Constant	0.04	2.163	0	0.985	1.041		

$R^2 = 0.475$, $\chi^2 = 51.941$, $P = 0.874$. Variables coding: age: 60–69 = 1, 70–79 = 2, 80+ = 3; education: middle school and below = 1, high school and above = 2; chronic disease: no = 0, yes = 1; caregivers: family members = 1, nursing workers = 2, not need = 3.

SE, standard error; K-A-P, Knowledge, Attitude, and Practice scores; LLC, lower limit of confidence interval; ULC, upper limit of confidence interval.

TABLE 4 Demographic characteristics of the participants (*n* = 24).

No.	Gender	Age	Duration (month)	Education	Residence	Income
N1	Male	68	/	High school	Rural	1
N2	Male	63	/	Junior school	Rural	1
N3	Male	86	1	High school	Urban	3
N4	Male	70	1	Junior school	Urban	3
N5	Female	66	2	Junior school	Urban	2
N6	Male	60	3	Junior school	Rural	1
N7	Female	68	1	University	Urban	2
N8	Male	62	1	Junior school	Urban	2
P9	Male	69	1	Primary school	Urban	1
N10	Female	72	1	High school	Urban	2
N11	Male	61	/	Junior school	Rural	1
N12	Male	74	1	University	Urban	3
N13	Male	72	2	Junior school	Urban	2
N14	Female	65	1	Primary school	Rural	2
N15	Male	67	2	High school	Urban	2
N16	Male	73	3	Primary school	Urban	1

/: have not received home hospice care; income 1: <1,000 Yuan/Month; income 2: (1000–3,000) Yuan/Month; income 3:>3,000 Yuan/Month.

TABLE 5 **Mapping of facilitators and barriers to the Anderson domains.**

Anderson	Dimension	Themes	Representative quotations
Prerequisite factors	Knowledge	Live better at home (+)	N13: Staying at home, I would live better.
		Save resources (+)	N1: It can be said that continuing to stay in hospitals is a waste of national resources.
		Informed by doctors or relatives (+)	N3: I do not know about hospice, but my daughter does. N8/N13: The doctors told me there was home hospice.
		Recognized not need for treatment (+)	N12: I did not believe that continuing therapy would work, so I refused to continue therapy and went home. N13: The doctor told me, and I understand that there's no point in any further treatment. N16: I realized I was dying, so I stopped chemo and stayed at home.
	Attitude	Awareness and acceptance of dying (+)	N3: Maybe I do not have much time left. I'd be better off at home. N13: I knew I am sick and dying.
		Doctors and nurses will visit at home (+)	N14: The doctors and nurses will visit me at home, which is much easier.
		Accept death calmly (+)	N3: I'm open-minded enough to look at death in peace, and when I die, just scatter my ashes at sea. N6: They (doctors) told me I did not have long to live, and I was coming to terms with it.
		Deny dying (−)	N1: I do not like to talk about it (death and home hospice care). N2: I was told by doctors, but I do not think I'm not yet (dying).
	Practice	Follow doctor's advice (+)	N12: We mainly followed the doctor's advice and stay at home, and usually did not take the initiative to ask for hospitalization.
		Follow the son 's decision (+)	N7: The choice to stay at home was basically the son's decision.
Enabling factors	Service resource	Convenient service (+)	N5: I think the service is good now and it's convenient to drive here once in a while. N9: Home hospice care is much better than before, after all, we did not have to go to the hospital all the time.
		Long distance from the service point (−)	N1: My home is about 20 km from the service point, and even a phone call at any time cannot make up for the distance. N4: It's best to stay at home, but it's too far away.
		Short distance from the service point (+)	N7: It's easy to pick up the painkillers after you take them, which is a 3 to 4 min drive. N15: The doctor advised me to take home hospice service because my home is not far from the service point, and I accepted.
		Low accessibility (−)	N1: If only this kind of service could be popularized in towns and villages. N11: I do not consider home hospice services, which are lacking mainly in rural areas
	Economics	Give up treatment due to economically insufficient (+)	N11: If the money is spent on treatment, we'll go home. N14: I wanted to give up and go home because the treatment was too expensive.
		Financial burden (+)	N11: Although my two children share the cost of my treatment, the financial pressure is still heavy. N12: Although we have a monthly income of 8, 000 yuan, the cost of treatment is so large that we still have to keep the money for basic living.
		Low income (+)	N1: I am a rural person with a low income and cannot afford the expensive treatment. N9: My son is the only one who works for money, so I have to accept home hospice services.
	Caregivers	Lack of caregivers (−)	N9: I'm not being cared for enough at home because we do not have enough people. N11: I had to stay at the hospital because my children had to work and could not take care of me.
	Relatives' feelings	Sense of guilt (+)	N1: My children are regretting paying little attention to my health and are now actively supporting my treatment.

(Continued)

TABLE 5 (Continued)

Anderson	Dimension	Themes	Representative quotations
Needs factors	Physiological	Meet pain relief needs (+)	N1: Because the pain is too intense to be relieved at home, you must come to the hospital for an intravenous drip. N7: It's actually better to manage pain at home. N11: My main symptom is pain. I would feel ok when that's relief.
		Immediately pain relief needs (−)	N1: Pain could be relieved in time staying in the hospital. N11: Sometimes it's too late, and the pain lasts a long time.
		Limited needs (+)	N10: Give me painkillers, and I'm content enough. N13: When the pain relief is achieved, we feel satisfied. N16: I do not really need anything other than pain relief.
		Sufficient self-care ability (+)	N3: I think I can take care of myself, so I might as well stay at home. N12: I chose to live at home mainly because I can still take care of myself.
	Society	Need for social communication (+)	N3: He'll feel better when he's at home and can hang out with colleagues and friends. N10: When I talked to my patient and learned that she had given up treatment, I would staying home and waiting to die.
		Concerns about disease privacy known by neighbors (−)	N5: It's not good for the neighbors to know about my illness. N11: If neighbors know I am sick, they will talk about my illness.
	Psychology	Heavy disease-related psychological burden (−)	N1: The psychological burden is heavy, and I cannot sleep well all night. So it's better to be at home than in a hospital. I worry if the medical staff is sufficient to provide home care when I am at home.
		Feel relax when with families or at home (+)	N3: I'm more relaxed when staying at home. N11: There are other family members to help me ease the mood when staying at home, but I must face it alone when in hospital.

TABLE 6 Combine and comparison between the quantitative and qualitative findings.

Anderson	Contents	Quantitative findings	Qualitative findings	Meta-inferences
Predisposing factors	Knowledge	Knowledge scores ($B = 0.439$, $p = 0.001$)	Informed by doctors or relatives (+)	Confirm: People with more knowledge of home hospice care are more likely to accept home hospice care. Extension: Healthcare staff and relatives can help terminal older adults learn about home hospice care. When older individuals perceive end-stage care as a misuse of medical resources, home hospice care can provide a higher quality of life in their final stage. Extension: Qualitative studies provide additional insights. It showed that accept terminal state and positive attitudes toward death had a positive effect on receiving services.
			Live better at home (+)	
			Save resources (+)	
			Recognized the need for treatment (+)	
	Attitude	Attitude scores ($B = -0.155$, $p = 0.054$)	Awareness and acceptance of dying (+)	Extension: The results were supplemented by qualitative studies. Older individuals tend to follow the advice of doctors and family members when making healthcare decisions.
			Recognize the role of home hospice care (+)	
			Accept death calmly (+)	
			Deny dying (−)	
	Practice	Practice scores ($B = 0.148$, $p = 0.133$)	Follow doctor's advice (+)	
			Follow the son 's decision (+)	
Enabling factors	Economics	Monthly income ($\chi^2 = 2.352$, $p = 0.308$)	Give up treatment due to economically insufficient (+)	Extension: Qualitative findings add insights. Economic factors require a comprehensive assessment of income and expenditure. When older adults perceive the financial burden, they are more inclined to accept services.
			Financial burden (+)	
			Low income (+)	
	Caregivers	Not need (family members = 0) ($B = -5.723$, $P = 0.001$)	Lack of caregivers (−)	Confirm: When there are sufficient caregivers, older people at the end of life tend to receive services.
	Service resource	–	Convenient service (+)	Extension: Qualitative studies provide evidence of older adults' concerns about home hospice resources. The availability, accessibility and convenience of the resource would be taken considered by older adults.
			Long distance from the service point (−)	
			Short distance from the service point (+)	
			Low accessibility (−)	
Need factors	Physiological needs	Physiological scores ($B = -0.236$, $p = 0.015$)	Meet pain relief needs (+)	Confirm: older adults people with little physiological needs are more likely to use home hospice services. Extension: Relieving pain symptoms is a basic need for older adults at home.
			Pain relief timely needs (−)	
			Limited needs (+)	
			Sufficient self-care ability (+)	
	Social needs	Social needs ($B = 0.532$, $P = 0.001$)	Need for social communication (+)	Confirm: Both qualitative and quantitative studies showed that social support positively affected the use of home hospice services by older people.
			Concerns about disease privacy known by neighbors (−)	Extension: Qualitative studies provide additional insight that stigma can prevent the older adults from accepting home hospice services.
	Psychological needs	Psychological needs ($B = -0.999$, $P<0.001$)	Heavy disease-related psychological burden (−)	Extension: The results were complemented by the quantitative and qualitative studies. When the sense of security is not satisfied, older adults tend to be hospitalized. When family members can provide psychological support for older adults, older adults tend to receive hospice services at home.
			Feel relax when with families or at home (+)	

older adults have indicated that the long distance between service locations and the lack of widespread resources are reasons they consider not to use home-based services. Terminally ill patients face a multitude of painful symptoms (50), especially those in the late stages of cancer. When resources to alleviate pain are not readily available, they might choose to be hospitalized. Therefore, attention should be paid to perfecting the rational allocation of distance and resources for home-based services by centering on community health services, with the main guidance from hospitals and auxiliary services from volunteers.

7.3 Demand factors associated with the utilization of home hospice care by the older adults

Interestingly, quantitative research has found that the higher the physiological and psychological needs, the less inclined they were to utilize home-based services. Qualitative research indicated that older adults did not have many needs for home-based services, which are urgent for pain relief. Home-based services are limited in China, with visits ranging from one time a month to one time a week, which hinders their ability to provide timely pain relief and a sense of security when symptoms arise (51). Therefore, home-based services are a good option when the demand is not high for older adults. Next, qualitative research findings further indicate that even within the context of limited services, family members' psychological support is a facilitating factor for utilization. In the future, a comprehensive assessment of the varying degrees of needs of older adults, such as the most urgent, urgent, and general, should be conducted to first meet the most pressing needs and guide families in psychological nursing skills, making resource allocation more rational and service development feasible. However, when there is a high level of social needs, the likelihood of older adults utilizing them increases, and they also express a need for community interaction. Contrary to social demands, they have indicated that the negative attitudes of neighbors toward the end of life can hinder utilization behavior. Studies have shown (52) that disease stigma can lead to a sense of shame and social alienation in older adults. Participating in community activities and receiving support from the community can increase the happiness of older adults and reduce their feelings of loneliness. It also indicates that community support involving medical personnel can extend the time that older adult individuals spend at home. Therefore, it is possible to provide support for home-based older adult care through community death education and the establishment of informal organizations that include medical staff.

8 Limitations

The following are the limitations of our study. The older adults who utilized home hospice care in this study were mostly patients in the late stages of cancer, and the results may not be as representative of other terminally ill older adult individuals. Second, the study was conducted in a less economically developed province in western China, and the economic factors may differ from other regions. Therefore, future studies could expand the range of diseases and regions under investigation, employing stratified sampling based on disease types and regional economies to make the study results more representative. Third, this study is a cross-sectional survey and cannot reflect the psychological factors at different stages of terminally ill patients. Future longitudinal studies could explore the utilization trends and associated factors of home hospice care. Fourth, due to the need for patients to recall and the influence of patients' social expectations, there is a certain recall bias and social expectation bias in the study. Finally, this cross-sectional study cannot establish a causal relationship.

9 Conclusion

In comparison with South Korea and China, the utilization rate in this study is only 13.55%, which fully demonstrates the gap between intention and acceptance. This further illustrates the significant importance of understanding the influencing factors. The factors influencing the utilization of home hospice care services by older adults are complex. The utilization of home-based services is influenced by both objective conditions and subjective intentions. Our study, guided by Andersen's Health Services Utilization Model, employs mixed methods to explore the potential factors in the decision-making of terminally ill older individuals regarding home-based hospice care. Ultimately, the positive enabling factors for utilization by older adults are identified as advanced age, chronic illness, and good knowledge of it. The main positive enabling factors are caregivers being nursing staff, a significant perceived economic burden, and accessible care resources, while the negative factor is the emotional involvement of families. Positive needs factors include social needs, and negative ones include physical and psychological needs. These results provide a comprehensive framework for understanding the facilitators and barriers to the utilization of home-based hospice care services by terminally ill older adults. In the future, intervention strategies to increase the utilization rate of home-based hospice care for older adults can be formulated based on these associated factors.

Data availability statement

The datasets presented in this study can be found in online repositories. The names of the repository/repositories and accession number(s) can be found below: the materials in this article are from the author's original research, and further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by the Ethics Committee of the Second Affiliated Hospital of Guangxi Medical University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

JP: Writing – original draft, Writing – review & editing, Data curation, Formal analysis, Investigation. XF: Formal analysis, Investigation, Writing – review & editing. XC: Data curation, Investigation, Writing – review & editing. LL: Investigation, Validation, Writing – review & editing. PD: Formal analysis, Investigation, Writing – review & editing. HW: Data curation, Visualization, Writing – review & editing. YC: Investigation, Supervision, Writing – review & editing. PH: Investigation, Validation, Writing – review & editing. DH: Investigation, Writing – review & editing. CL: Investigation, Writing – review & editing. YP: Investigation, Writing – review & editing. DF: Investigation, Project administration, Writing – review & editing. QP: Investigation, Methodology, Writing – review & editing. SL: Investigation, Project administration, Writing – review & editing. XP: Investigation, Resources, Writing – review & editing. LZ: Funding acquisition, Writing – review & editing. PT: Supervision, Validation, Writing – review & editing. HH: Funding acquisition, Methodology, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2025.1519712/full#supplementary-material

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Associations between perceived overload and quality of care in dementia family caregivers in China: mediating role of familism and social support

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Background: The quality of care (QoC) of people with dementia is an issue of widespread concern in public health. While perceived overload of family caregivers is thought to negatively affect QoC, the underlying mechanisms of this relationship are not well understood. This study aimed to examine the multiple mediating roles of familism and social support in the relationship between perceived overload and QoC among people with dementia (PwD) within the contemporary Chinese context.

Methods: A cross-sectional study was conducted between February 2023 and October 2023 in three hospitals located in three cities in Hubei Province, China. A total of 213 PwD and their family caregivers were recruited. Participants completed a general demographic questionnaire, the Chinese version of the Overload Scale, the Social Support Rating Scale (SSRS), the Familism Scale (FS), and the Exemplary Care Scale (ECS). Data were analyzed using SPSS 26.0 and the PROCESS macro.

Results: Perceived overload among family caregivers was directly related to QoC. Multiple mediation analysis revealed that the relationship between perceived overload and QoC was mediated by familism (effect: −0.111, 95% CI [−0.221, −0.034]) and social support (effect: −0.078, 95% CI [−0.163, −0.007]) both independently and serially (effect: −0.024, 95% CI [−0.054, −0.004]).

Conclusion: Familism and social support serve as multiple mediators in the relationship between perceived overload and QoC. This underscores the importance of incorporating familism and social support into intervention strategies aimed at enhancing QoC.

KEYWORDS

perceived overload, familism, social support, quality of care, dementia, family caregivers

1 Introduction

Dementia is a global issue, with the number of people with dementia (PwD) projected to reach 153 million by 2050 (1). In China, the prevalence of dementia is approximately 7%, affecting around 17 million people (2). More than 90% of PwD in China are cared for by informal family caregivers, influenced by traditional Chinese cultural values (e.g., Confucianism) and the limited availability of formal caregiving resources (3). The daily demands of caregiving, combined with the frustration caused by behavioral issues in PwD, place a significant burden on family caregivers, leading to severe perceived overload and potentially affecting the quality of care (QoC) provided to the patient (4). Low QoC has been associated with various adverse outcomes in PwD, such as higher mortality rates, a decline in life quality, frequent hospital readmissions, and an increased likelihood of institutionalization (5, 6). These consequences highlight the urgency of improving QoC for PwD to reduce these risks.

In China, family caregivers are often expected to take on caring roles due to traditional cultural values, particularly the cultural virtue of family care and filial piety in Confucianism. The strong sense of filial piety may partly explain why Chinese family caregivers of PwD experience more burdens and stresses compared to other racial/ethnic groups (7, 8). Meanwhile, with the rapid socio-economic development and changes in family structure in China, the traditional family care model is facing unprecedented challenges (9). As well as the underdeveloped Chinese dementia service system, family caregivers often lack the necessary support and resources (10). These further exacerbate their sense of overload. Therefore, it is becoming increasingly important to understand the mechanisms and conditions under which family caregivers' perceived overload affects the QoC they provide to PwD in the Chinese context.

1.1 The influence of perceived overload on quality of care

QoC refers to the degree to which informal care satisfies the needs of the care recipient, both quantitatively and qualitatively, and it encompasses multiple dimensions (11). Christie et al. (12) identified three domains of QoC: (a) potential for harmful behavior (PHB), (b) adequacy of care, and (c) exemplary care (EC). EC involves a caregiver's willingness and enthusiasm to provide care beyond fulfilling the basic needs of the older person, respecting their feelings, preferences, opinions, and values, while refraining from criticizing or reducing the individual's limitations (13). This research focuses on EC because empirical evidence suggests that reciprocal and respectful caregiving may contribute more significantly to high-quality care than its quantity or adequacy (13). Previous research on the mechanisms affecting the QoC has largely focused on institutional settings such as nursing homes, with few studies directly examining the impact of stress and psychosocial factors on the informal QoC received by patients (14, 15). Perceived overload manifests as emotional exhaustion, stress, and fatigue when an individual is unable to align their needs or resources with the demands of a specific task or environment (16). To better understand its impact on QoC, the Stress Process Model (SPM) proposed by Pearlin et al. (17) provides a useful conceptual framework. This model suggests that perceived overload functions as a significant stressor, potentially affecting caregivers' psychological state and behavioral attitudes, subsequently influencing the QoC they deliver in the context of family caregiving (17). There is substantial evidence indicating that perceived overload frequently results in poor QoC (18–21). For instance, Borghi et al. (20) have linked perceived overload with inappropriate emotional responses, a lack of patience, and reduced caregiving behaviors toward PwD during caregiving activities. Caregivers experiencing overload are prone to negative emotions such as elevated stress, exhaustion, and anxiety (22), which can impair their caregiving behaviors, potentially leading to neglect, impatience, or apathy in their interactions with care recipients (23). Building on these findings, we hypothesize that perceived overload negatively impacts QoC. While previous studies have explored the correlation between perceived overload and QoC, there is a gap in understanding the underlying mechanisms driving this relationship, which our study seeks to investigate.

1.2 The mediating role of familism

Familism is defined as an individual's strong connection and commitment to their family members, which refers to values about support, interconnectedness, obligations and loyalty to the family (24, 25). Familism culture values are belonged to support resource in SPM, it is highly relevant to informal caregiving, as caregivers often take on the responsibility of caring for their relatives based on the principles of familism (26). Some studies have confirmed that familism is one of the factors affecting QoC and psychological health of family caregivers of individuals with dementia (27–29). In China, familism, one of the core social and cultural values, deeply rooted in Confucian principles, emphasizes family interconnection and support. Song et al. (30) found that family caregivers with a strong sense of familial obligation have greater expectations of receiving support from other family members at home. This family-centered value helps caregivers receive emotional and practical assistance when facing challenges, making their experience less negative and stressful, which is a key factor in providing high QoC (9, 31). According to Sociocultural Stress and Coping Model (SSCM), familism has been shown to help mitigate various stressors and enhance their ability to cope with stressful events, thereby promoting their psychological well-being and influencing the caregivers' behavioral attitudes (25). Therefore, we hypothesize that perceived overload indirectly affects QoC through the mediation of familism. Although familism has gained increasing attention among Asian-American populations in North America, there is relatively little research on familism within the context of different ethnic groups in Asia (32). This study explores the impact of familism on informal caregiving within Chinese culture, aiming to provide new insights into the dynamics of family caregiving in the context of Chinese culture and potentially inform the development of support strategies and intervention measures.

1.3 The mediating role of social support

SPM has shown that social support is a key psychosocial factor affecting the relationship between the stressors experienced by family caregivers and their caregiving outcomes, as demonstrated by numerous empirical studies (33, 34). Social support refers to the various types of help and resources that individuals receive from their social networks, and it is a significant factor in shaping caregivers' attitudes, behaviors, and psychological stress (35). In China, familism emphasizes interdependence among individuals, which increases the perceived social support. As a result, caregivers may be more inclined to seek and receive help (36), thereby reducing stress and improving their ability to provide QoC. Liang et al.'s research found that perceived overload can severely hinder a family caregiver's ability to access and utilize social resources, which are a vital component of social support (37). This disruption impacts their capacity to receive practical assistance and emotional support from their social networks. Additionally, Bevan et al.'s study demonstrated that strong social support is closely associated with better QoC provided by family caregivers (38). Based on these findings, we hypothesize that social support mediates the relationship between perceived overload and QoC.

1.4 The chain mediation from familism to social support

Simultaneously, Family Ecosystem Theory (FET) (39) highlights the complex interactions between family members and their surrounding environment, showing how individual development is intricately shaped by these dynamics. Some researchers have argued that strong familism values increase individuals' emotional reliance on family support networks and encourage pro-social behaviors in times of crisis or emergency (40, 41). As a result, familism may play a central role in shaping the social support available to family caregivers. Therefore, we propose that familism and social support act as sequential mediators between perceived overload and QoC.

1.5 The current research

The existing literature examines the relationships among the variables of perceived overload, familism, social support and QoC separately, but there remains a gap in research on the complex relationship between perceived overload and QoC among family caregivers of PwD within the unique cultural and social context of China. For the first time, we developed a chain mediation model to explore this relationship, using the SPM as the theoretical framework and introducing familism and social support as chain-mediated variables. We hypothesized that: (1) perceived overload negatively affects QoC; (2) familism mediates the relationship between perceived overload and QoC; (3) social support mediates the relationship between perceived overload and QoC; and (4) perceived overload influences QoC through the combined mediating effects of familism and social support. The findings aim to understand the complex interplay between cultural factors and social support within the context of caregiving, offering insights that could guide the development of interventions to improve caregiver well-being and the QoC for PwD.

2 Materials and methods

2.1 Study design, procedure, and participants

A cross-sectional research design was employed. Using a non-probability convenience sampling method, PwD attending three tertiary hospitals in three cities, Wuhan, Xiangyang, and Yichang, Hubei Province, China, between February 2023 and October 2023 were included in this study. Patients diagnosed with dementia according to the criteria established by the Diagnostic and Statistical Manual of Mental Disorders, 5th edition, aged 60 or above and receiving home care. Those who had received paid service care at home were excluded. All caregivers were the primary caregivers of PwD. Primary informal caregivers are those who meet the following conditions: (1) being adult informal caregivers, such as spouses, children, and other family members; (2) spending at least four hours per day on caregiving for no less than 3 months (42–44); (3) often accompanying patients to see a doctor, the best understanding of the patient's condition, and basic living conditions; and (4) willing to participate in the study. Exclusion criteria were: (1) language and communication disorders, (2) severe physical or mental illness, (3) other major stressful events such as bereavement and divorce within past 3 months, or (4) planning to place the PwD in an older adult care facility within 6 months.

In this study, paper questionnaires were collected face-to-face and all investigators were uniformly trained. After being fully apprised of the purpose of the research, all participants granted written consent and filled out an anonymous questionnaire independently. If the respondents were illiterate, the answers were given in the form of questions and answers with the assistance of the investigators. The questionnaires were distributed and collected on the spot. After the questionnaire was completed, the investigators checked the questionnaire on the spot for omissions or obvious logical errors. If there were any problems, they were solved on the spot. Each questionnaire was completed within 20–30 min.

The sample size is based on a study that estimated the prevalence of dementia to be 7% (2). $u_\alpha = 1.96$, $\delta = 0.05$, $p = 7\%$. Based on the following formula (45), a minimum of 100 participants was required. The sample size was expanded by 20% to take into account factors such as sample loss or non-cooperation, ensuring a minimum of 125 participants. For structural equation modeling, a sample size exceeding 200 is recommended when dealing with more than 10 variables to ensure unbiased parameter estimates and convincing results (46). We finally collected a sample of 213 patients. The sample size met the requirements.

$$N = \frac{\mu_\alpha^2 p(1-p)}{\delta^2}$$

2.2 Measures

2.2.1 Demographic information

Utilizing a self-compiled questionnaire, we gathered demographic information for both the PwD and their caregivers. The information collected from PwD included age, gender, chronic disease, and activities of daily living (ADL). The ADL was assessed using the Barthel Index, which was completed by their caregivers. The data collected from the caregivers included age, gender, education level, place of residence, relationship with care recipients, living with care recipients, time of caring, length of care, self-rated health, affordability of living expenses.

2.2.2 Perceived overload

Caregivers' perceived overload was measured using the Overload scale (17). The 4-item Overload scale uses a 4-point Likert scale ranging from 1 (Not at all) to 4 (Completely), with higher scores implying higher levels of perceived overload. The Chinese version of the Overload scale was produced following Brislin's guidelines (47), and the scale has proven highly reliable. The Cronbach's α was 0.791 in this study.

2.2.3 The quality of care (QoC)

Quality of care was assessed using Chinese version of the Exemplary Care Scale (ECS) revised by Lau et al. (48). The ECS contains 11 items and comprises two components: provide (items 1–5) and respect (items 6–11). Each item is rated on a 4-point scale (0 = never, 1 = sometimes, 2 = often, and 3 = always). The total score ranges from 0 to 33. A higher total score indicates a higher QoC provided by informal caregivers. The Exemplary Care Scale has shown good reliability and validity in Chinese populations (48). The Cronbach's α was 0.816 in this study.

2.2.4 Familism

The Familism Scale (FS) revised by Sabogal et al. (24) was used to assess familism. The scale has nine items, each rated on a five-point Likert scale ranging from 1 ('strongly disagree') to 5 ('strongly agree'). It measures three distinct factors: familial obligations (items 1–2), familial support (items 3–5), and the family as a reference point (items 6–9). A higher score indicates a higher perception of familism. The Cronbach's α was 0.734 in this study.

2.2.5 Social support

The Familism Scale (FS) support was conducted using the Chinese version of the Social Support Rating Scale (SSRS) developed by Shuiyuan (49). The scale consists of 10-items which includes three dimensions: the subjective social support, objective social support, and the utilization of social support. Questions 1 to 4 and 8 to 10 are single-choice questions, with options (1), (2), (3), and (4) scoring 1, 2, 3, and 4 points, respectively. Question 5 asks about "the support and care received from family members," rated on a 4-point scale from 1 (none) to 4 (full support). Questions 6 and 7 are assessed based on the number of options selected, which means number of sources of help. The total score for social support ranges from 1 to 66. The higher the score, the greater the level of social support. The Social Support Rating Scale has shown good reliability and validity in Chinese populations (50). The Cronbach's α was 0.824 in this study.

2.3 Statistical analysis

SPSS version 26.0 and the PROCESS macro were employed to data analysis. $p < 0.05$ was considered to have statistical significance. Descriptive statistical analyses were conducted. Continuous variables were checked for normality with the P–P plots and characterized by means and standard deviations (SD). Categorical data were described frequencies and percentages. T-tests or one-way ANOVAs were calculated to compare the patients' and caregivers' demographic differences in the promotion of QoC. Multiple mediation models used these difference variables as covariates. The association among perceived overload, familism, social support and QoC were performed using Pearson's correlation coefficients. Hypothesis 1 (perceived overload negatively impacts QoC), Hypothesis 2 (familism plays a mediating role between perceived overload and QoC), Hypothesis 3 (social support mediating the relationship between perceived overload and QoC) and Hypothesis 4 (familism and social support play a chain mediating role between perceived overload and QoC) were tested by performing the mediation test on the PROCESS macro program of SPSS 26.0 plug-in (51). Mediating effects were tested and validated using 5,000 Bootstrap resamples and bias-corrected 95% confidence intervals (CIs). A significant mediation effect exists if the lower confidence interval (LLCI) and upper confidence interval (ULCI) do not contain zero (52).

3 Results

3.1 Characteristics of care recipients and informal caregivers

Table 1 lists the demographic characteristics of care recipients and caregivers. 213 care recipients were aged 60 to 100 (77.29 ± 9.42) years. Most care recipients were male (54.9%, $n = 117$), with moderate to severe dependence (64.3%, $n = 137$). Among the 213 caregivers, the ages were ranged from 20 to 92, with a mean age of 59.06 (SD = 14.33) years, Most caregivers were female (64.8%, $n = 138$). Other socio-demographic descriptions were detailed in Table 1.

3.2 Descriptive statistics and correlations among the main variables

The mean scores for perceived overload, familism, social support, and QoC are presented in Table 2. Additionally, Table 2 presents the results of the Pearson's correlation analysis conducted on the study variables. QoC was negatively correlated with perceived overload ($r = -0.621$, $p < 0.01$), and it was positively correlated with familism ($r = 0.361$, $p < 0.01$) and social support ($r = 0.527$, $p < 0.01$). Familism was negatively correlated with perceived overload ($r = -0.305$, $p < 0.01$), and positively correlated with social support ($r = 0.272$, $p < 0.01$). Social support was negatively correlated with perceived overload ($r = -0.378$, $p < 0.01$).

3.3 Multiple mediation model

Significant covariates (i.e., the care recipient's ADL, the caregiver's level of education, place of residence, relationship with the care recipient, time of caring, length of care, self-rated health, and affordability of cost of living) in the univariate analyses were controlled for in the mediation model. Utilizing 5,000 bootstrapping samples, we investigated the relationship between perceived overload and QoC, taking into account the mediating roles of familism and social support. The results are summarized in Table 3. The total indirect impact of perceived overload on QoC was significant (indirect effect = −0.213, SE = 0.070, 95% CI [−0.363, −0.090]). Perceived overload indirectly affected QoC through

TABLE 1 One-way analysis of QoC of the study participants with different characteristics (*N* = 213).

Characteristic	Group	N (%)	Mean ± SD	*t/F*
Care recipients				
Age (years)	60–74	88 (41.3)	16.97 ± 4.60	−0.466
	≥ 75	125 (58.7)	17.28 ± 5.00	
Gender	Male	117 (54.9)	16.58 ± 4.76	−1.910
	Female	96 (45.1)	17.84 ± 4.85	
Chronic disease	No	22 (10.3)	15.68 ± 5.85	−1.510
	Yes	191 (89.7)	17.32 ± 4.69	
ADL	No dependence	20 (9.4)	21.15 ± 3.94	9.538***
	Mild dependence	56 (26.3)	18.43 ± 5.06	
	Moderate dependence	43 (20.2)	16.56 ± 4.41	
	Severe dependence	94 (44.1)	15.81 ± 4.44	
Caregivers				
Age (years)	18–44	30 (14.1)	17.43 ± 4.07	0.140
	45–59	78 (36.6)	17.18 ± 5.28	
	60–74	77 (36.2)	17.22 ± 4.28	
	≥ 75	28 (13.1)	16.57 ± 5.82	
Gender	Male	75 (35.2)	17.44 ± 5.02	0.644
	Female	138 (64.8)	16.99 ± 4.74	
Education level	Primary school or below	45 (21.1)	14.98 ± 5.07	9.920***
	Secondary school	94 (44.1)	16.87 ± 4.82	
	High school or above	74 (34.8)	18.82 ± 4.10	
Place of residence	Rural	70 (32.9)	14.96 ± 5.39	−4.467***
	Urban and town	143 (67.1)	18.22 ± 4.15	
Relationship with care recipients	Spouse	76 (35.7)	17.11 ± 4.91	5.453**
	Children	110 (51.6)	17.84 ± 4.63	
	Other family members	27 (12.7)	14.48 ± 4.62	
Living with care recipients	Yes	161 (75.6)	17.13 ± 4.89	−0.072
	No	52 (24.4)	17.19 ± 4.70	
Time of caring (h/d)	4 to <8	64 (30.1)	18.11 ± 4.66	3.265**
	8–12	42 (19.7)	18.45 ± 4.41	
	>12	107 (50.2)	16.05 ± 4.96	
Length of care (year)	<1	70 (32.9)	18.11 ± 4.26	6.271**
	1–5	99 (46.4)	17.52 ± 4.86	
	>5	44 (20.7)	15.02 ± 4.69	
Self-rated health	Poor	42 (19.7)	15.38 ± 4.31	5.814**
	Fair	98 (46.0)	16.94 ± 4.93	
	Good	73 (34.3)	18.45 ± 4.67	
Affordability of living expenses	Difficult	62 (29.1)	13.68 ± 4.54	28.476***
	Somewhat difficult	66 (31.0)	18.50 ± 4.29	
	Not difficult	85 (39.9)	18.64 ± 4.83	

*$P < 0.05$, **$P < 0.01$, ***$P < 0.001$.

familism (indirect effect = −0.111, SE =0.049, 95% CI [−0.221, −0.034]) and social support (indirect effect = −0.078, SE = 0.040, 95% CI [−0.163, −0.007]). Furthermore, perceived overload indirectly impacted QoC through familism and social support in serial (indirect effect = −0.024, SE = 0.013,95% CI [−0.054, −0.004]). The direct impact of perceived overload on QoC was significant (direct effect = −0.601, SE =0.107, 95% CI [−0.811, −0.391]) (see Figure 1).

TABLE 2 Descriptive statistics and correlations among the variables (n = 213).

Variables	Mean ± SD	perceived overload	familism	social support	QoC
Perceived overload	9.63 ± 2.90	1			
Familism	33.38 ± 4.59	−0.305**	1		
Social support	39.25 ± 7.04	−0.378**	0.272**	1	
QoC	17.15 ± 4.83	−0.621**	0.361**	0.527**	1

*$P < 0.05$, **$P < 0.01$, ***$P < 0.001$.

TABLE 3 Summary results of the mediation analyses.

Path	Effect	SE	LLCI	ULCI
Total effect	−0.814	0.112	−1.035	−0.593
Direct effect	−0.601	0.107	−0.811	−0.391
Total indirect effect	−0.213	0.070	−0.363	−0.090
Indirect 1	−0.111	0.049	−0.221	−0.034
Indirect 2	−0.078	0.040	−0.163	−0.007
Indirect 3	−0.024	0.013	−0.054	−0.004

SE, standard error; LLCI and ULCI, lower level and upper level of the bias-corrected 95% bootstrap confidence interval. Direct effect = perceived overload → quality of care; Indirect 1 = perceived overload → familism → quality of care; Indirect 2 = perceived overload → social support →quality of care; Indirect 3 = perceived overload → familism → social support →quality of care.

4 Discussion

To the best of our knowledge, this is the first study to examine the role of familism and social support as mediators of the relationship between perceived overload and QoC among family caregivers of PwD in China. Different from Western caring culture, our research has revealed that both familism and social support are crucial resources in context of China. We combined SPM, SSCM and the FET to gain a better understanding of cultural influences in the care of PwD at home in China. Theoretical models developed based on western culture emphasize the role of social support, but familism of culture value is also important in the Chinese context.

Our study found that perceived overload was negatively associated with QoC, which aligns with previous research (19), confirming Hypothesis 1. In general, findings indicate that the QoC received by patients is significantly affected by various stressors experienced by family caregivers during daily caregiving activities. This highlights the key role of perceived overload in maintaining QoC. Specifically, caregivers experience perceived overload when the demands of care exceed their ability to cope, often resulting in fatigue and burnout (53). Hence, their capacity to provide care and support is reduced, leading to a decline in the QoC for PwD (54).

Our findings indicated that familism moderated the relationship between perceived overload and QoC, supporting Hypothesis 2. Consistent with previous studies, the attitudes and behaviors of family caregivers toward patients are influenced by both stressors and family environmental factors (39, 55). Family caregivers may experience fatigue and burnout due to intense perceived overload, which reduces their psychological resilience and coping abilities, making it difficult for them to fulfill family responsibilities (56). From the perspective of the "family obligation" dimension of familism, caregiving is seen as a family duty. Xu (57) research shows that obligation such as filial piety, helping family members, and maintaining family honor remains highly valued in contemporary Chinese families. Traditional Chinese culture emphasizes love and filial piety, this obligation extends beyond material support to include emotional companionship and respect (31). In addition, the family support is another dimension of familism. It refers to the emotional and practical assistance that family members provide to each other, which greatly enhances the psychological resilience of caregivers, allowing caregivers to better cope with stress and challenges (24). Furthermore, family as a reference dimension is the third dimension of familism, which highlights the pivotal role of family in shaping individual decision-making and behavior. Caregivers are likely to strive to provide higher QoC in line with their family's expectations and values (9, 24). As a result, caregivers with strong familism are more likely to provide high QoC in a compassionate and patient manner during caregiving activities. Therefore, understanding the interactions among perceived overload, familism and QoC is crucial for providing culturally grounded and effective support, ultimately promoting an environment for high-quality care.

The results also suggested that the mediating role of social support in perceived overload and QoC, supporting Hypothesis 3. High levels of social support have been shown to buffer the effects of perceived overload on family caregivers, aligning with the SPM (17). Family caregivers perceive higher levels of social support may reduce the reliance on negative coping strategies and, in turn, positively impacts the QoC provided by caregivers (58). Furthermore, when family caregivers receive help and care from family or friends, their fatigue is significantly reduced, and they are more willing to offer proactive care (59). In this study, the population from urban areas accounts for more than half. In China, there is a significant disparity in the level of social support between urban and rural areas, primarily due to differences in economic development levels, distribution of social resources, and infrastructure construction (10). According to data from the WHO in 2021, formal agreements and joint plans for dementia care in China are not yet fully developed, and the availability of social and economic protections is insufficient (60). Especially in rural areas, fewer services, accessing and utilizing limited resources make it harder for caregivers to obtain support (61).

The results also indicated that perceived overload influences QoC among caregivers through the serial mediation effects of familism and social support, confirming Hypothesis 4. The study suggests that familism may play a central role in shaping the social support available to family caregivers. Familism emphasizes emotional closeness and mutual assistance among family members (24). Emotional support allows family caregivers to feel cared for and understood by their family members when facing stress and challenges, thereby increasing their psychological resilience and sense of social support (62). By encouraging family members to help one another during difficult times, family caregivers can receive practical assistance (e.g., patient

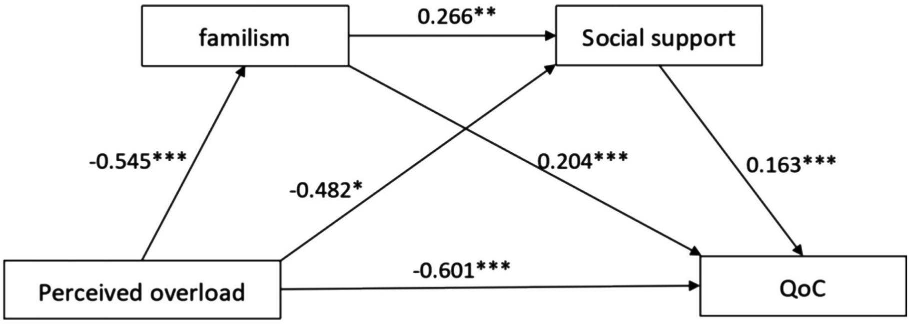

FIGURE 1
The multiple mediation model of familism and social support linking perceived overload and QoC of PwD (*N* = 213). QoC, quality of care. **p* < 0.05, ***p* < 0.01, ****p* < 0.001.

care, household chores, financial support) from other family members. As a result, family caregivers with high familism may receive more family support due to the close-knit nature of family relationships. In China, familism is deeply connected to cultural heritage and the reinforcement of traditional values. Mutual help and support among family members reflect the principles of filial piety and family harmony central to traditional Chinese culture, and these cultural values are passed down and strengthened through familism (31). When caregivers perceive overload, they rely not only on internal cultural values but also on external social support networks to cope. This dual support, cultural and social, helps reduce the physical and psychological stress experienced by family caregivers during the caregiving process, making them more attuned to the patient's needs and feelings and more likely to provide exemplary care.

4.1 Implications

This study provides a reference for interventions of improving QoC of PwD. By establishing correct cultural values and maintaining good family relationships, caregivers may experience greater family cohesion, a stronger sense of responsibility, and deeper emotional bonds, leading to more patient and compassionate caregiving (10). Social support interventions, such as support groups and skill-building workshops, could provide higher-quality care (63). Providing caregivers with necessary assistant social support resources is crucial to improve QoC (64). This suggests that the government should integrate various available resources, establish the caregivers of PwD social support system that is suitable for China's national conditions.

4.2 Limitations

Despite these strengths, this study has some limitations. Firstly, the cross-sectional design limits causal inferences. Future research should consider a longitudinal approach to better capture the dynamic effects of perceived overload, familism, and social support on QoC over time. Secondly, self-reported data on perceived overload, familism, social support, and QoC was used. Reliance on self-reported data may introduce bias due to participants' subjective interpretations and their tendency to respond in a socially desirable manner. Future studies could enhance objectivity by incorporating additional assessment methods like observations or data obtained from qualitative interviews. Thirdly, conducted in three hospitals in central China, our findings may not be generalizable to all dementia caregivers in China, especially given the country's regional and economic diversity. Future research with larger and more diverse samples should test the consistency of results across different regions and cultural settings. Lastly, while focusing on familism and social support, our study did not include other potential factors such as family financial resources, caregiver mental health, and availability of external support institutions. Future research could benefit from a broader range of variables for a more comprehensive evaluation of QoC.

5 Conclusion

This study clarified the mediating pathway between familism and social support among Chinese family caregivers of PwD. Familism and social support act as mediators in the relationship between perceived overload and QoC. By targeting interventions to reduce perceived overload while simultaneously enhancing the beneficial effects of familism and social support, we may achieve a direct enhancement in QoC. Additionally, alleviating perceived overload in caregivers of PwD may lead to an indirect improvement in QoC.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Wuhan University of Science and Technology, Wuhan 430,065, China. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

NZ: Conceptualization, Investigation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. CC: Conceptualization, Investigation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. XZ: Writing – review & editing. SC: Writing – review & editing. JS: Writing – review & editing. CS: Supervision, Validation, Writing – original draft, Writing – review & editing.

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Bridging accessibility gaps in urban community-based basic older adult care: a comprehensive framework validated in Xi'an, China

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Objectives: Accessibility is a critical factor in ensuring equitable public services. In urban older adult care systems, resource allocation and service disparities present unique challenges. The classical "5A" theory—availability, accessibility, affordability, adaptability, and acceptability—provides a robust framework for evaluating service delivery. However, its application in urban older adult care, especially in rapidly aging societies like China, remains limited. This study aims to develop and validate a framework to address affordability, resource allocation, and service mismatches in urban older adult care systems.

Methods: A web-based cross-sectional study was performed in 2023. A multi-phase methodology was adopted to construct the framework, grounded in the "5A" theory. Indicators were refined through expert consultations using the Delphi method, involving 20 experts, while the entropy weight method ensured objective indicator weighting. The framework was empirically validated in Xi'an, China, using survey data collected from 438 older adult residents across urban strata. A fuzzy comprehensive evaluation (FCE) method was employed to assess accessibility and identify key service gaps.

Results: This study constructs a comprehensive evaluation framework for basic older adult care services (BECS), structured around 5 primary dimensions, 14 sary indicators, and 37 tertiary indicators. Empirical validation in Xi'an further demonstrates the framework's scientific rigor and practical applicability. While the framework identifies strong spatial accessibility (3.8815), it also reveals critical gaps in affordability (3.1347) and psychological care (3.0862), confirming its effectiveness in diagnosing systemic disparities and guiding policy interventions.

Conclusion: This study introduces a novel accessibility evaluation framework tailored for basic older adult care services, addressing critical gaps in affordability, psychological care, and service responsiveness. Empirical results validate the framework's practicality and its alignment with the real-world conditions of urban aging societies. Furthermore, an innovative "Matching-Realization-Satisfaction" improvement pathway is proposed, offering actionable strategies to enhance accessibility and optimize service delivery. This framework serves as a replicable model for advancing equitable older adult care in rapidly aging urban communities.

KEYWORDS

accessibility, basic older adult care, urban community, evaluation framework, service equity

1 Introduction

Population aging remains a persistent global challenge (1). Population aging is not limited to developed countries; developing nations are also facing this demographic trend (2). By 2030, the global population aged 65 and older is expected to reach 994 million, and this figure is projected to rise to 1.6 billion by 2050 (3). Aging has become one of the most significant demographic trends of the 21st century (4) and will shape China's future demographic structure. According to the United Nations, these shifts highlight the growing urgency of addressing challenges posed by an aging population. By the end of 2023, individuals aged 60 and 65 and above are expected to account for 21.1 and 15.4% of China's total population, respectively (5). The escalating aging trend poses significant challenges to the nation's pension service system (6).

In the context of population aging and rapid social and economic transformations, expectations and preferences for living arrangements have undergone significant changes in recent decades, particularly in urban areas. The one-child policy, coupled with the rising participation of women in the workforce, has limited the younger generation's ability to care for the older adult (7). Consequently, Chinese society has sought alternative sources of older adult care support (8), with basic older adult care services emerging as the cornerstone of the country's multi-tiered older adult care system (9, 10). The release of Opinions on *Promoting the Construction of a BECS System* has established a strategic framework emphasizing material assistance and care services as its core components. Specifically, BECS includes essential services such as home-based care, which provides daily living support, healthcare, and in-home medical care; institutional care, which offers comprehensive long-term care and rehabilitation in dedicated facilities; health management, such as regular health check-ups, chronic disease management, and psychological health services; social participation and cultural engagement, which encourage older adult individuals to participate in community activities and foster intergenerational interactions; and policy support, such as financial subsidies and housing assistance tailored to the needs of disadvantaged groups. Despite significant progress in building its basic older adult care system, challenges persist, including urban–rural disparities, unequal resource distribution, and mismatches between service supply and demand (11), particularly in bridging the "last mile." Despite significant progress, challenges remain in China's basic older adult care system, such as urban–rural disparities, unequal resource distribution, and mismatches between service supply and demand, especially in addressing the "last mile."

Accessibility is a key requirement for building a modern Chinese-style public service system (12). Enhancing accessibility has become a critical policy objective for advancing the basic public service system. Accessibility focuses on the endpoints of service delivery, aiming to improve recipients' sense of access and satisfaction by enhancing the convenience and usability of public services, with greater emphasis on functional value. Ensuring that basic old-age services truly benefit older adult populations, while enhancing accessibility, is a pressing issue at this stage of service development. Despite progress in constructing a basic old-age care system across China, the lack of standardized evaluation metrics and frameworks persists.

We address the theoretical and practical demands of developing BECS by incorporating Western classical accessibility concepts and domestic research paradigms. First, we clarifiy the core elements and dimensions of basic older adult care service accessibility. Second, it employs the Delphi method, entropy weight method, and other approaches to construct and refine the evaluation index system for assessing the accessibility of BECS in urban communities. Representative areas are selected for empirical research to validate the system's rationality and feasibility. Finally, the evaluation results and current practices are analyzed to pinpoint key areas and priorities for improving the accessibility of basic older adult care services.

2 Materials and methods

2.1 Study design

We employed a cross-sectional design to evaluate disparities in the accessibility of basic older adult care services (BECS) in urban districts of Xi'an, using a multidimensional framework grounded in the '5A' theory: availability, accessibility, affordability, adaptability, and acceptability. This evaluation follows a systematic approach encompassing four stages: framework construction, indicator optimization, stakeholder empowerment, and application validation, as illustrated in Figure 1.

Stage 1: Initial Construction of the Indicator System—A systematic review and integration of relevant literature identifies core dimensions and detailed indicators for evaluating BECS in urban communities.

Stage 2: Optimization of the Indicator System—Indicators were developed using a structured literature review and expert consultations conducted through the Delphi method. This iterative process involved experts from gerontology, public health, and social welfare fields. A total of 5 primary dimensions, 14 sary indicators, and 37 tertiary indicators were finalized to comprehensively evaluate accessibility.

Stage 3: Indicator Weight Assignment—Weights are assigned using the entropy weighting method based on field research data, ensuring objectivity and reliability in the optimized indicator system.

Stage 4: Application and Validation of the Indicator System—A typical urban area in Xi'an is selected for empirical research. A Likert five-point scale and the fuzzy comprehensive evaluation method are employed to validate the system's effectiveness.

2.2 Conceptual model of accessibility of BECS in urban communities

Accessibility refers to the actual use of services by individuals in need rather than merely the presence of facilities, indicating the extent to which public service systems are effectively utilized (13). The concept of accessibility, originating in Western healthcare (14), is discussed in academia through two primary perspectives: service utilization and the degree of "fit." From the "service use" perspective, Andersen defines accessibility as individuals' actual utilization of health services, emphasizing the factors that either facilitate or hinder service use (15). Conversely, Penchansky and Thomas adopt a "fit" perspective, criticizing Andersen's exclusion of payment ability and defining accessibility as the degree of alignment between user needs and service systems (16). The matching perspective is widely recognized, forming the basis for classical models such as Katarina's "4A" framework (17) and Penchansky and Thomas's five-dimensional framework of accessibility, adaptability, affordability, availability, and acceptability (18). In older adult care,

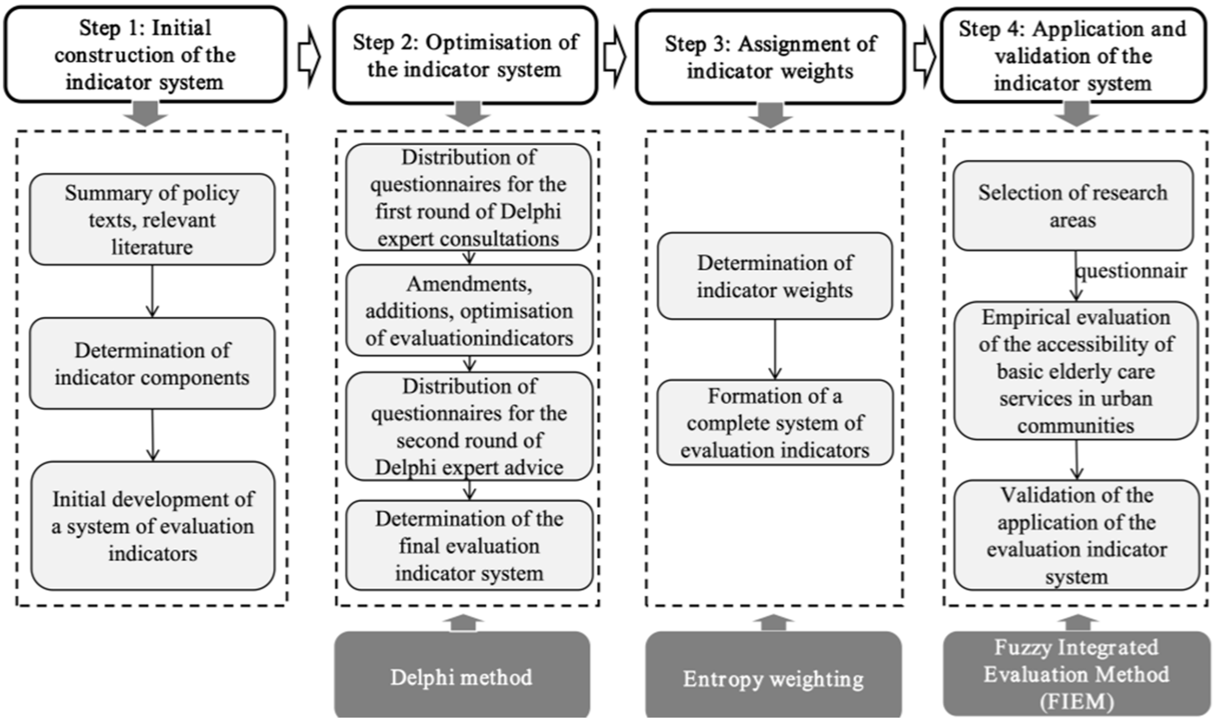

FIGURE 1
Research framework.

accessibility theory primarily evaluates service quality, often emphasizing the fit between services and user needs (19). Scholars have assessed older adult services through content, geographic and temporal, and economic accessibility. Others have refined these dimensions to construct models focusing on financial, content, and service mode accessibility (20). The "5A" model has also been widely adopted to evaluate older adult service quality comprehensively (21–23). Improving the accessibility of BECS to benefit the older adult population has emerged as a critical issue at the current stage of development.

Following the structural framework of "Definition-Assessment-Application," we define the accessibility of BECS as the degree of alignment between the needs of older adult individuals and the resources of the basic older adult care system. Specifically, it examines whether older adult individuals can access government- and community-provided care services adequately, conveniently, and efficiently and whether the available resources meet service demands. Considering the development and current practices of BECS in China's urban communities, we incorporate Penchansky and Thomas's "5A" analysis framework of health service accessibility. The five key dimensions—availability, accessibility, affordability, adaptability, and acceptability—are adapted to the BECS system. These dimensions are further refined and extended to construct the "5A" conceptual model of accessibility for BECS in urban communities, as illustrated in Figure 2.

2.3 Optimization of the indicator system based on the Delphi method

2.3.1 Questionnaire design

The Delphi Method is a research approach that gathers expert opinions through multiple rounds of structured correspondence to reach a consensus (24). The expert questionnaire in this study consists of two main sections: (1) This section collects basic information about the respondents, including their academic background, knowledge of basic older adult care services, and the rationale for completing the questionnaire. (2) This section asks respondents to rate the importance of indicators on a five-point Likert scale, ranging from 1 (least important) to 5 (most important). The indicator system in the questionnaire is old far based mainly on the accessibility theory and combined with national policy documents (see Supplementary material for details).

2.3.2 Expert selection

Based on the study requirements, 20 experts from relevant fields were invited to participate, as detailed in Table 1. The selection criteria for these experts were: (a) holding professional titles of intermediate level or higher; (b) having a deep understanding of the field with over 10 years of relevant experience; (c) possessing an undergraduate degree or higher academic qualification; (d) demonstrating willingness and availability to engage in this study actively. The co-ordination coefficients and statistical results of the two rounds of expert consultation are detailed in Supplementary material. The co-ordination coefficients for the first and second rounds are 0.328 and 0.332 respectively, and the tests of significance satisfy the statistical requirements, demonstrating the consistency of the expert opinions.

2.4 Determination of evaluation index weights based on the entropy weight method

The accessibility of BECS in urban communities is often assessed based on the subjective perceptions of the older adult. However,

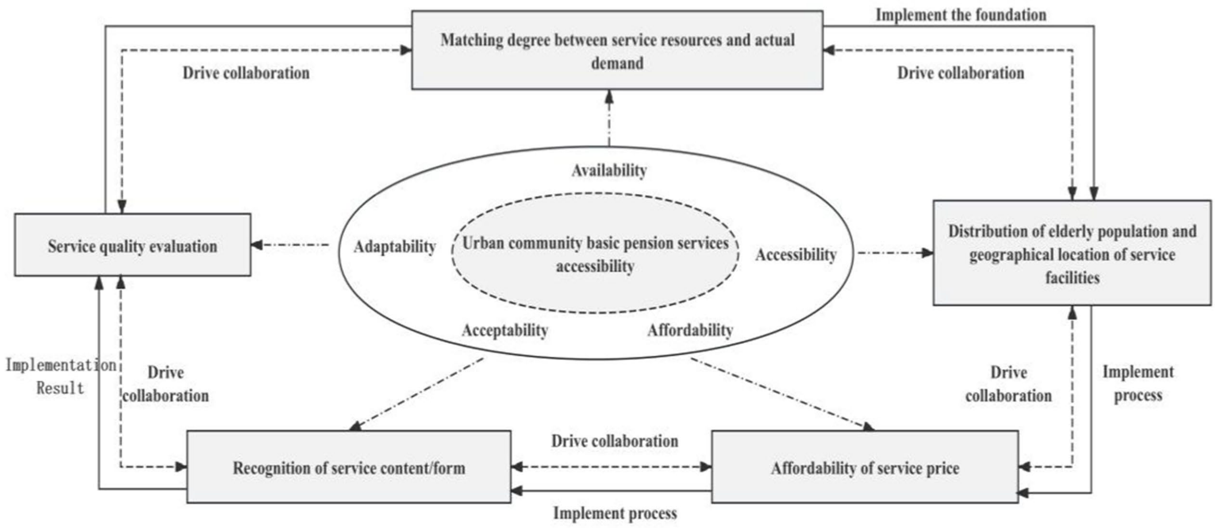

FIGURE 2
Conceptual model of '5A' accessibility of basic older adult services.

TABLE 1 Basic information on experts.

Project title	Categorization	Numbers	Component ratio (%)
Work unit	University/Research Institutions	7	35
	Government departments	4	20
	Institutions	3	15
	Pension organizations	6	30
Area of expertise	social security	6	30
	Older adult care	7	35
	Older adult services	2	10
	Administration	5	25
Years of specialization	Less than 10 years	6	30
	10–15 years	8	40
	More than 15 years	6	30
Professional designation	Intermediate	6	30
	Deputy senior	10	50
	Full senior	4	20

traditional subjective weighting methods have inherent limitations. Therefore, we employ the entropy weight method as an objective approach to assign weights for analysis (25). The detailed process of weight calculation is as follows:

(a) Data normalization.

Assuming that there are *n* evaluation objects and m evaluation indicators, the value of the jth indicator of the ith evaluation object is denoted as x_{ij}. Through data normalization, the differences arising from different scales of the indicators are eliminated in order to make the values of the indicators have the same scale and magnitude, so as to achieve the homogeneity of the values.

For positive indicators:

$$x_{ij}=\frac{X_{ij}-\min\left(X_{1j},X_{2j,\ldots,}X_{nj}\right)}{\max\left(X_{1j},X_{2j,\ldots,}X_{nj}\right)-\min\left(X_{1j},X_{2j,\ldots,}X_{nj}\right)} \tag{1}$$

For negative indicators:

$$x_{ij}=\frac{\max\left(X_{1j},X_{2j,\ldots,}X_{nj}\right)-X_{ij}}{\max\left(X_{1j},X_{2j,\ldots,}X_{nj}\right)-\min\left(X_{1j},X_{2j,\ldots,}X_{nj}\right)} \tag{2}$$

(b) Calculation of the weight of the ith evaluation object under the jth evaluation indicator:

$$P_{ij}=\frac{X_{ij}}{\sum_{i=1}^{n}X_{ij}} \tag{3}$$

(c) Calculate the entropy value of the jth indicator:

$$e_j=-k\sum_{i=1}^{n}p_{ij}\ln\left(p_{ij}\right),j=1,\ldots,m \tag{4}$$

(d) Calculate the information entropy redundancy (utility value):

$$d_j=1-e_j,j=1,\ldots,m \tag{5}$$

(e) Calculation of the weights of the indicators:

$$w_j=\frac{d_j}{\sum_{j=1}^{m}d_j},j=1,\ldots,m \tag{6}$$

Following the outlined process, the weights of the second-level indicators are calculated as the sum of the corresponding third-level indicator weights. Similarly, the weights of the first-level indicators are derived by aggregating the weights of the second-level indicators. The calculation of these weights is based on Equations 1–7, which detail the normalization and weighting procedures. The specific weight results, which will be presented later in Table 5, outline the accessibility evaluation indicator system and its associated weights for basic older adult services in urban communities. These results are detailed in the Results section (Section 3.2).

2.5 Application of the evaluation index system based on the fuzzy comprehensive evaluation method

2.5.1 Evaluation process

The fuzzy comprehensive evaluation method applies fuzzy mathematical theory to address evaluation factors with ambiguous boundaries and challenges in quantification (26). The fuzzy comprehensive evaluation (FCE) method was employed to integrate both qualitative and quantitative data for each dimension. This approach accommodates uncertainty and subjectivity inherent in survey responses, synthesizing scores to generate an overall accessibility evaluation. In addition to the structured Likert-scale questions providing quantitative inputs, qualitative data were also incorporated into the FCE analysis. Examples of qualitative data include: (1) Open-ended survey questions: Participants provided detailed feedback on their satisfaction with cultural activities, emotional support services, and accessibility of community facilities. These responses supplemented quantitative ratings and offered insights into unmet needs. (2) Field observations: During visits to community service centers, researchers documented observations related to facility usability, inclusiveness of service environments, and staff responsiveness, which informed the evaluation of adaptability and acceptability dimensions. (3) Caregiver narratives: For participants unable to complete the survey independently, caregivers contributed qualitative insights regarding the challenges and effectiveness of home-based care services.

The FCE process was employed to assess the accessibility of Xi'an's central city through the following steps:

1. Construct the evaluation factor set. Denote the set of indicators for this evaluation of the accessibility of BECS in urban communities by U, U = {u1, u2, …, um}.
2. Construct the evaluation set. The evaluation set is the result synthesized by the respondents' scores on the evaluation of the accessibility of basic older adult care services. The evaluation ratings are described by V = {V1, V2, …, V5}, where V1 means very satisfied, V2 means satisfied, V3 means average, V4 means dissatisfied, and V5 means very dissatisfied.
3. Determining the degree of affiliation. The number of samples corresponding to the evaluation levels of the 37 tertiary indicators can be obtained according to the scoring situation, divided by the total number of the corresponding, that is, to obtain the degree of affiliation corresponding to each level.
4. Construct the weight set. The weight of each indicator has been calculated according to the entropy weight method.
5. Compound operation of fuzzy matrix, through the synthetic operation of weight set W and evaluation result V, in order to precise the overall judgment vector of each indicator, and get the evaluation result corresponding to each indicator.

2.5.2 Selection of evaluation objects

Xi'an, the capital of Shaanxi Province, was chosen as the study site due to its unique demographic profile and its significance in addressing aging-related challenges in urban China. As of 2023, Xi'an has a population of approximately 13.08 million, with 15.5% aged 60 or older and 12.6% aged 65 or older (27), classifying it as a deeply aging society. The city has faced aging-related issues, such as an imbalance between the supply and demand for older adult care services, earlier than many other Chinese cities. Its advanced efforts in developing older adult care infrastructure and services make Xi'an an ideal location to test the feasibility and applicability of the proposed evaluation framework.

2.5.3 Questionnaire distribution and data collection

We focused on the central urban areas of Xi'an, including Xincheng, Beilin, Lianhu, Baqiao, Weiyang, and Yanta districts, as the sample region. A combination of stratified and random sampling was employed to ensure a diverse and representative sample across different urban strata. Eligible participants were required to meet the following criteria: (1) aged 60 years or older and (2) had previously received basic older adult care services.

Data collection was primarily conducted at community older adult service centers through face-to-face interviews and paper questionnaires, complemented by surveys in other community locations, such as activity centers and nearby parks. For participants with limited mobility or reduced self-care ability, caregivers or family members were permitted to complete the questionnaire on their behalf. This stratified sampling approach, combined with the targeted distribution of questionnaires, ensured the validity and authenticity of the responses while reflecting the diverse conditions of older adult residents in urban areas.

To determine the sample size, we applied the formula for large sample populations proposed by Wu (28):

$$n \geq \left(\frac{\mathrm{k}}{\acute{\mathrm{a}}}\right)^2 p\left(1-P\right) \tag{7}$$

where the significant level α is 0.05 (28) and the confidence level used for interval estimation is 1-α = 0.95, at which point the quantile k = 1.96, and according to this formula, the calculation yields $n \geq 384$.

To account for potential non-responses and ensure a robust sample size, a total of 438 questionnaires were distributed. Among these, 430 valid responses were recovered, resulting in a response rate of 98.17%. Missing data accounted for less than 5% of the total dataset, primarily due to incomplete demographic information. These missing values were addressed using multiple imputation to ensure data integrity without biasing the analysis. The respondents' basic information is detailed in Table 2.

3 Results

3.1 Analysis of questionnaire data for the Delphi method

3.1.1 Degree of expert authority

Expert authority degree coefficient (Cr) ≥ 0.70 is acceptable coefficient (29), expert authority coefficient (Cr) = (Ca + Cs) / 2, Ca is the basis of expert judgment. The Cr value ranges from 0 to 1, with higher values indicating greater expert authority. The quantitative results for expert authority are presented in Table 3.

3.1.2 Degree of coherence of expert opinions

The consistency of the evaluation indicators is assessed using Kendall's WWW harmony coefficient, which ranges from 0 to 1. Higher WWW values indicate greater consistency among expert opinions. As shown in Table 4, the significance test for the harmony coefficient yielded a *p*-value below the threshold of 0.05, confirming its statistical significance. Therefore, the expert evaluations demonstrated consistency and satisfied the criteria for indicator screening.

TABLE 2 Basic information of survey respondents.

Basic Information	Form	Percentage (%)
Genders	Male	51.85%
	Female	48.15%
Age	60–64 years	23.84%
	65–69 years	27.08%
	70–74 years old	24.31%
	75 and above	24.77%
Income situation	0–999 Yuan	16.67%
	1000–1999 Yuan	29.63%
	2000–3999 Yuan	41.90%
	4000Yuan and above	11.81%
Health situation	Health	23.84%
	Good	40.05%
	Fair	27.78%
	Unhealthy	8.33%
Residential situation	Living with spouse	42.13%
	Living with children	21.53%
	Living alone	19.68%
	Living with spouse and children	14.35%
	Other	2.31%

TABLE 3 Degree of authority of experts.

Rounds	Coefficient of appreciation (Ca)	Degree of familiarity(Cs)	Authority factor (Cr)
Round 1	0.91	0.85	0.88
Round 2	0.96	0.90	0.93

3.2 Construction of evaluation indicator system for accessibility of basic older adult services in urban communities

Following two rounds of Delphi expert consultation, a final evaluation indicator system for assessing the accessibility of BECS in urban communities was established. The system comprises 5 first-level indicators, 14 second-level indicators, and 37 third-level indicators, as detailed in Table 5. According to the weighting order presented in Table 5, affordability ranks highest, followed by availability, adaptability, acceptability, and accessibility. Among the 14 second-level indicators, resource provision emerges as the core element with the highest weight (0.0943), underscoring the critical role of abundant resources in ensuring access to older adult care services. Facility provision (0.077) and facility layout (0.0616) rank next, emphasizing the significance of sufficient older adult beds and diverse programs in meeting the varied needs of the older adult population. The prices of life care services (0.0820) and spiritual comfort services (0.0859) carry comparable weights, reflecting the older adult's dual focus on quality of life and emotional well-being.

3.3 Application of the evaluation index system for accessibility of BECS in urban communities

The primary, secondary, and tertiary indicators, along with the comprehensive evaluation results, were determined by de-fuzzifying the evaluation result set, as detailed in Table 6. Using the final calculated PPP value for de-fuzzification as an example, the comprehensive evaluation score for the accessibility of basic community older adult care services in Xi'an's urban center is:

$$5 \times 0.1241 + 4 \times 0.2989 + 3 \times 0.4005 + 2 \times 0.1390 + 1 \times 0.0374 = 3.3330$$

The empirical analysis in Xian's central urban area underscores the importance of affordability, availability, and adaptability in

TABLE 4 Degree of coordination between the two rounds of consultancies.

Degree of expert coordination		Entry	Kendall's W	χ^2	p
First round of consultations	Overall	58	0.328	373.792	0.000
	First level indicator	5	0.217	17.333	0.002
	Secondary indicators	14	0.113	29.263	0.006
	Third level indicators	39	0.390	296.663	0.000
Second round of consultations	Overall	56	0.332	365.012	0.000
	First level indicator	5	0.125	10.000	0.040
	Secondary indicators	14	0.246	64.059	0.000
	Third level indicators	37	0.307	220.906	0.000

TABLE 5 Evaluation indicator system for accessibility of basic older adult services in urban communities and its weights.

First level indicators	Weight	Secondary indicators	Weight	Third level indicators	Weight
A Availability	0.2329	A1 Facility layout	0.0616	A11 Number of community older adult service centers	0.0311
				A12 Building area of community older adult care service center	0.0305
		A2 Facility configuration	0.0770	A21 Number of beds in community older adult service centers	0.0464
				A22 Number of service facilities in community older adult care service centers	0.0306
		A3 Resource supply	0.0943	A31 Types of older adult services provided by community older adult service centers	0.0333
				A32 The number of older adult care service projects provided by community older adult care service centers	0.0304
				A33 Number of service personnel in community older adult service centers	0.0306
B Accessibility	0.0637	B1Space reachable	0.0283	B11 Distance from residence to community older adult care service center	0.0127
				B12 The convenience level from the residence to the community older adult care service center	0.0156
		B2Time achievable	0.0354	B21 Waiting time for nursing staff's on-site service	0.0184
				B22Time consumption from residence to community older adult care service center	0.0170
C Affordability	0.3161	C1 Affordability of prices for obtaining life care services	0.0820	C11 Meal assistance service	0.0202
				C12 Cleaning assistance service	0.0243
				C13 Agency service	0.0375
		C2 Affordable access to medical care services	0.1006	C21 Rehabilitation nursing services	0.0334
				C22 Health management services	0.0293
				C23 Healthcare Services	0.0379
		C3 Affordability of prices for obtaining mental comfort services	0.0859	C31 Emotional Communication Services	0.0444
				C32 Psychological counseling services	0.0415
		C4 Affordability of prices for cultural and entertainment services	0.0476	C41 Entertainment	0.0178
				C42 Education for the older adult	0.0298
D Acceptability	0.1366	D1 Acceptance of service content	0.0907	D11 Acceptance of life-care services	0.0224
				D12 Acceptance of medical care services	0.0193
				D13 Acceptance of mental comfort services	0.0267
				D14 Acceptance of cultural and recreational services	0.0223
		D2 Acceptance of service modalities	0.0459	D21 Acceptance of the home-based care (in-home) service approach	0.0274
				D22 Acceptance of daycare (day care) services	0.0185
E Adaptability	0.2507	E1 Satisfaction with facility construction	0.0736	E11Satisfaction with the layout of community older adult service facilities	0.0245
				E12 Satisfaction with the provision of community older adult service facilities	0.0245
				E13 Satisfaction with the aging-friendly construction of community older adult service centers (stations)	0.0246
		E2Satisfaction with quality of service	0.1318	E21 Satisfaction with life care services provided in the community	0.0244
				E22 Satisfaction with health care services provided in the community	0.0250
				E23 Satisfaction with mental comfort services provided in the community	0.0352
				E24 Satisfaction with cultural and recreational services provided by the community	0.0204
				E25 Satisfaction with service personnel	0.0268
		E3 Satisfaction with the service environment	0.0453	E31 Satisfaction with the internal environment of community older adult service centers	0.0244
				E32 Satisfaction with age-friendly environment in the community	0.0209

TABLE 6 Evaluation results of the accessibility of basic community-based older adult care services in the six urban districts of Xi'an City.

First level indicators	Score	Secondary indicators	Score	Third level indicators	Score
A	3.1544	A1	3.1542	A11	3.1442
				A12	3.1651
		A2	3.0816	A21	2.9790
				A22	3.2372
		A3	3.2135	A31	3.2071
				A32	3.2234
				A33	3.2114
B	3.6724	B1	3.8429	B11	3.8815
				B12	3.8116
		B2	3.5369	B21	3.4767
				B22	3.6022
C	3.2668	C1	3.4173	C11	3.6675
				C12	3.3744
				C13	3.3099
		C2	3.2142	C21	3.2303
				C22	3.2976
				C23	3.1347
		C3	3.0791	C31	3.0837
				C32	3.0742
		C4	3.4582	C41	3.7348
				C42	3.2930
D	3.5627	D1	3.5429	D11	3.6536
				D12	3.7349
				D13	3.2931
				D14	3.5650
		D2	3.6026	D21	3.5697
				D22	3.6511
E	3.3721	E1	3.3868	E11	3.3838
				E12	3.3652
				E13	3.4115
		E2	3.3210	E21	3.3045
				E22	3.3257
				E23	3.0862
				E24	3.4722
				E25	3.5255
		E3	3.4971	E31	3.5347
				E32	3.4535

ensuring equitable older adult care. These findings are critical for policymakers and healthcare providers, emphasizing key areas for prioritizing resource allocation and service improvements. A systematic assessment of the accessibility of community-based older adult care services in Xi'an's central urban districts (Baqiao, Weiyang, Yanta, Xincheng, Beilin, and Lianhu) was conducted using the fuzzy comprehensive evaluation method, with results presented in Figure 3. We result indicate that the overall accessibility score of Xi'an's six central urban districts is 3.3330, falling within the "average" range to "good." This reflects an overall efficient provision of public service facilities, adequately meeting the basic daily needs of most older adult residents.

The data reveal a structural imbalance between resource supply and growing demand, highlighting an availability dilemma (30). The availability score is 3.1544, with facility layout and equipment scoring 3.1542 and 3.0816, respectively,

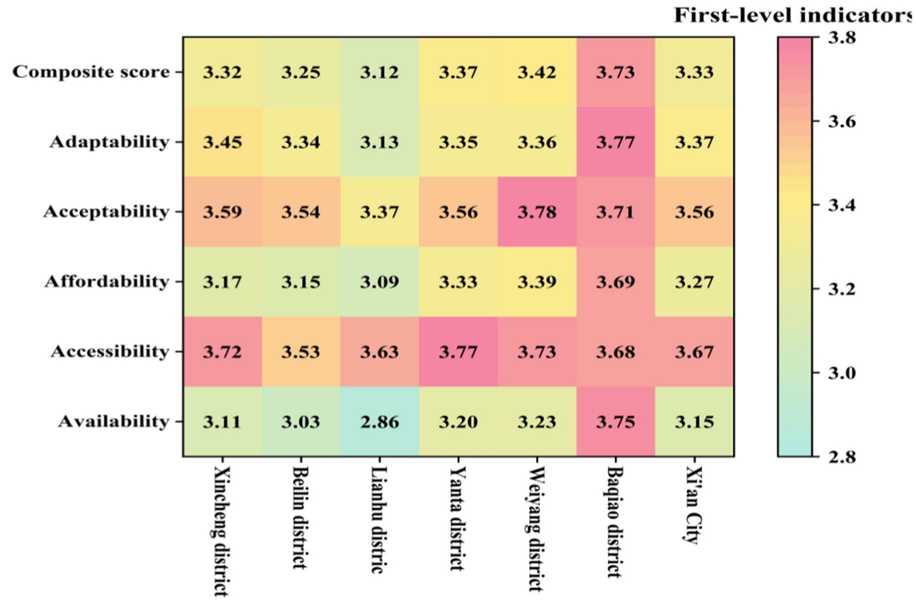

FIGURE 3
Hot map of accessibility evaluation results for BECS in urban communities.

suggesting that the infrastructure generally meets the basic needs of the older adult. However, the score for the number of beds is relatively low (3.2135), revealing a structural shortfall in resource capacity. This result reflects a lag in facility investment and planning relative to the surge in service demand caused by accelerated aging.

Accessibility is challenged by both spatial optimization and service responsiveness (31). The overall accessibility score is 3.6724, with spatial accessibility scoring a relatively high 3.8429, suggesting that the central city's service facility layout is reasonable. However, the time accessibility score is relatively low (3.5369), with waiting times for door-to-door services scoring only 3.4767, indicating significant room for improvement in service responsiveness. This disparity between spatial and temporal accessibility highlights the tension between facility centralization and service personalization. While centralized facility layouts provide spatial convenience, they limit the flexibility of service responsiveness, particularly in addressing personalized and urgent needs.

Affordability faces a dual imbalance in economic costs (32). The affordability score is 3.2668, with meal assistance services scoring the highest (3.6675) and healthcare services the lowest (3.1347). The high cost of healthcare services imposes a financial burden on low-income older adult groups, exposing a gap between basic living and healthcare needs. This finding underscores insufficient policy support and the limitations of the social security system in addressing high-cost healthcare services.

Acceptability faces challenges related to neglecting psychological needs and insufficient cultural adaptation. The acceptability score is 3.5627, with medical services scoring the highest (3.7349) and psychological comfort services the lowest (3.2931). The low score reflects insufficient psychological support services and unmet emotional and spiritual care needs among the older adult. This issue indicates an overemphasis on material needs in the older adult service system, with insufficient attention and resources allocated to soft needs such as emotional care and social participation.

Adaptability faces challenges due to the absence of a dynamic adjustment mechanism. The adaptability score is 3.3721, with high satisfaction in cultural and recreational services (3.4722) and the lowest satisfaction in spiritual comfort services (3.0862). The low satisfaction score highlights inadequate psychological support services and the absence of a dynamic adjustment mechanism to address the increasingly complex needs of the older adult. The mismatch between service supply and demand has resulted in a disconnect between service quality and the actual needs of the older adult.

These results underscore the systemic challenges in resource allocation and service capacity, necessitating policy interventions tailored to affordability and psychological care deficiencies.

4 Discussion

4.1 Comprehensive evaluation framework and key findings

We developed a comprehensive indicator system to assess the accessibility of basic older adult care services (BECS) in urban communities, structured around five dimensions: availability, accessibility, affordability, adaptability, and acceptability. Using Xi'an City as a case study, the framework highlights critical disparities in service provision. For instance, affordability received a score of 3.1347, indicating significant financial barriers for older adult residents, while spiritual comfort services scored 3.0862, revealing substantial gaps in emotional and psychological care. Conversely, spatial accessibility achieved a high score of 3.8815, reflecting effective infrastructure planning and facility distribution. However, delays in caregiver home visits, with a score of 3.4767, indicate persistent gaps in responsiveness

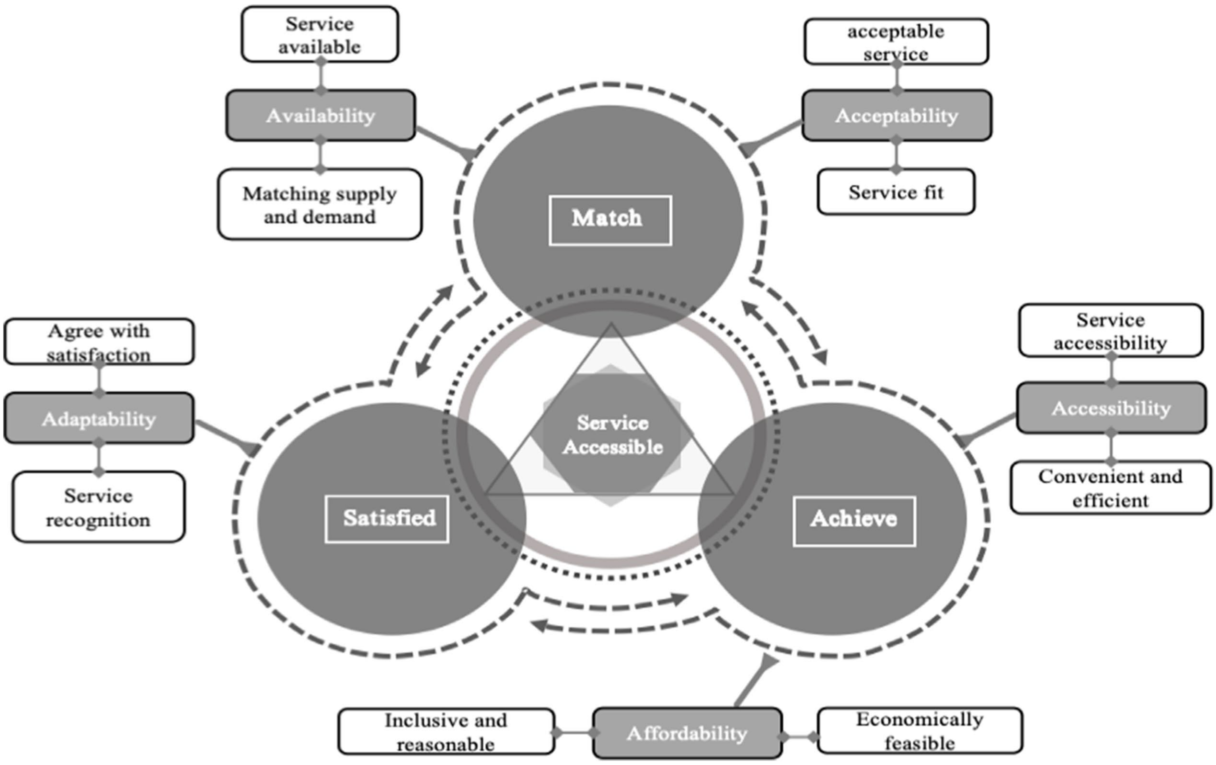

FIGURE 4
Pathway for improving the accessibility of BECS in urban communities.

and personalized care. These results underscore the multidimensional challenges facing urban older adult care systems and provide actionable insights for addressing them.

4.2 Unique characteristics of BECS and policy implications

A distinguishing feature of this study is its focus on the unique characteristics of BECS, emphasizing universal coverage and equity. BECS prioritize economically disadvantaged and health-compromised populations, contrasting with general older adult care frameworks that often target affluent groups with premium or personalized services. The results validate this distinction, as affordability and availability emerge as key dimensions requiring targeted interventions. The low affordability score of 3.1347 highlights the urgent need for financial subsidies, particularly for low-income older adult populations. The framework's emphasis on equity and inclusivity makes it a practical tool for guiding public welfare policy.

4.3 Systemic challenges and strategic solutions

As a deeply aging city, Xi'an faces systemic constraints such as resource imbalances and insufficient service capacity. While investments in infrastructure have enhanced spatial accessibility, affordability and psychological care deficiencies remain significant barriers. For example, while investments in infrastructure have enhanced spatial accessibility (score: 3.8815), persistent affordability challenges and gaps in psychological care (score: 3.0862) underscore the need for targeted investments. Addressing these challenges requires a multi-pronged strategy.

Based on these findings, We adopt a "demand–supply matching, service realization, and satisfaction enhancement" framework to examine strategies for improving the accessibility of BECS in urban communities (Figure 4). Effective demand–supply alignment requires a dynamic, data-driven approach to monitor demographic trends and forecast resource needs. Transitioning from reactive to proactive service models involves leveraging intelligent platforms to enable real-time resource allocation and optimize service delivery. Service realization depends on integrated funding mechanisms and age-friendly environments. A unified funding framework ensures efficient resource utilization, while investments in accessible infrastructure, including barrier-free facilities and digital adaptations, address the diverse needs of older adult populations. Enhancing satisfaction is critical for fostering continuous improvement, supported by comprehensive oversight mechanisms and innovative service delivery approaches. Comprehensive monitoring frameworks—incorporating governmental, non-governmental, and public stakeholders—facilitate accountability, while feedback systems inform actionable improvements. Innovative models, such as 'Internet + Older adult Care' and mutual assistance initiatives like 'time banking,' expand service options and enhance the well-being of older adults. Collectively, these strategies offer a holistic and adaptable blueprint for advancing the accessibility and equity of urban older adult care services.

4.4 Framework validation and policy implications

The validation in Xi'an confirms the framework's effectiveness in assessing and enhancing the accessibility of basic older adult care services. While spatial accessibility is strong (3.8815), affordability and psychological care remain key challenges, requiring targeted policy actions. To improve affordability, expanding financial support, such as subsidies for low-income older adult individuals and creating a long-term care security system, is essential. To address service adaptability, digital platforms like "Internet + Older adult Care" should be developed to integrate home-based care, telemedicine, and community mental health services, improving resource allocation and service efficiency. Strengthening home and community care, through home adaptations and family doctor services, will enhance the synergy between family and professional care.

In the long term, building a robust basic older adult care system must support equitable public services. By reducing accessibility and affordability gaps, governments can facilitate the transition from basic care to higher-quality, personalized services, promoting fairness and improving the well-being of older adult individuals in urban environments.

4.5 Limitations and future research directions

This study has certain limitations. First, the empirical analysis is confined to Xi'an City, which may restrict the generalizability of the findings. Future research should expand to additional cities or regions and conduct comparative analyses to validate the framework's broader applicability. Second, the study primarily uses quantitative methods, lacking an in-depth exploration of the older adult's subjective experiences and emotional needs. Future research could address this gap by incorporating qualitative methods to capture the psychological experiences and satisfaction evaluations of older adult individuals. Lastly, with the accelerating integration of artificial intelligence and digital platforms into older adult care, future research should explore their applications in service delivery and accessibility assessments, providing insights for developing older adult care systems in the new era.

5 Conclusion

This study introduces a novel framework for evaluating the accessibility of basic older adult care services (BECS), addressing critical dimensions such as availability, affordability, adaptability, and acceptability. Grounded in the "5A" theory, the framework was empirically validated in Xi'an, China, and revealed significant disparities in affordability and psychological care services, alongside strong performance in spatial accessibility. These findings underscore the urgent need for targeted policy interventions to address resource imbalances.

The proposed "Matching-Realization-Satisfaction" pathway provides targeted strategies, including demand–supply alignment and innovative service models, to enhance BECS accessibility. By leveraging dynamic demand–supply alignment, integrated funding mechanisms, and innovative service delivery models.

Despite its contributions, this study is limited by its focus on Xi'an City and its primary use of quantitative methods, which may not fully capture subjective experiences. Future research should expand the framework's application to diverse urban contexts and incorporate qualitative approaches to capture the subjective experiences of older adult individuals. Additionally, exploring the integration of artificial intelligence and digital platforms in service delivery could further enhance the framework's adaptability in the digital age.

This study advances the theoretical and practical understanding of older adult care accessibility, providing a scalable and adaptable framework to inform policy development and service optimization. By addressing the complex challenges of affordability, psychological care, and responsiveness, it contributes to building equitable and sustainable older adult care systems globally.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Participants provided their written informed consent to participate in this study in accordance with the national legislation and the institutional requirements.

Author contributions

YZ: Conceptualization, Data curation, Methodology, Resources, Writing – original draft, Writing – review & editing. MZ: Writing – review & editing. JH: Investigation, Resources, Validation, Writing – review & editing. RW: Conceptualization, Investigation, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Generative AI was used in the creation of this manuscript.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2025.1535987/full#supplementary-material

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Caregiving burden, social support, and psychological well-being among family caregivers of older Italians: a cross-sectional study

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Objectives: This study aimed to identify factors affecting the psychological well-being of family caregivers of dependent older adults in Italy. Understanding these variables is essential for designing interventions to prevent negative outcomes in at-risk caregivers. The research explored how varying levels of caregiving burden and types of perceived social support influence psychological well-being.

Methods: A cross-sectional study was conducted among 387 family caregivers of older adults in the Marche region (Italy) between November 2019 and March 2020. Data were collected via a structured questionnaire assessing psychological well-being (WHO-5 Well-Being Index), caregiving burden, and social support (COPE Index). Statistical analyses were performed using Jamovi software, with a significance threshold set at $p < 0.05$.

Results: A significant negative correlation was found between caregiving burden and psychological well-being [$r(364) = -0.540, p < 0.001$], with caregiving burden being a significant predictor of psychological well-being reduction ($R^2 = 0.290$; $F = 150$, $p < 0.001$). A threshold value of 2 (on a 1–4 scale) was identified, where caregiving burden predicted a significant reduction in psychological well-being. Conversely, greater perceived social support was positively correlated with better psychological well-being [$r\ (357) = 0.348$, $p < 0.001$] and was a significant predictor of it [$R^2 = 0.121$; $F = 49.2$, $p < 0.001$]. Support from social and health services had the most notable impact on psychological well-being. Moreover, social support mitigated the negative impact of caregiving burden on psychological well-being.

Conclusion: The study confirms that high caregiving burden adversely affects caregivers' psychological well-being, while social support plays a protective role. These findings highlight the need for interventions focused on reducing caregiving burden and enhancing support systems for family caregivers.

KEYWORDS

caregiving burden, social support, psychological well-being, older adults, Central Italy, long-term care (LTC)

1 Introduction

The anticipated increase in the older adult population in many countries worldwide, including Italy, represents a significant challenge. According to demographic projections by the Istituto Nazionale di Statistica (ISTAT),[1] by 2050, individuals aged 65 and over are expected to represent 34.9% of the Italian population. This demographic shift is likely to place considerable pressure on social protection systems and significantly increase the demand for older adult assistance services, as well as the involvement of family members in their care. Currently, much care is provided informally by family members (1), who play a crucial role in supporting frail older adults – those who "are infirm and experience significant difficulties in performing activities of daily living, resulting in a lack of independence and the need for extensive assistive care," as defined by the APA dictionary.[2] This type of care, also known as long-term care (LTC), encompasses a wide range of personal, social and medical services aimed at assisting individuals (particularly adults aged 60 years or above with functional or cognitive impairments) who are unable to perform activities such as eating, dressing and bathing independently.[3]

With the expected progressive growth of the older adult population, it is highly likely that the responsibilities of family caregivers will continue to intensify, exposing them to increasing strain and stress, thereby raising the urgent question of how to support them.

As previously mentioned, family caregivers are often responsible for the daily care of frail older adult relatives. While these care tasks are essential, they often come at a high personal cost. Numerous studies have demonstrated the negative impact of caregiving burden on the quality of life, health status and psychological well-being of family caregivers [e.g., (2, 3, 4–10, 54)]. In the Italian context, research has shown that family caregivers of frail older adults face significant challenges in maintaining their psychological well-being while managing the increasing demands of caregiving [e.g., (1, 11)].

Although there is considerable agreement about the detrimental effects of caregiving, much research has also highlighted the positive experiences associated with caring, such as a sense of fulfillment and satisfaction [e.g., (12–17, 53)]. However, these positive aspects often fail to compensate for caregiving fatigue, especially when care responsibilities are prolonged over time. Indeed, in many cases, the multiple demands of caregiving lead to burnout (18), stress (19), and other negative psychological outcomes [e.g., (20–22)].

A key factor that has been shown to mitigate the effects of caregiving burden is perceived social support, both emotional and instrumental. It has been consistently associated with lower levels of subjective distress and improved psychological well-being [e.g., (23–25)]. In the Italian context, research has also indicated that social support can play a crucial role in buffering the negative effects of caregiving [e.g., (26)], but the specific types of support that caregivers perceive as most beneficial and the extent to which they can effectively mitigate caregiving stress remain under-explored aspects.

Thus, despite the valuable insights provided by previous studies, several gaps remain. Firstly, there is a lack of knowledge about when caregiving becomes excessively burdensome and starts to negatively impact caregivers' psychological well-being. In other words, while much of the research focuses on the general effects of caregiving, few studies have identified the specific threshold at which the burden seems to become detrimental. Secondly, although the protective role of social support is widely recognized, there is a limited understanding of which types of support caregivers perceive as most effective in reducing the negative impacts of caring. Furthermore, the complex interaction between caregiving burden, social support and psychological well-being has not been adequately examined in a comprehensive manner, especially in the Italian context.

This study aims to fill the aforementioned gaps by (1) investigating the extent to which caregiving burden negatively impacts psychological well-being among family caregivers, (2) identifying the specific aspects of social support that most affect caregivers' psychological well-being, and (3) examining whether and how social support can mediate the relationship between caregiving burden and psychological well-being. In other words, the primary aims of the present research are (1) to determine how caregiving burden affects psychological well-being among Italian family caregivers of older adults; (2) to explore the role of specific aspects of social support in affecting family caregivers' psychological well-being; and (3) to identify whether social support acts as a buffer to alleviate the psychological strain due to caregiving.

These objectives will therefore be pursued by answering the following research questions (RQs):

- *RQ1*: Does caregiver burden affect psychological well-being? If so, to what extent?
- *RQ2*: Does social support influence psychological well-being? If so, which aspects have the most significant impact on caregivers' psychological well-being?
- *RQ3*: If caregiver strain negatively impacts caregivers' psychological well-being, can social support mediate this effect (i.e., act as a buffer)?

The answers to these questions could provide useful indications for the development of interventions aimed at reducing the burden on caregivers, enhancing their psychological well-being and improving the care they provide.

2 Materials and methods

2.1 Data collection and sampling

This cross-sectional study draws on data collected in the Marche region (Italy) by the survey titled '*The perspective of older people with LTC needs and their family caregivers in the Marche region*' (27), commissioned by the Marche Region Authority to deepen the understanding of the care needs of vulnerable older people living in this area of Central Italy and their primary family caregivers.

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[1] https://www.istat.it/wp-content/uploads/2022/09/REPORT-PREVISIONI-DEMOGRAFICHE-2021.pdf, last accessed 18 September 2024.

[2] Available at https://dictionary.apa.org/frail-elderly, last accessed 25 September 2024.

[3] WHO definition for long-term care, available at https://www.who.int/europe/news-room/questions-and-answers/item/long-term-care, last accessed 26 September 2024.

The sampling followed a convenience/purposive method (28). Older people were identified first by the pensioners' trade unions to which older individuals or their relatives had sought support for accessing LTC services, e.g., the State Care Allowance ("Indennità di Accompagnamento" in Italian), a monetary cash benefit provided by the Government to individuals with a severe level of disability.

Older individuals were included and considered eligible to participate in the study if they (a) signed the informed consent form and volunteered to participate in the study, and (b1) received the State Care Allowance (which ensured a high degree of disability) or (b2) although they did not receive the State Care Allowance, they reported a score of less than 9 on a 12-item scale measuring their level of autonomy in Activities of Daily Living (ADL), based on the Barthel Index (29), and the Instrumental Activities of Daily Living (IADL (30)). This screening was conducted through face-to-face interviews administered by trained volunteers from the trade unions.

Once recruited, older individuals were screened for eligibility, and the interviewers planned an appointment to meet them in person and administer the questionnaire at their homes. The interviewers then asked them to indicate their primary family caregiver to also participate in the survey. Subsequently, the interviewer contacted the primary caregiver, screened them and if eligible, scheduled another appointment at the caregiver's home or in the trade union office.

Family caregivers – who were all Italian-speaking – were included in the sample if they were caregivers of older individuals with LTC needs, were 25 years of age or older, had been providing direct assistance to the older relative for at least 1 year, did not have a cognitive impairment and signed the informed consent.

For older individuals, we did not conduct a sample size study; however, to ensure the highest correspondence between the sample selected for this study and the universe of older people with LTC needs living in the Marche region, we estimated the share of the over-75 population with severe mental and physical limitations for each of the 13 health districts in which the health service of the Marche Region is articulated (at this level, care pathways are activated and integration between health and social activities is realized). This share was then stratified by age (using three groups: 75–79, 80–84, and 85+) and gender, and the results were used as a basis to identify the minimum number of respondents to be interviewed in each district (31). The interviewers visited the interviewees' homes and administered the questionnaire face-to-face. In about half of the cases, the person in need of care was unable to fill in the survey unassisted, and the primary caregiver completed the questionnaire as a proxy for them for all questions not requiring a subjective response.

As for the caregivers, the sample size was determined based on the older individuals' sample size.

All data were collected anonymously, in compliance with the guidelines set forth in EU Regulation No. 679 of the European Parliament and of the Council of 27 April 2016, as well as the Helsinki Declaration (2013). The study was submitted for approval to the Ethics Committee of the National Institute of Health and Science on Aging (INRCA), which deemed approval unnecessary since the investigation did not involve clinical patients.

Data collection was carried out by the primary pensioners' trade union volunteers between November 2019 and March 2020 in the aforementioned 13 health districts of the Marche Region, including both inland and coastal areas.

2.2 Measures

Considering the two targets, the survey comprised two common assessment tools: the first included a series of questions designed to assess the condition and requirements of frail older individuals with LTC needs; the second consisted of a set of questions specifically targeted at caregivers, aiming to gain insights into their condition and needs. Except for questions about ADL and IADL (29, 30), the questionnaire for older individuals did not include other psychometrically validated scales. The questionnaire for family caregivers embedded *ad-hoc* multiple-choice and open-ended questions on socio-demographic aspects, family caregivers' burden, well-being, formal and informal support received, and work-life balance issues. It also included some validated scales for measuring caregiving burden (the 7-item subscale of the Carers of Older People in Europe Index - COPE Index), psychological well-being (the World Health Organization's Five-Well-Being Index -WHO-5), and social support (the 4-item subscale of the Carers of Older People in Europe Index - COPE Index), which are described in detail below.

In this study, we focused exclusively on the outcome measures of the family caregivers' questionnaire.

2.2.1 Personal information data

Family caregivers answered a series of questions designed to identify the characteristics of the sample considered (e.g., gender, age, level of education, parental status with the older adult care recipient).

2.2.2 Caregiver burden

Caregiver burden was measured by four specific questions tailored for this study, aiming to assess the extent to which caregivers perceive a loss of personal time due to caring for the older adult person (1. *Do you feel that you do not have enough time for yourself because of the time spent on the older adult person?*), as well as their perceived levels of stress resulting from caring for the older adult and coping with other responsibilities (2. *Do you feel stressed between caring for the older adult person and trying to cope with other responsibilities?*), levels of fatigue (3. *Do you feel fatigued when caring for the older adult person?*) and sense of the insecurity (4. *Do you feel insecure about what to do for your older adult person?*). Respondents were asked to rate on a 5-point Likert scale from 0 (never) to 4 (almost always). The internal consistency of the items was good, with a Cronbach's alpha of 0.80. Additionally, caregiving burden was also measured by the 7-item subscale of the Carers of Older People in Europe Index (COPE Index) (2, 55, 56), specifically item 1. *Do you find caring too demanding?*; 2. *Does assisting create any difficulties for you in your relations with your friends?*; 3. *Does caring have a negative effect on your physical health?*; 4. *Does caring create difficulties for you in your relationships with your family?*; 5. *Does caring cause you financial difficulties?*; 6. *Do you feel 'trapped' in your role as a carer?*; 7. *Does caring have a negative effect on your emotional balance?* Respondents rated items on a 4-point Likert scale from 1 (always) to 4 (never), except for item 7, where the rating was reversed (1 = never, 4 = always). The values of the first six items were inverted to match item 7 and previous items. The scale showed good internal consistency (Cronbach's alpha = 0.84). Following Balducci et al. (2), an exploratory factor analysis (EFA) – the results of which are not reported in detail due to space limitations – revealed a 3-factor structure, one of which is represented by the caregiver burden subscale, replicating Balducci et al.'s findings. To assess the construct validity of the COPE Index subscale, a confirmatory factor analysis (CFA) was also conducted on the seven items. All items loaded on the same factor, with estimates ranging from 0.480 to 0.723, supporting the unidimensional structure of the COPE Index Caregiver Burden subscale. The overall fit indices suggest that the model fits the data well, with a CFI of 0.973, a TLI of 0.959 (both values above 0.95) and a RMSEA of 0.0664 (i.e., below 0.08).

Furthermore, to account for the multiple components of care burden, we computed a new summary index called 'total care burden'. Principal component analysis (PCA) and exploratory factor analysis (EFA) showed that all items (i.e., the four specifically tailored for this study and the 7 of the COPE subscale) loaded on a single factor, explaining 47.9% of the variance. The new index had high internal consistency, with a Cronbach's alpha of 0.888.

2.2.3 Well-being

The family caregivers' psychological well-being was assessed using the Italian version of the World Health Organization's Five-Well-Being Index (32–34), which is available in PDF format on the WHO-Five website at the following link.[4] The WHO-5 is a self-report measure assessing subjective psychological well-being, consisting of five statements that respondents rate on a 6-point Likert scale ranging from 0 (not at all) to 5 (all the time). Respondents were asked to provide answers that come closest to how they have felt in the past 2 weeks to the following five assertions: *I have felt cheerful and in good spirits*; *I have felt calm and relaxed*; *I have felt active and vigorous*; *I woke up feeling fresh and rested*; *My daily life has been filled with things that interest me.* Higher scores correspond to a higher level of well-being; conversely, lower scores correspond to a lower level of well-being. The raw score is calculated by adding up the scores given by respondents for the five answers and ranges from 0 (lowest well-being) to 25 (highest well-being). A score below 13– as suggested by many studies in the literature [e.g., (35, 36, 57)] – indicates a poor state of well-being and is an indication to perform the depression test. The raw score can be multiplied by 4 to give a percentage score ranging from 0 (worst) to 100 (best). In this case, the cut-off is set at 50. Cronbach's alpha and McDonald's omega were both 0.90. To assess the construct validity of the WHO-5 Index, a CFA was conducted. The factorial loadings are strong (ranging from 0.694 to 0.866) and statistically significant, showing that each item contributes significantly to the latent factor. However, the Chi-square results [χ^2 (5) = 54.9, $p < 0.001$] and the high RMSEA (0.162) indicate a misfit of the model to the data, despite the high values of CFI (= 0.96) and TLI (= 0.92). In other words, although CFI and TLI suggest that the model satisfactorily explains an important part of the variance, the high RMSEA deserves attention.

Respondents' well-being was also measured by:

- The initial item of the SF-36 Health Survey (37–41), which assesses individuals' overall perception of their *general health* on a 5-point Likert scale ranging from 1 (excellent) to 5 (poor). Nonetheless, we preferred to reverse values, so that 1 stands for poor and 5 for excellent;
- One question specifically tailored for this study to explore the caregiver's assessment of their *quality of life* over the past 2 weeks. Again, respondents were asked to answer on a 5-point Likert scale ranging from 1 (very good) to 5 (very bad). In this scale, we preferred to reverse values, so that 1 would refer to very poor and 5 to very good.

Since our questionnaire measured well-being using different items that assess specific components, we calculated a new summary index called 'total well-being'. PCA results indicated that all items loaded optimally on a single factor, explaining 63.6% of the variance. Similarly, EFA confirmed that all items loaded optimally on a single factor. Cronbach's alpha for this new index was 0.897, indicating high internal consistency.

2.2.4 Social support

Social support, a complex and multidimensional construct [see (42)] – encompassing both the general perception of being supported by friends and family networks, as well as by health and social services – was assessed through the 4-item subscale of the Carers of Older People in Europe Index (COPE Index) (2, 55, 56), specifically item 1. *Do you feel adequately supported by your friends/neighbors?*; 2. *Do you feel adequately supported by your family?*; 3. *Do you feel adequately supported by health and social services (public, private, or voluntary)?*; 4. *Overall, do you feel adequately supported in your role as an assistant?*). Respondents rated on a 4-point Likert scale from 1 (Never) to 4 (Always). This subscale measures the extent to which caregivers feel supported by their family, friends, and health and social services. In our sample, Cronbach's alpha and McDonald's omega were, respectively, 0.576 and 0.611. Although both values are poor, they are nevertheless acceptable (43–45). Specifically, since Cronbach's alpha tends to increase with the number of items on the scale, adding more well-aligned items (in this case, for example, concerning other specific types of social support) could improve internal consistency. As the scale is multidimensional, refinement of the subscales could lead to better consistency in each dimension. A CFA was also conducted for this subscale. The factor loadings are all significant, but there is variability in the strength of their associations (which range from 0.317 to 0.736) with the latent factor. The fit indices suggest that the model has a moderate fit to the data. While the CFI is good (= 0.962), the RMSEA (= 0.0910, i.e., above 0.08), the TLI (= 0.887, i.e., below 0.90), and the Chi-square results [χ^2 (2) = 8.41, $p = 0.015$] indicate that the model might require some improvements to better represent the underlying data.

Social support was also measured by two questions specifically tailored for this study to find out whether caregivers think they can rely on others, i.e., whether they can find someone to substitute in case of illness or need for a break. Respondents were asked to choose among three different possible answers: I could find quite easily (1); I could find with difficulty (2); I could not find anyone (3).

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[4] https://www.psykiatri-regionh.dk/who-5/Documents/WHO5_Italian.pdf; last accessed on 24 March 2024.

2.3 Data analysis

Data were analyzed using Jamovi (Version 2.3.21.0), an open statistical software,[5] built on top of the R statistical language[6], and RStudio. Both descriptive and inferential (*t*-test, ANOVA, correlations, linear regressions, Receiver Operating Characteristic – ROC - analysis, multivariate logistic regression, and mediation) analyses were performed. Descriptive statistics have been used to summarize the characteristics of the sample, including measures of central tendency (e.g., mean) and variability (e.g., standard deviation) for continuous variables. For categorical variables, frequencies and percentages were reported. Inferential statistics were used to show the relationships between continuous variables (e.g., caregiver burden and well-being), with Pearson's correlation coefficients computed to assess the strength and direction of linear relationships. Additionally, linear regression models were performed to determine whether one variable predicts another. For categorical variables, tests such as Chi-square were used to examine the association between different groups. Missing data were handled systematically. Since the proportion of missing data was low, a complete-case analysis was performed. A standard level of statistical significance (*p*-value) was set at 0.05. Any p-value below this threshold was considered statistically significant. Alongside *p*-values, 95% confidence intervals (CIs) were reported for effect sizes in regression models and other inferential tests. CIs were calculated to provide a range of values within which the true parameter value likely lies. Reporting confidence intervals offers insight into the precision of the estimates and is more informative than p-values alone.

3 Results

3.1 Sample characteristics

Out of the 387 individuals who completed the questionnaire, 251 (64.9%) were female, while 136 (35.1%) were male. The participants' ages ranged from 25 to 89, with a mean age of 63.3 (SD = 11.4). This value is particularly noteworthy as it indicates that our sample of family caregivers for dependent older adult individuals consists largely of individuals who are themselves older adult or nearing that stage. Moreover, over half (56.6%) of the family caregivers in our sample provide care without assistance from non-family caregivers, thus exclusively taking on the burden of caring. Among the participants, 62.5% were daughters or sons of the assisted older persons, while 21.4% were spouses. Most caregivers (55.6%) live in the same household as the person they are caring for, which could make caring even more stressful. On average, they spend 60.8 h per week caring for the older adult. For a more comprehensive overview of the sample characteristics, please refer to Supplementary Table S1.

In the following section, descriptive and inferential analyses concerning the variables taken into consideration will be presented.

3.2 Descriptive and inferential analyses

3.2.1 Caregivers' care burden

As mentioned in the methodology section, caregiver burden was first measured using four questions specifically designed for this purpose. Higher scores (4 = 'almost always') indicate a higher perceived care burden. As shown in Table 1, caregivers assigned an average score between 2 and 3 (indicating responses between 'sometimes' and 'often') to questions about lack of personal time, stress, and caregiving fatigue. They assigned an average score between 1 and 2 (indicating responses between 'rarely' and 'sometimes') to the question about insecurity related to caring for the older relatives. When combining the percentages of respondents who answered sometimes (2), often (3) and almost always (4) for the items on lack of personal time (74.4%), perceived stress (75.6%), and caregiving fatigue (70.4%), the overall rate for each item is approximately 70%. Only the item related to insecurity in providing care shows a distinct pattern, with a higher percentage of respondents assigning lower values, thus implicitly suggesting that they feel confident about caring for the person most of the time.

To test whether gender and age affect the level of burden experienced, t-test and ANOVA were used (see Table 2). T-test (applied to the mean value of the four items) revealed no significant differences based on caregivers' gender [$t\ (384) = -1.35$, $p = 0.178$]. However, when the four items were analyzed separately, a statistically significant difference emerged in terms of perceived stress for caring tasks and managing responsibilities, with women caregivers reporting significantly more stress than men [$t\ (384) = -2.08$, $p = 0.038$]. ANOVA test revealed instead that age significantly impacts the perceived burden of care [$F\ (4,\ 128) = 3.67$, $p = 0.007$]. Specifically, post-hoc tests indicated that caregivers over 80 perceive a significantly higher care burden than the 60–69 age group ($p = 0.002$).

However, correlation analysis (Pearson's $r = 0.094$, $p = 0.066$) and linear regression ($R^2 = 0.00880$; $F = 3.41$, $p = 0.06$) showed no significant relationship between age (as a continuous variable) and perceived care burden, meaning that advancing age alone is not a reliable predictor of increasing perceived care burden.

In addition to the four items, caregiver burden was also measured using the 7-item subscale of the COPE index. As shown in Table 3, the respondents in our sample gave an average score between 2 and 3 (indicating answers between 'sometimes' and 'often') to items 1, 2, 6, and 7. Specifically, caregivers reported that they sometimes or often perceived their caregiving activities as being too demanding (mean = 2.53), responsible for difficulties with friends (mean = 2.08), a source of their feeling of being trapped in their role (mean = 2.10), and having negative effects on their own emotional well-being (mean = 2.04). Conversely, they assigned an average score between 1 ('never') and 2 ('sometimes') to items 3, 4, and 5, indicating that they only rarely or sometimes perceived their caregiving activities as being responsible for negative effects on their physical health (mean = 1.96), causing difficulties with their family (mean = 1.61), or leading to financial difficulties (mean = 1.72).

Again, the t-test – calculated on the mean of the 7-item subscale of the COPE Index – showed no significant differences based on the gender of the caregiver [$t\ (376) = -1.78$, $p = 0.076$]. However, when the t-test was calculated on the seven items separately, there were statistically significant differences between men and women on the items measuring the negative impact of caregiving on physical health [$t\ (384) = -2.34$, $p = 0.019$] and emotional well-being [$t\ (384) = -2.53$,

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[5] Retrieved from https://www.jamovi.org

[6] Retrieved from https://cran.r-project.org

TABLE 1 Descriptive statistics and response frequencies for care burden items.

Care burden	N	Mean	Lower 95%CI	Upper 95%CI	SD	Variance	Never (0)		Rarely (1)		Sometimes (2)		Often (3)		Almost always (4)	
							N	%	*N*	%	*N*	%	*N*	%	*N*	%
1. Not having time for oneself	386	2.19	2.08	2.30	1.13	1.28	33	8.5	66	17.1	133	34.5	103	26.7	51	13.2
2. Feeling stressed	386	2.25	2.13	2.37	1.19	1.43	43	11.1	51	13.2	119	30.8	114	29.5	59	15.3
3. Feeling fatigue	386	2.07	1.95	2.19	1.21	1.47	54	14	60	15.5	125	32.4	99	25.6	48	12.4
4. Feeling of insecurity	386	1.38	1.26	1.49	1.15	1.33	105	27.2	115	29.8	101	26.2	45	11.7	20	5.2

The CI of the mean assumes sample means follow a t-distribution with N - 1 degrees of freedom.

TABLE 2 *T*-test and ANOVA values concerning the 4 custom-designed questions measuring care burden.

	Statistic test	Statistical value
Gender		
Care burden total score (mean score for the four items)	*T*-test	$t = -1.35$, df = 384, $p = 0.178$
1. Not having time for oneself	*T*-test	$t = -1.18$, df = 384, $p = 0.237$
2. Feeling stressed	*T*-test	$t = -2.08$, df = 384, $p =$ **0.038***
3. Feeling fatigue	*T*-test	$t = -1.90$, df = 384, $p = 0.059$
4. Feeling of insecurity	*T*-test	$t = -1.01$, df = 384, $p = 0.311$
Age		
Care burden total score	ANOVA	$F = 3.67$, df1 = 4, df2 = 128, $p =$ **0.007***

$p = 0.012$], with female caregivers reporting significantly more negative impacts of caregiving, both physically and emotionally. Regarding age, ANOVA test did not reveal any statistically significant differences across the various caregiver age groups [F (4, 123) = 1.56, $p = 0.188$] (see Table 4). It should be noted, however, that the mean scores of caregivers aged 70–79 and 80 and over were higher than 2, indicating that they often feel that caregiving has a negative impact on their relationships, physical health and emotional well-being. In contrast, younger age groups reported consistently lower mean scores.

Even when age is treated as a continuous variable, correlation analysis (Pearson's r = 0.093, $p = 0.072$) and linear regression analysis ($R^2 = 0.00857$, $F = 3.25$, $p = 0.072$) do not reveal significant relations, again confirming that the age of the caregiver alone is not a predictor of increased perceived care burden.

Although the four items specifically designed in this study to measure care burden and the COPE index subscale measure different aspects of perceived caregiving burden, they appear to be complementary features of the same dimension. This is indicated by the results of the correlation analysis (which was carried out after converting all scores into z-scores to standardize the measures), according to which Pearson's r coefficient was found to be 0.691, a highly significant value ($p < 0.001$), and it is also confirmed, as previously mentioned in the methodological section, by PCA and EFA that showed that all items load optimally on a single factor, we labeled 'total care burden'.

3.2.2 Caregivers' well-being

In terms of psychological well-being, as measured by the WHO-5 scale, descriptive analysis reveals that more than half of the caregivers in our sample scored below the cut-off point of 13, which suggests the administration of a depression test. The mean score was 11.1 (SD ± 6.27). Although a clear trend emerged, with women showing lower well-being scores than men, this difference is not statistically significant [t (372) = 1.89, $p = 0.059$]. Conversely, when data are split by age, ANOVA indicates a clear pattern, according to which psychological well-being significantly declines with increasing age [F (4, 134) = 3.31, $p = 0.005$] (see Table 5).

As revealed by the post-hoc test, the significance is due to the difference between the younger (under 50 years) and the older group (70–79 years, $p = 0.023$; and 80 and over, $p = 0.002$).

TABLE 3 Descriptive statistics for COPE index subscale measuring care burden.

Cope index subscale for care burden	*N*	Missing	Mean	Lower 95% CI	Upper 95% CI	SD	Variance
1. Do you find caregiving too demanding?	385	2	2.53	2.44	2.62	0.893	0.797
2. Does caregiving cause difficulties in your relationship with your friends?	385	2	2.08	1.98	2.18	0.986	0.972
3. Does caregiving have a negative effect on your physical health?	386	1	1.96	1.87	2.04	0.871	0.759
4. Does caregiving cause difficulties in your relationship with your family?	387	0	1.61	1.53	1.69	0.778	0.606
5. Does caregiving cause you financial difficulties?	385	2	1.72	1.63	1.81	0.907	0.823
6. Do you feel trapped in your role as caregiver?	386	1	2.10	2.01	2.20	0.975	0.950
7. Does caregiving have a negative effect on your emotional well-being?	386	1	2.04	1.95	2.13	0.901	0.811

The CI of the mean assumes sample means follow a t-distribution with N - 1 degrees of freedom.

TABLE 4 *T*-test and ANOVA values concerning Cope Index subscale measuring care burden.

	Statistical test	Statistic value
Gender		
Overall Cope Index subscale for care burden	*T*-test	$t = -1.78$, df = 376, $p = 0.076$
1. Do you find caregiving too demanding?	*T*-test	$t = -0.7238$, df = 383, $p = 0.470$
2. Does caregiving cause difficulties in your relationship with your friends?	*T*-test	$t = -1.2232$, df = 383, $p = 0.222$
3. Does caregiving have a negative effect on your physical health?	*T*-test	$t = -2.3478$, df = 384, $p =$ **0.019***
4. Does caregiving cause difficulties in your relationship with your family?	*T*-test	$t = -1.6848$, df = 385, $p = 0.093$
5. Does caregiving cause you financial difficulties?	*T*-test	$t = 0.0591$, df = 383, $p = 0.953$
6. Do you feel trapped in your role as caregiver?	*T*-test	$t = -0.6655$, df = 384, $p = 0.506$
7. Does caregiving have a negative effect on your emotional well-being?	*T*-test	$t = -2.5350$, df = 384, $p =$ **0.012***
Age		
Cope Index subscale for care burden	ANOVA	$F = 1.56$, df1 = 4, df2 = 123, $p = 0.188$

These results are also confirmed by correlation (Pearson's r coefficient was found to be −0.181, $p < 0.001$), and linear regression analyses ($R^2 = 0.0328$; $F = 12.6$, $p < 0.001$), which suggest that increasing age of the caregiver is a predictor of lower psychological well-being.

Since well-being is a complex construct, in addition to measuring it using the WHO-5 scale, it was also assessed using two other items: one measuring the overall perception of general health and the other quality of life.

As for the *general health status*, family caregivers' overall perception was rated by most of the respondents (46.5%) as *fair*. The average rating was 2.59 on a scale ranging from 1 (poor) to 5 (excellent). Although some differences in the well-being of caregivers based on gender were found, with men reporting higher levels of well-being (average score of 2.70) compared to women (average score of 2.53), these differences were not statistically significant, as indicated by the t-test results [t (379) = 1.91, $p = 0.056$]. Conversely, ANOVA test showed statistically significant differences according to age [F (4, 129) = 9.96, $p < 0.001$] (see Table 6).

Specifically, the post-hoc test revealed that younger caregivers, i.e., those aged under 50, rate their health as significantly better (mean value = 3.11) than older caregivers, particularly those aged 60–69, 70–79, and 80-plus. However, there is no significant difference in health ratings between younger caregivers and those aged 50–59. Conversely, the over-80s rate their health as significantly worse (mean value = 2.31) than those aged 50–59. Finally, the group aged 50–59 rated their health as significantly better (mean value = 2.73) than the group aged 70–79 (mean value = 2.31). These results are statistically confirmed by correlation (Pearson's r coefficient was found to be −0.298, $p < 0.001$) and linear regression ($R^2 = 0.0890$; $F = 37.0$, $p < 0.001$) analyses, which indicate that caregiver's general health status perception worsens as age increases. In other words, increasing age of the caregiver is a predictor of worsening health.

As for the *perceived quality of life over the past 2 weeks*, a high percentage of family caregivers (46.7%) assessed it as 'Neither good nor poor'. The average rating on a scale of 1 (very poor) to 5 (very good) was 3.38. Since higher scores indicate higher perceived quality of life, the caregivers in our sample seem to be near the middle of the scale. Although there are some gender-related differences in quality of life, with men assigning higher mean values (3.46) compared to women (3.34), this difference is not statistically significant [t (381) = 1.63, $p = 0.105$]. Conversely, ANOVA test showed statistically significant differences based on age [F (4, 129) = 7.04, $p < 0.001$]. Like the results for the general health assessment, caregivers' ratings of their own quality of life are significantly influenced by age (see Table 7). The post-hoc test shows statistically significant differences, with younger caregivers (under 50) reporting better quality of life

TABLE 5 WHO-5 scores and statistical tests.

Group	Total (N)	WHO-5 raw score	SD	Below the threshold		Above the threshold		Total (%)	Statistic test	Statistical value
				N	%	*N*	%			
Gender									T-test (gender)	$t = 1.89$, df = 372, $p = 0.059$
M	132	11.09	6.27	63	16.8% (30.1%)	69	18.4% (41.8%)	35.3% (100%)		
F	242	10.06	6.23	146	39.0% (69.9%)	96	25.7% (58.2%)	64.7% (100%)		
Tot.	374	11.01	6.27	209	55.9% (100%)	165	44.1% (100%)	100%		
Age									ANOVA (age)	$F = 3.31$, df1 = 4, df2 = 134, $p =$ **0.005***
70–79	57	10.07	6.28	34	9.1% (16.3%)	23	6.1% (13.9%)	15.2% (100%)		
60–69	139	11.42	6.27	70	18.7% (33.5%)	69	18.4% (41.8%)	37.1% (100%)		
50–59	101	11.18	5.98	58	15.5% (27.8%)	43	11.5% (26.1%)	27.0% (100%)		
≥ 80	42	8.74	5.93	34	9.1%, (16.3%)	8	2.1% (4.8%)	11.2% (100%)		
Under 50	35	14.06	6.36	13	3.5% (6.2%)	22	5.9% (13.3%)	9.4% (100%)		
Tot.	374	11.01	6.27	209	55.9% (100%)	165	44.1% (100%)	100%		

scores compared to older caregivers. Specifically, those over 80 rated their quality of life significantly lower than younger groups, especially those aged 50–59 and 60–69. These findings are further supported by the correlation analysis (Pearson's $r = -0.205$, $p < 0.001$) and linear regression analysis ($R^2 = 0.0393$; $F = 16.6$, $p < 0.001$), both of which indicate that as caregivers age, their quality of life decreases. In other words, advancing caregiver age is a predictor of lower quality of life.

Since our questionnaire assessed well-being through several components (psychological well-being, general health, perceived quality of life), we conducted – after transforming all the scores of the different variables into z-scores to standardize the measures – a correlation analysis. Its results reveal that caregivers' subjective assessment of their own health status correlates positively and significantly with their assessment of their own quality of life [r (376) = 0.39, $p < 0.001$], thus, a better assessment of one's health corresponds to a better assessment of one's quality of life. Similarly, the correlations between psychological well-being and health status [r (367) = 0.48, $p < 0.001$], as well as between psychological well-being and quality of life [r (372) = 0.65, $p < 0.001$], are significant. Therefore, higher scores for general health and quality of life are associated with higher scores for psychological well-being. The PCA and EFA analyses also confirmed, as previously discussed in the methodological section, that the items used for psychological well-being (measured by the WHO-5), perceived general health and quality of life measure a same underlying dimension, that we called 'total well-being'.

3.2.3 Perceived social support

As for the COPE index quality of support subscale, data analysis reveals that caregivers in our sample assigned an average score of 2 to 3 (corresponding to responses ranging from 'sometimes' to 'often') to items 1, 2, and 4. For item 2, the average rating fell between 3 ('often') and 4 ('always'). This suggests that the caregivers in our sample reported feeling supported by friends, health and social services, and generally in their role sometimes or often; additionally, they indicated that they felt supported by their own family 'often' or 'always' (see Table 8). However, Table 8 also highlights that a significant percentage of respondents felt poorly supported by friends and neighbors (35.3% 'never' and 29.1% only 'sometimes'), and by social and health services (26.4% 'never' and 42.7% only 'sometimes').

Regarding perceived support, the t-test revealed no significant difference according to gender [t (369) = −0.57, $p = 0.563$]. Similarly, the ANOVA test applied to age did not show any statistically significant difference [F (4, 118) = 1.72, $p = 0.149$] (See Table 9).

Social support is a very multifaceted construct that encompasses both the overall perception of being supported by friends and family networks, as well as by health and social services. In the questionnaire administered to our sample, in addition to the COPE social support subscale, two other questions were included to assess whether caregivers could rely on someone in times of need. When asked if someone would be available to assist them in caring for the older adult person if they were ill, the majority of caregivers (44.8% + 43.8% = 88.6%) responded positively. Similarly, a significant proportion of caregivers (42.6% + 44.2% = 86.8%) also answered affirmatively when asked if there would be someone available to take care of the older adult person in their absence, allowing them a break from caregiving duties (see Table 10).

No statistical differences were found regarding gender and age for both questions. As for gender, the χ^2 for the first and second

TABLE 6 Caregivers' perceived health status: frequencies, percentages and statistical tests.

	Frequencies	%	M	SD	Statistic test	Statistical value
Health status overall perception score						
1. Poor	16	4.2%				
2. Fair	177	**46.5%**				
3. Good	142	37.3%				
4. Very good	39	10.2%				
5. Excellent	7	1.8%				
Tot.	381	100%				
Health status score by gender						
					T-test	$t = 1.91$, df $= 379$, $p = 0.056$
Male	135		2.70	0.858		
Female	246		2.53	0.765		
Tot.	381		2.59	0.802		
Health status score by age						
					ANOVA	($F = 9.96$, df1 $= 4$, df2 $= 129$), $p <$ **0.001***
70–79	59		2.31	0.701		
60–69	143		2.57	0.774		
50–59	102		2.73	0.869		
≥ 80	42		2.31	0.680		
Under 50	35		**3.11**	0.676		

TABLE 7 Caregivers' perceived quality of life: frequencies, percentages and statistical tests.

	Frequencies	%	*M*	SD	Statistic test	Statistical value
Quality of life overall perception score						
1.Very poor	2	0.5%				
2.Poor	31	8.1%				
3.Neither good nor poor	179	**46.7%**				
4.Good	161	42.0%				
5.Very good	10	2.6%				
Tot.	383	100%				
Quality of life score by gender						
					T-test	$t = 1.63$, df 381, $p = 0.105$
Male	135		3.46	0.667		
Female	248		3.34	0.707		
Tot.	383		3.38	0.695		
Quality of life score by age						
					ANOVA	$F = 7.04$, df1 $= 4$, df 2 $= 129$. $p <$ **0.001***
70–79	59		3.31	0.650		
60–69	144		3.40	0.713		
50–59	101		3.40	0.634		
≥ 80	43		3.02	0.707		
Under 50	36		3.81	0.624		

questions were respectively: χ^2 (2, N = 386) = 1.20, $p = 0.550$, and χ^2 (2, $N = 385$) = 1.85, $p = 0.371$; as for age, the χ^2 for the first and the second questions were respectively: χ^2 (8, $N = 386$) = 6.25, $p = 0.619$, and χ^2 (8, $N = 385$) = 6.95, $p = 0.542$. In other words, caregivers' personal belief that they can count on the support of someone else in case of illness or need for a break does not seem to be influenced by age or gender.

After presenting the data for each of the variables and dimensions studied, the following analyses are carried out to answer specifically and in more detail the three research questions underlying this paper.

TABLE 8 Descriptive statistics and response frequencies for COPE index subscale measuring social support.

COPE index subscale for social support	*N*	Mean	Lower 95%CI	Upper 95%CI	SD	Variance	Never (1)		Sometimes (2)		Often (3)		Always (4)	
							N	%	*N*	%	*N*	%	*N*	%
1. Do you feel well supported by friends or neighbors?	382	2.13	2.03	2.24	1.043	1.087	135	**35.3**	111	**29.1**	86	22.5	50	13.1
2. Do you feel supported by your family?	381	3.32	3.24	3.41	0.860	0.740	17	4.5	48	12.6	111	**29.1**	205	**53.8**
3. Do you feel well supported by health and social services?	382	2.13	2.04	2.22	0.904	0.817	101	**26.4**	163	**42.7**	85	22.3	33	8.6
4. Overall, do you feel well supported in your role of caregiver?	386	2.77	2.68	2.86	0.871	0.758	28	7.3	116	**30.1**	158	**40.9**	84	21.8

3.2.4 Caregiving burden and psychological well-being

Before addressing RQ1 (*Does caregiver burden affect psychological well-being? If so, to what extent?*), a correlation analysis was performed on the various measures used to evaluate caregiving burden and well-being. The results revealed significant associations, indicating that as caregiving burden increases, well-being decreases, and vice versa (see Table 11).

Specifically:

- Each of the three variables used to measure well-being is negatively and significantly correlated with the two variables measuring care burden.
- The two variables measuring care burden are – as already mentioned at the end of section 3.2.1 – positively correlated with each other, thus indicating that they capture different aspects of the same underlying dimension.
- The three variables measuring individual well-being - as already mentioned at the end of section 3.2.2 – are positively correlated with each other, demonstrating that they also capture different aspects of the same underlying dimension.

Given the highly significant results of internal reliability (Cronbach's index), PA and EFA for both 'total well-being' (items of WHO-5, general health, and quality of life), and 'total care burden' (items specifically designed for testing care burden, and COPE subscale for caregiver burden), as pointed out in the methodological session, we also calculated the correlation between these two new variables. The analysis once again revealed a significant negative correlation (Pearson's $r = -0.582$, $p < 0.001$) indicating that as care burden increases, well-being decreases. Moreover, linear regression analysis confirmed that changes in caregiver burden predict changes in caregiver well-being ($R^2 = 0.339$; $F = 184$, $p < 0.001$).

Specifically addressing RQ1, we tested whether caregiver burden is a predictor of poor psychological well-being and at what point it leads to psychological distress, by conducting linear regression and receiver operating characteristic (ROC) analyses.

Linear regression analysis revealed that care burden is a significant predictor of psychological well-being, both when the four items specifically designed are taken into account ($R^2 = 0.197$; $F = 91.3$, $p < 0.001$) and when the Cope index subscale is used ($R^2 = 0.290$; $F = 150$, $p < 0.001$). These results indicate that as caregiving burden increases, psychological well-being significantly decreases.

To identify the point at which perceived fatigue leads to a decline in psychological well-being, we also conducted a ROC analysis, assuming a value ≤13 on the WHO-5 scale as the cut-off for poor psychological well-being. We sought to determine at what average level of caregiver burden (as measured separately by the COPE subscale and by the four items specifically designed) our sample began to exhibit poor psychological well-being. Operationally, we considered the WHO-5 scale as a dichotomous dependent variable (scores above 13 indicate good well-being, scores equal to or below 13 indicate poor well-being) and as covariates once for the COPE caregiver burden subscale and once for the four items specifically designed for measuring care burden.

As for the COPE subscale for care burden, the ROC analysis identified an optimal cut-off value of 2 (on a 4-point Likert scale ranging from 1 to 4, with 1 = 'never'; 2 = 'sometimes'; 3 = 'often'; 4 = 'always'). This means that a score above 2 (frequency 'sometimes'

TABLE 9 COPE Index subscale for social support: frequencies, percentages and statistical tests.

COPE index subscale for social support	*N*	Mean	Lower 95% CI	Upper 95% CI	SD	Statistical test	Statistical value
Gender						*T*-test	$t = -0.57$, df = 369, $p = 0.563$
Male	133	2.57	2.48	2.66	0.531		
Female	238	2.61	2.52	2.69	0.654		
Tot.	371	2.59	2.53	2.65	0.612		
Age						ANOVA	($F = 1.72$, df1 = 4, df2 = 118), $p = 0.149$
70–79	57	2.78	2.61	2.94	0.626		
60–69	138	2.54	2.43	2.64	0.613		
50–59	102	2.60	2.49	2.70	0.546		
≥ 80	40	2.49	2.28	2.71	0.661		
Under 50	34	2.62	2.38	2.86	0.680		

TABLE 10 Capacity to find a substitute.

	Yes, I could find someone quite easily		Yes, I could find someone, but with some difficulty		No, nobody	
Items	N.	%	N.	%	N.	%
If you were ill, would there be someone who could help you in caring for the older adult person?	173	44.8%	169	43.8%	44	11.4%
If you needed a break from caring, would there be someone who could take care of the older adult person in your place?	164	42.6%	170	44.2%	51	13.2%

TABLE 11 Correlation matrix.

		4 items specifically designed for measuring care burden	COPE Index subscale for care burden	General health	Quality of life	Psychological well-being (WHO-5)
4 items specifically designed for measuring care burden	Pearson's r	—				
	df	—				
	p- value	—				
COPE Index subscale for care burden	Pearson's r	**0.691*****	—			
	df	375	—			
	p- value	< 0.001	—			
General health	Pearson's r	**−0.269*****	**−0.339*****	—		
	df	378	370	—		
	p- value	< 0.001	< 0.001	—		
Quality of life	Pearson's r	**−0.457*****	**−0.546*****	**0.398*****	—	
	df	381	372	376	—	
	p- value	< 0.001	< 0.001	< 0.001	—	
Psychological well-being (WHO-5)	Pearson's r	**−0.444*****	**−0.540*****	**0.484*****	**0.657*****	—
	df	372	364	367	372	—
	p- value	< 0.001	< 0.001	< 0.001	< 0.001	—

*$p < 0.05$; **$p < 0.01$; ***; $p < 0.001$. Caregiving burden and well-being.

or more) indicates a higher probability of low psychological well-being, while a score below 2 may correspond to a lower probability of low psychological well-being. In other words, a value of 2 is the point at which the burden of care (measured by the COPE subscale) begins to predict a significant reduction in psychological well-being (see Figure 1).

As for the mean value of the four items specifically designed for measuring care burden, the ROC analysis identified an optimal

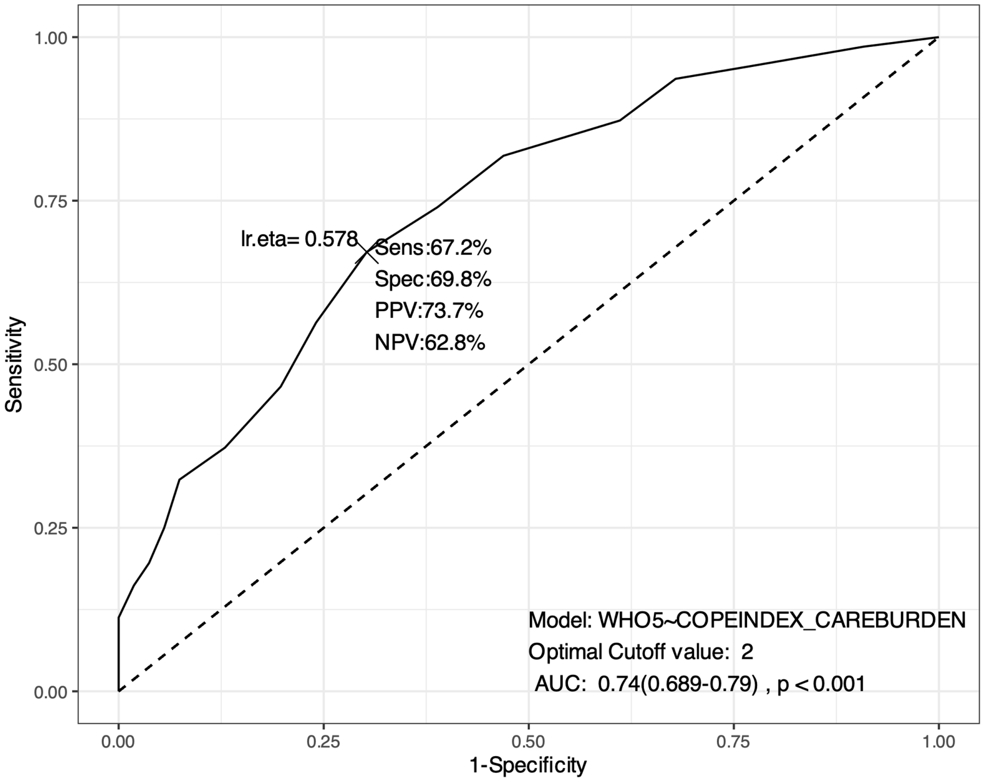

FIGURE 1
ROC Curve. Identification of cut-off value for caregiving burden (measured by COPE subscale). *This ROC analysis suggests that the model has a reasonably good performance in discriminating between different levels of psychological well-being based on caregiving burden, with a good balance between sensitivity (the model's ability to identify true positives, i.e., cases where the psychological well-being is correctly identified given the care burden) and specificity (the model's ability to identify true negatives, i.e., cases where psychological well-being is correctly identified as unaffected by caregiving burden). The AUC: 0.74 (0.689–0.79), $p < 0.001$ indicates a good level of accuracy of the model in discriminating between those who have low psychological well-being and those who do not.

cut-off the value of 1.75 (on a 5-point Likert scale ranging from 0 to 4, with 0 = 'never'; 1 = 'rarely'; 2 = 'sometimes'; 3 = 'often'; 4 = 'almost always'). In this case, a score above 1.75 signals a higher probability of low psychological well-being, while a score below 1.75 signals a lower probability of low psychological well-being. In other words, a value of 1.75 is the point at which the burden of care begins to predict a significant reduction in psychological well-being (see Figure 2).

These results can be used to identify individuals who may need additional support to improve their psychological well-being when experiencing a significant caregiving burden (equals 2 when measured with the COPE subscale and 1.75 when measured with the four specifically developed items).

3.2.5 Social support and psychological well-being

To address the first part of RQ2 (*Does social support influence psychological well-being?*), correlation and regression analyses were carried out. As expected, correlation analysis suggests that perceived social support (measured by the COPE subscale index) positively impacts carers' psychological well-being (measured by WHO-5) [$r(357) = 0.348$, $p < 0.001$] (Table 12).

Linear regression analysis supports this, indicating that social support is a significant predictor of psychological well-being ($R^2 = 0.121$; $F = 49.2$, $p < 0.001$).

3.2.6 Multivariate logistic regression

Multivariate logistic regression was conducted to further explore the relationship between perceived caregiver burden and psychological well-being, specifically identifying the weight of each aspect of caregiving on psychological well-being, as well as to identify which dimensions of social support have the greatest impact on perceived psychological well-being, thus addressing the second part of RQ2 (*which aspects of social support have the most significant impact on caregivers' psychological well-being?*).

In the table below, the 'Estimate' column shows the coefficients in log-odds form. More precisely, the estimation output highlights whether the effect of the predictors on the variable of interest is positive or negative.

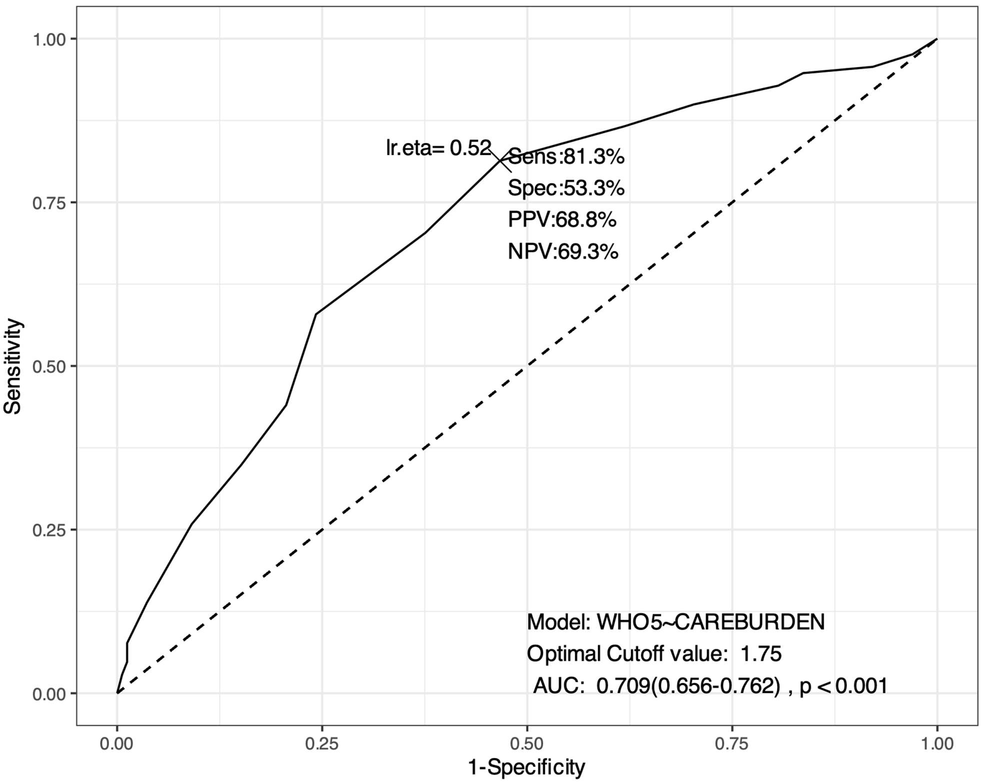

FIGURE 2
ROC Curve. Identification of cut-off value for caregiving burden (measured by the four specifically designed items). *This ROC analysis suggests that the model has a reasonably good performance in discriminating between different levels of psychological well-being based on caregiving burden, with a good balance between sensitivity (the model's ability to identify true positives, i.e., cases where the psychological well-being is correctly identified given the care burden) and specificity (the model's ability to identify true negatives, i.e., cases where psychological well-being is correctly identified as unaffected by caregiving burden). The AUC: 0.709 (0.656–0.762), p < 0.001 indicates a good level of accuracy of the model in discriminating between those who have low psychological well-being and those who do not.

TABLE 12 Correlation matrix.

		Psychological well-being (WHO-5)	COPE Index subscale for social support
Psychological well-being (WHO-5)	Pearson's r	—	
	df	—	
	p- value	—	
COPE Index subscale for social support	Pearson's r	0.348***	—
	df	357	—
	p- value	< 0.001	—

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$. Social support and psychological well-being.

Table 13 shows only those items from the different scales that have a significant impact on the dependent variable (i.e., psychological well-being exclusively measured with WHO-5).

Regarding the four items specifically designed for measuring care burden, Table 13 shows that:

- Lower levels of stress in caring and coping with responsibilities ('Do you feel stressed between caring for the older adult person and trying to cope with other responsibilities?' with 0 = 'never', 1 = 'rarely', and 2 = 'sometimes') have a significant impact on psychological well-being; hence, less stress corresponds to greater well-being. Although the relationship is significant for all values of the variable, it is observed that the significance decreases when the variable takes values of 1 and 2. In other words, at values of 1 and 2, the variable loses its significance, as a higher level of stress would have a negative effect on well-being.
- Lower levels of fatigue in caring ('Do you feel fatigued when caring for the older adult? with 0 = 'never', and 1 = 'rarely') also have a significant effect on psychological well-being; in other words, lower levels of perceived fatigue correspond to higher psychological well-being.

TABLE 13 Aspects of social support having the greatest impact on psychological well-being.

Multivariate logistic regression						
		Value	Estimate	SE	z- value	Pr(>|z|)
4 items specifically designed for measuring care burden	Feeling stressed about caring and coping with other responsibilities	0	1.9431	0.6129	3.171	0.00152**
	Feeling stressed about caring and coping with other responsibilities	1	1.4118	0.5526	2.555	0.01062**
	Feeling stressed about caring and coping with other responsibilities	2	0.8232	0.4976	1.654	0.09806*
	Feeling fatigued in caring	0	1.47032	0.64318	2.286	0.0223**
	Feeling fatigued in caring	1	1.01750	0.54053	1.882	0.0598*
	Feeling insecure in caring	0	1.2818	0.6516	1.967	0.04916*
COPE index subscale (care burden)	Assisting causes difficulties with friends	4	1.5382	0.6292	2.445	0.0000***
	Assisting negatively impacts on the state of physical health	4	0.6495	0.4826	1.346	0.0885*
	Assisting causes difficulties in relations with your family	4	0.4836	0.0863	5.604	0.0000***
	Assisting cause economic difficulties	4	**−0.5927**	0.0636	−9.319	0.0000***
COPE index subscale (social support)	Feeling supported by health and social services	1	0.5923	0.2764	2.1429	0.0162**
	Feeling supported by health and social services	2	0.6238	0.3097	2.0142	

- Lower levels of insecurity in caring ('Do you feel insecure about what to do for your older adult person?' with 0 = 'never') also correspond to greater psychological well-being.

Additionally, regarding caregiving burden, as measured by the COPE index subscale, the reported absence of perceived difficulties in relationships with friends (*'Does caring cause any difficulties in your relationships with friends?'*) and family (*'Does caring cause any difficulties in your relationships with family?'*), as a result of caregiving tasks, and the absence of a negative effect of caring on personal physical health (*'Does caring have a negative effect on your physical health status?'*) also have a significant impact on psychological well-being. In other words, the less people feel that caring has a negative impact on their relationships (with friends and family) and on their own physical health, the better their self-reported psychological well-being. Conversely, greater financial difficulties (*'Does providing assistance cause you financial difficulties?'*) have a negative impact on psychological well-being.

On the COPE Index social support subscale, only the item concerning social and health services (*Do you feel adequately supported by health and social services (public, private, or voluntary?)*) is significantly associated with well-being at higher levels. In other words, the greater the perceived support from social and health services, the greater the reported psychological well-being. This information could be used to enhance social and health services, given their crucial role in the psychological well-being of caregivers. If psychological well-being is closely related to the extent to which caregivers feel supported by these services, then improving the quality of services should increase the likelihood of caregivers achieving good levels of psychological well-being.

3.2.7 Mediation analysis

After addressing the first two RQs, a mediation analysis was conducted using the following variables:

- WHO-5 (dependent variable);
- Subscale COPE index for care burden (predictor);
- Subscale COPE index for social support (mediator).

This analysis aimed to answer RQ3 (*If caregivers' burden negatively affects their psychological well-being, does the perception of social support mediate this relationship?*) (Figure 3).

The analysis revealed a significant direct and indirect effect of the care burden on psychological well-being, with the direct effect accounting for the majority of the total effect (88%). Although social support plays a smaller and partial role in explaining the relationship between care burden and psychological well-being (12%), it is nonetheless statistically significant ($p = 0.001$; Table 14). Therefore, although social support does not neutralize the negative impact of caregiver burden on psychological well-being, it contributes to buffering (i.e., reducing) its negative impact, confirming the importance of social support as a mitigating factor. The estimates patch confirms that: the greater the care burden experienced, the lower the perceived social support (a); the greater the social support experienced, the greater the psychological well-being (b); the greater the care burden experienced, the lower the psychological well-being experienced (c).

Even if we calculate the mediation analysis using the four items specifically designed to measure care burden as a predictor, the results would be similar (Table 15). In this case, although the direct effect

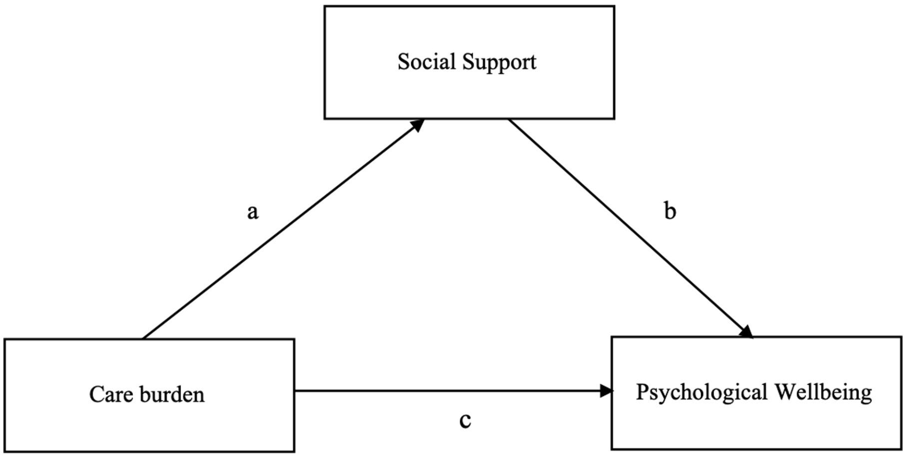

FIGURE 3
Mediation model.

accounts for the majority of the total effect (83.5%), social support plays a slightly larger, though still partial, role in explaining the relationship between care burden and psychological well-being (16.5%). As the *p*-value (0.001) indicates, this role is statistically significant.

4 Discussion

Family caregivers play a crucial role in caring for frail older people. Research shows that caregiving can have both positive and negative effects on caregivers' well-being. On the one hand, providing care may enhance the caregivers' sense of purpose and satisfaction, particularly when the role is taken voluntary. Studies, such as those by Weinstein and Ryan (46), and by Hui et al. (47), suggest that pro-social behavior can improve well-being for both caregivers and recipients. Other research confirms that caring for older relatives can foster feelings of fulfillment and satisfaction [e.g., (12–15, 17)]. However, when the demands of caregiving and the related burden exceed individual resources, it can lead to negative outcomes. Thus, caregivers, particularly family caregivers of older adults, often face significant physical, emotional, and psychological strain. This is well-documented in studies showing a decline in caregivers' quality of life and psychological well-being [e.g., (2, 5–7, 9, 54)]. In this complex situation, the perception of social support – whether from other family members, friends, or services – can play a crucial role in reducing stress [e.g., (25)] and improving the psychological well-being of family caregivers of older adults [e.g., (23, 24)].

RQs that guided this study aimed to understand whether caregiving burden negatively impacts individual psychological well-being and, conversely, whether social support has a positive influence, while also exploring these relationships more thoroughly.

5 Conclusion

5.1 Caregiving burden

Regarding *caregiver burden,* a significant portion of our sample reported high levels of time deprivation, fatigue, feelings of imprisonment, and difficulties in maintaining social relationships. These findings are consistent with previous research, such as that by Rokicka, and Zajkowska (48), who found that carers of older adults, especially co-residents, often sacrifice personal activities and social interaction. An unbalanced trade-off between time devoted to caring for others and time devoted to oneself can be detrimental to health, life satisfaction and well-being. Returning to our research, although our analysis did not reveal any significant gender differences, women generally reported higher levels of stress and more pronounced declines in their physical and mental health compared to men. Similarly, older caregivers also reported higher levels of perceived fatigue, although advancing age *per se* did not emerge as a reliable predictor of perceived fatigue.

5.2 Psychological well-being

In terms of psychological *well-being*, as measured by the WHO-5, our findings are consistent with those of Santini et al. (49) in a similar population (i.e., 100 family caregivers of older adult people with incontinence), but lower than the average score measured in an Italian sample from the general population by Carrozzino et al. (32), which reported an average score of 11.64 ± 4.95. In our study, 55.9% of caregivers also scored below the reference cut-off of 13, indicating poor psychological well-being. This highlights the pervasive issue of low psychological well-being among family caregivers in similar caregiving roles. No significant gender differences were found. However, age emerged as a significant predictor of well-being, suggesting that the advancing age of caregivers predicts a significant decline in their psychological well-being, as well as in their perceived health and quality of life.

5.3 Social support

In line with the results of other research on family caregivers of older people [e.g., (25)], a significant proportion of our respondents reported feeling poorly supported by friends, neighbors, and social

TABLE 14 Mediation estimates and path estimates.

		Label	Estimate	SE	*Z*	*p*	% Mediation
Mediation estimates	Effect						
	Indirect	a × b	−0.0897	0.0273	−3.29	0.001	12.0
	Direct	c	−0.6560	0.0649	−10.11	< 0.001	88.0
	Total	c + a × b	−0.7457	0.0611	−12.20	< 0.001	100.0
Path estimates	Path						
	Subscale COPE care burden → Subscale COPE social support	a	−0.524	0.0675	−7.77	< 0.001	
	Subscale COPE social support → Psychological well-being (WHO-5)	b	0.171	0.0472	3.63	< 0.001	
	Subscale COPE care burden → Psychological well-being (WHO-5)	c	−0.656	0.0649	−10.11	< 0.001	

The buffering role of social support (measured through the COPE Index subscale) in mediating the relation between care burden (measured through the COPE Index subscale) and psychological well-being (measured via WHO-5).

TABLE 15 Mediation estimates and path estimates.

		Label	Estimate	SE	*Z*	*p*	% Mediation
Mediation estimates	Effect						
	Indirect	a × b	−0.0943	0.0252	−3.74	< 0.001	16.5
	Direct	c	−0.4768	0.0612	−7.79	< 0.001	83.5
	Total	c + a × b	−0.5712	0.0589	−9.70	< 0.001	100.0
Path estimates	Path						
	Care burden measured by the four questions specifically designed → Subscale COPE social support	a	−0.441	0.0622	−7.09	< 0.001	
	Subscale COPE social support → Psychological well-being (WHO-5)	b	0.214	0.0487	4.39	< 0.001	
	Care burden measured by the four questions specifically designed → Psychological well-being (WHO-5)	c	−0.477	0.0612	−7.79	< 0.001	

The buffering role of social support (measured through the COPE Index subscale) in mediating the relation between care burden (measured through the four questions specifically designed) and psychological well-being (measured via WHO-5).

and health services, irrespective of gender and age. Despite this, only a small percentage of caregivers reported that they could not find a replacement in case of illness or need for a break. Conversely, many respondents mentioned having someone available to take over caregiving duties in their absence, allowing them some respite.

5.4 Caregiving burden and psychological well-being

Addressing RQ1, our analysis aligns with the findings of a systematic review by Del-Pino-Casado et al. (50), who identified caregiver burden as a key risk factor for depressive symptoms in caregivers of older adults. Our findings revealed a significant correlation between increased caregiving burden and decreased psychological well-being. Focusing solely on the results from the analysis of the responses provided by our sample to the validated scales items (COPE Index subscale for care burden and WHO-5 for psychological well-being), a significant negative correlation was found between caregiving burden and psychological well-being [r (364) = −0.540, $p < 0.001$], with caregiving burden emerging as a significant predictor of reduced psychological well-being ($R^2 = 0.290$; $F = 150$, $p < 0.001$). Through ROC analysis, we determined a threshold value (which for the COPE Index subscale is equal to 2 on a 1–4 scale) at which caregiver burden begins to negatively impact psychological well-being. As previously mentioned, the results confirmed that caregiver burden does not significantly impact caregivers' psychological well-being as long as it does not exceed a certain level. These findings have critical implications, suggesting that interventions to support caregivers facing significant burdens could prevent deterioration or worsening of their psychological well-being. This result also suggests that regular monitoring of caregiving burden and early intervention with psychosocial support could help prevent caregivers from reaching a critical point that could lead to more severe psychological outcomes. Moreover, in our sample, multivariate logistic regression allowed us to identify the specific factors of caregiving burden that seem to most significantly impact psychological well-being. The analysis revealed that psychological well-being is higher when caregivers experience lower levels of stress, fatigue, and insecurity in their caregiving roles, and when caregiving tasks have a reduced impact on their relationships. These findings confirm the need to monitor caregiving burden in specific personal and relational domains of caregivers of frail older people with LTC needs. The aim should be to keep levels of stress, fatigue and personal insecurity low, to limit the impact of caregiving burden on relationships, and to intervene promptly when these levels are exceeded.

5.5 Social support and psychological well-being

As for RQ2, the relationship between perceived social support and psychological well-being was also found to be highly significant: greater perceived social support correlates with better psychological well-being. Focusing strictly on the results of the analysis of responses provided by our sample to the validated scale items (COPE Index subscale for social support and WHO-5 for psychological well-being), a positive correlation was found between greater perceived social support and better psychological well-being [r (357) = 0.348, $p < 0.001$], with social support emerging as a significant predictor of psychological well-being ($R^2 = 0.121$; $F = 49.2$, $p < 0.001$). These results are partially consistent, among others, with the findings of Leung et al. (51), who demonstrated that support from friends significantly reduces caregiver burden and improves mental health outcomes. Similarly, Muñoz-Bermejo et al. (58) highlighted that the perceived social support can contribute to improving mental well-being, especially for older caregivers. De Maria et al. (52) also observed that perceived support from family and friends improved the health-related quality of life of both older adults and their informal caregivers. In our sample, multivariate logistic regression analysis emphasized that support from health and social services plays a critical role in determining caregivers' psychological well-being. While support from friends, family and neighbors is important, formal services emerged as the most significant factor. The greater the perception of support from services, the higher the reported psychological well-being.

5.6 The mediating role of social support between care burden and psychological well-being

Finally, concerning RQ3, mediation analysis confirmed that social support plays a buffering role in mitigating the negative impact of caregiving burden on psychological well-being. Even though caregiving can be demanding, knowing that one can rely on social support – mainly from services – helps in reducing its adverse effects on caregivers' psychological well-being.

Overall, these findings underline the importance of robust social support networks and, in particular, the urgency of investing in health and social services to alleviate the psychological burden of caregivers and improve their general well-being. In other words, increased public investment in health and social services could enhance the well-being of caregivers and, consequently, that of the older adults they care for.

5.7 Limitations and future research

While this study provides valuable insights, several limitations should be acknowledged.

First, the generalizability of the findings is limited due to the sample of caregivers, which is not representative of the Italian population of family caregivers of frail older adults. Furthermore, data collection was conducted in a single session, preventing the calculation of test–retest reliability, which limits the robustness of the results. In addition, although the items of the scales used (WHO-5 and the two subscales of the COPE index) have been shown to adequately measure the latent factors (psychological well-being, caregiver burden and social support), they do not always seem to fully fit our data. This may be due to several factors, including the limited number of items on each scale, as well as, the socio-demographic differences of our sample, the differing contexts in which the surveys were administered and completed (either at home or in a union office), which may have influenced the atmosphere and comfort levels of the participants. Another limitation relates to the format of the questions (all closed), which may have limited the carers' ability to fully express their attitudes, perceptions, and viewpoints. Moreover, although guidelines recommend administering a depression screening when low psychological well-being is detected (as was the case for many in our sample), this step was not implemented, highlighting a significant gap between research knowledge and practical intervention.

Future research should aim to overcome these limitations by adopting more robust methodologies, but it should also aim to achieve new goals. A longitudinal approach, for instance, could involve measuring key variables before and after specific training or support interventions. Additionally, comparative studies could be useful, such as comparing informal caregivers of older adult individuals with formal caregivers or contrasting caregivers of older adult people with those caring for individuals with different needs (e.g., children with special needs). Cross-cultural studies would also be insightful, allowing for comparisons of psychological well-being among caregivers in countries with different healthcare and social support systems.

5.8 Implications for policy

A shift in the paradigm for managing interventions to support families dealing with the challenges of frailty and LTC seems urgent. This change should embrace a community-based approach to reduce the isolation in which carers often find themselves, as caring responsibilities are often seen as an 'essentially private affair' within Italian society. This change would alleviate some of the burden traditionally placed on family members.

The findings of this study offer valuable practical insights. Firstly, it highlights the importance of maintaining ongoing communication between caregivers and service providers. Listening to caregivers' needs and regularly monitoring their psychological health are essential to promptly address potential risks. Neglecting such risks can adversely affect both caregivers and those they care for. Secondly, the study underscores the need to invest in developing and offering training programs for family caregivers. These programs should equip them with practical skills to effectively manage the needs of older assisted relatives and cope with the stress of their duties, thus reducing both the perceived burden and the likelihood of adverse psychological outcomes. This becomes even more urgent in contexts like ours, where a high percentage of caregivers are older adult themselves or approaching this stage of life. Improving access to services and training programs, including overcoming barriers related to service locations, is critical to ensuring that caregivers can fully utilize available resources.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: The data presented in this study are available upon request from the corresponding author. The data are not publicly available because they are still the object of ongoing analyses. Requests to access these datasets should be directed to Ramona Bongelli, ramona.bongelli@unimc.it.

Ethics statement

The requirement of ethical approval was waived by Ethics Committee of the National Institute of Health and Science on Aging (INRCA) for the studies involving humans because Ethics Committee of the National Institute of Health and Science on Aging (INRCA). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

BR: Conceptualization, Data curation, Formal analysis, Methodology, Software, Supervision, Writing – original draft, Writing – review & editing. BG: Conceptualization, Methodology, Supervision, Writing – review & editing. PA: Conceptualization, Formal Analysis, Methodology, Software, Writing – review & editing. FM: Conceptualization, Writing – review & editing. GC: Conceptualization, Writing – review & editing. SF: Conceptualization, Writing – review & editing. LG: Conceptualization, Data curation, Supervision, Writing – review & editing. SS: Conceptualization, Data curation, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2024.1474967/full#supplementary-material

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Caregiving burdens of task time and task difficulty among paid and unpaid caregivers of persons living with dementia

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Background: Demands of caregivers of persons living with dementia (PLWD) are often influenced by the context of their caregiving situation. This study examines common and unique factors associated with caregiving burden in terms of task time and task difficulty among paid and unpaid caregivers of PLWD.

Methods: Cross-sectional baseline survey data were analyzed from 107 paid and unpaid caregivers of PLWD participating in a larger NIH-funded study assessing the feasibility of using a novel in-situ sensor system. Oberst Caregiving Burden Scale constructs of task time and task difficulty served as dependent variables. Two least squares regression models were fitted, controlling for contextual items related to the caregiver, care recipient, and caregiving logistics.

Results: Caregivers whose care recipients were female ($B = -0.29$, $p = 0.006$), had more chronic conditions ($B = 0.31$, $p = 0.011$), and had lower Mini-Mental State Exam scores ($B = -0.20$, $p = 0.015$) reported higher task time burdens. Caregivers whose care recipients had other paid caregivers ($B = 0.30$, $p = 0.031$) and spent more months/years caring for their care recipients ($B = 0.28$, $p = 0.004$) reported higher task time burdens. Caregivers' task time burden was positively associated with their emotional stress level ($B = 0.30$, $p = 0.020$). Caregivers' task difficulty burden was positively associated with their emotional stress ($B = 0.30$, $p = 0.029$) and depressive symptomatology ($B = 0.32$, $p = 0.002$).

Discussion: Results reinforce the relationship between caregiver burden and mental health impacts. While the care recipient's disease profile and needs were drivers of task time burden, which may also require coordination with other paid caregivers, task difficulty was emotionally driven. Findings highlight the importance of caregiver support services and programming for mental health.

KEYWORDS

unpaid caregiver, paid caregiver, strain, mental health, caregiver burden, dementia

1 Introduction

Approximately 21% of Americans (53 million) provide unpaid care for a family member, friend, or neighbor (1). Of those, about half care for persons living with dementia (PLWD) (2). Beyond unpaid care, between 25 and 50% of community-dwelling PLWD also receive paid care (3). Given dementia caregiving is considered a chronic stressor (4) examining ways to address the burden of caring for PLWD is an important area of research (5).

Paid and unpaid caregivers are exposed to a challenging caregiving context that impacts their physical and psychological wellbeing (6, 7). However, the complex nature of dementia caregiving carries an added burden compared to non-dementia care environments. For example, caregiving tasks are more intense and require more time to perform for PLWD compared to other care recipients. PLWD also require more assistance with activities of daily living (ADL) and instrumental activities of daily living (IADL) and require assistance for a longer duration (8–11). Because of this high care burden context, caregivers of PLWD report significantly poorer physical and mental health outcomes than other caregivers (9–12).

Research on the care burden and demands of caregivers of PLWD has identified several key contributing factors. Functional decline and ADL-IADL performance progressively worsen as dementia progresses, thereby increasing levels of dependency on others (13–16). In a longitudinal study, the average hours of care per month for community-dwelling PLWD increased by 131 h over an eight-year period (17). The occurrence and severity of behavioral and neuropsychiatric symptoms (BNPS) also worsen as dementia progresses, which increases the complexity of care (14, 16, 18–21). The burden of caring for PLWD becomes even more complicated when the individual has other comorbid conditions (22). Several studies report that care tasks become more difficult and time consuming as the number and severity of chronic conditions increase (16, 22).

Overall, caregiver burden may be more pronounced among caregivers of female PLWD. When examining all-cause dementia, females exhibit faster decline in cognitive and executive functioning (23) and more neuropsychiatric symptoms such as delusions, hallucinations, and depression than men (24–28). Paradoxically, females also experience higher chronic disease and frailty burden, despite having lower mortality rates (29–31). Thus, female PLWD may require greater assistance for longer periods than males of the same age.

The demands of caregiving typically increase as duration of care extends. In contrast to adaptation theory, wear-and-tear theory posits that providing care for an extended period can have a negative impact on the caregiver (32). Prolonged caregiving can take a considerable toll on an individual and the cumulative effects of chronic stress and caregiver burden may erode an individual's ability to provide care effectively. In a three-year longitudinal study, prolonged caregiving was associated with increased burden in caregivers without support (33). Moreover, because individuals with advanced dementia require more assistance, caregiver task difficulty and time may increase over time (20). Individuals may be more likely to seek paid caregiving support to ease the burden of care (34).

Most research confirms that high intensity care demands, such as ADL and IADL assistance, are associated with worse emotional and physical health outcomes for caregivers (7, 35, 36). For example, completing physically demanding care tasks, such as bathing, dressing, and transferring (7, 37, 38), is associated with increased risk of emotional, physical, and financial burden (39). Similar findings have been reported elsewhere (40, 41). However, a separate systematic review concluded that objective measures of care demands, such as number of tasks and assistance with ADLs or IADLs, do not always contribute to poorer quality of life (42), which underscores the variability in perceptions of the degree of difficulty of the care context among caregivers.

1.1 Measurement of caregiving burden

Caregiver burden is a multi-dimensional concept that comprises of multifactorial stressors including the emotional, physical, social, and financial strain of providing care to individuals with chronic illnesses (43). Most studies and measures look at general caregiver burden alone or in a single dimension, such as subjective or objective indicators of burden (44). Additionally, most U.S.-based studies use the Zarit Burden Interview, a measure of subjective experiences of burden to examine caregiver burden (45). More robust and targeted measures should be used to identify the unique domains, particularly related to objective indictors and sources of care-related burden (46). For example, subjective measures of care burden are more consistently associated with quality of life; whereas objective measures such as caregiving demands and time spent caring are not consistently related to health-related outcomes (42). While most studies examine time spent per day or duration of caregiving, less is known about the task time- and difficulty-related aspects of caregiving burden. The Oberst Scale enables the examination of how time and task difficulty influence caregiver burden (47), which can aid the investigation of objective indicators of burden.

Because time- and task-related difficulty contribute to emotional stress in caregivers (48), it is important to examine these dimensions of burden. Researchers contend that identifying the source of caregiver burden, specifically time- and difficulty-related care tasks that contribute to stress, is important for designing effective interventions (44, 47). By identifying the specific source of burden, practitioners can enhance intervention development and delivery (46). The purposes of this study were to identify the prevalence of caregiving burden among paid and unpaid caregivers of PLWD and examine the common and unique factors associated with caregiving burden in terms of task time and task difficulty.

2 Methods

2.1 Participants and procedures

Data were collected from paid and non-paid caregivers of PLWD as part of a larger Small Business Innovative Research Phase

II grant funded by the National Institute of Aging (1R44AG065118-01). The objectives of the program were to remotely monitor device usage and real time location of PLWD in home and assisted living settings and analyze continuous sensor data in attempt to recognize activities of daily living (ADL) over an 18-month period. Caregiver and care recipient dyads were initially recruited into the study from assisted living facilities, home care entities, and home health companies. However, because of lock-down and visitation restrictions during COVID-19, recruitment from these settings was limited. Expanded recruitment strategies also included recruitment from healthcare facilities (e.g., physicians' offices, pharmacies, and senior housing), Area Agencies on Aging, Meals on Wheels sites, and other community outreach (e.g., community presentations/tabling, flyers, newspaper articles, radio, social media).

Inclusion criteria for caregivers required that they: (a) be fluent in English to understand and sign consent documents; (b) have a high school diploma or equivalent; (c) be age 18 years or older; (d) provide care to care recipient with cognitive impairment at least 6 h per week; (e) willing to complete all requested questionnaires and checklists at baseline and at 9- and 18-month follow-ups; (f) plan to continue providing care to care recipient for the study duration; (g) not be pregnant; and (h) be willing to wear or carry a sensor tag or key fob while providing care to care recipient.

Once recruited and consented into the study, participants completed a series of questionnaires and assessments. This study utilizes the questionnaire administered to the paid and unpaid caregivers at baseline. Other than the care recipients' Mini-Mental State Examination (MMSE) score collected at baseline, other data about the care recipient was reported by the caregiver. The caregiver baseline instrument included items about the caregiver's sociodemographics, the care recipient's sociodemographics (reported by the caregiver), caregiving situation and logistics (e.g., time and duration of care, living situation, relationship to care recipient), caregiver's physical and mental health and self-care behaviors, caregiver's perceptions about caregiving, and caregiver's perceptions about the use of technology (i.e., in caregiving and non-caregiving contexts). Approval for this study was obtained from the Texas A&M University Institutional Review Board (#2019-0250F).

2.2 Measures

2.2.1 Dependent variables

The dependent variables for this study were from the Oberst Caregiving Burden Scale (OCBS). The OCBS is a 15-item questionnaire used to measure 15 common caregiving tasks related to personal, direct, indirect, interpersonal, and support care (49, 50). For each task sub-scale, the measure allows participants to respond in two ways; rating the time related to the task and the difficulty associated with the task. Response choices for the time on task sub-scale use a 5-point Likert-type scale ranging from "none" (scored 1) to "a great amount" (scored 5). Time sub-scale scores range from 18 to 90, with higher scores indicating more time-related burden. Response choices for the task difficulty sub-scale use a 5-point Likert-type scale ranging from "not difficult" (scored 1) to "extremely difficult" (scored 5). Difficulty sub-scale scores range from 18 to 90, with higher scores indicating more difficulty-related burden. In the current sample, the internal reliability coefficients (i.e., Cronbach's alpha) for the time and difficulty sub-scales were 0.918 and 0.932, respectively.

2.2.2 Caregiver characteristics

Sociodemographic characteristics of the caregiver included in analyses were age and sex (i.e., male, female). Caregivers reported their relationship with their care recipient (i.e., spouse, paid caregiver, adult child, other relative/non-relative) and if they lived with their care recipient (i.e., no, yes). Caregivers also reported the duration in which they provided care to their care recipient [i.e., <3 months (scored 1), 3 to <6 months, 6 months to <1 year, 1 year to <2 years, 2 to <5 years, 5 to <10 years, 10+ years (scored 7)], which was treated continuously in analyses. Caregivers were also asked to report information about their physical and mental health. Variables included in this study were self-reported physical strain, emotional stress, and depressive symptomatology, each of which were treated continuously in analyses. For physical strain, participants were asked "How much of a physical strain would you say that caring for the care recipient is for you?" Response choices for this single item ranged from "not a strain at all" (scored 1) to "very much a strain" (scored 5). For emotional stress, participants were asked "How emotionally stressful would you say that caring for the care recipient is for you?" Response choices for this single item ranged from "not at all stressful" (scored 1) to "very stressful" (scored 5). For depressive symptomatology, participants were asked two items, "Over a typical 2-week period, how often have you been bothered by the following problems?: (a) Little interest or pleasure in doing things; and (b) feeling down, depressed, or hopeless." Response choices for these items ranged from "not at all" (scored 0) to "nearly every day" (scored 3). Responses for these items were summed to create a composite score ranging from 0 to 6, with higher scores indicating more depressive symptomatology.

2.2.3 Care recipient characteristics

Sociodemographic characteristics of the care recipient included in analyses were age and sex (i.e., male, female). Caregivers reported the number of chronic health conditions in which their care recipient had been diagnosed from a 'check all that apply' list of 15 conditions. Endorsed conditions were summed to create a count variable, which was treated continuously in analyses. Care recipients' home environment included whether they resided in a single-family home, individual apartment or condominium, independent living community, or assisted living facility. Caregivers reported if their care recipient also had other paid caregivers (i.e., no, yes). At baseline, per the parent study protocol, a Mini-Mental State Examination (MMSE) was performed with all care recipients (51). The abbreviated MMSE is an 11-item cognitive function test administered in a paper-pencil format, which is among the most widely recognized tools for assessing cognitive states (52). Possible scores range from 0 to 30 (i.e., lower scores indicating more cognitive impairment) and was treated continuously in analyses.

2.3 Statistical analyses

All analyses were performed using SPSS (version 29). Descriptive statistics were calculated for all study variables, which were compared across unpaid and paid caregiver subgroups. OCBS composite scores, item-specific scores for time and difficulty sub-scales, were calculated and compared across unpaid and paid caregiver subgroups. Pearson's Chi-square tests were used to identify proportional differences for categorical variables across caregiver groups. Independent sample t-tests were used to identify mean differences for continuous variables across caregiver groups. Two ordinary least squares (OLS) regression models were fitted to identify factors associated with OCBS time and difficulty sub-scales, respectively. The models were adjusted for characteristics of the caregiver, care recipient, and caregiving situation. Statistical significance was defined as $p < 0.05$.

3 Results

Baseline data were analyzed from 109 paid and unpaid caregivers of PLWD (Table 1). On average, the caregivers were age 58.87 (±15.76; range: 19–85) years. Most caregivers were female (78.4%), 56.0% lived with their care recipient, and 63.3% self-identified as unpaid caregivers. In terms of the relationship with their care recipients, 33.9% of caregivers reported being their spouse, 18.3% were their adult children, 11.0% were their other relatives, and 11.9% were non-relatives. About 62% of caregivers provided care to their care recipient for one or more years, with 26.6% providing care for five or more years. On average, caregivers reported providing 30.14 (±26.71) weekly hours of care to their care recipient. When comparing caregiver characteristics by caregiver type, on average, paid caregivers were younger than unpaid caregivers (i.e., 47.54 vs. 65.56, $t = 6.77$, $p < 0.001$) and cared for their care recipients for shorter durations ($t = 2.62$, $p = 0.010$). Relative to unpaid caregivers, smaller proportions of paid caregivers were male (i.e., 28.8% vs. 10.3%, $\chi^2 = 4.92$, $p = 0.027$) and lived with the care recipient (i.e., 81.2% vs. 12.5%, $\chi^2 = 48.44$, $p < 0.001$). Relative to unpaid caregivers, smaller proportions of paid caregivers were the spouse (i.e., 52.2% vs. 2.5%, $\chi^2 = 27.87$, $p < 0.001$) or adult child (i.e., 24.6% vs. 7.5%, $\chi^2 = 4.96$, $p = 0.026$) of their care recipients.

When reporting on behalf of their care recipient, on average, caregivers reported their care recipients were age 78.90 (±8.49; range: 64–100) years and had 2.08 (±2.96) chronic health conditions. Most care recipients were female (57.5%) and resided in single-family homes (65.1%). An additional 17.4% resided in individual apartments or condominiums and 16.7% resided in independent living community or assisted living facility. On average, care recipients' baseline MMSE score was 22.60 (±2.67; range: 13–28), with most falling in the mild cognitive impairment range. When comparing care recipient characteristics by caregiver type, a smaller proportion of paid caregivers cared for male care recipients (i.e., 62.1% vs. 10.0%, $\chi^2 = 27.70$, $p < 0.001$). On average, relative to unpaid caregivers, care recipients of paid caregivers had more chronic conditions (i.e., 1.07 vs. 3.87, $t = -4.02$, $p < 0.001$). Relative to unpaid caregivers, smaller proportions of paid caregivers had care recipients that resided in single-family homes (i.e., 79.4% vs. 42.5%, $\chi^2 = 24.20$, $p < 0.001$) and had additional paid caregivers for their care recipients (i.e., 82.4% vs. 50.0%, $\chi^2 = 11.30$, $p < 0.001$).

Table 2 reports the average scores for the OCBS sub-scale composite scores as well as average score for each sub-scale item, which are compared by caregiver type. On average, caregivers' OCBS time sub-scale scores were 39.82 (±13.27) and their OCBS difficulty sub-scale scores were 25.62 (±11.25). OCBS time and difficulty sub-scale scores were significantly positively correlated ($r = 0.60$, $p < 0.001$). For the OCBS time sub-scale, the five tasks with the highest time-related burden were household tasks, emotional support, monitoring symptoms, transportation, and errands. For the OCBS difficulty sub-scale, the five tasks with the highest difficulty-related burden were behavior problems, emotional support, communicating with care recipient, household tasks, and communicating with healthcare professionals.

When comparing the OCBS time sub-scale by caregiving type, no significant difference in the composite score was observed between unpaid and paid caregivers. On average, relative to paid caregivers, unpaid caregivers reported higher time burdens with transportation ($t = 3.07$, $p = 0.003$) and finances ($t = 2.29$, $p = 0.024$). Conversely, on average compared to unpaid caregivers, paid caregivers reported time burdens with household tasks ($t = -2.10$, $p = 0.038$), emotional support ($t = -2.80$, $p = 0.006$), monitoring symptoms ($t = -3.64$, $p < 0.001$), treatments (medications) ($t = -2.82$, $p = 0.006$), personal care ($t = -2.31$, $p = 0.023$), and mobility ($t = -2.37$, $p = 0.020$).

When comparing the OCBS difficulty sub-scale by caregiving type, unpaid caregivers reported higher average composite scores than paid caregivers ($t = 3.20$, $p = 0.002$). On average, relative to paid caregivers, unpaid caregivers reported higher difficulty burdens with household tasks ($t = 2.42$, $p = 0.017$), emotional support ($t = 3.30$, $p = 0.001$), transportation ($t = 3.24$, $p = 0.002$), errands ($t = 2.81$, $p = 0.006$), behavior problems ($t = 2.02$, $p = 0.046$), planning activities ($t = 2.81$, $p = 0.006$), communicating with the care recipient ($t = 2.76$, $p = 0.007$), finances ($t = 2.46$, $p = 0.015$), and finding resources ($t = 3.25$, $p = 0.002$).

Table 3 reports findings from the OLS regression model fitting caregivers' task time burden. On average, caring for men, compared to women, was associated with lower task time burden ($\beta = -0.29$, $p = 0.006$). Caring for care recipients with higher baseline MMSE scores ($\beta = -0.20$, $p = 0.015$) and more chronic health conditions ($\beta = 0.31$, $p = 0.011$) was associated with higher task time burden. On average, caregivers who cared for their care recipient for longer durations ($\beta = 0.28$, $p = 0.004$) and whose care recipients also had other paid caregivers ($\beta = 0.30$, $p = 0.031$) reported higher task time burden. On average, higher emotional stress levels experienced by caregivers was also positively associated with higher task time burden ($\beta = 0.30$, $p = 0.020$).

Table 3 also reports findings from the OLS regression model fitting caregivers' task difficulty burden. On average, caregivers with higher emotional stress levels experienced higher task difficulty burden ($\beta = 0.30$, $p = 0.029$). On average, caregivers with higher depressive symptomatology levels experienced higher task difficulty burden ($\beta = 0.32$, $p = 0.002$).

4 Discussion

This study identified several factors associated with caregiving task time and task difficulty burden among paid and unpaid caregivers of PLWD (47, 48). Care recipients' characteristics can affect the degree of burden experienced by unpaid and paid caregivers. Results from the present study reveal that task time burden was influenced by several factors including the sex, physical condition, and cognitive status of the care recipient. Research suggests that caring for men is generally more difficult than caring for women (53); however, in the present study, caring for men was associated with lower task time

TABLE 1 **Sample characteristics by caregiver type.**

Variables	Total (n = 109)	Unpaid (n = 69)	Paid (n = 40)	χ^2 or t	p
Caregiver characteristics					
Caregiving status					
Unpaid caregivers	63.3%	–	–		
Paid caregivers	36.7%	–	–		
Age (years) [range: 19–85]	58.87 (±15.76)	65.56 (±13.09)	47.54 (±13.32)	6.77	<0.001
Sex				4.92	0.027
Female	78.1%	71.2%	89.7%		
Male	21.9%	28.8%	10.3%		
Lives with their care recipient				48.44	<0.001
Yes	56.0%	81.2%	12.5%		
No	44.0%	18.8%	87.5%		
Relationship to recipient					
Spouse	33.9%	52.2%	2.5%	27.87	<0.001
Adult children	18.3%	24.6%	7.5%	4.96	0.026
Other relatives	11.0%	10.1%	12.5%	0.14	0.705
Non-relatives	11.9%	11.6%	12.5%	0.02	0.888
Hours care for recipient weekly [range: 0–100]	30.14 (±26.71)	33.00 (±29.23)	25.28 (±21.25)	1.58	0.117
Length of time cared for recipient [range: 1–7]	4.10 (±1.80)	4.43 (±1.78)	3.53 (±1.69)	2.62	0.010
Care recipient characteristics					
Age (years) [range: 64–100]	78.90 (±8.49)	78.06 (±8.07)	80.25 (±9.07)	−1.29	0.201
Sex				27.70	<0.001
Female	57.5%	37.9%	90.0%		
Male	42.5%	62.1%	10.0%		
Number of chronic conditions [range: 0–15]	2.08 (±2.96)	1.07 (±0.71)	3.87 (±4.31)	−4.02	<0.001
Living arrangement				24.20	<0.001
Single-family homes	65.7%	79.4%	42.5%		
Individual apartments or condominiums	17.6%	13.2%	25.0%		
Independent living community or assisted living facility	16.7%	7.4%	32.5%		
Has additional paid caregivers				11.30	<0.001
Yes	28.0%	17.6%	50.0%		
No	72.0%	82.4%	50.0%		
MMSE scores [range: 13–28]	22.60 (±2.67)	22.48 (±2.81)	22.79 (±2.44)	−0.56	0.579

burden. Women have greater risk of functional impairment and cognitive decline than men (23, 54), factors that may contribute to higher ADL- and IADL-dependency. This may explain the higher task time burden associated with caring for women.

Findings also suggest that caregivers of PLWD with more chronic conditions and lower cognitive function report higher task time burden. The care dependent/time interaction is well-established in the literature. Specifically, low ADL and IADL levels increase caregiving time (13, 20, 22, 41). This care encompasses assistance with basic daily activities and ongoing medical care (55, 56), which can include frequent medications, symptom management, monitoring, and more care planning. Coordinating care with multiple healthcare providers, which is common for individuals with multiple chronic conditions (57), requires time-consuming effort to be allocated to care coordination and communication, contributing to the higher task time burden.

Task time burden reported by caregivers of PLWD with lower cognitive function can be due to the additional support and supervision that is required as the disease progresses. Dementia is a progressive disease, which results in declining independence and deteriorating cognitive function in the care recipient over time. Caregivers of PLWD in more advanced stages of the disease are often involved in providing constant supervision for the safety of the care recipients and may spend more time assisting with communication and interpreting the needs of their care recipients (17, 21, 58, 59).

Caregivers working with other paid caregivers and those providing longer duration of care also reported higher task time burden related to caregiving. Duration of care is among the strongest predictors

TABLE 2 OCBS sub-scale composite and item-specific scores by caregiver type.

Variables	OCBS time sub-scale					OCBS difficulty sub-scale				
	Total ($n = 109$)	Unpaid ($n = 69$)	Paid ($n = 40$)	t	p	Total ($n = 109$)	Unpaid ($n = 69$)	Paid ($n = 40$)	t	p
OCBS sub-scales (composite scores)	39.82 (±13.27)	39.12 (±13.62)	41.03 (±12.73)	−0.72	0.472	25.62 (±11.25)	28.04 (±11.42)	21.45 (±9.73)	3.20	0.002
OCBS sub-scale items										
Household tasks	3.48 (±1.34)	3.28 (±1.38)	3.83 (±1.20)	−2.10	0.038	1.83 (±1.04)	2.01 (±1.08)	1.53 (±0.91)	2.42	0.017
Emotional support	3.36 (±1.22)	3.12 (±1.17)	3.78 (±1.21)	−2.80	0.006	1.94 (±1.19)	2.20 (±1.24)	1.50 (±0.96)	3.30	0.001
Monitoring symptoms	3.27 (±1.23)	2.96 (±1.22)	3.80 (±1.07)	−3.64	<0.001	1.75 (±1.03)	1.87 (±1.04)	1.55 (±0.99)	1.57	0.119
Transportation	2.96 (±1.52)	3.29 (±1.43)	2.40 (±1.52)	3.07	0.003	1.75 (±1.16)	1.99 (±1.28)	1.35 (±0.77)	3.24	0.002
Errands	2.94 (±1.40)	3.07 (±1.39)	2.70 (±1.42)	1.34	0.183	1.68 (±0.96)	1.87 (±0.98)	1.35 (±0.83)	2.81	0.006
Behavior problems	2.74 (±1.40)	2.71 (±1.41)	2.80 (±1.40)	−0.32	0.748	2.06 (±1.26)	2.25 (±1.23)	1.75 (±1.26)	2.02	0.046
Planning activities	2.72 (±1.32)	2.63 (±1.23)	2.88 (±1.47)	−0.88	0.383	1.65 (±0.99)	1.84 (±1.02)	1.33 (±0.86)	2.81	0.006
Communicating with healthcare professionals	2.69 (±1.41)	2.78 (±1.31)	2.53 (±1.55)	0.91	0.366	1.76 (±1.08)	1.86 (±1.09)	1.59 (±1.07)	1.23	0.223
Communicating with care recipient	2.65 (±1.35)	2.54 (±1.32)	2.85 (±1.39)	−1.16	0.247	1.86 (±1.15)	2.09 (±1.16)	1.48 (±1.04)	2.76	0.007
Finances	2.44 (±1.55)	2.70 (±1.53)	2.00 (±1.50)	2.29	0.024	1.75 (±1.08)	1.94 (±1.11)	1.43 (±0.96)	2.46	0.015
Finding resources	2.42 (±1.36)	2.60 (±1.37)	2.10 (±1.30)	1.88	0.063	1.57 (±0.95)	1.77 (±1.00)	1.23 (±0.73)	3.25	0.002
Treatments (medications)	2.26 (±1.13)	2.01 (±0.96)	2.68 (±1.29)	−2.82	0.006	1.46 (±0.82)	1.54 (±0.82)	1.33 (±0.83)	1.30	0.198
Personal care	2.19 (±1.17)	2.00 (±1.13)	2.53 (±1.18)	−2.31	0.023	1.54 (±0.85)	1.59 (±0.86)	1.45 (±0.82)	0.86	0.393
Mobility	2.06 (±1.10)	1.87 (±1.01)	2.38 (±1.17)	−2.37	0.020	1.47 (±0.80)	1.54 (±0.85)	1.35 (±0.70)	1.24	0.220
Planning care while away	1.81 (±1.23)	1.78 (±1.09)	1.85 (±1.46)	−0.29	0.776	1.56 (±1.14)	1.72 (±1.21)	1.30 (±0.97)	1.99	0.050

caregiver burden (20, 44). While having a team of caregivers may intuitively appear to support caregivers, it can also require additional coordination among the caregivers. These additional time-consuming tasks include coordinating care tasks and schedules among caregivers, communicating key information across the caregiving team, and ensuring care services are consistent across the team (60). These tasks are often time consuming and when added to caregiving duty, it can result in burden associated with task time. It may also result in conflicts in the care team, which further increases the time spent resolving differences and disagreements.

In the current study, caregivers with higher emotional stress reported higher task time and task difficulty burden; whereas depressive symptomology contributed to higher burden related to task difficulty. Caregiving can have an intense emotional toll on the caregiver (7, 36, 61, 62). Among caregivers with pre-existing mental health conditions, the emotional burden from caregiving can be further amplified (63). Feelings of stress, fatigue and being overwhelmed from caregiving tasks can result from caregivers juggling the management of their own mental health while coping with the demands of caregiving, and having reduced resilience to cope with caregiving demands (64, 65). Additionally, there is a robust association between care burden and psychological distress among PLWD caregivers compared to individuals caring for stroke survivors or persons with frailty but no cognitive decline (66). Individuals with symptoms of depression are also more likely to face social isolation and lack of social support (67, 68). Given the importance of social support in managing caregiver burden, the lack of this can be a driving factor that increases the burden felt by caregivers with pre-existing mental health conditions (69).

In the current study, paid and unpaid caregivers reported differences in caregiving situations and caregiving burdens. Unpaid caregivers more frequently cared for individuals with fewer chronic comorbidities, but they were more likely to provide care within single-family homes, be the care recipients' spouse or adult child, and provide care without additional paid caregiver support. While task time composite scores were similar across paid and unpaid caregivers, unpaid caregivers felt more time burden associated with managing logistics (i.e., transportation, finances) and paid caregivers expressed the time burdens associated with direct patient care (e.g., monitoring symptoms, treatment, personal care, mobility). These findings support previous literature about the unique challenges of unpaid caregivers to balance the time needed for caregiving duties, family responsibilities, and employment demands (1, 70). As such, while these tasks may not require large amounts of time per se, the time taken from other competing demands may cause feelings of burden among unpaid caregivers who are not being compensated for their time spent

TABLE 3 Factors associated with task time and task difficulty burdens (composite sub-scale scores).

Variables	OBCS task time burdens					OBCS task difficulty burdens				
				95% CI					95% CI	
	Beta	*t*	*p*	Lower	Upper	Beta	*t*	*p*	Lower	Upper
Caregiver age	−0.14	−1.23	0.223	−0.31	0.07	0.09	0.73	0.468	−0.11	0.24
Caregiver female (vs. male)	0.04	0.49	0.623	−4.00	6.63	0.09	1.03	0.309	−2.36	7.36
Care recipient female (vs. male)	−0.29	−2.83	0.006	−13.23	−2.31	0.03	0.32	0.753	−4.20	5.79
Care recipient number of chronic conditions	0.31	2.60	0.011	0.33	2.50	0.02	0.15	0.884	−0.92	1.07
Care recipient MMSE score	−0.20	−2.49	0.015	−1.82	−0.20	−0.08	−0.95	0.347	−1.09	0.39
Care recipient lives in single family home (vs. no)	0.14	0.87	0.390	−5.08	12.88	−0.10	−0.59	0.554	−10.67	5.76
Care recipient lives in individual apartment (vs. no)	0.07	0.48	0.633	−7.86	12.84	−0.19	−1.19	0.237	−15.14	3.80
Caregiver lives with care recipient (vs. no)	0.11	0.85	0.397	−4.02	10.01	0.01	0.06	0.952	−6.22	6.61
Caregiver is spouse to care recipient (vs. no)	−0.07	−0.54	0.594	−9.73	5.60	−0.03	−0.23	0.818	−7.83	6.20
Caregiver is child to care recipient (vs. no)	−0.01	−0.06	0.950	−7.14	6.70	0.02	0.17	0.863	−5.78	6.88
Caregiver is paid caregiver for care recipient (vs. unpaid)	−0.14	−0.99	0.325	−12.88	4.33	−0.21	−1.46	0.149	−13.64	2.11
Care recipient has other paid caregivers (vs. no)	0.30	2.20	0.031	0.78	15.55	−0.07	−0.47	0.642	−8.34	5.17
Duration caregiver has cared for care recipient	0.28	3.01	0.004	0.67	3.32	0.06	0.63	0.533	−0.83	1.59
Caregiver physical strain level	0.08	0.67	0.503	−1.81	3.67	0.05	0.44	0.661	−1.95	3.06
Caregiver emotional stress level	0.30	2.37	0.020	0.48	5.61	0.30	2.23	0.029	0.28	4.97
Caregiver depressive symptomatology level	0.15	1.53	0.130	−0.36	2.75	0.32	3.22	0.002	0.88	3.73
	Adjusted R Square = 0.486					Adjusted R Square = 0.428				

caregiving (1, 70). Unpaid caregivers reported higher task difficulty composite scores compared to paid caregivers. Unpaid caregivers generally reported more task difficulty managing logistics (e.g., household tasks, transportation, errands, finances), coordination (e.g., planning activities, finding resources), and interactions with their care recipient (e.g., emotional support, communicating with care recipient). Relative to paid caregivers, unpaid caregivers may perceive these tasks to be more difficult because they have not been formally trained to execute these tasks (71) or have limited finances to acquire caregiving support or resources (71). Further, unpaid caregivers may perceive tasks as more difficult because of the emotional distress related to the failing health or suffering of a loved one (72).

Study findings align with policy priorities of national organizations (73, 74), who recommend policy changes and strategies to support paid and unpaid caregivers in the United States. Reported difficulty associated with household tasks, errands, and transportation reinforce the need to build the national infrastructure of available, accessible, and affordable home- and community-based services (HCBS). These services can provide support to caregivers and provide them with respite opportunities to meet their own household logistics and emotional demands. Strategies to improve access and utilization of HCBS can include tax deductions for out-of-pocket care expenses, long-term care social insurance options, or paid family leave for employed caregivers (73). Expressed difficulty communicating with healthcare professionals highlights the need for productive and informed interactions between caregivers and the care recipients' healthcare providers. Strategies to improve healthcare providers' understanding about the unique caregiving circumstances of their care recipients include routinizing formal assessment of unpaid caregiving needs in clinical settings and incentivizing healthcare systems to incorporate unpaid caregivers into healthcare decision making processes (73). Considering the growing need for paid caregivers and the expanding caregiving workforce gap, dedicated efforts are needed to improve paid caregiver wages for HCBS for paid caregivers, expand training and vocational opportunities to grow the workforce, and establish standardized training and accreditation nationwide (73, 74).

4.1 Limitations

The present study is not without limitations. The study's data were self-reported and participant responses may reflect social desirability and recall biases. The study sample was of modest size and consisted of both paid and unpaid caregivers. Therefore, despite identifying differences in caregiving situations and OCBS-related scores by caregiving paid/unpaid status, it is difficult to make strong generalizations regarding paid versus unpaid caregivers. Consequently, further research with larger and more diverse samples is necessary to understand caregiver task time and difficulty burden more thoroughly between paid and unpaid caregivers of PLWD. The sample consisted primarily of women making it difficult to conduct a comprehensive sex-based analysis of caregiver burden. This study did not control for potential confounding factors such as the caregivers' history of depression, self-reported chronic conditions, or other aspects of wellness. Details pertaining to the caregiving tasks performed by the caregiver (based on the specific needs of the care recipient such as dressing, bathing, or incontinence tasks) were not uniformly collected in a robust manner, which limited the interpretation of the OCBS scores.

A strength of the current study was its novel use of the two-dimension OCBS, which is unique given its scoring can transcend unidimensional scales of caregiver burden or strain and contextualize findings in terms of task time and task difficulty. However, other more mainstream burden scales [e.g., the Zarit Caregiver Burden Scale (45)] should be used in concordance with the OCBS for consistency within the broader published literature and comparison to other studies. The OCBS sub-scales have no known clinical thresholds or scoring cut-points to indicate severity levels of caregiver burden. Future studies should attempt to determine such thresholds to make the OCBS clinically actionable in terms of risk identification and referral to programs and services. Additionally, future studies should attempt to utilize more objective measures of caregiving tasks and care recipient needs (e.g., use of wearables or sensors) to complement subjective self-reported measures.

5 Conclusion

This study examined factors associated with caregiving burden in terms of task time and task difficulty among paid and unpaid caregivers of PLWD. Our study's results highlight the relationship between objective measures of caregiver burden and the impact on mental health. While the care recipient's disease profile and needs were drivers of task time burden, which may also require coordination with other paid caregivers, task difficulty was emotionally driven. Caregiving burdens differed in terms of task time and task difficulty by the caregivers' paid/unpaid status. Findings from our study have implications for clinicians, practitioners, and community organizations working to support caregivers of people living with dementia. More specifically, our study's findings highlight the critical need for caregiver support services and mental health programming.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors without undue reservation.

Ethics statement

The studies involving humans were approved by Texas A&M University Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participant.

Author contributions

MS: Funding acquisition, Project administration, Writing – review & editing, Methodology, Formal analysis, Investigation, Writing – original draft, Conceptualization. JS: Writing – original draft, Writing – review & editing. MN: Writing – original draft, Writing – review & editing. GH: Methodology, Investigation, Writing – review & editing, Funding acquisition. SL: Investigation, Writing – review & editing, Methodology. CK: Writing – review & editing. J-DB: Writing – review & editing. EC: Writing – review & editing. SK: Writing – review & editing. MB: Writing – review & editing. AM: Writing – review & editing. LW: Writing – review & editing. ZR: Writing – review & editing. JH: Writing – review & editing. MO: Investigation, Funding acquisition, Project administration, Writing – review & editing, Methodology.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

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Construction of community home-based older adult care service model based on modular design concept

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Objectvie: To address the supply–demand mismatch in community home-based older adult care services amid China's deepening aging population crisis.
Methods: This study employs a modular design concept, selecting Liaoning Province—the region with the nation's highest aging rate—as the research area. A questionnaire survey was conducted among 331 community-dwelling older adults, and multiple linear regression analysis was applied to identify factors influencing care service demands.
Results: Key findings include: (1) Older adult' demands manifest a five-dimensional structure (life assistance, medical care, spiritual/cultural engagement, rights protection, and age-friendly modifications), with spiritual/cultural engagement (score rate: 68.40%) and age-friendly modifications (67.67%) being the most urgent needs. (2) Subgroups including advanced age (≥71 years), disabled, living alone, highly educated, and chronic disease individuals exhibited significantly higher demand intensity ($p < 0.05$). For instance, the regression coefficient (B) for medical care demand among the disabled reached 0.545. (3) Based on these results, a modular service framework was constructed, featuring five functionally independent core modules. A dynamic service package combination function was innovatively proposed, utilizing a module activation coefficient ($\alpha_{k,i}$) and an module weighting factor ($\beta_{k,i}$) to achieve precise customization.
Conclusion: Centered on community residents' committees (CRCs) as coordination hubs, this model enables dynamic monitoring and optimization through the Demand-Service Matching Index (DSMI), offering an actionable solution to reconcile fragmented resources and heterogeneous demands, thereby supporting both older adults and their caregivers in regional older adult care systems.

KEYWORDS

community home-based older adult care service, demand, supply, modular, model construction, caregiver support

1 Introduction

Population aging represents a global phenomenon, initially pioneered by developed nations. In recent years, China has experienced a notably accelerated pace of population aging, surpassing both developed countries and the global average (1). According to the 2023 National Report on the Development of Aging Initiatives in China, by the end of 2023, the population aged 60 and above reached 296.97 million, accounting for 21.1% of the total population, while those aged 65 and above stood at 216.76 million (15.4% of the total population). Projections indicate that by mid-century, China's population aged 60 and above will approach 500 million, constituting 35% of its total population, thereby transitioning China into a super-aged nation confronting profound aging-related challenges (2). Population aging has emerged as a critical challenge for China. Data from China's Seventh National Population Census reveal that Liaoning Province, with a resident population of 42.59 million, hosts 10.954 million individuals aged 60 and above (25.72% of its population) and 17.42% aged 65 and above. This positions Liaoning as the region with the highest proportion of older population in China, facing unprecedented older adult care pressure. Consequently, this study selects Liaoning Province as its empirical context.

Another distinctive feature of China's population structure is the concurrent progression of population aging and family miniaturization. The prevalence of "4–2-1" or "4–2-2" family frameworks—where four grandparents and two parents support one or two children—has substantially diminished traditional family-based older adult care capacity. Meanwhile, institutional care services face limitations in development and managerial capabilities, compounded by public skepticism toward institutional models (3). The growing demand for older adult care disproportionately relies on informal care networks, primarily family members, who often operate with limited resources and formal support. This places a significant physical, psychological, and social burden on these caregivers, compromising the quality of care and their own well-being (4, 5).

Community is the fundamental unit of social governance. Community home-based older adult care services are centered around the community, integrating medical and health resources with older adult care services. Through convenient and professional services, they provide continuous and integrated services such as hospitalization, rehabilitation care, and stable living care for older adults (2). By synthesizing the strengths of both family-based and institutional care, community home-based care optimally accommodates seniors' preference for "aging in place." It concurrently alleviates familial caregiving burdens, reduces long-term care costs, and mitigates fiscal pressures on governments (6). Consequently, it has emerged as a crucial supplement to family-based care and a primary modality for addressing aging-related challenges, increasingly favored by older adults.

Despite its advantages, current community home-based older adult care services face challenges such as unequal service distribution, limited service scope, and a mismatch between service supply and demand (7, 8), necessitating urgent systemic improvements. Modularization is a design strategy developed to manage complexity and variety; its core principle involves decomposing a complex system into independent, interchangeable functional units (modules) that can be combined to create customized solutions (9). While foundational applications are in engineering and product design (e.g., LEGO®, IKEA®) (10), the concept has gained significant traction in healthcare and long-term care settings. In the healthcare sector, modular design principles have been applied to the development of the ICU Real-Time Informatics System (11), the construction of healthcare value assessment frameworks (12), and the implementation of cross-departmental, cross-domain solutions that systematically address complex challenges such as sustainable economic growth and universal health coverage (13). In the context of long-term care, modular design has been proposed as an effective strategy to address the heterogeneous needs of older adults while enhancing the efficiency and effectiveness of care delivery (14). The modular approach allows for the creation of flexible service architectures that can be efficiently configured to individual needs, thereby promoting system responsiveness while reducing the burden on caregivers through clear, standardized support options. By breaking down complex care needs into manageable service components, modular design enables more precise matching of services to individual requirements, significantly improving resource allocation and caregiver efficiency.

This integration of modular design into long-term care, particularly within community settings, represents a paradigm shift from rigid, one-size-fits-all service models to flexible, person-centered solutions. This approach is especially pertinent in addressing the multifaceted challenges faced by informal caregivers (often family members), who constitute the backbone of older adult care systems in many societies, including China. The relentless physical, emotional, and financial strain on these caregivers frequently leads to burnout, compromising the quality of care for both the older adult and the caregiver's own well-being (4). Modular design principles offer a promising framework to mitigate these challenges. By deconstructing complex care needs into standardized, manageable service units, the modular approach can reduce the cognitive and logistical burden on caregivers, providing them with a clear menu of support options that can be efficiently configured to meet evolving needs (14). This not only empowers caregivers by enhancing the predictability and accessibility of resources but also fosters a more sustainable care ecosystem. Therefore, applying modular design to community home-based care is not merely an operational improvement but a strategic intervention aimed at supporting the crucial caregiver workforce upon which the system relies.

Communities, as social entities within defined geographical boundaries, exhibit significant heterogeneity and complexity due to variations in demographic composition, regional planning, and economic development. Modular design principles offer distinct advantages in decomposing complex tasks into relatively simple functional units. Their organizational and technical flexibility enables effective adaptation to inter-community variations and complexities, thereby constituting a viable design framework for contemporary community home-based older adult care services and and building a more sustainable ecosystem for both care recipients and caregivers.

Consequently, this research focuses on addressing two pivotal questions: (1) What specific service items do older adults demand in community home-based care? Which factors significantly influence these demands? (2) Can complex older adult care tasks be decomposed into relatively simple functional units with homogeneous attributes? Can communities optimize resource allocation and provide targeted support to caregivers by selectively combining modular units according to the intensity of older adult care demands within the jurisdiction? This study proposes a modular service model designed to address the heterogeneous demands of older adults while also providing structured support to formal and informal caregivers through customizable service bundles. Through an empirical investigation of older adult residents in Liaoning Province, this study resolves these research questions.

2 Research on the current status of community home-based older adult care service demand

2.1 Questionnaire design and survey methods

2.1.1 Questionnaire design for service demand assessment

Based on a comprehensive review of domestic and international literature (6, 15, 16), analysis of national and local older adult care policies, referencing home- and community-based care service standards and essential requirements (17), and consultation with domain experts, this study developed *the Survey Questionnaire on Current Demand for Community Home-Based Older Adult Care Services*. The questionnaire comprises two sections: basic demographic information and community home-based older adult care service demands. The service demand section encompasses five dimensions with 19 items: life assistance, medical care, spiritual/cultural engagement, rights protection, and age-friendly modifications. All items were measured using a 5-point Likert scale: 1 = Not needed at all, 2 = Slightly needed, 3 = Neutral, 4 = Moderately needed, 5 = Strongly needed. Higher scores indicate stronger demand for the specific service.

2.1.2 Data collection and processing

Liaoning Province, which has the highest level of population aging in China, comprises 14 cities. This study employed a two-stage sampling strategy: four cities (Shenyang, Jinzhou, Dalian, and Anshan) were first selected through random sampling. Within each city, a convenience sampling method was used to recruit adults aged 60 and above in community public spaces as study participants. This study was conducted in accordance with the Helsinki Declaration and was approved by the Ethical Review Committee of Affiliated Zhongshan Hospital Dalian University (Approval No: KY2023-110-1). The sample size was estimated based on the recommendation of including 5–10 times the number of independent variables in the research tool (18), with an additional 20% allowance for potential missing data. Given that the questionnaire contained 19 variables, the required sample size was calculated to be 114 to 228 participants. Questionnaires were distributed on-site with guidance provided for completion, collected subsequently, and checked for completeness of responses. A total of 357 questionnaires were distributed, with 331 valid questionnaires recovered, yielding a valid response rate of 92.72%.

Data analysis was performed using SPSS 26.0 software. Continuous variables not following a normal distribution are expressed as median (interquartile range) [M (P25, P75)]. Group comparisons were conducted using the Mann–Whitney U test (two groups) or Kruskal–Wallis H test ($K \geq 3$ groups). Multiple linear regression was employed to identify independent factors influencing demands for community home-based older adult care services. Prior to regression, key assumptions were verified: linearity was assessed via scatterplots, independence of residuals was confirmed with a Durbin-Watson statistic near 2, normality and homoscedasticity of residuals were examined using P–P plots and scatterplots, respectively. Multicollinearity was assessed using variance inflation factors (VIF) and tolerance (T) statistics ($VIF < 5$ and $Tolerance > 0.1$ for all variables). Variables with $p < 0.05$ in univariate analyses were included in the multivariate model using the Enter method. A p-value below 0.05 was considered statistically significant.

The statistical analysis strategy in this study was designed to provide an empirical foundation for the subsequent construction of the modular service model. Specifically, the significant influencing factors identified by the multiple linear regression analysis and their standardized regression coefficients (B values) were intended to be directly used to calculate the individual weighting factors (β_i). Concurrently, the score distribution for each demand dimension (e.g., median and interquartile range) was to inform the determination of thresholds (e.g., the 75th percentile) for the module activation coefficients (α_k). The complete mathematical formulation of the module dynamic combination mechanism, including the service bundle function, and the operational details of the Demand-Service Matching Index (DSMI) are elaborated in Section 3 (Model Construction).

2.2 Survey results on the status of community home-based older adult care service demand

2.2.1 Descriptive statistics of service demand items

The demand level for community home-based older adult care services, ranked from highest to lowest based on score rate, was as follows: spiritual/cultural engagement (68.40%), age-friendly modifications (67.67%), life assistance (65.38%), medical care (63.82%), and rights protection (62.92%). The specific scoring situation is shown in Table 1.

2.2.2 Univariate analysis of demand across subgroups

The results of the univariate analysis, comparing demand scores across different demographic and health subgroups using non-parametric tests (Mann–Whitney U or Kruskal-Wallis H test), are summarized in Table 2. Significant differences ($p < 0.05$) in demand were observed based on age, education level, spouse status, living arrangement, self-care ability, and the presence of chronic diseases. ① Age: Participants were categorized into four age groups: 60–65 years (108, 32.63%), 66–70 years (74, 22.36%), 71–80 years (110, 33.23%), and ≥81 years (39, 11.78%). Overall, demand for community home-based older adult care services increased significantly with age. Notably, older adults aged ≥71 years exhibited significantly higher demand across all service categories. ② Education level: Participants were divided into two groups based on educational attainment: junior high school or below (250, 75.53%), and senior high school or above (81, 24.47%). Older adults with higher education levels demonstrated greater demand for services. ③ Spouse: Individuals who were never married, divorced, or widowed were defined as "without a spouse." Those without a spouse (94, 28.40%) exhibited higher demand for all services compared to those with a spouse (237, 71.60%). ④ Number of children: The distribution of participants by number of children was: 0 children (9/331, 2.7%), 1 child (148/331, 44.7%), 2 children (112/331, 33.8%), 3 children (43/331, 13.0%), and 4 children (19/331, 5.7%). Participants were grouped as having ≤1 child or ≥2 children to assess the impact on service demand. Results indicated that older adults with fewer children relied more heavily on medical care and spiritual/cultural engagement compared to those with more children. ⑤ Living alone: Older adults living alone (57, 17.22%) exhibited significantly stronger demand for community home-based older adult care services than non solitary older adults (274, 82.78%), with significantly higher demand scores across all service categories (all $p < 0.001$). ⑥ Self-care ability: Define older adults who are partially or completely unable to take care of themselves as disabled older adults. The results showed that the demand score of disabled older adults (65, 19.64%) was significantly higher than that of fully independent individuals (266, 80.36%; $p < 0.01$), especially in terms of life assistance and medical

TABLE 1 Scores of various items in the demand for community home-based care service among the older adult (*n* = 331).

Service items	[M(P25, P75)]	Service items	[M(P25, P75)]
Life assistance	**3.40 (3.00–3.80)**	**Spiritual/Cultural engagement**	**3.33 (3.00–4.00)**
Hygiene care	3.00 (2.00–4.00)	Spiritual comfort	3.00 (3.00–4.00)
Mobility assistance	3.00 (2.00–3.00)	Leisure activities	4.00 (3.00–4.00)
Catering services	3.00 (3.00–4.00)	Self-actualization	3.00 (3.00–4.00)
Entrusted agency services	3.00 (3.00–4.00)	**Rights protection**	**3.00 (2.67–4.00)**
Emergency maintenance	4.00 (3.00–5.00)	Conflict mediation	3.00 (3.00–4.00)
Medical care	**3.17 (2.67–3.83)**	Legal consultation/aid	3.00 (2.00–4.00)
Health management	4.00 (3.00–4.00)	Policy service promotion	3.00 (2.00–4.00)
Preventive healthcare	3.00 (3.00–4.00)	**Age-friendly modifications**	**3.50 (3.00–4.00)**
Diagnosis & treatment	3.00 (3.00–4.00)	Indoor modifications	3.00 (2.00–4.00)
Rehabilitation guidance	3.00 (2.00–4.00)	Public environment modifications	3.00 (3.00–4.00)
Nursing care	3.00 (2.00–4.00)		
Emergency rescue	3.00 (2.00–4.00)		

Bold font indicates the average scores across the five dimensions.

care services, where the difference was the greatest. ⑦ Income levels: Primary income sources for participants were pensions and retirement benefits. Monthly income was categorized into four levels: 0–1,500 yuan (28, 8.46%), 1,501–3,000 yuan (138, 41.69%), 3,001–4,999 yuan (113, 34.14%), and >5,000 yuan (52, 15.71%). Significant between-group differences were only found for demand related to age-friendly modifications ($p = 0.037$), with individuals earning ≤1,500 yuan per month expressing the highest demand. ⑧ Chronic diseases: Participants were dichotomized based on the presence of chronic diseases (e.g., hypertension, coronary heart disease, diabetes, rheumatism). Compared to those without chronic diseases (96, 29.00%), individuals with chronic conditions (235, 71.00%) exhibited significantly higher demand for life assistance ($p < 0.001$), medical care ($p < 0.001$), rights protection ($p = 0.024$), and age-friendly modifications ($p = 0.003$).

2.2.3 Multivariate analysis of influencing factors

To identify independent factors influencing demand, multiple linear regression analyses were performed for each of the five demand dimensions. The results are presented in Table 3. The assumptions of linear regression were verified prior to analysis (as detailed in Section 2.1.2). Variables such as advanced age, disability, living alone, and higher education level were significant predictors of higher demand across multiple service modules. ① Life assistance: Regression analysis identified age, education level, spouse, living arrangement, self-care ability, and chronic disease as independent significant factors influencing demand for life assistance (all $p < 0.05$). Specifically: Demand was significantly higher among older adults aged 71–80 ($B = 0.215$, $p = 0.013$) and ≥81 years ($B = 0.287$, $p = 0.037$) compared to those aged 60–65. Individuals with a higher education levels exhibited greater demand ($B = 0.265$, $p = 0.001$). Demand was significantly higher among those without a spouse ($B = 0.206$, $p = 0.037$) and those living alone ($B = 0.381$, $p = 0.001$). Disabled older adults showed the most pronounced increase in demand ($B = 0.403$, $p < 0.001$). ② Medical care services: Demand for medical care services was significantly influenced by age, education level, spouse, living arrangement, self-care ability, chronic disease, and number of children (all $p < 0.05$). Individuals aged 71–80 years reported higher demand ($B = 0.258$, $p = 0.008$), while the ≥81 years group showed no significant difference ($p = 0.324$) compared to 60–65 years. Those with a higher education levels placed greater emphasis on medical care ($B = 0.399$, $p < 0.001$). Individuals with ≥2 children exhibited lower demand ($B = -0.207$, $p = 0.010$). Demand was significantly higher among those with chronic diseases ($B = 0.253$, $p = 0.003$) and disabled ($B = 0.545$, $p < 0.001$). ③ Spiritual/cultural engagement: Age, education level, living arrangement, and number of children significantly impacted demand for spiritual/cultural engagement. Demand was higher in the 71–80 years group ($B = 0.344$, $p = 0.004$). Individuals with a higher education levels ($B = 0.379$, $p = 0.001$) and those living alone ($B = 0.533$, $p = 0.001$) reported significantly greater demand. Individuals with ≥2 children exhibited lower demand ($B = -0.249$, $p = 0.012$). ④ Rights protection: Education level, self-care ability, and number of children were the primary factors influencing demand for rights protection. Individuals with a a higher education levels demonstrated greater concern for rights protection ($B = 0.512$, $p < 0.001$). Disabled older adults showed higher demand for rights protection ($B = 0.551$, $p < 0.001$). ⑤ Age-friendly modifications: Low-income and disabled groups exhibited the most urgent need for age-friendly modifications. Individuals with an income >5,000 yuan reported significantly lower demand ($B = -0.726$, $p = 0.001$), while the low-income group (0–1,500 yuan) showed the highest demand, reflecting the constraints imposed by economic conditions on housing modifications. Disabled individuals exhibited the strongest demand intensity ($B = 0.697$, $p < 0.001$).

2.3 Discussion of factors influencing community home-based older adult care services demands

This study categorized the demand for community home-based older adult care services into five dimensions: life assistance, medical care, spiritual/cultural engagement, rights protection, and age-friendly modifications. Demand within each dimension was evaluated using a Likert 5-point scale, where higher scores indicated stronger demand

TABLE 2 Comparison of demand for community home-based older adult care services for older adults with different characteristics [M (P25, P75)].

Characteristic		Service items				
		Life assistance	Medical care	Spiritual/Cultural engagement	Rights protection	Age-friendly modifications
Age group (years)	60–65	3.00 (2.65–3.40)	3.17 (2.33–3.17)	3.33 (3.00–3.92)	3.00 (3.00–3.92)	3.00 (3.00–4.00)
	66–70	3.10 (2.75–3.45)	3.00 (2.13–3.33)	3.00 (2.00–4.00)	3.00 (2.00–3.33)	3.00 (2.00–4.00)
	71–80	3.40 (3.00–4.00)	3.17 (2.83–4.00)	4.00 (3.00–4.33)	3.00 (3.00–4.00)	4.00 (3.00–4.50)
	≥81	3.80 (3.40–4.00)	3.50 (3.17–4.00)	4.00 (2.33–4.00)	3.00 (2.33–4.00)	4.00 (2.50–4.50)
	F value	44.849	33.935	18.094	12.137	20.487
	p value	0.000*	0.000*	0.000*	0.007*	0.000*
Education level	Junior high school or below	3.30 (2.80–3.60)	3.17 (2.50–3.54)	3.33 (3.00–4.00)	3.00 (2.00–3.67)	3.50 (2.88–4.00)
	Senior high school or above	3.40 (3.00–4.00)	3.50 (3.00–4.00)	3.67 (3.00–4.67)	3.33 (3.00–4.67)	4.00 (3.00–5.00)
	Z value	−2.244	−3.472	−3.21	−4.57	−2.16
	p value	0.025*	0.001*	0.000*	0.000*	0.030*
Spouse	None	3.80 (3.40–4.00)	4.00 (3.17–4.17)	4.00 (3.33–4.67)	3.67 (3.00–4.00)	4.00 (3.50–4.50)
	Yes	3.20 (2.80–3.40)	3.00 (2.33–3.33)	3.33 (3.00–4.00)	3.00 (2.00–3.33)	3.00 (2.75–4.00)
	Z value	−7.688	−7.917	−5.720	−4.397	−5.814
	p value	0.000*	0.000*	0.000*	0.000*	0.000*
Number of children	≤1	3.40 (3.00–3.80)	3.17 (3.00–3.83)	3.67 (3.00–4.00)	3.00 (3.00–4.00)	3.50 (3.00–4.00)
	≥2	3.40 (2.80–3.60)	3.17 (2.33–3.83)	3.33 (2.33–4.00)	3.00 (2.00–3.33)	3.50 (2.00–4.00)
	Z value	−0.728	−2.557	−3.262	−4.632	−1.805
	p value	0.467	0.011*	0.001*	0.000*	0.071
Living arrangement	Living alone	4.00 (3.50–4.20)	4.00 (3.17–4.58)	4.00 (4.00–4.83)	4.00 (3.00–4.00)	4.00 (4.00–4.50)
	Not living alone	3.20 (2.80–3.40)	3.00 (2.33–3.50)	3.33 (2.67–4.00)	3.00 (2.00–3.67)	3.00 (2.50–4.00)
	Z value	−7.493	−6.930	−6.569	−5.329	−4.715
	p value	0.000*	0.000*	0.000*	0.000*	0.000*
Self-care ability	Fully independent	3.20 (2.80–3.40)	3.00 (2.33–3.33)	3.33 (3.00–4.00)	3.00 (2.33–3.67)	3.00 (3.86–4.00)
	Disabled	4.00 (3.60–4.20)	4.00 (3.50–4.67)	4.00 (3.00–5.00)	4.00 (3.00–4.67)	4.00 (4.00–5.00)
	Z value	−8.121	−8.119	−4.179	−4.544	−6.265
	p value	0.000*	0.000*	0.009*	0.002*	0.000*
Income levels (yuan/month)	0–1,500	3.40 (3.20–4.00)	3.17 (2.71–4.08)	4.00 (3.08–4.92)	3.67 (2.67–3.92)	4.00 (3.13–4.50)
	1,501–3,000	3.20 (2.80–3.60)	3.08 (2.33–4.00)	3.33 (3.00–4.00)	3.00 (2.00–4.00)	3.00 (2.00–4.00)
	3,001–4,999	3.40 (3.00–3.80)	3.17 (3.00–4.00)	3.33 (3.00–4.00)	3.00 (3.00–3.83)	3.50 (3.00–4.00)
	>5,000	3.40 (3.00–3.75)	3.17 (2.63–3.50)	3.33 (3.00–4.00)	3.00 (2.67–4.00)	3.00 (2.00–4.00)
	F value	6.574	5.312	7.635	3.034	8.481
	p value	0.087	0.150	0.054	0.386	0.037*
Chronic diseases	None	3.00 (2.45–3.55)	2.83 (2.21–3.33)	3.67 (2.33–4.00)	3.00 (2.00–4.00)	3.00 (2.00–4.00)
	Yes	3.40 (3.00–3.80)	3.17 (3.00–4.00)	3.33 (3.00–4.00)	3.00 (3.00–4.00)	4.00(3.00–4.00)
	Z value	−3.516	−4.411	−0.202	−2.250	−2.930
	p value	0.000*	0.000*	0.840	0.024*	0.003*

*$p<0.05$.

for that specific category of services. The results revealed that the overall demand for community home-based older adult care services among the older adult is at a medium to low level (with scores ranging from 62.92 to 68.40% across dimensions). This phenomenon may be potentially associated with both traditional Chinese cultural values and the specific characteristics of the older adult sample in this study. On one hand, influenced by Confucian principles emphasizing filial piety, a majority of older adults in China still prefer aging in place and receiving care from family members (19). On the other hand, as the study sample was recruited from public community spaces,

TABLE 3 Regression analysis results of demand for community home-based older adult care services.

Dimension	Variables		Non standardized coefficient		Standardized Coefficient	*t*	Significance	Collinearity statistics	
			B	Standard error	Beta			Tolerance	VIF
Life assistance	Constant		2.789	0.082		34.126	0		
	Age (year)	66–70	−0.062	0.092	−0.036	−0.678	0.498	0.746	1.341
		71–80	0.215	0.087	0.14	2.488	0.013*	0.654	1.528
		≥81	0.287	0.137	0.128	2.098	0.037*	0.558	1.792
		60–65	0						
	Education level	Senior high school or above	0.265	0.081	0.157	3.266	0.001*	0.897	1.115
		Junior high school or below	0						
	Spouse	None	0.206	0.098	0.128	2.095	0.037*	0.553	1.808
		Yes	0						
	Living arrangement	Living alone	0.381	0.115	0.198	3.301	0.001*	0.575	1.74
		Not living alone	0						
	Self-care ability	Disabled	0.403	0.111	0.221	3.642	0.000*	0.565	1.771
		Fully independent	0						
	Chronic diseases	Yes	0.17	0.076	0.106	2.24	0.026*	0.922	1.084
		None	0						

(Continued)

TABLE 3 (Continued)

Dimension	Variables		Non standardized coefficient		Standardized Coefficient	*t*	Significance	Collinearity statistics	
			B	Standard error	Beta			Tolerance	VIF
Medical care	Constant		2.707	0.099		27.478	0		
	Age (year)	66–70	−0.167	0.101	−0.083	−1.647	0.101	0.736	1.359
		71–80	0.258	0.097	0.145	2.667	0.008*	0.633	1.579
		≥81	0.151	0.153	0.058	0.988	0.324	0.541	1.85
		60–65	0						
	Education level	Senior high school or above	0.399	0.093	0.205	4.284	0.000*	0.82	1.22
		Junior high school or below	0						
	Spouse	None	0.326	0.108	0.176	3.012	0.003*	0.553	1.809
		Yes	0						
	Living arrangement	Living alone	0.294	0.128	0.133	2.296	0.022*	0.564	1.772
		Not living alone	0						
	Self-care ability	Disabled	0.545	0.121	0.259	4.486	0.000*	0.565	1.771
		Fully independent	0						
	Chronic diseases	Yes	0.253	0.083	0.137	3.036	0.003*	0.922	1.084
		None	0						
	Number of children	≥2 children	−0.207	0.079	−0.124	−2.608	0.010*	0.835	1.197
		1 child	0						

(Continued)

TABLE 3 (Continued)

Dimension	Variables		Non standardized coefficient		Standardized Coefficient	*t*	Significance	Collinearity statistics	
			B	Standard error	Beta			Tolerance	VIF
Spiritual/Cultural engagement	Constant		3.202	0.098		32.808	0		
	Age (year)	66–70	−0.15	0.125	−0.068	−1.198	0.232	0.736	1.358
		71–80	0.344	0.119	0.177	2.879	0.004*	0.635	1.574
		≥81	0.045	0.188	0.016	0.241	0.810	0.545	1.836
		60–65	0						
	Education level	Senior high school or above	0.379	0.114	0.178	3.327	0.001*	0.837	1.195
		Junior high school or below	0						
	Spouse	None	0.169	0.133	0.083	1.268	0.206	0.558	1.793
		Yes	0						
	Living arrangement	Living alone	0.533	0.158	0.22	3.375	0.001*	0.565	1.769
		Not living alone	0						
	Self-care ability	Disabled	0.162	0.147	0.070	1.100	0.272	0.588	1.7
		Fully independent	0						
	Number of children	≥2 children	−0.249	0.098	−0.136	−2.538	0.012*	0.835	1.197
		1 child	0						

(Continued)

TABLE 3 (Continued)

Dimension	Variables		Non standardized coefficient		Standardized Coefficient	*t*	Significance	Collinearity statistics	
			B	Standard error	Beta			Tolerance	VIF
Rights protection	Constant		2.986	0.122		24.514	0		
	Age (year)	66–70	−0.371	0.125	−0.165	−2.954	0.003*	0.736	1.359
		71–80	0.081	0.12	0.041	0.674	0.501	0.633	1.579
		≥81	−0.465	0.189	−0.161	−2.46	0.014*	0.541	1.850
		60–65	0						
	Education level	Senior high school or above	0.512	0.115	0.236	4.445	0.000*	0.82	1.22
		Junior high school or below	0						
	Spouse	None	0.105	0.134	0.051	0.784	0.434	0.553	1.809
		Yes	0						
	Living arrangement	Living alone	0.33	0.158	0.133	2.087	0.038*	0.564	1.772
		Not living alone	0						
	Self-care ability	Disabled	0.551	0.15	0.234	3.665	0.000*	0.565	1.771
		Fully independent	0						
	Chronic diseases	Yes	0.146	0.103	0.071	1.42	0.156	0.922	1.084
		None	0						
	Number of children	≥2 children	−0.29	0.098	−0.155	−2.949	0.003*	0.835	1.197
		1 child	0						

(Continued)

TABLE 3 (Continued)

Dimension	Variables		Non standardized coefficient		Standardized Coefficient	*t*	Significance	Collinearity statistics	
			B	Standard error	Beta			Tolerance	VIF
Age-friendly modifications	Constant		3.42	0.216		15.844	0		
	Age (year)	66–70	−0.414	0.14	−0.168	−2.952	0.003*	0.744	1.344
		71–80	0.055	0.134	0.025	0.412	0.681	0.641	1.561
		≥81	−0.321	0.214	−0.101	−1.498	0.135	0.532	1.879
		60–65	0						
	Education level	Senior high school or above	0.458	0.131	0.192	3.491	0.001*	0.799	1.252
		Junior high school or below	0						
	Spouse	None	0.324	0.151	0.143	2.148	0.032*	0.548	1.825
		Yes	0						
	Living arrangement	Living alone	0.071	0.176	0.026	0.405	0.686	0.574	1.742
		Not living alone	0						
	Self-care ability	Disabled	0.697	0.17	0.27	4.106	0.000*	0.558	1.793
		Fully independent	0						
	Chronic diseases	Yes	0.187	0.117	0.083	1.599	0.111	0.905	1.105
		None	0						
	Income levels (yuan/month)	1,501–3,000	−0.408	0.195	−0.196	−2.093	0.037*	0.275	3.639
		3,001–4,999	−0.368	0.199	−0.17	−1.849	0.065	0.286	3.498
		>5,000	−0.726	0.226	−0.258	−3.214	0.001*	0.376	2.662
		0–1,500	0						

*$p < 0.05$.

functionally dependent individuals or those of advanced age with the most urgent service needs may not have been adequately represented.

2.3.1 Age and self-care ability: key variables for demand differentiation

The demand for life assistance (71–80 years: $B = 0.215$, $p = 0.013$; ≥81 years: $B = 0.287$, $p = 0.037$) and medical care (71–80 years: $B = 0.258$, $p = 0.008$) increased significantly with age, a trend directly associated with declining physical function. Disabled older adults (partially/completely dependent) exhibited significantly higher demand across all service categories (life assistance: $B = 0.403$; medical care: $B = 0.545$; rights protection: $B = 0.551$; age-friendly modifications: $B = 0.697$; all $p < 0.001$), confirming that physical health status imposes a fundamental constraint on essential care needs (20). Among all age groups of older adults, individuals aged 66–70 exhibited relatively lower overall demand for services. This phenomenon may be attributed to two factors: on the one hand, compared to the oldest-old, they are generally healthier, more physically active, and more independent (21); on the other hand, having largely passed the adaptation period following the conventional retirement age of 55–60 in China, this group tends to exhibit greater stability in both psychological and daily living status.

2.3.2 Education level: a moderating factor for demand perception and acceptance

Older adults with a senior high school education or above exhibited significantly higher demand across all service categories. This phenomenon can potentially be explained by several factors: ① Enhanced information access and openness: Individuals with higher education levels typically possess greater capacity for information acquisition and demonstrate greater openness to novel concepts. Community home-based eldercare, as a relatively novel concept in eldercare provision, may be more readily accepted by this group and perceived as capable of meeting their multifaceted needs (22). ② Socioeconomic status and quality-of-life focus: Older adults with higher educational attainment often enjoy relatively higher social status and income levels. Consequently, they tend to place greater emphasis on maintaining quality of life in later years, fulfilling psychosocial and cultural aspirations, and safeguarding their legitimate rights and interests (23).

2.3.3 Living arrangement: highlighting the vulnerability of living alone older adults

Individuals living alone exhibited significantly higher demand for life assistance ($B = 0.381$, $p = 0.001$), medical care ($B = 0.294$, $p = 0.022$), and spiritual/cultural engagement ($B = 0.533$, $p = 0.001$) compared to their non-solo-living counterparts. This model reflects an increased reliance on community services resulting from the absence of familial support structures. A previous study (24) did not find that marital status affects the demand for informal care among older adults. The results of this study, however, indicate that older adults living with a spouse have significantly lower demand for life assistance and medical care. This finding suggests that mutual support between spouses also plays an important role in meeting care needs in later life. Therefore, these findings underscore the critical role of spousal support as a primary buffer against care dependency, highlighting that living arrangement, particularly solitary living, serves as a key indicator for identifying older adults at high risk of requiring comprehensive community-based services.

2.3.4 Economic income: limited overall impact but structural differences exist

Overall, income demonstrated no significant effect on demand for the majority of services ($p > 0.05$). This limited influence may be potentially attributable to the mitigation of financial constraints through widespread medical insurance coverage (25) and local subsidy policies (e.g., senior age allowances). A notable exception emerged concerning demand for age-friendly modifications. The low-income group (0–1,500 yuan) exhibited significantly higher demand compared to the high-income group (>5,000 yuan: $B = -0.726$, $p = 0.001$). This disparity likely reflects poorer housing conditions among low-income individuals, necessitating greater need for environmental adaptations. Furthermore, this result underscores that income differentials exert a more pronounced influence on demand for non-essential services compared to core care needs.

In summary, age, self-care ability, education level, and living arrangement are significant factors influencing the demand for community home-based older adult care services among the older adult. To enhance service delivery, community decision-makers should systematically survey the older adult within their jurisdiction, incorporate key influencing factors such as living arrangement and chronic diseased into an early warning system for demand assessment, and refine the community home-based older adult care service system across multiple dimensions to achieve precise service matching. Establish a demand-based tiered response system, prioritizing disabled individuals, advanced-age seniors (≥71 years), and living alone older adults as key target groups. For advanced-age disabled individuals, provide integrated home-based care combining medical/nursing services with life assistance where necessary. Establish a regular visitation system to enhance psychosocial support for living alone older adults. Tailor Service Promotion & Delivery: Develop pictorial service manuals and appoint community eldercare advisors to improve service awareness and accessibility for less-educated seniors; Offer value-added services such as legal consultations and cultural salons for highly-educated seniors. Foster a tripartite support network connecting "Community-Family-Medical Institutions," promoting data interoperability. Additionally, foster a "time-banking" mutual support system to incentivize younger seniors to serve their older counterparts, thereby mobilizing the agency of older adults in actively responding to population aging.

2.3.5 Implications for caregiver support

Our findings on the heterogeneity of older adults' demands have direct implications for alleviating caregiver burden. The significantly higher service needs identified among subgroups such as the disabled, those living alone, and the advanced-aged underscore the intense pressure faced by their caregivers. For instance, the strong demand for life assistance and medical care among the disabled older adults ($B = 0.403$ and 0.545, respectively) aligns with existing literature (20) highlighting the elevated physical and psychological strain on caregivers supporting individuals with high dependency. The modular service model proposed in section 3 of this study directly addresses this issue by providing structured and standardized support bundles. By providing a clear framework for what services are needed and how they can be combined, the model acts as a decision-support tool, guiding caregivers and service providers toward more effective and comprehensive care plans. This structured approach not only mitigates the overwhelming uncertainty often experienced by family caregivers but also empowers them by enhancing the predictability and accessibility of resources, thereby contributing to a more sustainable care ecosystem.

3 Construction of a modular community home-based older adult care service model

3.1 Theoretical foundation of the modular design framework

Modular design is a methodology that decomposes complex systems into independent, interchangeable functional units. Its core elements comprise: components (the smallest functional units), modules (clusters of components), interfaces (mechanisms for inter-module collaboration), and bundles (customized combinations of modules) (14). Within community home-based older adult care services, service items fulfilling specific older adult needs (such as hygiene care and rehabilitation guidance) can be regarded as components; clusters of functionally related services (such as the life assistance module and the medical care module) can be viewed as modules. Inter-module interfaces facilitate collaboration through service referrals, supervision, evaluation, and other mechanisms among responsible entities. Among these, the Community residents' committees (CRCs), as a grassroots mass self-governance organization, plays a crucial role in organizing resident self-governance, coordinating community affairs, providing public services, liaising with government agencies, and promoting community development. It serves as a pivotal hub connecting various responsible entities and plays a key role in service oversight and evaluation. Bundles constitute customized service combination plans tailored to the needs of specific target groups (such as living alone older adults or disabled older adults). Based on the aforementioned core elements of modular design, this study constructed a modular design framework diagram applicable to community home-based older adult care services, as shown in Figure 1.

3.2 Division and functional definition of core service modules

Based on demand dimension clustering (Table 1) and regression analysis (Table 3), five core functional modules were constructed (Table 4).

3.3 Module dynamic combination mechanism

3.3.1 Mathematical representation of service bundles

Define the module combination function, i.e., the service bundle generation formula:

$$S_i = \sum_{k=1}^{5} \alpha_{k,i} \cdot \beta_{k,i} \cdot \mathrm{M}_k$$

S_i: Customized service bundle for the *i-th* older adult.

M_k: The *k-th* core module ($k = 1, 2, \ldots 5$).

$\alpha_{k,i}$: Module activation coefficient. A binary variable that determines whether the *k-th* service module is activated for the *i-th* older adult. Its value is determined by the following rule: the individual's demand score is compared to the 75th percentile (P75) threshold of the module's demand score distribution, which is calculated based on the entire sample ($n = 331$). If the individual's score $\geq$ the P75 threshold, then $\alpha_{k,i} = 1$, activating the module; otherwise, $\alpha_{k,i} = 0$.

$\beta_{k,i}$: Module Weighting Factor. A continuous variable representing the relative demand intensity of the *i-th* older adult for the *k-th* module. Its value is derived from the sum of the standardized regression coefficients (*B* values) of the significant variables influencing the demand for that specific module. The β value for each module is

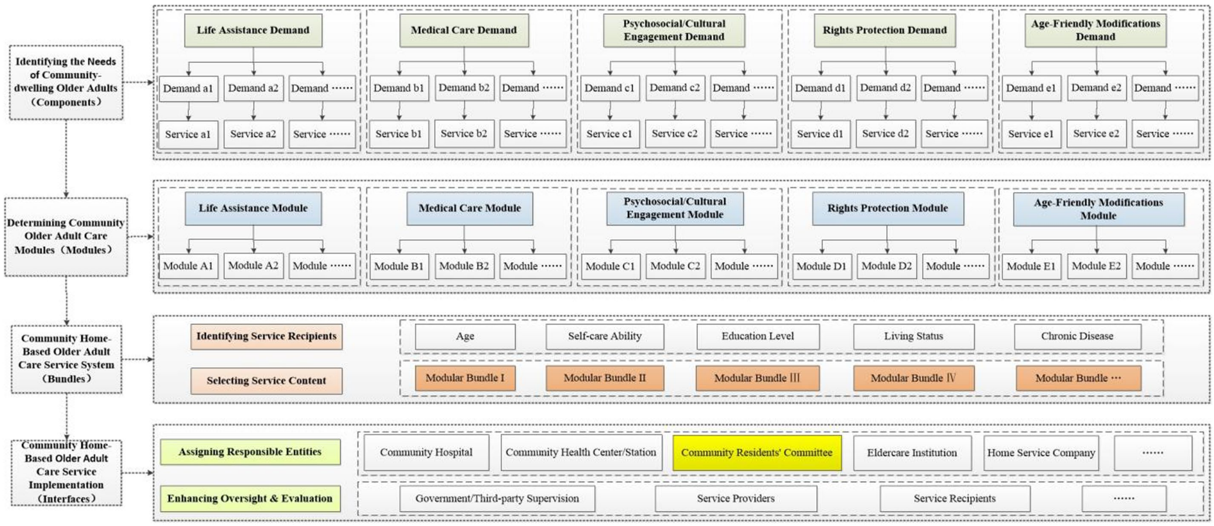

FIGURE 1
Modular design framework for community home based older adult care services.

TABLE 4 Core modules and functional definitions of community home-based older adult care services.

Module	Core components	Target population (evidence source)	Functional boundary
Life Assistance Module	Hygiene care, Catering services, Emergency maintenance, Entrusted agency services	Age ≥71 years ($B = 0.215$), Disabled ($B = 0.403$), Living alone (=0.381)	Provides daily living support and resolves basic life obstacles
Medical Care Module	Health management, Preventive healthcare, Diagnosis & treatment, Emergency rescue, Rehabilitation guidance	Living alone ($B = 0.294$), Chronic disease ($B = 0.253$), disabled ($B = 0.545$)	Integrates basic medical and nursing services to reduce acute health risks
Spiritual/Cultural Engagement Module	Spiritual comfort, Leisure activities, Self-actualization	Senior high school education or above ($B = 0.379$), Living alone ($B = 0.533$)	Promotes social participation, alleviates loneliness, and enhances psychological well-being
Rights Protection Module	Legal consultation/aid, Policy service promotion, Conflict mediation	Senior high school education or above ($B = 0.512$), Living alone ($B = 0.33$), Disabled ($B = 0.551$)	Safeguards the legitimate rights and interests of older adults
Age-Friendly Modifications Module	Indoor modifications, Public environment modifications	Low-income (0–1,500 yuan/month), Disabled ($B = 0.697$)	Improves residential safety and prevents environmental hazards

calculated only by summing the B values of the variables that have a statistically significant impact on that module, as identified in Table 3.

Application Example: Grandmother Zhang, aged 82, with diabetes and hypertension, widowed, living alone, and disabled. Demand assessment scores: Life assistance = 4.2, Medical care = 4.2, Spiritual/Cultural engagement = 3.5, Rights protection = 3.5, Age-friendly modifications = 4.0. Customize a modular community home-based older adult care service package for this older adult as follows:

(1) Life assistance module.

$\alpha_{\text{Life Assistance, Grandmother Zhang}} = 1$ (Demand score 4.2 > Threshold 3.8);
$\beta_{\text{Life Assistance, Grandmother Zhang}} = 0.287$ (Age) + 0.206 (Without a spouse) + 0.381 (Living alone) + 0.403 (Disabled) = 1.277.

(2) Medical care module.

$\alpha_{\text{Medical Care, Grandmother Zhang}} = 1$ (Demand score 4.2 > Threshold 3.83);
$\beta_{\text{Medical Care, Grandmother Zhang}} = 0.326$ (Without a spouse) + 0.294 (Living alone) + 0.545 (Disabled) + 0.253 (Chronic disease) = 1.418.

(3) Spiritual/Cultural engagement module.

$\alpha_{\text{Spiritual/Cultural Engagement, Grandmother Zhang}} = 0$ (Score 3.5 < Threshold 4.0).

(4) Rights protection module.

$\alpha_{\text{Rights Protection, Grandmother Zhang}} = 0$ (Score 3.5 < Threshold 4.0).

(5) Age-friendly modifications module.

$\alpha_{\text{Age-Friendly Modifications, Grandmother Zhang}} = 1$ (Score 4.0 = Threshold 4.0).
$\beta_{\text{Age-Friendly Modifications, Grandmother Zhang}} = 0.324$ (Without a spouse) + 0.697 (Disabled) = 1.021.

Based on the above analysis, the customized service bundle for Grandma Zhang is as follows:

$S_{\text{Grandma Zhang}} = (1 \times$ Life assistance module$) \times 1.277 + (1 \times$ Medical care module$) \times 1.418 + (0 \times$ Spiritual/Cultural engagement module$) + (0 \times$ Rights protection module$) + (1 \times$ Age-friendly modifications module$) \times 1.021$.

3.3.2 Dynamic monitoring and feedback

A Demand-Service Match Index (DSMI) is established to automatically optimize module combinations.

$$\text{DSMI} = \frac{\text{Actual service coverage rate}}{\text{Expected demand coverage rete}} \times \text{Service Satisfaction}$$

Module recombination was automatically triggered when the DSMI value fell at or below 0.8. This threshold was set empirically to indicate a significant misalignment between service provision and measured demand, prompting a revision of the activated modules or their weighting to improve service-person match.

3.4 Implementation safeguards for the modular community home-based older adult care service model

3.4.1 Accurate demand identification and dynamic adaptation of service bundles

The provision of community home-based older adult care services must align with the service expectations and priority needs of the older adult within the community. Results from Section 2: Research on the current status of community home-based older adult care service demand in this study indicate that age, disabled, living alone, and chronic disease are core influencing factors on older adults' demand for these services. Service provision must therefore use these core factors as decision anchors. Based on the results of the multivariate regression analysis of the 331 older adults in this study, advanced age (≥71 years), living alone, and disabled individuals constitute Tier-1 Priority Recipients. The service bundle function is employed to determine activated modules and their respective weighting coefficients (where $\alpha_{k,i}$ is determined by comparing the demand score to the 75th percentile, and $\beta_{k,i}$ is obtained through standardized calculation of the regression coefficient B values). Module reconfiguration or service upgrade is triggered when DSMI ≤ 0.8. Leveraging the community older adult demographic profiling database, the service bundle matching values are regularly updated to ensure resource allocation aligns with demand intensity.

3.4.2 Collaborative governance by multiple stakeholders

To achieve the Chinese government's goal of providing older adult care with security, happiness, and fulfillment, it is necessary to establish a multi-dimensional service system that covers life assistance, medical care, psychosocial support, and other domains. Given the inherent limitations of any single entity in independently providing comprehensive community home-based older adult care services, collaborative governance involving multiple stakeholders has become an essential paradigm for achieving effective service delivery (5, 26). Within this framework: ① The government plays a leading role (27), undertaking responsibilities for strategic planning, resource investment (including funding and personnel training), establishing modular service standards, and fostering a supportive ecosystem for diverse service providers. ② Service providers and module executors (e.g., medical institutions, home service companies, social work organizations) must clearly define their service content and delivery methods. ③ A formal tripartite agreement is established among the government, service providers, and older adult service recipients to clarify rights and responsibilities and implement the collaborative governance model. ④ The Community Residents' Committee (CRC), leveraging its comprehensive grasp of demographic profiles of the older adult, medical services, home care services, and other integrated information within its jurisdiction, serves as a coordinating hub and exercises oversight functions.

The successful implementation of this modular model hinges on seamless collaboration between the community care system and family caregivers. The model is not designed to replace familial support but to augment it. For instance, the 'Life Assistance Module' can provide respite care services, offering temporary relief to family carers, while training programs can be organized to enhance their caregiving capabilities. Furthermore, the Community Residents' Committee (CRC), serving as the central hub, should establish formal communication channels with families to facilitate information sharing (e.g., through regular caregiver meetings or digital platforms), ensuring care plans are coordinated and that the modules effectively complement the care provided by families.

To translate the modular framework into sustainable practice, each module requires a clear implementation pathway. For example, the Medical Care Module could be operationalized through formal partnerships between CRCs and local primary health centers, specifying protocols for regular health screenings, emergency response, and chronic disease management. Similarly, the Life Assistance Module could be delivered by vetted and trained home service companies or community volunteer organizations, whose service standards and pricing are regulated and made transparent through the smart platform. This detailed delineation of responsibilities and operational workflows ensures that the modular design moves beyond a theoretical concept to an actionable, collaborative service delivery mechanism.

3.4.3 Refining the oversight and evaluation mechanism

Establishing a comprehensive evaluation indicator system is the primary basis for ensuring the quality of eldercare services. It enables service quality to be institutionalized and standardized in a concrete and explicit manner, facilitating implementation and assessment (26). To drive continuous improvement, a three-tiered evaluation chain can be established, encompassing governmental/third-party supervision, self-assessment by service providers, and feedback from end-users. This chain should be supported by a fully open, smart online interactive information platform—leveraging internet technology and led by the government—with support from community offline platforms. This platform enables the responsible parties of various service modules to publish service content and pricing, and to conduct self-evaluations. Concurrently, older adult recipients provide satisfaction feedback through the platform after service consumption. The government or third-party regulatory agencies are responsible for full-process supervision based on this integrated information. Crucially, for any module with a Demand-Service Match Index (DSMI) score of ≤ 0.8, the responsible parties are required to identify the causes and implement corrective improvements. This entire process, from evaluation and feedback to mandated correction, forms a closed-loop quality monitoring system.

3.4.4 Supporting caregivers through modular service delivery

Beyond its direct benefits to older adults, the successful implementation and sustainability of the modular model fundamentally depend on its capacity to support the formal and informal caregivers upon whom the system relies. This model is explicitly designed to function as a supportive framework that reduces the uncertainty and burden often experienced by family caregivers. For instance, the life assistance module can be configured to include respite care services, offering temporary relief to family carers, while training programs can be organized to enhance their caregiving capabilities. Concurrently, the medical care module integrates professional health resources, reducing the family's direct medical care burden and associated stress. Furthermore, the central coordinating role of the Community Residents' Committee (CRC) ensures that caregivers have a clear and reliable point of contact for service coordination, information, and psychosocial support. This structured approach not only empowers caregivers by enhancing the predictability and accessibility of services but also fosters a more sustainable care ecosystem by preventing caregiver burnout and promoting the well-being of those providing care.

4 Limitations

This study analyzed the service demands of community-dwelling older adults and their influencing factors through empirical investigation, proposing a modular community home-based older adult care service model grounded in modular design principles. This offers a novel paradigm for addressing the "supply–demand mismatch" in such services and providing structured support to caregivers. However, several limitations warrant acknowledgment: First, the convenience sampling method may underrepresent frail, homebound, or cognitively impaired older adults who are less likely to frequent public community spaces. Consequently, the expressed demand levels in this study might be a conservative estimate, as the most vulnerable seniors with the highest care needs are potentially omitted. To address this sampling bias in future research and practical implementation, proactive strategies such as collaboration with community health stations for home-visit assessments or targeted recruitment through neighborhood registries of vulnerable elders are recommended to ensure a more comprehensive representation of the older adult. Second, the data relied on self-reported measures, which are susceptible to social desirability bias. Older adults, particularly those with lower education levels, might underreport their needs due to a desire to be perceived as self-reliant, a tendency to normalize their hardships, or a lack of awareness that certain services could be available. This could further contribute to an underestimation of true demand, especially in psychosocial and rights protection domains. Future studies could combine quantitative surveys with qualitative in-depth interviews to better uncover latent needs and mitigate this bias. Third, the proposed modular service bundle algorithm and dynamic adaptation mechanism (e.g., S_i, DSMI index, weighting factor β) lack empirical validation. Future research must prioritize pilot testing this model in diverse community settings. Such pilots are essential to evaluate its practicality, identify potential barriers related to financial constraints, workforce shortages, and policy variability, and iteratively refine the framework for real-world application. Finally, although we stratified age into four groups, the category of $\geq$81 years encompasses a highly heterogeneous population with vastly different levels of vitality and need. A more granular age classification (e.g., 81–85, 86–90, 90+) in studies with a larger sample size would provide deeper insights into the evolving priorities of the "oldest-old" and allow for even more precise module customization.

Despite these limitations, this study constructs a modular service model that responds to the dual challenge of meeting the heterogeneous demands of community-dwelling older adults while simultaneously providing critical support to their caregivers. By translating complex care needs into a flexible architecture of service modules, our approach offers a pragmatic pathway to mitigate the caregiver burden-a central concern of this research topic. The model's emphasis on dynamic adaptation and multi-stakeholder collaboration, centered on the Community Residents' Committee (CRC), provides a scalable framework for communities seeking to build more resilient and sustainable care ecosystems that support both older adults and those who care for them.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

This study was conducted in accordance with the Helsinki Declaration and was approved by the Ethical Review Committee of Affiliated Zhongshan Hospital Dalian University (Approval No: KY2023-110-1). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

XZ: Conceptualization, Funding acquisition, Supervision, Writing – original draft. LC: Supervision, Writing – review & editing. XL: Data curation, Investigation, Software, Writing – original draft. YL: Supervision, Writing – review & editing. BH: Data curation, Investigation, Software, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Determinants of community-based home care service demand among urban older adults in Shanxi, China: a cross-sectional psychological perspective

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Introduction: Given China's large population and the severity of its aging issue, community-based home care has become the primary approach to addressing older adults' care needs.

Methods: This study combined follow-up visits and questionnaire surveys, using univariate analysis of variance (ANOVA) and multivariate logistic regression to examine the demand for community-based home care services among urban community older adults in Shanxi Province, China.

Results: Logistic regression results identified several significant influencing factors: monthly income, occupation, living conditions, community neighborhood relationships, and community mutual assistance.

Discussion: This study clarifies the characteristics of demand for community aged care services among urban older adults in Shanxi, providing important reference for optimizing such services.

KEYWORDS

community older adult residents, community-based home care, older adult care service demand, Shanxi, a cross-section survey

1 Introduction

The acceleration of global aging has led to a gradual increase in the proportion of the older adults in the total population of various countries, which not only affects family structures but also poses new challenges to social economic, cultural, and healthcare systems. According to the United Nations, by 2050, the number of people aged 65 and above will reach 2 billion, accounting for over 16% of the global total population (1). In China, data from the 2020 population census shows that there are approximately 264 million people aged 60 and above, making up 18.7% of the total population, and it is projected that the number of people aged 65 and above will reach 200 million by 2050 (2–4). In response to this trend, China has actively promoted community-based aging in place, an innovative model that provides community-based life care and service support for the older adults, enabling them to live a dignified, independent, and secure life in a familiar family environment (5). This model, which emphasizes the autonomous choices and personalized needs of the older adults, is in line with the preference of 98.4% of China's older adults population for home care (6). It not only aligns with traditional Chinese filial piety values and the emotional attachment of the older adults to their residential and community environments (7–9) but also helps alleviate the pressure of institutional care and the scarcity of nursing resources, given the immature development of China's nursing home market (10). Additionally, drawing on the successful experience of community-based aging in place from countries like Nordic nations and Japan (11, 12), and leveraging the opportunities brought by intelligent technologies such as telemedicine and smart homes (13–16), China is striving to advance the development of community-based home care.

However, there are deficiencies in the governance of aging in China communities. Despite the promotion of community-based aging in place and the diversification of service forms, the coverage and satisfaction of existing community-based home care services still need to be improved. There may be issues such as inadequate integration of resources, lack of personalized services, and insufficient responsiveness to the diverse needs of the older adults in daily living, medical and health care, and emotional support.

Against this backdrop, this study intends to adopt a combination of quantitative and qualitative methods to conduct a cross-sectional survey on the home care service needs of the older adults in urban communities in Shanxi Province. The main purpose is to comprehensively analyze their needs at multiple levels, collect specific information on their needs for daily living, medical and health care, and emotional support, and assess the coverage and satisfaction of existing services, so as to provide a reference for improving the community-based aging governance in China.

2 Subjects and methods

2.1 Research subjects

This study selected Shanxi Province in North China as the sample for conducting a cross-sectional study. According to the 2021 7th National Population Census Bulletin, the proportion of the population aged 60 and above in China accounted for 18.70%, in Shanxi Province, the proportion of the population aged 60 and above is 18.92%, which has exceeded the national average (17, 18). To gain a deeper understanding of the existing issues in community-based home care and the challenges and needs faced by older adults in urban communities during the aging process at home. A total of 1,046 participants from Shanxi Province completed the questionnaire survey in this study. The selection criteria for participants included the following inclusion and exclusion criteria. Inclusion criteria: (1) individuals aged 60 and above; (2) older adults residing in urban communities; (3) older adults capable of independently and clearly expressing their personal preferences; (4) older adults willing to cooperate and participate in the research. Exclusion criteria: (1) older adults with mental disorders or their caregivers (Excluding the older adults and caregivers with mental disorders, due to their highly special care needs, this study focuses on the general needs of the general older adults in the community, and the follow-up research will be specific to this group); (2) older adults unwilling or unable to cooperate with the research; (3) older adults whose family members do not consent to their participation in this study. Written informed consent was obtained from all participants.

2.2 Methods

A cross-sectional survey was conducted from November 22, 2022, to January 2, 2023. This study employed a combination of online and offline methods based on the practical circumstances during the survey process. To avoid age discrimination resulting from the digital divide, multiple methods were employed for questionnaire collection. Online questionnaires accounted for a significant proportion of the collected responses. These questionnaires were generated using the "QuestionStar" software and were disseminated and shared through older social groups, WeChat moments, social media, and other channels.

2.3 Questionnaire design

The first section primarily investigates the respondents' basic information and demographic characteristics, including residential address, age, gender, marital status, children's status, educational level, and past occupations. The purpose is to gather insights into the basic profile of the surveyed older individuals.

The second section focuses on investigating the living conditions of the respondents, including their housing situation, daily activities and dietary habits, older adult care preferences, economic situation, and relationships with family members. The objective is to gain an understanding of the challenges and needs faced by older individuals in their daily lives.

The third section primarily investigates the health status of the respondents, including their health conditions such as sleep patterns, chronic illnesses, and mental well-being. It also covers the medical situation of the older, including health management, healthcare expenses, and medical insurance. The objective is to understand the main challenges and needs of the older population regarding their health.

The fourth section primarily evaluates the status of community-based older adult care services, including the level of coverage, user experience, satisfaction level, and the alignment between service offerings and the needs of the older. The objective is to understand the current situation of community-based older adult care services, identify areas for improvement, and explore directions for enhancement.

The fifth section primarily investigates the relationship between the older and the community, the willingness of the older to participate in community-based mutual support for older adult care, and their willingness to use age-friendly applications related to older adult care. The purpose is to understand the feasibility of implementing community-based mutual support for older adult care.

2.4 Data analysis

All survey data were analyzed using SPSS 23.0 for statistical analysis. Descriptive statistics were used to report measures such as mean ± SD or percentages (%). Group comparisons were conducted using t-tests and one-way analysis of variance (ANOVA). Multivariate logistic regression analysis was employed to identify influential factors. A significance level of $p < 0.05$ indicated statistically significant differences.

3 Results

3.1 Population characteristics of urban community older residents

The population characteristics of older residents in urban communities are shown in Table 1. Among the 1,046 participants, more than half of the respondents were female (67.7%) and married (85.4%). The majority of participants had children (98.8%), received retirement pensions (65.74%), and had a level of education no lower than junior high school (84.035%). Most of the respondents had a monthly income greater than 2000 yuan (69.99%), and 78.8% were economically independent. In this survey, the age group of 60–65 accounted for 48.279%, 66–70 accounted for 31.5487%, 71–75 accounted for 11.8546%, 76–80 accounted for 3.7284%, and those over 80 accounted for 4.5889%. Table 1 shows that there are differences in the demand for community-based older adult care among different genders ($p < 0.01$), monthly income levels ($p < 0.001$), education levels ($p < 0.001$), and past occupations ($p < 0.001$). Retired cadres have a higher demand for community-based older adult care, followed by workers and farmers (Table 1).

3.2 Assistance situation for urban community-dwelling older in home-based care

Currently, 14.8% of older residents aged 60 and above in urban communities live alone in their daily lives, while 45.3% of older residents prefer to be accompanied by their partners and family members for older adult care. The study found that having children ($p < 0.001$) and living with a spouse ($p < 0.001$) were associated with lower willingness for community-based older adult care. In terms of daily life arrangements, those who receive care from the government or community neighbors have a higher demand for community-based older adult care ($p < 0.001$). Older residents living in welfare institutions have a higher demand for community-based older adult care ($p < 0.001$). Our study also revealed that older adults who expressed a desire to select older adult groups, community neighbors, and volunteers as companions in their old age had a significantly higher demand for community-based home care ($p < 0.001$; Table 2).

3.3 Home-based care service situation for urban community-dwelling older

We surveyed the status of community-based older adult care services for older residents in urban communities. The results showed that currently, the biggest challenge faced by older people aged 60 and above in terms of older adult care is inadequate funding (70.94%). As for the current national medical and older adult care policies, 53.1% of the participants have some knowledge of them. We found that older people without medical insurance coverage tend to have a lower demand for community-based older adult care, and those who currently do not receive home-based older adult care services from the community also have a relatively lower demand for community-based older adult care (Table 3).

3.4 Community mutual aid in the urban area

In urban communities, 42.7% of older residents have lived in the community for over 15 years, 53.3% have harmonious relationships

TABLE 1 Population characteristics of urban community older residents.

Variable	Total (n)	%	Have community-based home care services needs	%
Gender			n	%
Male	338	32.3	250	74.0
Female	708	67.7	581	82.1
χ^2				9.187
p-value				0.002
Age				
60–65	505	48.3	403	79.8
66–70	330	31.5	260	78.8
71–75	124	11.9	95	76.6
76–80	39	3.7	31	79.5
>80	48	4.6	42	87.5
χ^2				2.643
p-value				0.619
Monthly income				
<2000	314	30.0	176	56.1
2001–3,000	211	20.2	109	51.7
3,001–4,000	243	23.2	184	75.7
4,001–5,000	186	17.8	102	54.8
>5,000	92	8.8	60	65.2
χ^2				36.34
p-value				<0.001
Education level				
Elementary school	167	16.0	111	66.5
Junior High School	370	35.4	224	60.5
High School	285	27.2	211	74.0
College	170	16.3	105	61.8
Undergraduate	48	4.6	20	41.7
Postgraduate	6	0.6	2	33.3
χ^2				28.049
p-value				<0.001
Occupation				
Cadres	221	21.1	171	77.4
Employees	467	44.6	344	73.7
Individuals	110	10.5	49	44.5
farming	138	13.2	101	73.2
Unemployed	84	8.0	54	64.3
Other	26	2.5	12	46.2
χ^2				51.541
p-value				<0.001

TABLE 2 Assistance situation for urban community-dwelling older in home-based care.

Variable	Total (n)	%	Have community home care needs	%
Children				
None	13	1.2	12	92.3
1	327	31.3	228	69.7
2	491	46.9	325	66.2
3	153	14.6	128	83.7
4	51	4.9	42	82.4
≥5	11	1.1	10	90.1
χ^2				25.952
p-value				<0.001
Marital status				
Unmarried	10	1	6	60
Married with spouse	893	85.4	628	70.3
Divorced	32	3.1	22	68.8
Widowed	107	10.2	84	78.5
Other	4	0.4	3	75.0
χ^2				3.824
p-value				0.43
Living arrangement				
Self	109	10.4	87	79.8
Spouse	414	39.6	204	49.3
Children	329	31.5	217	66.0
Relatives	58	5.5	49	84.5
Healthcare professionals, caregivers, volunteers	40	3.8	34	85.0
Government, community, and group care	36	3.4	31	86.1
Older groups, community neighborhoods, volunteers	43	4.1	37	86.0
Other	17	1.6	12	70.6
χ^2				86.737
p-value				<0.001
Willing older companion				
Companions, family members	474	45.3	232	48.9
Healthcare professionals, caregivers, volunteers	420	40.2	158	37.6
Older groups, community neighbors, volunteers	152	14.5	150	98.7
χ^2				169.142
p-value				<0.001
Parent–child relationship				
Very good	730	69.8	477	65.3
Fairly good	203	19.4	172	84.7
Poor	9	0.9	4	44.4
Fair	86	8.2	54	62.8
Very poor	18	1.7	12	66.7
χ^2				31.997
p-value				<0.001

(Continued)

TABLE 2 (Continued)

Variable	Total (n)	%	Have community home care needs	%
Residence status				
Living alone	155	14.8	123	79.4
Living with partner	696	66.5	342	49.1
Living with children	132	12.6	81	61.4
Welfare sector	35	3.3	33	94.3
Living with a nanny (caregiver)	28	2.7	20	71.4
χ^2				72.494
p-value				<0.001

TABLE 3 Home-based care service situation for urban community-dwelling older.

Variable	Total (n)	%	Have community home care needs	%
Medical insurance situation			n	%
Publicly funded medical care	222	21.2	171	77.0
Urban workers' medical insurance	420	40.2	290	69.0
Urban and rural residents medical insurance	289	27.6	191	66.1
Commercial medical insurance	55	5.3	45	81.8
None	60	5.7	36	60
χ^2				14.038
p-value				0.007
Knowledge of national pension policy				
Yes	555	53.1	454	81.8
No	491	46.9	365	74.3
χ^2				8.541
p-value				0.003
Whether the community provides home care services				
Yes	409	39.1	340	83.1
No	637	60.9	379	59.5
χ^2				64.732
p-value				<0.001

with their neighbors, and 90.2% would turn to their neighbors for help when facing difficulties. Our research found a positive correlation between the demand for older adult care and community factors such as length of time living in the community, neighborly relationships, participation in community activities, support for community mutual aid projects, and participation in community service activities (Table 4).

3.5 Correlation analysis between home-based care service situation and community mutual aid for urban community-dwelling older

The correlation analysis between the status of community-based older adult care services and community mutual aid among urban older residents is shown in the table. We use the Odds Ratio (OR) to measure the strength of association between groups, and the 95% Confidence Interval (95% CI) is used to assess the reliability of the OR. Logistic regression analysis showed that monthly income, previous occupations, living conditions, community neighbors, and community mutual aid all affect the demand for community-based older adult care among older residents ($p < 0.05$; Table 5).

4 Discussion

Given the enormous population size and severe aging issue in China, Community-based Home Care for the Older may become the primary approach to address the aging population's needs (19). Moreover, according to the United Nations projections, the population of older individuals aged 65 to 79 in China is expected to increase in the future. Consequently, there will be a growing and increasingly diverse demand for older adult care services (20).

This study investigated the older adult care needs of urban community-dwelling older adults. By gaining an understanding of the home care assistance situation among older residents in urban communities, it can be observed through an analysis of their children's circumstances that older residents without children have a higher demand for community-based home care, while the majority of those with children have relatively lower demand. Furthermore, among urban community-dwelling individuals aged 60 and above, 14.8% choose to live alone, while 45.3% prefer to live with their partners or family members for their older adult care. This indicates a close relationship between the older's living choices and their social support networks, as they prefer to have companionship during their later years (21). Among them, older residents living with spouses and family members exhibit lower demand for community-based home care. This may be attributed to the presence of family members who

TABLE 4 **Community mutual aid in the urban area.**

Variable	Total (n)	%	Have community home care needs	%
Community lifetime				
Less than 1 month	38	3.6	16	42.1
Less than 1 year	41	3.9	17	41.5
1–5 years	232	22.2	143	61.6
6–10 years	159	15.2	116	73.0
10–15 years	129	12.3	96	74.4
More than 15 years	447	42.7	331	74.0
χ^2				41.3
p-value				<0.001
Neighborhood relationship				
Very good	558	53.3	386	69.2
Better	335	32.0	260	77.6
Fair	146	14.0	73	50.0
Not good	7	0.7	1	14.3
χ^2				55.9
p-value				<0.001
Willing to ask for help from neighbors when in trouble				
Yes	944	90.2	684	72.5
No	102	9.8	35	34.3
χ2				62.3
P-value				<0.001
Willing to help the community in any way they can				
Yes	997	95.3	706	70.8
No	49	4.7	13	26.5
χ2				42.6
P-value				<0.001
Whether they want to exist online or offline to solve the problems in the process of aging				
Yes	967	92.4	699	72.3
No	79	7.6	20	25.3
χ^2				75.0
p-value				<0.001
Support for community-based mutual help programs for neighbors				
Support	867	82.9	632	72.9
Fair	172	16.4	92	53.5
Do not support	7	0.7	1	14.3
χ^2				35.444
p-value				<0.001
Participation in service activities provided by community neighborhood support programs				
Willingness	856	81.8	638	74.5
Generally	173	16.6	81	46.8
Reluctant	17	1.6	5	29.4
χ^2				64.719
p-value				<0.001

(Continued)

TABLE 4 (Continued)

Variable	Total (n)	%	Have community home care needs	%
Willing to age with community neighbors through mutual help				
Willing	809	77.3	619	76.5
Generally	205	19.6	104	50.7
Not willing	32	3.1	6	18.8
χ^2				92.035
p-value				<0.001

provide companionship and support, reducing the need for additional community-based home care services. On the other hand, older individuals living alone have a relatively higher demand for community-based home care services. Additionally, there is currently a higher demand for community-based home care services from older people who are cared for by the government or their community neighborhoods. This could be due to their lack of family support or the inability of family members to fully cater to their older adult care needs. Furthermore, older residents living in welfare facilities also display higher demand for community-based home care, potentially because of their more vulnerable living conditions, necessitating greater social support. Moreover, the study found that older adults tend to prefer older peers, community neighbors, and volunteers as intended companions for their older adult care, indicating their willingness to receive support and care from the community rather than relying solely on family members. This demand underscores the importance of community-based home care services, as they can provide older individuals with more social opportunities and community support, enhancing their sense of well-being and quality of life (22). Regarding living conditions, the research revealed that 14.8% of urban community-dwelling older residents live alone. Furthermore, older residents living in welfare facilities exhibit higher demand for community-based home care ($p < 0.001$). Additionally, the study also found that older residents receiving care from the government or community-based neighborhood assistance display higher demand for community-based home care ($p < 0.001$). This emphasizes the crucial role of government and community care in meeting the home care needs of older adults. These research findings indicate the significance of family support and government or community-based neighborhood assistance for the home care demand.

Community mutual support can stimulate social engagement and a sense of responsibility among older adults, enriching their lives and enhancing interpersonal relationships, quality of life, and well-being (23, 24, 25). Data analysis revealed a positive correlation between community support and older adult care needs, including factors such as the amount of time spent in the community, neighborly relationships, participation in community activities, support for community mutual aid projects, and engagement in community service activities. A significant proportion of the older residents expressed their willingness to contribute to the community according to their abilities. Additionally, the majority of older adults reported harmonious relationships with their neighbors and a willingness to seek help from them when facing difficulties. These findings highlight the positive impact of community mutual support on the older residents' care needs. Through community mutual support, older adults can establish positive neighborly relationships and access more community support and services.

By exploring the influence of community mutual assistance on the demand for community-based home care for the older and analyzing a series of variables, it was found that there is a positive correlation between factors such as the duration of the community residence, neighbor relationships, participation in community activities, support for community mutual assistance projects, and participation in community service activities. The research results indicate that over 42.7% of the older residents have been living in the community for more than 15 years, and among this group, 74.0% express demand for community-based home care services. This finding suggests that as older residents spend more time in the community, they are more inclined to choose the home care services provided by the community. The positive correlation between community mutual aid and nursing needs may be due to the increased accessibility of services, and mutual aid networks promote the dissemination of service information and the docking of resources. At the same time, social cohesion is enhanced, and good neighborhood relations enhance the trust and willingness of the older adults to use community services (26).

Furthermore, logistic regression analysis was conducted to explore the association between the provision of community-based home care services and community mutual assistance among older residents in urban areas. The analysis identified several factors that influence the care demands. Firstly, monthly income was found to be moderately associated with the care demands for community-based home care services among older residents. This may be attributed to the fact that older residents with lower incomes require more economic support and services provided by the community, whereas those with higher incomes have more options and resources to address their care needs independently. Secondly, the previous occupation of the older residents also influences their care demands for community-based home care and their level of participation in community mutual assistance. Additionally, the living arrangements of older residents were found to be closely associated with their care demands for community-based home care services and their level of participation in community mutual assistance. This may be because older residents living with family members can receive more support and care from their families but also require more community services and assistance to meet their specific care needs. The availability of community-based home care services and the level of support for neighborly mutual assistance projects significantly impact the care demands of older residents and their participation in community mutual assistance. This suggests that the absence of community-based home care services may lead to more difficulties and challenges for older residents

TABLE 5 Correlation analysis between home-based care service situation and community mutual aid for urban community-dwelling older.

Variable	OR	95% Confidence interval	*p*
Monthly income (Ref. below 2000)			
2001–3,000	1.193	0.841–1.649	0.322
3,001–4,000	0.518	0.355–0.756	0.001
4,001–5,000	1.330	0.914–1.934	0.136
≥5,000	0.861	0.527–1.407	0.621
Previous Occupation (Ref. Cadre)			
Employee	1.223	0.839–1.782	0.303
Individual	4.258	2.607–6.954	<0.001
farming	1.253	0.767–2.047	0.378
unemployed	1.900	1.100–3.281	0.028
Other	3.990	1.735–9.177	0.001
Children (Ref. no children)			
1	5.211	0.668–40.620	0.119
2	6.129	0.790–47.542	0.070
≥3	2.052	0.382–11.025	0.401
Residence status (Ref. living alone)			
Living with partner	3.979	2.624–6.033	<0.001
Living with a son or daughter	2.420	1.434–4.085	0.001
Welfare sector	0.233	0.053–1.023	0.048
Living with a nanny (caregiver)	1.538	0.620–3.810	0.333
Does the community provide aging-in-place services (Ref. yes)			
No	3.354	2.477–4.543	<0.001
Will neighbors seek help when in trouble (Ref: Yes)			
No	5.036	3.266–7.765	<0.001
Willing to help the community in any way they can (Ref. Yes)			
No	6.718	3.512–12.853	<0.001
Whether they want to exist online and offline to solve problems in the process of aging (Ref. Yes)			
No	7.694	4.546–13.024	<0.001
The degree of support for the community to carry out neighborhood mutual help programs (Ref. Support)			
General	2.339	1.673–3.269	<0.001
Do not support	16.136	1.932–134.741	0.002
The degree of participation in service activities provided by community neighborhood mutual aid projects (Ref. willing)			
Generally	3.164	2.301–4.350	<0.001
Unwilling	14.118	5.726–34.809	<0.001

during their care process, making them more reliant on community support and mutual assistance. Moreover, communities with higher levels of support for neighborly mutual assistance projects correspondingly exhibit higher levels of participation in community mutual assistance among older residents. This indicates that neighborly mutual assistance projects in the community can stimulate the willingness of older residents to participate and enhance community cohesion and mutual assistance networks (9). Additionally, the study found that the personal characteristics of older residents also influence their care demands for community-based home care services and their participation in community mutual assistance. The attitudes of older residents toward community mutual assistance and support also impact their care demands for community-based home care services and their level of participation. Older residents who are willing to provide help and support to the community are more likely to require community-based home care services and actively participate in community mutual assistance activities (27).

5 Limitation

Despite providing valuable insights into the care demands and community mutual assistance among older residents in urban China, this study has several limitations. Firstly, the sample of the study was limited to older residents in a specific city in northern China, which may restrict the generalizability and applicability of the results to other regions and populations. Secondly, the study relied on cross-sectional survey methods, which have methodological and design limitations. Additionally, the extensive questionnaire length may have led to some participants responding inattentively or providing arbitrary answers, potentially introducing data biases. There may still be a selection bias in the difference in the online/offline ratio, and the older adults with low digital literacy may be underrepresented. Finally, although this study provided some understanding of the care demands and community mutual assistance among older residents in urban China and offered valuable insights for future community-based care services, further research is needed to explore the causal relationships between relevant variables and elucidate the specific mechanisms driving the satisfaction of care demands.

6 Conclusion

Our results revealed the demand for community-based home care services and some decision factors among the older residents in urban communities in China. Based on these findings, researchers can develop more targeted community-based care policies and services based on these factors to improve the quality and coverage of community-based home care services. In practice, governments and communities should allocate resources for community-based home care services according to the specific needs of different gender and age groups, aiming to meet the demands of the older and enhance their quality of life. Additionally, in the process of promoting the development of community-based home care services, attention should be paid to the influence of gender and age factors, and more targeted policies and measures should be formulated. Additionally, scientific design of community-based older adult care services and exploring the use of mobile applications to establish community mutual assistance platforms offer valuable data references and innovative approaches for future older adult care services. Through continuous improvement and innovation, we can create a healthier, more convenient, and fulfilling community life for older adults, thereby increasing their happiness and quality of life and contributing positively to the sustainable development of society. Compared with Japan's diverse community-based older adults care services and the Nordic comprehensive community-based medical-social support system, there is still a gap in the service integration and resource investment of China's community home-based older adults care, and the results of this study provide a basis for learning from international experience to optimize local services.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Research Ethics Committee (CERec) of the Autonomous University of Barcelona. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

HL: Conceptualization, Project administration, Data curation, Formal analysis, Methodology, Investigation, Visualization, Writing – original draft, Writing – review & editing. SS: Conceptualization, Data curation, Formal analysis, Writing – original draft, Writing – review & editing. EB: Conceptualization, Writing – review & editing. XW: Conceptualization, Methodology, Funding acquisition, Investigation, Formal analysis, Writing - original draft, Writing - review & editing, Supervision.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Correction note

A correction has been made to this article. Details can be found at: 10.3389/fpubh.2025.1694051.

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Facilitators and barriers of help-seeking for persons with dementia in Asia—findings from a qualitative study of informal caregivers

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Background and aim: The deterioration in cognition of persons with dementia (PWD) makes their caregivers key players in their help-seeking process. This study aimed to identify the facilitators and barriers of help-seeking for persons with dementia in Asia from the perspective of their informal caregivers.

Methods: A qualitative methodology was adopted in the current study. Twenty-nine informal caregivers of PWD in Singapore were interviewed between April 2019 and December 2020. All interviews were audio-recorded and transcribed verbatim for the analysis.

Results: The transcripts were analyzed using inductive thematic analysis. The results revealed four major themes with 12 sub-themes, including (1) Barriers to diagnosis-seeking (i.e., lack of knowledge and awareness of dementia, emotional denial, resistance from PWD, and delays in the healthcare system); (2) Facilitators of diagnosis-seeking (i.e., synergy between awareness of dementia and an active diagnosis-seeking intention and incidental diagnosis resulting from seeking treatment for comorbid conditions); (3) Barriers to treatment-seeking (i.e., challenges from PWD and disease, challenges faced by caregivers when seeking treatment for PWD, and challenges imposed by the COVID-19 pandemic); (4) Facilitators of treatment-seeking (i.e., caregivers' capabilities of handling PWD, cooperation/compliance from PWD, and an integrated care plan for PWD).

Conclusion: The findings highlight the importance of raising public awareness, enabling health professionals to tailor psychosocial interventions better, and improving community support through dementia awareness and education.

KEYWORDS

informal caregivers, dementia, help-seeking, diagnosis-seeking, treatment-seeking, qualitative

1 Introduction

Dementia is a chronic and progressive syndrome that affects cognitive function and behavior among persons with dementia (PWD) (1). Currently, more than 55 million people around the world are living with dementia, and this number is expected to increase by 10 million new cases each year as the world's population ages (2, 3), to 78 million by 2030 and 139 million by 2050 (4). According to the World Health Organization (WHO), it is the seventh leading cause of death and one of the major causes of disability and dependency among older people (3).

In comparison to other chronic conditions, dementia is a more frequent cause of care dependency among older individuals (1, 5, 6). As the disease progresses, PWD gradually lose their ability to care for themselves and independently perform activities of daily living such as bathing, household chores, and cooking. Many PWD would thus require full-time care, especially in the advanced stage, mostly from their family members (7). Studies suggest that more than three-quarters of PWD receive care in the community (8). Informal caregivers are usually the first to notice the symptoms of dementia among PWD, and therefore, they are actively involved in the help-seeking journey (9, 10). Timely diagnosis of dementia is considered of major importance to ensure adequate access to care and support for PWD. A study conducted by Eichler et al. (11) has provided evidence that routine screening improved the identification of dementia considerably and increased the diagnosis rate. Another prospective study demonstrated that PWD received a formal diagnosis through routine screening, and PWD may benefit more if they were treated with anti-dementia medications earlier (12).

The pathway to a diagnosis of dementia is believed to begin with the family's or patient's recognition of early symptoms, followed by active help-seeking from a primary care doctor who either diagnoses the condition or refers the patient to a specialist (13). By identifying individuals at risk of dementia in the preclinical stage and providing appropriate support and interventions, healthcare providers can help to delay or mitigate the onset of symptoms and improve outcomes for those affected by the condition. Caregivers play a dynamic role throughout the care journey and are often the primary source who encourage older adults to seek help (14). The diagnostic process can be lengthy and frustrating (15). According to previous studies, there is always a considerable time lapse between the first symptom seen or noticed and a formal diagnosis, which can be as long as 2–3 years (10, 14). The study conducted by McCleary et al. (10) explored experiences of South Asian Canadians. Early signs were attributed to aging or personality. Before seeking medical attention, family carers modified physical or social environments to accommodate the symptoms, and help-seeking was delayed up to 4 years. Another study showed that individuals may wait for 1–3 years from the onset of symptoms before receiving the diagnosis (14). A recent European study found that the average length of time lapse between PWD or their informal caregivers noticing problems and a diagnosis being made was just over 2 years (16). Receiving the diagnosis can be a shock or a relief to patients, and disclosure is an important part of management; earlier diagnosis seems to be associated with easier transitions and might delay the need for a move from home (17).

Help-seeking is a dynamic and complex process that can be influenced by many factors such as health, quality of life, treatment options, and the cost of healthcare services; and understanding help-seeking behavior for specific conditions can help to identify and reduce delays in diagnosis and treatment (18). There has been considerable research into barriers to help-seeking for dementia diagnosis over the last 30 years, with many recommending improvements in knowledge and awareness among health professionals and the public to reduce delays and facilitate diagnosis (19). Stigmatizing beliefs about dementia and inadequate knowledge were found to be the main barriers preventing people from seeking help (20). In terms of service use, various other research findings have shown that PWD and their informal caregivers use fewer services in comparison to other people in need of care (21, 22). Research suggests that the first phases of the caregiving process are critical and that the timely use of community services potentially delays institutionalization (23).

Singapore is a multiethnic, developed country in Southeast Asia, with a resident population consisting predominantly of Chinese (75.6%), Malays (15.1%), and Indians (7.6%) (24). The proportion of residents aged 65 years and above is rising at a faster pace compared to the last decade. Early diagnosis of dementia is important as this allows PWD and their informal caregivers to engage with support services and plan for the future. A study in Singapore—the Well-being of the Singapore Elderly (WiSE)—established the prevalence of dementia to be 10% among Singapore residents aged 60 years and above (25). Another study showed that the majority of the general practitioners in Singapore were positive toward the early diagnosis of dementia, endorsed the need to improve the quality of life of PWD and their informal caregivers, and preferred more training to equip themselves in the management of dementia (26). The Singapore government launched the Community Resource, Engagement and Support Team (CREST), which focuses on raising public awareness of dementia, promoting early recognition of at-risk individuals, and providing emotional support to individuals and their informal caregivers to acquire knowledge and skills to manage better (27). Despite all these efforts, studies on barriers and facilitators to help-seeking from the perspective of caregivers of PWD remain scarce. This study aimed to identify the facilitators and barriers of timely diagnosis-seeking and access to the treatment of dementia experienced by informal caregivers of PWD.

2 Materials and methods

2.1 Study design

Data for the current study were part of a qualitative project aimed at understanding the caregiving experiences of informal caregivers of PWD in Singapore.

2.2 Study participants

The eligibility criteria of this study were (1) Singapore citizens and permanent residents, (2) aged 21 years and above, (3) taking care of a patient who has been formally diagnosed with dementia, and (4) able to communicate in English, Mandarin, Malay, or Tamil. Those caregivers providing care to a PWD who was institutionalized in nursing homes at the point of recruitment, those who had difficulties in understanding the consent process, and the caregivers who did not visit the PWD on a weekly basis were excluded. In total, 29 informal caregivers were interviewed.

2.3 Data collection

Convenience sampling was employed to recruit potential participants from two sites: the outpatient clinics of the Institute of Mental Health (the sole tertiary mental health provider in Singapore) and a geriatric outpatient clinic of a general hospital (i.e., Changi General Hospital). Additionally, the study team contacted caregivers who had participated in previous research studies and had consented to future contact. Furthermore, using the snowball sampling method participants who completed the interview were invited to refer their friends who were also caregivers of PWD to join the study. The data were collected between April 2019 and December 2020, which coincided with the global pandemic caused by the novel coronavirus (COVID-19). Due to the restrictions on physical and social contact, data were collected via semi-structured interviews conducted either face-to-face or online via the Zoom platform.

2.4 Study procedures

Potential caregivers who expressed interest in the study were followed up by the study team via telephone to ascertain their willingness and availability to participate. Prior to the commencement of the interviews, a written informed consent was obtained from all participants. After that, participants were required to fill out a short survey on their sociodemographic information. Qualitative data were collected via semi-structured interviews. The interview guide was developed by the research team based on the literature and their experiences working with local informal caregivers of PWD, and it was reviewed by our senior researchers to ensure that it was appropriate (Table 1). Each interview was conducted by an experienced qualitative researcher using an interview guide accompanied by a note-taker (QY, YJZ, ES, and AJ). Questions covered topics including the reason for seeking help for the PWD, diagnosis, and treatment-seeking process and their feelings, and challenges while taking care of PWD. Probing questions were asked to clarify doubts and obtain valid information. Interviews continued until the research team deemed data saturation had been reached (28). The interviews were typically between 1 and 1.5 h. All interviews were audio-recorded and then transcribed verbatim with any identifying information removed. Transcripts of interviews conducted in other languages were translated into English. A total of 29 interviews were completed, among which six were conducted online via Zoom due to the COVID-19 restrictions implemented during the study period. The interviews were mainly conducted in English (QY, YJZ, ES, and AJ), while two were conducted in Chinese (QY, and YJZ). The methodology has been reported in detail in an earlier article (29). Ethical approval for this study was obtained from the National Healthcare Group Domain Specific Review Board (study reference number: 2018/01069) in Singapore.

TABLE 1 Interview guide.

Topics	Questions
Rapport building	Tell me something about yourself
	What's your relationship with the persons with dementia (PWD)?
	How long have you stayed with the PWD?
	Or how often did you visit the PWD?
	What do you know about dementia?
	How did you get to know this information?
	When did you start taking care of the PWD?
Diagnosis-seeking	Is it before or after the formal diagnosis?
	If before—(1) When did you decide to take [the patient] to see the doctor? Or what made you think [the patient] should see the doctor?
	(2) Can you share a bit more about the process of seeking diagnosis for [the patient]?
	(3) Did you encounter any challenges or difficulties during the diagnosis-seeking process? (e.g., from family members, healthcare system, etc.). If yes, please elaborate.
	(4) How did you feel when you got to know the diagnosis of [the patient]?
	If after—(1) how did you feel when you had to take over the caregiving responsibility?
Treatment-seeking	What are the challenges and barriers you encountered during the treatment-seeking process?
	How do you think these challenges and barriers could be overcame?

2.5 Data analysis

The qualitative data were analyzed using an inductive thematic approach (30). This method was selected for its utility in exploring multiple perspectives, highlighting similarities and differences, providing well-structured guidelines for handling data, and identifying unanticipated insights, all of which facilitate the generation of clear and organized findings (30, 31). The data analysis comprised three iterative steps: data reduction, grouping, and abstraction (30). In particular, four transcripts were selected at random and distributed to the study team members (QY, YJZ, ES, and AJ) for repeated reading and the generation of their own codes. Subsequently, discussions were held to standardize, condense, and group these preliminary codes into a codebook with clear definitions of the codes. Multiple rounds of discussions were held for this purpose. Once the codebook had been finalized, all four team members proceeded to code three of the same transcripts in order to establish inter-rater reliability. Upon achieving a satisfactory kappa coefficient of 0.803 via NVivo Version 11, all 29 transcripts were distributed to the four researchers for independent coding.

The analysis for this study focused on identifying the barriers and facilitators associated with the help-seeking process for PWD. The lead authors systematically organized the codes related to these aspects into potential overarching themes. Subsequently, the lead authors reviewed and refined these themes. This involved evaluating whether the codes within each theme cohesively contributed to the overarching theme and assessing whether the themes accurately reflected the meanings of the data. Dependability was sustained by discussions among the team members at every stage of data collection and analysis. The team also established the study's transferability by employing diverse research contexts (i.e., spouse caregivers and child caregivers), assuming that the findings and understandings might

TABLE 2 Sociodemographic profile of participants.

Variables		Mean (SD)	
Age (years)		56.3 (6.5)	
		N	**%**
Gender	Male	6	20.7
	Female	23	79.3
Ethnicity	Chinese	26	89.7
	Malay	2	6.9
	Indian	1	3.4
Relationship with person with dementia	Spouse	2	6.9
	Daughter	20	69.0
	Son	4	13.8
	Others	3	10.3
Domestic helper to support daily caregiving activities	Yes	15	52.0
	No	14	48.0

TABLE 3 Overview of themes and sub-themes.

Themes	Sub-themes
Barriers to diagnosis-seeking	Lack of knowledge and awareness of dementia
	Emotional denial
	Resistance from the PWD
	Delays in the healthcare system
Facilitators of diagnosis-seeking	Synergy between awareness of dementia and an active diagnosis-seeking intention
	Incidental diagnosis resulting from seeking treatment for comorbid conditions
Barriers to treatment-seeking	Challenges from PWD and the disease
	Challenges faced by caregivers when seeking treatment for PWD
	Challenges imposed by the COVID-19 pandemic
Facilitators of treatment-seeking	Caregivers' capabilities of handling PWD
	Cooperation/compliance from PWD
	Integrated care plan for PWD

be generalized in other research sites. This was to ensure that we had reached thematic saturation with the data collection. All analyses were conducted using NVivo Version 11. Furthermore, in maintaining anonymity, only gender and age were included in the verbatim quotations.

3 Results

Twenty-nine caregivers participated in the study. The sociodemographic profile of the participants is shown in Table 2. The mean age of the participants was 56.3 years (SD = 6.5) and ranged from 46 to 72 years. The majority of participants were of Chinese ethnicity ($n = 26$, 89.7%) and daughter caregivers ($n = 20$, 69.0%). Approximately half of the caregivers ($n = 15$) had hired a domestic helper to assist in their daily caregiving activities.

The results revealed four major themes with 12 sub-themes, including (1) Barriers to diagnosis-seeking (i.e., lack of knowledge and awareness of dementia, emotional denial, resistance from PWD, and delays in the healthcare system); (2) Facilitators of diagnosis-seeking (i.e., synergy between awareness of dementia and an active diagnosis-seeking intention, and incidental diagnosis resulting from seeking treatment for comorbid conditions); (3) Barriers to treatment-seeking (i.e., challenges from PWD and disease, challenges faced by caregivers when seeking treatment for PWD, and challenges imposed by the COVID-19 pandemic); (4) Facilitators of treatment-seeking (i.e., caregivers' capabilities of handling PWD, cooperation/compliance from PWD, and an integrated care plan for PWD). The overview of themes and sub-themes is shown in Table 3.

3.1 Barriers to diagnosis-seeking

3.1.1 Lack of knowledge and awareness of dementia

The majority of caregivers reported a lack of knowledge and awareness of dementia. While caregivers observed early changes in the behavior of the PWD, caregivers either avoided or ignored these behavior changes or could not connect these behavior changes with dementia due to a lack of awareness. Some caregivers waited until they started struggling with the PWD's symptoms, then brought them for consultation, which, in the end, delayed the diagnosis.

> *Uhh … ok … I have … personally my family do not have dementia, so I have never seen … I'm not really associated with a dementia patient. So I do not know what to expect.* (P07/58/F).
>
> *I can recall that … I was … not sure what I should say … ridiculed by the doctor, even though at that time I did not quite feel it, that I did not understand what dementia and Alzheimer's was all about this kind of thing.* (P14/65/M).

3.1.2 Emotional denial

Emotional denial usually happens when caregivers are aware of the disease, but they refuse to admit and face the issue. This was seen in a few caregivers, where they deliberately ignored the potential disease as, to them, dementia is a 'death sentence' and this resulted in a delay in receiving the diagnosis.

> *Err we sus … my father suspected that she's (referring to mother) borderline demented even before she became … fully became demented. There is all these tell-tale signs. My father keep telling me "eh maybe there is some problem with her, there is some problem with her" But we sort of resisted going for proper check-up until the fall in the hospital that forced us to have the check-up anyway because my mother hates going to the hospital.* (P06/68/M).
>
> *I was in denial, when my mom started showing signs and symptoms. Because … to me it's a death sentence that can be very long.* (P25/47/F).

3.1.3 Resistance from the PWD

Caregivers faced resistance from the PWD during the diagnosis-seeking process. Such resistance might be shown as various excuses to not visit the hospital or being uncooperative during the consultation or medical check-ups. These challenges increase the difficulties of getting a proper diagnosis for the patients and prolong the diagnosis-seeking period.

> *Somehow she … she can be very resistant you know. She resisted … even the senior assistant cannot handle her. Yea even if you want to push her into that, the brain scan, you cannot, she refused to participate.* (P05/62/F).
>
> *It took after a while because he wasn't quite willing, it was only I think after he fell and have a fracture of … that they are able to do more, more, more, more stuff with him and all that so that then … it was only then the geriatric doctor come, come and really, come in and finally after do not know how long but he … his process is very long because of all the, the different resistance and all that kind of thing and all the different episodes.* (P10/56/F).

3.1.4 Delays in the healthcare system

Another challenge faced by the caregivers was delays in the healthcare system. Many caregivers reported that the long waiting time to see a doctor was the biggest challenge, as they had to struggle with the PWD's behavior, such as restlessness, shouting, and not being cooperative with the clinic staff during this period. Furthermore, since many tests were usually needed, caregivers might be referred multiple times to different places and must handle similar scenarios repeatedly.

> *…they say you have to wait for the test, you have to wait for the scan, you have to wait for this and then yeah to me it's long la but I do not know ah, what is the, what is the, from department to department is it long or to them it's normal, you know what I mean?* (P05/62/F).
>
> *…excuse me, we had to see one doctor then the doctor will refer and then after that you have to go to another place, tell the story again and then they'll refer again. So, the problem is before you actually get the scan, you always got to see one doctor. So a lot of appointments la so that was a challenge la.* (P09/53/F).
>
> *Yah, because partly is the appointment is every three months. So every three months for a year is about four times. four times, so that is why that every three months when they do a test the following—the next three months then we can get results. And then they—they will order another test, then another three months, then we can get the results. So at the end when they get to confirm it's about a year time.* (P16/58/F).

In addition, some caregivers also mentioned that some clinicians seemed to lack awareness of dementia as well, which resulted in a detour in their diagnosis-seeking journey.

> *when she was 57–58 that kind of thing, now she is 64. And when we went to see her former company's doctor whom she was close with, even then the doctor also dismissed 'no lah XXX is too young to have dementia' that kind of thing. So we lost some time actually to the early intervention.* (P14/65/M).

3.2 Facilitators of diagnosis-seeking

This theme, which comprised two sub-themes, comprised caregivers' narratives about their personal experiences and opinions that prompted them to seek a diagnosis of dementia.

3.2.1 Synergy between awareness of dementia and an active diagnosis-seeking intention

The first sub-theme identified was a synergy between awareness of dementia and an active intention to seek a diagnosis. According to some caregivers, their understanding about dementia symptoms and characteristics played a crucial role in prompting them to seek help for PWD. Recognizing the behavioral changes, caregivers, armed with insightful knowledge, brought the PWD to the appropriate professionals for assistance.

> *Because I noticed a few nights she was—in the middle of the night she was peeping at the door hole you know, at the opposite neighbor, and then she told us that the neighbor is watching us, keeping an eye on us, tailing us, neighbor dislike us, quite a number of times you know. So I was getting very suspicious, there was nobody opposite when you peep at that—So I told her that since she's getting old, maybe it's good to go for a brain check. Doctor will be able to help her, make her, help her to remember things better because now and then she forgets at that point of time so she willingly go with us and doctor confirm that she has dementia.* (P24/66/F).

For some caregivers, this awareness stemmed from significant others, such as friends or other family members, who possessed information about dementia and the pertinent help-seeking processes.

> *…she (nurse friend of caregiver) came for my sister's funeral, because we are actually family friends, so I decided that maybe I should get her advice because she's also a nurse, right and she's the one who told me that it could be Dementia, yes. So what I did, if I go to polyclinic, it will take time for them to get the appointment to see a doctor, right? So what I did, I called up XXX Hospital, I went direct as a private patient, yes, private so it was quite fast, much much more fast. So they gave me an appointment in less than two weeks.* (P01/55/M).
>
> *Before that, I have actually not much knowledge about dementia. Only when my mom starts to repeat herself, ask the same question. Then I realized that maybe something is not right with her. So during one of the follow-up session at the polyclinic, I actually requested the doctor to refer her to hospital Y for a check-up. So we went for the appointment and then the doctor asked to do a MRI. And actually, from there, the results show her brain has actually shrinked, and the doctor says she is having moderate dementia.* (P03/56/F).

3.2.2 Incidental diagnosis resulting from seeking treatment for comorbid conditions

The second sub-theme highlighted incidental diagnosis resulting from seeking treatment for comorbid conditions. In some cases, caregivers were following up with polyclinics (primary care clinics) or tertiary hospitals to manage the chronic physical conditions of the

PWD. If any changes in behaviors were reported by the caregiver, they received immediate referrals to specialists without any delay from the treating clinicians. At other times, the treating clinicians themselves noticed the symptoms and alerted the family about the diagnosis. This proactive approach ensured that caregivers were able to get a timely diagnosis of dementia for their PWDs.

> *Then when she was in the hospital, she could not quieten down. In the middle of the night, she wants to go home. Then she forgot that she has knee … she has a hip replacement, she wanted to walk … yeah … so that was when we discovered that … yah lah … you know … that she has dementia.* (P07/58/F).
>
> *They did several test, several visits, I think may be two, three months. Previously, before that [HOSPITAL B], because we are also going [HOSPITAL B] for some other test. She was a heart centre patient there. So they did several test and then they say that she was diagnosed as having Parkinson. But also not conclusive. So we also never bother because was ok that time, so only [HOSPITAL A] confirm is dementia, then started treatment.* (P13/50/F).
>
> *So, so then two years ago, that means like the third year, third year she got stroke again. This time it's second time. So and then three months later she went for the routine check-up with geriatric and she failed the assessment this time, for that time so they diagnosed her with early stage dementia.* (P18/46/F).

3.3 Barriers to treatment-seeking

3.3.1 Challenges from PWD and the disease

The first sub-theme was the challenges imposed by PWD and their disease. PWDs exhibited behavioral problems like restlessness or being loud and agitated during the treatment-seeking process, and this was usually very challenging for caregivers. In addition, some PWDs had mobility issues because of their other chronic health conditions including surgery, falls, etc. so they had difficulty going to the hospital to seek treatment. Some PWDs had difficulties expressing their needs during their consultation with specialists. They were either unable to express their issues or refused to communicate with the doctors.

> *When we bring her to see a geriatrician, at this point in time she does not know how to explain. So it's through our explanation.* (P05/62/F).
>
> *I mean a few times the doctor had want to talk to me personally and all that kind of thing. He cannot wait outside the clinic for 5 min, he will barge in and say, why is it taking so long? Then the doctor … so got to wrap up. So it's, it's from going to the hospital to taking the taxi to even inside the consultation, it's always kind of a little fights that he put up all throughout, all throughout. So, tiring.* (P10/56/F).
>
> *now his leg cannot really walk a lot so it's kind, somehow of leceh (troublesome) you understand … to bring him there.* (P15/52/F).
>
> *Oh it was a real chore, because she hates the hospital right. You can see that she will cook up all kinds of stories "today I have a tummy ache you know, I do not think I can walk to the … to the taxi stand" because I do not drive, "I do not think I can take bus you know, I very headache I've a lot of headache," or "I think it's about to rain you know, better not let us not get caught in the rain, so let us not … call the hospital and say next week." So this is the problem I face, the resistance about going to visit the hospital.* (P06/68/M).

3.3.2 Challenges faced by caregivers when seeking treatment for PWD

The second sub-theme was challenges faced by caregivers when seeking treatment. The main challenges encountered among caregivers were role conflicts. Some caregivers reported difficulties in handling work/family and caregiving simultaneously. For working caregivers, they would need to take time off from their work to accompany the PWD to the hospital which might affect their work. Some caregivers mentioned the high costs during this process. A few caregivers also expressed their negative attitudes towards treatment options and made the decision regarding the medications on behalf of the PWD without consulting with the doctor.

> *A lot of difficulties because I'm actually inside the operational department. I'm actually one of the main person there. So actually if I need to take time-off to attend to my family's needs of course it will affect the operation of the company itself.* (P01/55/M).
>
> *Ok from the medical part per se, … so many tests and they had to rule out all these so we are really not sure all the time, is this necessary, is that necessary to do. So it's quite costly to have to keep on going for … and time because I'm… I have to work, I have to take care of other people as well, my children were younger then and you know in between taking care of my mom and all these things so, it was quite challenging ah.* (P09/53/F).
>
> *So only thing she got this illness is already happen you know… the only thing that the doctor gave what sort of medicine can help her … let her eat … eat the medicine for about two-three years. My sister say that the medicine actually got side effect, so try not to take. Because take can also never get improve. So we start never let her take. Now only take (medicines for high) blood pressure and vitamin tab.* (P023/56/F).

3.3.3 Challenges imposed by the COVID-19 pandemic

The third sub-theme was the challenges imposed by the COVID-19 pandemic. Some caregivers faced difficulties during the pandemic. PWDs regular follow-up appointments were changed from a few months (of regular follow-up) to yearly follow-up due to the COVID-19 pandemic. During the pandemic, PWD had to comply with several restrictions such as wearing a mask all the time in hospital or daycare settings, which was challenging for them. This led to their refusal to attend daycare centers. At the same time, a number of day care centers were also closed down, which led to a lack of social and stimulating activities for PWD.

> *Emm … last time is every six to … within six to eight months like that to see the doctor. But now due to Covid-19, almost drag to almost … coming to one year. Yah … because we … because we changed the appointment due to COVID-19 lah. So it's a bit longer … slightly longer.* (P23/56/F).

> *so—because I wanted her to go to this ABC elder care. She went there for a while but when Covid started, they want clients to wear mask whole day and she does not like mask so she refuses to go there anymore. So I got to plan for her.* (P24/66/F).

3.4 Facilitators of treatment-seeking

3.4.1 Caregivers' capabilities of handling PWD

The first sub-theme was caregivers' capabilities of handling PWD. Some caregivers used various strategies to bring their PWDs to clinical appointments, such as a reward system, encouraging words, and casual visits to the hospital, which reduced the agitation and anxiety in PWD.

> *Oh, yeah yeah! Let say ah … that day is the appointment, so I will not tell him in advance lah. Firstly he would forget, secondly he will keep on asking again and again. So usually I will tell him on the very day itself, early in the morning lah. Then he will tell me say that what is it I need to go, I'm Ok … that kind of thing lah. He always say that I'm OK, the memory is very normal, old people also got short memory problem.* (P12/63/F).
>
> *she is now at this stage … because I used a reward system to do … modify her behavior. So every time she goes to the doctor … 5 years down the road … every time she goes I will reward her with a lovely meal. So, she will get to eat what she likes, at the restaurant or whatever food at the hawker center. So, she will find going to the doctor very enjoyable….* (P25/47/F).

3.4.2 Cooperation/compliance from PWD

The second sub-theme was related to the PWD being cooperative/compliant. Few caregivers mentioned that their loved ones were willing to take medications and agreeable to going for various tests, assessments, etc. Some PWD had a good rapport with the doctor, so they could easily follow all the instructions given by the healthcare professionals and caregivers. Having a cooperative PWD helped the caregiver to take care of the PWD confidently and calmly during the treatment-seeking process.

> *Er no, treatment, during the treatment everything is very normal. In fact when we visit her she's very good mood one. I mean there's a, there's small area where you can visit and they'll push her out, then buy her something to eat. So she'll very good mood one. Ah there's also struggling la I think.* (P08/56/M).
>
> *Going to the doctor, yes, definitely compliant, he is a bit of a hypochondriac he loves going to the doctor so I got no problem with that.* (P26/49/F).

3.4.3 Integrated care plan for PWD

The third sub-theme was having an integrated treatment plan for PWD and their comorbid conditions. PWD sometimes may also have other comorbid conditions; from this perspective, a treatment plan covering all the health conditions of the PWD was very helpful. It saved caregivers a lot of time and effort in managing the health of the PWD.

> *OK. Previously we go to the polyclinic for her high cholesterol, her hypertension. So ever since we go to Hospital Z for this dementia, so the doctor says we can go Hospital Z and have a one-stop, no need to go to poly, which I think is also good for me. Otherwise we have to go two places you see. So now everything is all under Hospital Z, even when she do her blood test.* (P03/56/F).

4 Discussion

In this study, we identified facilitators and barriers to help-seeking among caregivers of PWD in Singapore. The results revealed four major themes including barriers to diagnosis-seeking (such as lack of knowledge and awareness of dementia, emotional denial, resistance from PWD, and delays in healthcare system), facilitators of diagnosis-seeking (such as awareness of dementia, incidental diagnosis resulting from seeking treatment for comorbid conditions), barriers to treatment-seeking (such as challenges from PWD, challenges faced by caregivers, and challenges imposed by COVID-19 pandemic), and facilitators of treatment-seeking (such as caregivers' capabilities of handling PWD, cooperation from PWD and integrated care plan for PWD). Our results show that barriers to help-seeking for diagnosis and treatment do share some commonalities, such as challenges posed by PWD, long waiting times at clinics/hospitals, and lack of awareness of dementia symptoms. However, in most scenarios, they are quite distinct, and the factors to be taken into account for seeking timely diagnosis and proper treatment are quite different. Diagnosis-seeking is the period from the caregiver noticing the potential symptoms (9), initiating the diagnosis-seeking process from healthcare professionals to receiving the formal diagnosis from healthcare organizations (32). Timely diagnosis-seeking usually leads to a better follow-up and early intervention, which might significantly slow down the disease progression and thus lower the caregiving burden (33, 34). Treatment-seeking refers to the regular follow-ups and management of PWD. During this period, the deterioration is usually steady and slow (35).

Several barriers were identified which possibly led to delayed diagnosis among PWD in Singapore, including a lack of awareness among caregivers, emotional denial of caregivers, resistance from PWD, and delays within the healthcare system (19, 36–38). Given the close proximity with the PWD, caregivers are usually the first to notice the potential symptoms of dementia exhibited by PWD (9, 37). However, a lack of awareness due to a lack of knowledge of dementia and its symptoms makes it difficult for caregivers to relate these symptoms to dementia (19, 20, 38, 39). Instead, they might consider it as a normal part of aging (40), which delays the diagnosis of dementia (16). The second barrier was emotional denial. This happened when caregivers could recognize the symptoms of dementia but refused to acknowledge it and were therefore reluctant to bring the PWD for diagnoses (41–44). This is a type of avoidance coping wherein caregivers facing a dementia diagnosis may not want to accept it as it could lead to anxiety and uncertainty about the future. Such uncertainties are quite normal when individuals encounter unknown situations. However, more studies are needed to understand this better, to investigate the rationale, and to explore how to best help caregivers with such coping strategies—one possible way could be acceptance and commitment therapy training. Other than caregiver factors, resistance from PWD might also delay the diagnosis. There are several reasons for the resistance, such as a lack of understanding of dementia or the self-stigma associated with this disease (20, 45, 46). These issues highlight the need for public education on dementia, especially among older adults and those who are taking care of them (39, 47). Last but not least, the waiting time for appointments and assessments, which are delays inherent to healthcare systems, might also lead to delays in diagnosis. Even in the best-case scenario, it might still take months for PWD to receive their diagnosis (48, 49). This usually requires system-level adjustments such as organizing a separate fast lane in the current healthcare system to speed up the diagnosis process (50).

In all, three themes of barriers during treatment-seeking were identified. These included challenges from PWD, caregivers themselves, and the COVID-19 pandemic. PWD physical conditions, such as immobility, were reported to be a big challenge to caregivers, as it is very challenging to transfer them from home to the healthcare facility and back (51, 52). In Singapore, transportation services for wheelchair-bound older adults are available, however, it might not be well known among caregivers and the costs associated may be financially challenging for some of them. Considering this, telemedicine/teleconsultation might be a good alternative and the hospitals could consider introducing more of such services. Other than transportation, caregivers also reported that PWD sometimes have difficulties expressing their needs of PWDs. This becomes more obvious as the disease progresses and after PWDs gradually lose their ability to communicate (53, 54). A daily caregiving log might be helpful. However, more research is needed in this area to identify and implement better solutions. Caregivers might also encounter other issues, such as role conflicts or financial burdens (19, 49, 55). Both of these issues would require additional investments, such as providing more respite services to enable the flexibility of caregivers and more subsidies to reduce their burden. The long waiting time and the poor management of comorbidities are two other important reasons for caregivers' reluctance to bring their PWDs for regular follow-ups (19, 43). In this case, adopting an integrated care plan comprising multiple healthcare professionals might be helpful. Last but not least, the impact of the COVID-19 pandemic was indeed quite huge on caregivers and PWD (56). However, after the high acceptance of immunization and the evolution of less detrimental mutations of the virus, it is a lesser concern right now in Singapore.

There are several practical implications of our findings. Firstly, timely diagnosis of dementia is never easy; it requires the cooperation of PWD, their caregivers, and healthcare professionals. Public awareness of dementia and its course, as well as trained healthcare professionals in the primary care setting can ensure early recognition and diagnosis of dementia (16, 33). From this perspective, more public health campaigns focusing on public education of dementia might be very helpful. Secondly, proper follow-up care of PWD, especially those with comorbidities requires an integrated care plan. Such a care plan should consider all the needs of PWDs and ensure better care quality. For caregivers, a one-stop comprehensive care plan can help them save their energy and resources, which are spent navigating across the systems, and this would lower their caregiving burden as well (57, 58). Finally, as technology advances, more and more options for remote care and remote consultation are available (59, 60). Such services are particularly suitable for informal caregivers looking after PWD for two reasons: firstly, during the treatment process, most clinicians rely on regular follow-ups to review PWD's status and to decide whether to adjust the medications of the PWD. However, since the disease is quite stable, some of the follow-up appointments could be changed to teleconsultation and caregivers can opt for the traditional face-to-face consultation only when necessary. This would help caregivers avoid challenges such as transportation and handling PWD's symptoms in a public area. Secondly, some digital apps can facilitate the hiring of volunteers or paid caregivers to provide short-term respite services. This could be very helpful especially when caregivers encounter emergencies. However, careful checks must be put in place by these app operators to review these volunteers or paid caregivers to ensure that they are trustworthy and capable of providing such care.

4.1 Strength and limitations

There are several strengths of this study. Firstly, this is the first qualitative study on barriers and facilitators of help-seeking for PWD from the perspective of informal caregivers in Asia. Sampling was purposive for characteristics that could have an impact on help-seeking for dementia and continued until theoretical saturation was reached. Data analysis was iterative and carried out independently by researchers to maximize the yield of themes and concepts. There are some limitations in this study as well. Firstly, in terms of the ethnic background of caregivers, there was an overrepresentation of Chinese ethnicity, and thus, culturally specific themes that may have emerged from the analyses were not observed. Secondly, the study participants were recruited using the snowball sampling method, and caregivers were also invited to refer their peers to join. However, this may have introduced a degree of bias, as the participants may only have been drawn from a relatively small number of caregiver circles. This may limit the generalizability of the study findings. Finally, the interviews happened only after the dyads had reached the service, findings may be affected by recall bias as the caregivers were asked to report when they first noticed symptoms and to comment on the level of difficulty of the help-seeking process retrospectively.

5 Conclusion

In conclusion, this study identifies important facilitators and barriers to help-seeking for PWD from the perspective of their informal caregivers in Singapore through a qualitative approach. A total of four major themes with 12 sub-themes were identified. Caregivers with sufficient knowledge of dementia seem to detect the symptoms early, hence resulting in early diagnosis and treatment. However, if caregivers do not have any knowledge and awareness, they might mistake dementia symptoms as a normal aging process. Possible solutions include an increased focus on public education, raising public awareness regarding what is and what is not a sign of normal aging, annual cognitive screening done by primary care providers, and appropriate community and healthcare support for the caregivers and the PWD both during and post diagnosis (19, 61, 62). These facilitators may overcome such barriers; however, the initiatives need to be monitored for efficacy.

Data availability statement

The original contributions presented in the study are included in the article. Data may be available upon reasonable request and subjected to approval by the Institutional Review Board (IRB). This is a requirement mandated for this research study by our IRB and funders. Requests to access the dataset should be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by the National Healthcare Group's Domain Specific Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

AJ: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – original draft, Writing – review & editing. QY: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. ES: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – review & editing. YZ: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Supervision, Writing – review & editing. RG: Writing – review & editing. LN: Writing – review & editing. MS: Conceptualization, Funding acquisition, Investigation, Project administration, Resources, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Factors influencing the informal caregiving needs among the older adult population in Jiangmen City, China: a cross-sectional study

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Objective: Although China has a vast population, less attention has been paid to the status and training needs of informal caregivers. This study aimed to assess the training needs of the informal caregivers in Jiangmen city, located in Guangdong Province in southern China.

Methods: Three communities within a district of Jiangmen City were selected, and primary caregivers of older adults were invited to complete a self-developed training needs questionnaire. A total of 250 questionnaires were distributed, and 237 questionnaires were finally collected. Of the collected questionnaires, 214 (90.4%) were deemed valid.

Results: Informal caregivers reported a substantial caregiving burden. About 78.5% of informal caregivers had not received formal caregiving training, and over 91.1% expressed a need for such training. In terms of training content, the dimension of older adults care knowledge received the highest scores, followed by health care techniques and daily living care skills, while rehabilitation care techniques scored the lowest. The mean item score was 4.17 ± 0.88. Multi-stepwise regression analysis indicated that training needs of informal caregivers were significantly associated with age, education, employment status, and relationship to the care recipient.

Conclusion: There is a strong demand for informal caregiver training in Jiangmen, Guangdong. Training needs were significantly associated with caregivers' age, education, employment status, and relationship to the care recipient.

KEYWORDS

informal care, training needs, current situation investigation, caregiving, cross-sectional study

Introduction

Population aging is a great challenge globally due to increasing life expectancy and decreased fertility rate, especially in mainland China with a vast population (1, 2). A trend similarly is observed in many developed countries, including the USA, UK, France, and Germany (3). On this basis, home-based informal caregiving, community-based residential care, and institutionalized care have been advocated and become increasingly significant modes of care provision. According to Article 49 of the Constitution of the People's Republic of China, *"Parents have the duty to rear and educate their minor children, and children who have come of age have the duty to support and assist their parents"* (4). This constitutional provision reflects the traditional Confucian value of filial piety, which remains deeply embedded in Chinese culture and social norms. On this basis, most of the older adults care is given by their family members.

Informal caregiving refers to the unpaid care and assistance provided primarily by family members, relatives, or close friends to older adults with functional limitations. As a type of care usually provided by family members, it assists the older adults with functional limitations in their daily lives with no paid compensation (5). Informal caregiving for the older adults is often a long-term commitment, involving not only basic daily support but also more complex tasks such as rehabilitation training and the management of chronic diseases (6). The scope and intensity of caregiving tasks vary widely, depending on the number of caregiving hours, specific care needs, and the level of support available. Compared with the nursing caregivers, informal caregivers, typically family members without formal training, are more likely to experience significant physical and psychological stress (7). The lack of professional knowledge and caregiving skills often contributes to a gradual decline in care quality, negatively affecting the health and well-being of older adults over time.

Studies in the USA and the UK have demonstrated that untrained informal caregivers are at increased risk of caregiver burden, depression, and reduced care quality (8). Evidence from randomized controlled trials and systematic reviews shows that targeted caregiver training programs can significantly reduce caregiving burden, enhance coping skills, and improve outcomes for both caregivers and care recipients (9). Despite a vast population in China, limited attention has been paid to the status and training needs of informal caregiving in the Chinese population. Previous research found that greater caregiving load was significantly associated with higher caregiver burden, with social support intensity playing a key moderating role (10). However, while the impact of caregiving burden has been acknowledged, relatively little is known about the specific skills and support informal caregivers require to improve care quality and reduce stress. Accordingly, this study sought to identify the training needs of informal caregivers in Jiangmen City, China, with a focus on the types of caregiving skills required, preferred training formats, and factors associated with those needs.

Materials and methods

Subjects

This questionnaire-based survey was conducted via an online platform,[1] and participants were recruited from three residential communities in three communities from a district of Jiangmen City, located in Guangdong Province in southern China. Jiangmen is part of the economically developed Pearl River Delta region and has a rapidly aging population due to both urbanization and increasing life expectancy. The selected communities represent a mix of urban and suburban areas, with varying levels of access to healthcare and eldercare resources, making them suitable for assessing the training needs of informal caregivers. The inclusion criteria were as follows: (a) individuals who self-identified as the primary caregivers for disabled older adults, defined as persons with significant physical or cognitive impairments, or diagnosed with Alzheimer's disease, who required assistance with basic life support, disease caring and rehabilitation; (b) caregivers who provided such care without receiving any financial compensation; (c) possessed sufficient cognitive and communication ability to understand the study's purpose and procedures and to provide informed consent; and (d) voluntarily participate in this survey. The individuals with paid compensation, with bias in the understanding of this study, or not willing to participate in the survey were excluded from this study. Caregiving roles and care recipient conditions were verified through screening questions at the beginning of the questionnaire. Participants were asked to indicate the relationship to the care recipients, the types of care tasks they performed (e.g., feeding, bathing, medication administration), and the specific health conditions of the older adults person they cared for. The ethical approval was waived by the board of the ethics committee of our college.

Questionnaire designing and validation

To ensure the scientific validity and relevance of the questionnaire content, a two-round Delphi method was employed. A total of 20 experts in geriatric care were invited to participate, including professionals from hospitals, long-term care institutions, and academic settings located in Guangzhou, Wuhan, and Beijing (Supplementary File 1). Among them, 13 experts held senior or associate senior professional titles, 12 held a master's degree or higher, and all had more than 5 years of experience in older adults care or related fields. In the first round, experts were asked to rate the relevance and clarity of each item on a 5-point Likert scale and provide qualitative suggestions for revision. Feedback was analyzed quantitatively and qualitatively. Items with a mean score below 4.0 or a coefficient of variation (CV) greater than 0.25 were subject to revision or removal. In the second round, the revised questionnaire was redistributed, and experts re-evaluated the items. Kendall's coefficient of concordance (W) was calculated to assess the level of consensus, with $W > 0.70$ indicating strong agreement. After the second round, consensus was reached on all items, and the final version of the questionnaire was established based on expert feedback and a small-scale pilot test.

The questionnaire consisted of three parts: (i) The questionnaire for collecting the demographic information, including sex, age, marriage, employment, education, health condition, relationship with the older adults in care, and the assistance involved in the care. (ii) Informal caregiving information, including hours spent in caregiving, average hours spent in caregiving per day, source of caregiving knowledge. (iii) Training-need assessment scale for informal caregivers. It comprised 18 items, organized into four logically related dimensions established through the two-round Delphi process: (a) older adults caregiving knowledge (five items), covering psychological and physiological characteristics of older adults, common chronic diseases, medication guidance, and nutritional/dietary needs; (b) life-care technology (five items), focusing on daily living support skills such as feeding, bathing, dressing, toileting, and safe mobility assistance; (c) health caring technology (five items) including disease monitoring, first aid for emergencies (e.g., falls, choking, injuries), infection prevention, and basic nursing procedures; and (d) rehabilitation caring (two items) involving guidance on functional training and mobility rehabilitation for older adults. The number of items per dimension in the training needs scale reflects the relative

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[1] https://www.wjx.cn/

Abbreviations: COPD, hypertension and chronic obstructive pulmonary disease; DM, diabetes mellitus; QoL, quality of life.

importance and demand for different types of elder care knowledge and skills, resulting in the observed differences across dimensions. A scale of 1–5 was designated for each item, with 1 score demonstrating not necessary and 5 score demonstrating very necessary. Caregivers selected the appropriate score based on their own conditions. A high score indicated a high training need for the informal caregiving. The scale had been tested for reliability and validity, showing an acceptable Cronbach's Alpha coefficient.

Methodology

After obtaining the consent of the community committee, the questionnaires were distributed to the survey respondents who met the inclusion criteria from April 2023 to October 2023. The investigators of this research team were all qualified and received professional training before distributing the questionnaire in filling in the remarks during the survey, distributing and collecting the questionnaires, as well as timely answers to questions raised by the survey respondents. A total of 250 questionnaires were distributed, and 237 questionnaires were finally collected. Among the collected questionnaires, 214 (90.4%) questionnaires were effective. A questionnaire was considered valid if it met the following criteria: all essential items were completed without missing data; the responses were internally consistent (e.g., no logical contradictions); and the respondent met the inclusion criteria. We applied multi-stepwise regression to identify the key factors influencing the training needs. This approach allows us to systematically evaluate multiple potential predictors while controlling for confounding variables, and to select the most significant variables that contribute to variations in caregivers' training needs.

Statistical analysis

After removing the invalid questionnaires, the data from the eligible questionnaires were entered into the Excel. All the data were analyzed using the SPSS 26.0 software. Continuous variables normally distributed were expressed as mean ± standard deviation (SD). Descriptive statistical analysis was used to analyze the scores of each dimension of the demographic information, caregiving data, and training need scale. Student's *t*-test and variance analysis were used to analyze the needs of respondents with different characteristics. Variables with a p value of less than 0.05 in the univariate regression analysis was adopted into the multiple stepwise regression, to identify the risk factors for the training need of informal caregiving. A p value of less than 0.05 was considered to be statistical significance.

Results

Basic demographics of the informal caregivers

In total, 214 subjects (female: 153; male: 61) accomplished the questionnaire. The majority of informal caregivers (62.1%) were aged 40 years or older. Merely 22.4% of the caregivers obtained a bachelor's degree or more. About 56.6% of the caregivers showed a son/daughter-in-law or daughter/son-in-law relationship with the older adults care recipients. In addition, 19.6% of the caregivers showed a history of chronic disease (Table 1).

Training needs of informal caregivers

Table 2 summarized the caregiving characteristics of the informal caregivers. About 42.5% had been providing care for up to 12 months, followed by those caring for 3 months or less (38.8%), 3–6 months (14.7%), and 6–12 months (4.7%). In terms of average daily caregiving time, 43.9% reported less than 2 h per day, followed by 2–6 h (37.9%), 6–12 h (12.1%), and more than 12 h (6.1%). The majority of caregivers (78.5%) had not received any professional training prior to providing informal care. Among all respondents, 61.2% expressed a perceived need for professional caregiving training. Among those who had received training, most had only been trained in basic life support (23.9%), with the primary sources of training being experienced friends or family members.

Score of training needs for informal caregivers in various dimensions

Table 3 presented the training needs score of informal caregivers. Among the four dimensions of the training needs assessment scale, older adults caregiving knowledge received the highest mean score (4.17 ± 0.88), followed by health care technology (4.14 ± 0.82), life-care technology (4.04 ± 0.95), and rehabilitation care (3.92 ± 1.05). Within the training needs scale, two items showed a mean score of less than 4, including functional impairment (i.e., speech, movement, swallowing) and user guides to the commonly utilized facilities (e.g., wheelchairs and walkers). The top needs for the informal caregiving training were the necessities for the caring of chronic diseases including diabetes mellitus (DM), hypertension and chronic obstructive pulmonary disease (COPD) (Table 4).

Multiple stepwise regression analysis

With the needs score as the dependent variable, we adopted the variables with statistical significance ($p < 0.05$) in the univariate analysis into the multiple stepwise regression analysis. Based on univariate analysis (Table 5), informal caregivers with different age, working status, educational level and relationship with the older adults under care showed different training needs.

The multiple stepwise regression analysis results are shown in Table 6. Compared with caregivers aged <30 years, those aged 40–50 years ($B = 0.51$, 95% CI: 0.25 ~ 0.76, $p < 0.001$) and 50 years or more ($B = 0.43$, 95% CI: 0.14 ~ 0.73, $p = 0.004$) had significantly higher training needs. Relative to full-time workers, unemployed ($B = 0.71$, 95% CI: 0.46 ~ 0.95, $p < 0.001$) and retired caregivers ($B = 0.46$, 95% CI: 0.10 ~ 0.82, $p = 0.01$) reported higher needs. Higher education was linked to lower needs, with college and bachelor's degree or above scoring lower than primary education ($B = -0.42$, 95% CI:−0.75 ~ −0.09, $p = 0.012$). Compared with sons- or daughters-in-law and daughters or sons-in-law, other relatives ($B = -0.41$, 95%CI: −0.65 ~ −0.17, $p < 0.001$) and non-relatives ($B = -0.57$, 95%CI: −0.88 ~ −0.25, $p < 0.001$) had significantly lower scores.

TABLE 1 General information of informal caregivers.

Variables	Number (percentage)
Gender	
Male	61 (28.5%)
Female	153 (71.5%)
Age	
<30 years	50 (23.4%)
30–40 years	31 (14.5%)
40–50 years	91 (42.5%)
>50 years	42 (19.6%)
Marriage	
Married	146 (68.2%)
Not-married	61 (28.5%)
Divorced and/or widowed	7 (3.3%)
Employment	
Full-time employment	95 (44.4%)
Part-time employment	34 (15.9%)
No job	53 (24.8%)
Retired	16 (7.5%)
Farmer	16 (7.5%)
Education	
Preliminary school	21 (9.8%)
Middle school	44 (20.6%)
High school	42 (19.6%)
College	59 (27.6%)
Bachelor's degree or more	48 (22.4%)
Relationship	
Spouse	12 (5.6%)
Son/daughter-in-law	74 (34.6%)
Daughter/son-in-law	47 (22.0%)
Other relations	60 (28.0%)
Social relationship (e.g., friends or neighbors)	21 (9.8%)
Family assistance during the informal caregiving	
Yes	109 (50.9%)
No	105 (49.1%)
Monthly income	
≤2,000 CNY	57 (26.6%)
2,000–4,000 CNY	51 (23.8%)
4,000–6,000 CNY	55 (25.7%)
>6,000 CNY	51 (23.8%)
Health status of the caregivers	
Good	140 (65.4%)
Moderate	66 (30.8%)
Poor	8 (3.7%)
Chronic diseases	
Yes	42 (19.6%)
No	172 (80.4%)

TABLE 2 Caregiving situation of informal caregivers.

Variables	Number (frequency)
Total caregiving time	
<3 months	83 (38.8%)
3–6 months	30 (14.0%)
6–12 months	10 (4.7%)
>12 months	91 (42.5%)
Caregiving time per day	
<2 h	94 (43.9%)
2–6 h	81 (37.9%)
6–12 h	26 (12.1%)
>12 h	13 (6.1%)
Received professional training on the caregiving	
Yes	46 (21.5%)
No	168 (78.5%)
Necessity for the training on caregiving	
Extremely	83 (38.8%)
Yes	112 (52.3%)
No	19 (8.9%)
Received training for the caregiving	
Care positioning, quality and ability recognition	17 (12.0%)
Physical and ability assessment	28 (19.7%)
Basic life care	34 (23.9%)
Medication	22 (15.5%)
Care for functionally impaired older adults people	13 (9.2%)
Emergency rescue	13 (9.2%)
Dementia care	6 (4.2%)
Palliative care	9 (6.3%)
Tools for obtaining the caregiving knowledge	
Friends and relatives with care experience	139 (26.1%)
Professional nursing	89 (16.7%)
Online resource and television program	105 (19.7%)
Books	70(13.1%)
Education from elders	95 (17.8%)
Care-related lectures and forums	35 (6.6%)

TABLE 3 Training needs scores of informal caregivers in various dimensions.

Variables	Number of question	Score
Older adults care knowledge	5	4.17 ± 0.88
Life care knowledge	5	4.04 ± 0.95
Health care knowledge	6	4.14 ± 0.82
Rehabilitation care knowledge	2	3.92 ± 1.05
Total	18	4.10 ± 0.77

TABLE 4 Score on training needs items among informal caregivers.

Dimension	Entry	Score
Older adults care knowledge	Guidance on knowledge related to the physiological and anatomical characteristics of the older adults	4.00 ± 1.07
	Nursing guidance for common psychological and mental problems	4.19 ± 0.97
	Guidance on common chronic diseases in the older adults such as DM, hypertension, and COPD	4.29 ± 0.94
	Diet and nutrition guidance	4.24 ± 0.95
	Daily life and TCM healthcare knowledge guidance	4.04 ± 1.04
Life care knowledge	General dietary care techniques for the eating and drinking	4.08 ± 1.04
	Guidelines on providing oral, hair, and skin care, as well as morning and evening hygiene support	4.04 ± 1.04
	Guidance on excretion care techniques for constipation and urinary incontinence	4.00 ± 1.01
	Sleep care	4.00 ± 1.00
	Technical guidance on safety and transfer care	4.07 ± 1.02
Health care knowledge	Guidance on drug-use safety	4.20 ± 0.91
	Guidance on measuring vital signs including temperature, respiration, pulse and blood pressure	4.14 ± 0.88
	Special dietary care guidance	4.13 ± 0.96
	Guidance for the caring of the older adults with Alzheimer disease	4.05 ± 1.04
	First aid guidance for the older adults on falling, choking, injuries, and fractures	4.27 ± 0.85
	Palliative care guidance	4.09 ± 0.96
Rehabilitation care knowledge	Rehabilitation training and care guidance for older adults people with functional impairment in language, movement and swallowing	3.94 ± 1.09
	Guidance on the use of common assistive devices for the older adults such as wheelchairs and walkers	3.90 ± 1.04

COPD, chronic obstructive pulmonary disease; DM, diabetes mellitus; TCM, traditional Chinese medicine.

Discussion

Caring the older adults presents a significant challenge for families, particularly in China, where population aging is accelerating. In some developed countries, family caregiving has been incorporated into the long-term care insurance system (11, 12), however, in most of Asian countries, adult children are expected to assume primary responsibility for supporting and caring for their aging parents, due to cultural norms of filial piety and legislative requirements (13). This reliance on informal caregiving has led to considerable burdens for family members. Thus, attention should be paid to these individuals in order to alleviate their stress and improve the quality of life (QoL) for both caregivers and care recipients. This study was designed to investigate the current landscape of informal caregiving in Jiangmen City and to identify the factors associated with caregiving needs, based on findings from a cross-sectional survey.

Informal caregiving has been associated with reduced quality of life, poorer overall well-being, increased risk of severe depression, and substantial financial strain (14). Despite these challenges, most informal caregivers have limited access to professional training and receive no financial compensation for their efforts (15, 16). In the present study, 47.2% of informal caregivers have provided care for more than 6 months, and 56.1% offered care for more than 2 h per day, and 18.2% reported caregiving durations exceeding 6 h daily. Additionally, over half of the respondents were not engaged in full-time employment while providing care, reflecting the significant time commitment and economic burden associated with informal caregiving. These results were consistent with the previous studies (14). Notably, 78.5% of informal caregivers had not received any form of professional training, and over 90% expressed a need for such training. These results implied the urgent and unmet demand for structured training programs to support informal caregivers in delivering safe and effective care. In our survey, some caregivers had received only basic life-support training, with a lack of professional guidance. Informal caregivers primarily acquired caregiving knowledge through informal channels, such as advice from friends or relatives with caregiving experience, online resources and television programs (17). Very few participants had access to structured training delivered by formal institutions or professional caregivers. Consistent with the previous studies (18, 19), our data showed that the caregiving responsibilities were predominantly undertaken by middle-aged, unemployed women. These findings underscore the critical need for accessible, standardized, and professionally led training programs to better equip informal caregivers in China.

Our study showed a substantial demand for caregiving training among informal caregivers, with an overall score of 4.17 ± 0.88. Among the four dimensions, knowledge related to older adults care received the highest score, encompassing psychological and physiological guidance, information on common chronic diseases, and dietary and nutritional advice. This elevated need may reflect the high prevalence of chronic conditions among older adults (20), for which caregivers require more specialized knowledge, including medication management and disease-specific dietary recommendations. The score for rehabilitation caring was the lowest among these items. This may be attributed to the perception that rehabilitation should be conducted by trained professionals, such as physicians or institutional nurses, rather than informal caregivers. Among the 18 items assessed across the four dimensions, the top three priorities identified were: guidance on managing common chronic diseases in older adults (e.g., hypertension, DM, and COPD); first aid

TABLE 5 Univariate analysis for the training needs of the informal caregivers.

Variables	Number	Score	*t*-value	*P*-value
Gender			−1.749	0.084
Male	61	3.93 ± 0.98		
Female	153	4.16 ± 0.66		
Age			13.620	<0.001
<30 years	50	3.67 ± 0.83		
30–40 years	31	3.76 ± 1.07		
40–50 years	91	4.32 ± 0.47		
>50 years	42	4.38 ± 0.66		
Marriage			0.779	0.460
Married	146	4.13 ± 0.72		
Not-married	61	4.07 ± 0.82		
Divorced and/or widowed	7	3.77 ± 1.28		
Employment			5.423	<0.001
Full-time employment	95	3.84 ± 0.93		
Part-time employment	34	4.24 ± 0.70		
No job	53	4.33 ± 0.42		
Retired	16	4.44 ± 0.51		
Farmer	16	4.21 ± 0.49		
Education			6.914	<0.001
Preliminary school	21	4.58 ± 0.94		
Middle school	44	4.42 ± 0.81		
High school	42	3.99 ± 0.56		
College	59	4.01 ± 0.60		
Bachelor's degree or more	48	3.79 ± 0.82		
Relationship			4.242	0.003
Spouse	12	4.42 ± 0.72		
Sons or daughters-in-law	74	4.17 ± 0.55		
Daughters or sons-in-law	47	4.33 ± 0.51		
Other relations	60	3.89 ± 0.89		
Social relationship (e.g., friends or neighbors)	21	3.74 ± 1.22		
Family assistance during the informal caregiving			−0.399	0.690
Yes	109	4.08 ± 0.85		
No	105	4.12 ± 0.68		
Monthly income			1.828	0.143
≤2,000 CNY	57	4.26 ± 0.62		
2,000–4,000 CNY	51	3.99 ± 0.78		
4,000–6,000 CNY	55	3.97 ± 0.77		
>6,000 CNY	51	4.16 ± 0.88		
Health status of the caregivers			0.914	0.403
Good	140	4.06 ± 0.81		
Moderate	66	4.13 ± 0.70		
Poor	8	4.42 ± 0.41		
Chronic diseases			−0.141	0.888
Yes	42	4.08 ± 0.84		
No	172	4.10 ± 0.75		

TABLE 6 **Multiple stepwise regression analysis results with demand score as the dependent variable.**

Variables	Unstandardized coefficients	95% CI	*t*-value	*P*-value
Aged less than 30	Reference			
Aged 30–40 years	0.02	−0.29 to 0.34	0.14	0.89
Aged 40–50 years	0.51	0.25–0.76	3.97	<0.001
Aged 50 or more	0.43	0.14–0.73	2.90	0.004
Full-time occupation	Reference			
Part-time occupation	0.18	−0.09 to 0.45	1.33	0.18
No job	0.71	0.46–0.95	5.72	<0.001
Retired	0.46	0.10–0.82	2.50	0.01
Farmer	0.20	−0.16 to 0.56	1.08	0.28
Preliminary school	Reference			
Middle school, high school	−0.31	−0.63–0.02	−1.88	0.06
College, bachelor's degree or more	−0.42	−0.75 to −0.09	−2.54	0.012
Sons or daughters-in-law, daughters or sons-in-law	Reference			
Spouse	−0.04	−0.44 to 0.36	−0.21	0.83
Social relationship (e.g., friends or neighbors)	−0.41	−0.65 to −0.17	−3.36	<0.001
Other relations	−0.57	−0.88 to −0.251	−3.54	<0.001

procedures (e.g., for falling, choking, injury and fracture); and diet and nutrition guidance. These findings are in line with previous studies, which have consistently shown that informal caregivers express the most urgent need for knowledge regarding chronic disease management (21), first aid (22), and older adults nutrition (23).

Caregivers of different age groups showed different needs for the informal caregiving training (19). Our findings indicate that older caregivers, particularly those aged 40–50 years and above, reported higher training needs, which may reflect their more intensive caregiving roles, longer daily care hours, and potentially lower adaptability to new caregiving knowledge acquisition channels compared with younger caregivers. In contrast, younger caregivers may rely more on self-learning via digital resources, reducing their perceived need for formal training. This may be attributed to their younger age and generally higher educational attainment, which enables them to access caregiving knowledge independently through the internet, books, and other self-directed channels (24). Education level was also a key determinant, with lower educational attainment linked to higher demand for training. This aligns with the notion that caregivers with limited educational backgrounds may face greater challenges in understanding disease management, medication use, and rehabilitation techniques without structured guidance. This finding aligns with previous studies showing that lower educational attainment is associated with a higher perceived caregiving burden (25, 26). These findings suggest the importance of adopting stratified and tailored training strategies. For older caregivers with lower levels of education, easily accessible formats such as popular science videos, animated content, and other visually engaging materials may facilitate understanding and knowledge retention. In contrast, for more educated caregivers, expert-led seminars or in-depth lectures on geriatric conditions may offer a more appropriate and effective training modality.

Significant differences were reported in the training needs of informal caregivers with different working conditions (27). Employment status further influenced training demand: unemployed and retired caregivers expressed stronger needs in this study, likely due to their greater availability for caregiving and reliance on it as a primary daily activity. Balancing employment responsibilities with caregiving duties can constrain their involvement in direct care, thereby reducing their perceived need for formal training (28). This finding was consistent with the study by Rachiel, which showed that full-time employment was associated with reduced hours spent on informal caregiving as early as the 1980s (29). Therefore, for informal caregivers with full-time employment, training program should offer greater flexibility in terms of timing, delivery methods, and formats. This approach would enable them to access essential caregiving knowledge efficiently, without imposing additional time and energy burdens, thereby improving the quality of care they provide. In our study, significant differences were observed in the training needs and dimensions among informal caregivers with varying relationships to the older adults. Among them, compared with sons or daughters-in-law, and daughters or sons-in-law, those shared a social relationship or other relations with the older adults reported significantly lower training needs. This may reflect the closer familial or blood ties between these caregivers and the care recipients, which could foster a stronger intrinsic motivation to enhance their caregiving skills and provide higher-quality care.

There are inevitably some limitations in this study. First, this is a retrospective study, which could not eliminate the possibility of selection bias. Second, the sample size is not large, and in the future, we will carry out a study with a large sample size. Third, the study did not capture detailed information regarding the specific training content desired by respondents, nor did it account for the potential use of alternative or supplementary caregiving arrangements. Forth, training dimensions were not grouped as logically and systematically as might be ideal, which may affect the clarity and readability of the framework. Last, the generalizability of these findings may be limited due to the unique social, cultural, and economic characteristics of Jiangmen. Differences in caregiving practices, family structures, and available resources across regions could influence the applicability of the results to other settings. Due to many direct relatives living abroad, most caregivers were other relatives or friends, potentially affecting generalizability. Therefore, caution should be exercised when extrapolating these findings beyond Jiangmen, as training needs and caregiving dynamics may vary in different contexts.

In summary, there is a great need for informal caregiver training in Jiangmen city, Guangdong, China. More than half of the informal caregivers had not received formal training in older adults care and demonstrated a strong demand for such training. Multi-stepwise regression analysis indicated that training needs were significantly associated with caregivers' age, education level, employment status, and relationship to the care recipient.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The ethic approval was waived by institutional review board of the Guandong Jiangmen Chinese Medicine College. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

YZ: Formal analysis, Writing – original draft. HZ: Data curation, Writing – review & editing. SHe: Data curation, Writing – review & editing. SHu: Data curation, Writing – review & editing. XZ: Data curation, Writing – review & editing. FF: Data curation, Writing – review & editing. GZ: Methodology, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Factors related to social disconnectedness among older unpaid caregivers

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Background: Older unpaid caregivers often face social isolation and loneliness, yet risk factors for social disconnection remain largely unexplored. As the demand for unpaid caregiving rises with an aging population, there is a need for targeted interventions to reduce social disconnectedness in this vulnerable group. This study aimed to identify determinants of social disconnectedness.

Methods: Data came from a sample of 701 unpaid caregivers aged 60 + who completed an internet-based survey assessing sociodemographics, health status, financial strain, social environment, and social disconnectedness. Four sequential regression models were used to identify the unique contribution of these factors related to social disconnectedness.

Results: The first model ($F = 3.94$, $p < 0.001$, $aR^2 = 0.030$) showed that older age ($\beta = -0.15$, $p < 0.001$), self-identifying as being Black ($\beta = -0.10$, $p = 0.008$), and higher education ($\beta = -0.11$, $p = 0.041$) were associated with lower social disconnectedness. Adding health factors in the second model ($F = 15.33$, $p < 0.001$, $aR^2 = 0.170$) revealed that, in addition to age and education, chronic conditions ($\beta = 0.12$, $p = 0.001$) and possible depression ($\beta = 0.35$, $p < 0.001$) were associated with social disconnectedness. Including financial strain in the third model ($F = 15.52$, $p < 0.001$, $aR^2 = 0.212$) showed that household income ($\beta = -0.10$, $p = 0.012$) and financial stress ($\beta = 0.18$, $p < 0.001$) were additionally associated with social disconnectedness. The final model ($F = 23.42$, $p < 0.001$, $aR^2 = 0.366$) that included social environmental factors showed that age ($\beta = -0.07$, $p = 0.033$), possible depression ($\beta = 0.22$, $p < 0.001$), financial stress ($\beta = 0.16$, $p < 0.001$), and levels of community belonging ($\beta = -0.20-0.58$, $p < 0.001$) were significantly related to the risk of disconnectedness.

Conclusion: Findings highlight possible intervention targets that have the potential to reduce social disconnectedness among older unpaid caregivers. Particularly, addressing depressive symptoms, reducing financial stress, and enhancing community belonging are essential components to mitigate social disconnectedness risk in this population.

KEYWORDS

unpaid caregivers, older adults, social environment, financial strain, social disconnectedness

Introduction

Unpaid caregivers, also known as informal, family, or friend caregivers, play an essential role in supporting individuals with chronic illnesses, disabilities, or age-related conditions (1, 2) by providing care to them without professional training or compensation (3). As such, unpaid caregiving often entails considerable physical, emotional, and financial burdens (1). Many unpaid caregivers dedicate substantial amounts of time providing care, which can limit their ability to engage in social activities, nurture relationships, and participate in community gatherings (4). This risk of social disconnectedness is particularly pronounced for older unpaid caregivers as they face their own age-related challenges, such as physical limitations, declining health, and reduced mobility, which further isolate them from social interactions, leaving them especially vulnerable as they balance their caregiving responsibilities with their personal well-being (5).

Social disconnectedness is the state characterized by a lack of social connection—an umbrella term that encompasses various dimensions of social relationships, including structural (e.g., size of social networks, marital status, living situation, social isolation), functional (e.g., received and perceived social support, loneliness), and quality-related (e.g., satisfaction with relationships, conflict) aspects of an individual's world (6, 7). Social disconnectedness has a significant impact on health and overall well-being across all age groups (8, 9). The consequences of social isolation and loneliness in caregivers, as well as its influence on the care recipients are well documented (10). While extensive research exists on the risks of social isolation among the older adult population at large, there remains a significant gap in understanding its prevalence and implications among older unpaid caregivers. Furthermore, most studies on social disconnectedness in this group have focused on one aspect of social disconnectedness that generally taps into either structural or functional dimension (11–13) and have not considered diverse aspects of social disconnectedness simultaneously, limiting a comprehensive understanding of the social disconnectedness risk faced by unpaid caregivers.

Caregiving for older adults can negatively affect unpaid caregivers financially due to decreased work hours and household income, high costs of care, and reduced capacity to work (14, 15). A recent review noted that unpaid caregivers face both direct financial costs (i.e., out-of-pocket expenses) and indirect financial costs (i.e., changes in household finances due to reduced labor participation) resulting in significant financial strain on this population (16). Financial strain is a robust predictor of social isolation across the life course, particularly for older adults (17), due to a lack of resources and/or increased labor commitments that result in an inability to engage in leisure and social activities (18). The resulting lack of engagement exacerbates social disconnectedness, creating a vicious cycle of isolation. Given that unpaid caregivers often provide support for extended periods (i.e., years), they are at particular risk for chronic social disconnectedness. However, access to community resources and strong connections within the community can serve as protective factors against the dual burdens of financial strain and social disconnectedness faced by unpaid caregivers.

Social environment plays an important role in health and well-being and is directly related to social disconnectedness (19). Social environment refers to the physical and social contexts in which individuals live, work, or interact, including workplaces, parks, or neighborhoods (including urban, rural or remote areas) (20). This environment influences unpaid caregiver's lives, including their sense of belonging and access to community resources (21). For example, caregivers in rural or remote areas may have limited access to health care services and community programs, which can exacerbate the effects of an already challenging caregiving role and possibly increase the risk of social disconnectedness.

Understanding the factors that contribute to the risk of social disconnectedness in older unpaid caregivers is crucial for designing targeted interventions that can effectively mitigate isolation and reduce its negative impact on health and well-being. To address this gap in the literature, the purpose of this study was to identify different types of factors associated with social disconnectedness risk among unpaid caregivers aged 60 and older.

Methods

Data source

Data were analyzed from a cross-sectional, internet-delivered questionnaire targeting adults ages 60 years and older residing in the United States (22). Participants were recruited nationwide through a Qualtrics Internet Panel (23) between June 2019 and September 2019. To address potential sampling bias introduced by online convenience sampling, quota sampling parameters were employed to diversify the sample across key demographic characteristics, including age, sex, race, and geographic location (22, 24). After participants were identified by Qualtrics, they were presented with a link to the online questionnaire, which required acknowledgment of an Institutional Review Board (IRB)-approved information sheet. Participation in the study was voluntary, and participants could choose to stop taking the survey at any time. Participants were compensated by Qualtrics for their participation, not the research team, in accordance with the Qualtrics Internet

Panel policy. A total of 4,101 older adults completed the survey, of which 19 were omitted for missing data on all questions. To align with the study's focus on unpaid caregivers, participants who indicated "yes" to a question about providing unpaid regular care or assistance to a friend or family member with a health problem or disability were included in the analyses. The resulting analytic sample was 701 unpaid caregivers ages 60 years and older. All survey procedures were approved by the Texas A&M University IRB (IRB2019-0375).

Variables and measures

Sociodemographics

Measures used to identify participant characteristics included self-reported age (i.e., range from 60 to 94 years), sex (i.e., male, female), ethnicity (i.e., non-Hispanic, Hispanic), race (i.e., White or Caucasian, Black or African American, Another Race), education level (i.e., high school education or less, some college, college graduate or more), and whether the participant lived alone (i.e., no, yes).

Health factors

Health factors included the number of chronic conditions and possible depression. Participants were asked to report if a healthcare provider told them they had any of 19 chronic conditions (e.g., arthritis, diabetes, high cholesterol, high blood pressure, cancer, chronic pain, osteoporosis, urinary incontinence). The number of self-reported chronic conditions were summed to create a composite score. Depressive symptoms were measured by the two-item version of the Patient Health Questionnaire (PHQ-2) (25, 26). This brief assessment contains the first two items of the PHQ-9 (27), which measures the two cardinal symptoms of depression: depressed mood and anhedonia. The PHQ-2 asks participants to report the frequency they "felt down, sad, or hopeless" and "had little interest or pleasure in doing things" in the past 2 weeks. Response choices were on a 4-point Likert scale that ranged from "not at all" (scored 0) to "nearly every day" (scored 3). These items were summed, with a total score ranging from 0 to 6. The scores were dichotomized using the recommended cutoff of ≥3, indicating those with possible depression (28).

Financial strain

Financial strain was assessed using annual household income, current employment status, and a four-item financial stress scale. Participants were asked to self-report their annual household income [i.e., ranging from "less than $10,000" (scored 1) to "$60,001 or more" (scored 6) in $10,000 increments] and if they were currently employed (i.e., "no" or "yes"). Further, participants were asked a series of four items to determine whether they were worried or stressed about having enough money regarding (a) paying their rent or mortgage; (b) buying nutritious meals; (c) buying medications; and (d) meeting their basic needs. Response choices for each item were on a 5-point Likert scale that ranged from "never" to "always." Based on the frequency distribution, each item was dichotomized as "never/rarely" (scored 0) and "sometimes/usually/always" (scored 1). These four items were summed to create a composite score ranging from 0 to 4 (Cronbach's alpha = 0.84), with higher scores indicating more financial stress.

Social environment

Social environment included rurality/urbanicity of participant's residence, access to resources, and community belonging. Participants' county of residence was geocoded based on the 2013 Rural–Urban Continuum Codes (RUCC), which were the most current at the time of data collection. These codes indicate population density within a given county and range from 1 to 9, where higher values indicate residing in more rural areas (29). To capture access to local resources, participants were asked to indicate if "it is easy for me get to appointments, grocery stores, places of worship, and other locations." Response choices for this item were "yes" (scored 0) and "no" (scored 1), with higher scores indicating more access to resources. Finally, participants were also asked to rate their sense of belonging to their local community, using a 4-point Likert scale. Response choices were "very weak" (scored 1), "somewhat weak" (scored 2), "somewhat strong" (scored 3), and "very strong" (scored 4).

Social disconnectedness risk

The primary outcome of interest was the risk of social disconnectedness among participants, measured by the Upstream Social Interaction Risk Scale (U-SIRS-13) (22, 30). This 13-item scale asked participants to report the frequency of feeling disconnected in terms of physical opportunities to interact with others and the emotional fulfillment of such interactions (or lack thereof). Response choices were on a 3-point Likert scale and included "none of the time" (scored 1), "some of the time" (scored 2), and "often" (scored 3). Each item was then dichotomized based on the directionality of the wording to create items scored as "no risk" (scored 0) and "risk" (scored 1). Items were then summed to generate a continuous score from 0 to 13, with higher scores indicating higher risk for social disconnectedness. Cronbach's alpha for the U-SIRS-13 in the sample was 0.80, which aligns with the strength of reliability coefficients identified in other studies (22).

Data analysis

All analyses were performed using IBM SPSS Statistics (Version 29). First, descriptive statistics were computed for the sample. Then, we fitted a series of sequential ordinary least squares regression models to examine the relative importance of participants' sociodemographic characteristics, health factors, financial strain, and social environments on the risk for social disconnectedness. Variable sets were sequentially added as blocks into each subsequent regression model (i.e., a total of four blocks). The proportion of error variance controlled for by each model (i.e., Adjusted R Square) was compared across the four regression models. Regression diagnostics were conducted to assess the assumptions of multivariable linear regression, including the absence of multicollinearity among the variables by checking the variance inflation factor (VIF). For all statistical tests, effects were considered significant at $p < 0.05$.

Results

Table 1 provides demographic information about participants. The average age was 69.05 (±5.02) years. Most participants were female (63.6%), non-Hispanic (80.0%), and White or Caucasian (71.1%). Most

TABLE 1 Sample characteristics ($n = 701$).

Variable	% or Mean (±SD)
Upstream Social Interaction Risk Scale (range: 0 to 13)	3.57 (±2.76)
Sociodemographic factors	
Age (range: 60–94 years)	69.05 (±5.02)
Female	63.6%
Male	36.4%
Non-Hispanic	80.0%
Hispanic	20.0%
White or Caucasian	71.1%
Black or African American	21.5%
Another Race	7.4%
Highest Level of Education: High School or Less	16.4%
Highest Level of Education: Some College	37.1%
Highest Level of Education: College Graduate or More	46.5%
Live Alone: No	79.3%
Live Alone: Yes	20.7%
Health factors	
Number of Self-Reported Chronic Conditions (range: 0–18)	3.47 (±2.57)
PHQ-2 for Depression Symptoms: Scores 0–2	90.4%
PHQ-2 for Depression Symptoms: Scores 3–6	9.6%
Financial strain	
Annual Household Income (in ~$10,000 increments)	5.03 (±1.94)
Employed: No	79.0%
Employed: Yes	21.0%
Financial Stress Scale (range = 0–4)	1.08 (±1.45)
Social Environment	
RUCC for Residential Rurality (range: 1–9)	1.93 (±1.62)
Ease Getting to Appointments and Other Locations: Yes	92.4%
Ease Getting to Appointments and Other Locations: No	7.6%
Sense of Belonging to Local Community: Very Weak	6.7%
Sense of Belonging to Local Community: Somewhat Weak	24.8%
Sense of Belonging to Local Community: Somewhat Strong	46.6%
Sense of Belonging to Local Community: Very Strong	21.8%

participants reported either having some college education (37.1%) or a college degree or more (46.5%). About 21.0% of participants lived alone. Participants reported 3.47 (±2.57) chronic conditions on average, and 9.6% screened positive for possible depression (PHQ-2 ≥ 3). Participants' average household income was between $40,000 and $50,000, 79.0% were not employed, and had low worry/stress about money (i.e., average score of 1.08). Participants primarily resided in metropolitan areas (i.e., average RUCC of 1.93), with 92.4% reporting being able to easily get to appointments, grocery stores, places of worship, and other locations. About 31% of participants reported having a "somewhat weak" or "weak" sense of belonging to their local community.

Table 2 reports findings from the sequential ordinary least squares regression models. The first model (Model A: sociodemographic factors only; $F = 3.94$, $p < 0.001$, $aR^2 = 0.030$) showed that each additional year of age ($\beta = -0.15$, $p < 0.001$) and self-identifying as being Black/AA ($\beta = -0.10$, $p = 0.008$) were associated with lower risk for social disconnectedness. Participants who attended some college ($\beta = -0.15$, $p = 0.007$) or had college education or more ($\beta = -0.11$, $p = 0.041$) had lower risk for social disconnectedness compared to high school or less than high school levels of education.

The second model added health factors to the analysis (Model B: sociodemographics + health factors; $F = 15.33$, $p < 0.001$, $aR^2 = 0.170$) and showed that age and education remained significant predictors of lower social disconnectedness risk. Further, self-reported chronic condition ($\beta = 0.12$, $p = 0.001$) and having possible depression ($\beta = 0.35$, $p < 0.001$) were additionally associated with higher risk for social disconnectedness.

The third model (Model C: sociodemographics + health factors + financial burden; $F = 15.52$, $p < 0.001$, $aR^2 = 0.212$) showed that, in addition to the significant findings from Models A and B, higher annual household income was associated with lower risk for social disconnectedness ($\beta = -0.10$, $p = 0.012$), whereas being more worried or stressed about money was associated with higher risk for social disconnectedness ($\beta = 0.18$, $p < 0.001$).

The final model (Model D: sociodemographics + health factors + financial burden + social environment; $F = 23.42$,

TABLE 2 Ordinary least squares regression models.

Variable	Model A				Model B				Model C				Model D			
	95% CI				95% CI				95% CI				95% CI			
	Beta	*P*	Lower	Upper	Beta	*P*	Lower	Upper	Beta	*P*	Lower	Upper	Beta	*P*	Lower	Upper
Age	−0.15	<0.001	−0.12	−0.04	−0.13	<0.001	−0.11	−0.03	−0.10	0.004	−0.10	−0.02	−0.07	0.033	−0.07	0.00
Male (vs. Female)	0.04	0.353	−0.23	0.64	0.03	0.354	−0.21	0.59	0.05	0.198	−0.13	0.65	0.01	0.702	−0.28	0.42
Hispanic (vs. Non-Hispanic)	−0.01	0.752	−0.63	0.46	−0.04	0.308	−0.77	0.24	−0.05	0.143	−0.86	0.13	−0.03	0.304	−0.68	0.21
Black or African American (vs. All Other Races)	−0.10	0.008	−1.21	−0.19	−0.07	0.050	−0.95	0.00	−0.11	0.002	−1.21	−0.27	−0.05	0.111	−0.78	0.08
Another Race (vs. All Other Races)	−0.03	0.524	−1.09	0.56	−0.01	0.843	−0.84	0.69	0.00	0.901	−0.79	0.70	−0.02	0.643	−0.83	0.51
Some College Education (vs. All Other Levels)	−0.15	0.007	−1.43	−0.22	−0.15	0.002	−1.44	−0.32	−0.10	0.037	−1.15	−0.04	−0.08	0.084	−0.94	0.06
College Education or More (vs. All Other Levels)	−0.11	0.041	−1.20	−0.02	−0.11	0.032	−1.14	−0.05	−0.03	0.558	−0.74	0.40	0.00	0.932	−0.53	0.49
Lives Alone (vs. Lives With Others)	0.03	0.395	−0.29	0.73	0.03	0.418	−0.28	0.66	−0.01	0.864	−0.51	0.43	0.02	0.550	−0.30	0.56
Number of Self-Reported Chronic Conditions					0.12	0.001	0.05	0.20	0.08	0.028	0.01	0.16	0.05	0.093	−0.01	0.12
Depression Symptoms 3 + (vs. Scores of 0–2)					0.35	<0.001	2.61	3.90	0.30	<0.001	2.19	3.47	0.22	<0.001	1.48	2.66
Annual Household Income Level									−0.10	0.012	−0.26	−0.03	−0.05	0.202	−0.17	0.04
Not Employed (vs. Employed)									0.00	0.997	−0.47	0.47	0.02	0.539	−0.29	0.56
Financial Stress Scale									0.18	<0.001	0.20	0.48	0.16	<0.001	0.18	0.44
RUCC for Residential Rurality													0.02	0.438	−0.06	0.15
Ease Getting to Appointments and Other Locations													0.06	0.060	−0.03	1.28
Somewhat Weak Belonging to Local Community (vs. All Other Levels)													−0.20	<0.001	−1.98	−0.55
Somewhat Strong Belonging to Local Community (vs. All Other Levels)													−0.48	<0.001	−3.32	−1.93
Very Strong Belonging to Local Community (vs. All Other Levels)													−0.58	<0.001	−4.65	−3.14
	Adjusted R Square = 0.030				Adjusted R Square = 0.170				Adjusted R Square = 0.212				Adjusted R Square = 0.366			

$p < 0.001$, a$R^2 = 0.366$) showed that age ($\beta = -0.07$, $p = 0.033$), possible depression ($\beta = 0.22$, $p < 0.001$), and financial stress ($\beta = 0.16$, $p < 0.001$) remained significantly associated with higher social disconnectedness. Compared to those with very weak belonging to their local community, participants who reported somewhat weak ($\beta = -0.20$, $p < 0.001$), somewhat strong ($\beta = -0.48$, $p < 0.001$), or very strong ($\beta = -0.58$, $p < 0.001$) community belonging had lower risk for social disconnectedness.

Figure 1 illustrates the additive contributions of each block of variables in terms of model fit (i.e., higher Adjusted R Square values indicate stronger models in that that the included variables explain more variance in social disconnectedness) for Models A through D (i.e., starting with sociodemographic characteristics and sequentially adding, health factors, financial strain, and social environment variables). Each block meaningfully increases the model's explanatory power, with the final model accounting for 36.6% of the variance in social disconnectedness.

Discussion

This study identified the unique contributions of sociodemographic, health, financial, and social environmental factors to social disconnectedness risk among older unpaid caregivers aged 60 and above. The findings underscore critical areas for both prevention and intervention strategies to mitigate social disconnectedness in this population. One of the most significant findings was the strong and consistent association between probable depression and increased risk of social disconnectedness across all three models in which it was included. This finding aligns with previous research indicating that mental health, such as depression, can exacerbate feelings of isolation and hinder the ability to engage in social activities (31, 32). Depressive symptoms may lead to withdrawal from social networks, reduced motivation to seek social support, and a diminished sense of belonging (32). Given that caregivers often experience emotional strain due to their caregiving responsibilities, it is critical for health care professionals to screen for depressive symptoms early and address depression using evidence-based interventions, such as behavioral activation (33), and cognitive-behavioral therapy (34, 35). However, caregivers are often "hidden patients" making it difficult for healthcare providers to identify them and intervene on their behalf. To address this concern, Holiday and colleagues (2022) developed the C.A.R.E. framework (36) – Caregiver well-being, Advanced care planning, Respite, and Education—which is designed to educate clinicians about the need to support family caregivers and connect them to interventions and support. Dissemination of the C.A.R.E. framework could enhance clinicians' efforts to screen for depression and social disconnectedness in this population. Ultimately, reducing depressive symptoms could result in improved emotional well-being, greater engagement in social interactions, and reduced social disconnectedness risk.

Financial stress was another significant factor associated with social disconnectedness risk among unpaid caregivers. The financial burden associated with caregiving responsibilities, including out-of-pocket costs such as health care expenses for care recipients, can significantly limit the caregivers' ability to use resources for participating in social activities to maintain connections (15). This financial strain is particularly pronounced among spousal caregivers, who are more vulnerable compared to adult children caring for parents. This is important to highlight particularly among older caregivers who are retired and reliant on fixed incomes (37). Further, caregiving responsibilities may reduce working hours for unpaid

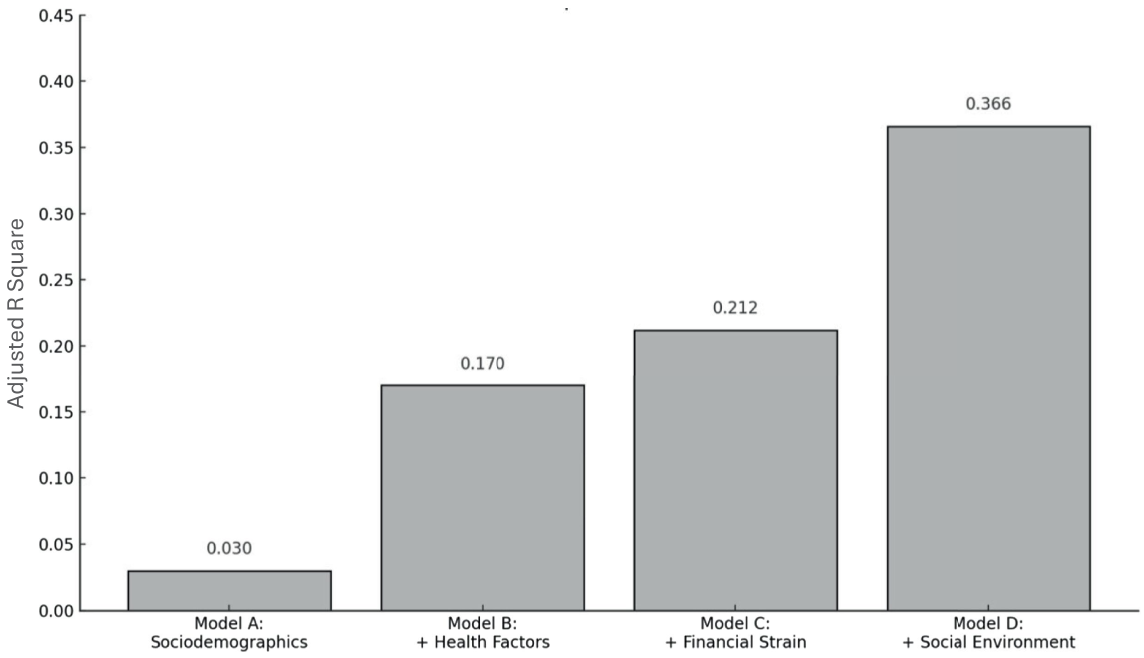

FIGURE 1
Sequential contribution to explained variance in social disconnectedness. Bar chart displays adjusted R Square values for each sequential regression model. Model A includes sociodemographics; Model B adds health factors; Model C adds financial strain; and Model D adds social environment variables. Each block meaningfully increases the model's explanatory power, with the final model accounting for 36.6% of the variance in social disconnectedness.

caregivers who are still in the workforce (38). Strategies to address financial stress should extend beyond providing financial assistance to include employment support programs for unpaid caregivers to help them balance work and caregiving responsibilities. As individuals increasingly remain in the workforce beyond traditional retirement age, sustaining employment may provide caregivers with financial stability, social engagement opportunities, and a sense of purpose. Promoting caregiver-inclusive institutional policies (e.g., such as flexible work hours, expanded caregiving leave, and remote work options) may play a critical role in mitigating financial stress and preserving social connection, especially among those providing ongoing unpaid care while working. In addition, providing free or low-cost respite services could allow unpaid caregivers to engage in more social activities or re-enter the workforce, which can mitigate the risk of social disconnectedness.

A strong sense of community belonging was identified as a significant factor mitigating the risk of social disconnectedness among older unpaid caregivers, underscoring the importance of social integration and community involvement in reducing isolation within this population. Research demonstrates that a sense of belonging to one's community may serve as a protective buffer against caregiving burden (39) through collective efforts in problem solving and inducing a greater sense of identity (40). Community-based interventions that promote social inclusion, such as neighborhood programs, support groups, and local activities, could foster a stronger sense of belonging and reduce the risk of social disconnectedness. Interpersonal strategies such as peer mentoring may help reduce isolation and foster a sense of community, which could help reduce social disconnectedness risk (41, 42). Technology-based interventions may help to facilitate social participation for caregivers who have impaired physical functioning or no longer drive, as well as for individuals who are in a high intensity caregiving context (43). Taking an upstream approach to intervention by targeting unpaid caregivers that are living in certain high risk social environments, such as those in isolated areas or with limited access to resources, is critical.

Caregivers who self-identify as Black or African American had reduced risk of social disconnectedness. This contrasts with existing literature that shows higher levels of social isolation in racial and ethnic minorities due to structural inequities and discrimination (44) but aligns with the evidence on protective effects of being a racial/ethnic minority caregiver through increased access to social support (45). Caregivers who self-identify as Black or African American may benefit from stronger ties to family, friends, fictive kin, and community (46) which provide emotional and social support that enhances social connections. Previous studies suggest that Black or African American communities may have more robust unpaid caregiving networks and a cultural emphasis on collective support, which can foster a sense of community (45). However, this finding warrants further exploration to better understand the complex interplay between race, caregiving, and social connection. It also highlights the need for culturally tailored interventions that build upon existing strengths within communities (47).

Several limitations should be considered when interpreting the findings. First, the study relied on a non-probabilistic, internet-based sample, which may introduce selection bias. While the study attracted participants from a range of sociodemographic backgrounds, participants with internet access and the ability to complete online surveys may not fully represent the broader population of older unpaid caregivers, particularly those who are more socially isolated or economically disadvantaged. This study may have also excluded unpaid caregivers experiencing higher levels of burden who lacked the time or capacity to engage in this study. Similarly, the sampling methodology may have inadvertently excluded individuals who are less digitally connected—such as those with limited internet access, lower digital literacy, or greater social isolation. These individuals may represent a particularly vulnerable subgroup of caregivers who face compounded barriers to social engagement and support. As a result, our findings may underestimate the true prevalence or severity of social disconnectedness among the broader population of older unpaid caregivers. Future research should consider using mixed-modal recruitment strategies to ensure inclusion of digitally disconnected individuals and to more comprehensively assess social risks across the caregiving spectrum. Second, we did not collect information about the care recipients or specific caregiving contexts, including the types or intensities of caregiving. For example, caring for an individual with Alzheimer's disease or related dementias differs significantly from caring for someone with mobility challenges. As such, the potential influence of these distinct caregiving contexts on the risk of social disconnectedness among unpaid caregivers warrants further investigation. Future research should incorporate more detailed measures of caregiving roles and responsibilities to better understand how specific caregiving contexts contribute to social disconnectedness among older unpaid caregivers. Differentiating between caregiving subtypes may also help tailor interventions to those at greatest risk of social isolation. Third, the study did not assess whether participants were the primary caregivers or part of a broader caregiving network. Understanding whether additional caregivers co-provide care could offer valuable insights into how caregiving networks influence social connectedness. Fourth, the cross-sectional design of the study limits the ability to infer causal and direction of the relationships between identified risk factors and social disconnectedness. Longitudinal studies are needed to clarify the directionality and temporal dynamics of how sociodemographic characteristics, health factors, and caregiving contexts influence social connectedness as older unpaid caregivers age. Lastly, since the current study used the PHQ-2 to assess depressive symptoms (27), our findings should be interpreted with caution, recognizing that they reflect screening-level indicators rather than formal diagnoses.

Conclusion

This study contributes to the growing body of knowledge on social disconnectedness risk among older unpaid caregivers by identifying key risk factors reflecting intervention targets. Through sequential regression modeling, this study assessed the unique contributions of various factors related to social disconnectedness risk in older unpaid caregivers. Addressing depressive symptoms, reducing financial stress, and enhancing community belonging are essential components to mitigate social disconnectedness risk in this population. Given the projected growth of older unpaid caregivers, this research highlights an urgent need to provide resources and services that promote social connection, strengthen supportive networks, and improve overall well-being among older unpaid caregivers.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Institutional Review Board (IRB) at Texas A&M University (IRB2019-0375). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin because procedures were reviewed and approved by the Institutional Review Board (IRB) at Texas A&M University (IRB2019-0375). Given the cross-sectional and anonymous nature of the survey, the IRB determined that this research meets the criteria for U.S. Human Research Protection (HRPP) Exemption in accordance with 45 CFR 46.104. Instead of written consent, participants were provided with information sheet presented in the first page of the Survey Participants needed to click 'I agree' to acknowledge receipt and continue taking the actual survey. The study was performed in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards.

Author contributions

MY-J: Conceptualization, Writing – original draft, Writing – review & editing. JS: Writing – review & editing. CB: Writing – review & editing. JLS: Writing – review & editing. HC: Writing – review & editing. AP: Writing – review & editing. YZ: Writing – review & editing. CEV: Writing – review & editing. J-DB: Writing – review & editing. KK: Writing – review & editing. WJ: Writing – review & editing. TW: Writing – review & editing. MO: Writing – review & editing. MLS: Formal Analysis, Investigation, Methodology, Validation, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Generative AI statement

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Impact of nurses' health beliefs about caring for older adults on their own preparation for old age

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Background: The older adults is increasing worldwide, and South Korea in particular is experiencing a rapid increase in the older adults. In this situation, related research targeting nurses who care for the older adult is necessary.
Objective: This study was to examine the relationships among preparation for old age and health beliefs, and the factors influencing preparation for old age of young nurses in their 20s and 30s who care for older adults in general hospitals.
Methods: A cross-sectional descriptive design was employed. Participants were 110 nurses working in general hospitals, South Korea. Measures were the general characteristics list, the preparation scale for old age, and health belief scale.
Results: Level of preparation for retirement ($\beta = -0.53$, $p < 0.001$), department ($\beta = 0.34$, $p < 0.001$), health beliefs ($\beta = 0.32$, $p < 0.001$), desired retirement age ($\beta = 0.19$, $p = 0.022$), annual salary ($\beta = -0.18$, $p = 0.048$), and chronic disease ($\beta = 0.17$, $p = 0.028$) were all statistically significant variables in the Step-2 regression model. Explanatory power was 69.2%.
Conclusion: Improving preparation for retirement and health beliefs could promote preparation for old age. Department, desired retirement age, annual salary, and chronic disease need to be considered when developing and implementing interventions for improving preparation for old age. Nursing managers or nurses need pay attention to factors influencing preparation for old age of young nurses caring for older adult patients in general hospitals.

KEYWORDS

old age, preparation, health belief, retirement, nurse

Introduction

South Korea, a rapidly aging OECD nation, sees its older population projected to exceed 46.4% by 2070 (1, 2). This demographic shift raises living costs and heightens the need for early retirement planning (3, 4). Young people in their 20s and 30s, crucial for preparing a super-aged society, often lack readiness, as shown by a 2022 Statistics Korea Retirement Readiness Survey (5–8). Effective old-age preparation counters potential health, financial, and social challenges. With issues like pension depletion looming, young individuals proactively need to plan for secure, fulfilling later years, independent of limited social security (9–11).

It is worth noting that nurses can directly participate in the care of old adults, both in terms of their physical health and their social and psychological life after retirement. Through this experience, nurses can reflect thoroughly on the success of their future life after retirement (12, 13). In addition, while caring for sick old adults, nurses may indirectly experience changes in their perception of life after retirement and reflect on their health beliefs related to their illness (14, 15). Health beliefs are known to be crucial predictors of an individual's health-related behavior. They are firm beliefs that individuals are vulnerable to illness and that the occurrence of the disease is serious (16). In other words, if they perceive that there are numerous benefits to their health beliefs and fewer obstacles, they are more likely to engage in health-promoting behaviors. In this approach, health beliefs help people anticipate negative situations and pursue a healthy life by taking positive and proactive behaviors when they think their health may be threatened or when they are concerned that they will get sick (17). Health beliefs are actually a significant predictor of an individual's health-related behaviors and can significantly influence preparation for old age. These beliefs include perceptions of vulnerability to disease and the severity of disease occurrence. The more benefits and fewer perceived barriers to health beliefs an individual perceives, the more likely they are to engage in health-promoting behaviors. Therefore, health beliefs anticipate negative situations and encourage positive behaviors to maintain a healthy lifestyle, which is essential for planning for a stable old age. Preparation for old age involves proactive planning and actions to handle potential challenges in later life, such as illnesses, poverty, and loneliness. It includes detailed planning for physical, economic, social, and psychological concerns that may arise during old age (17). These health beliefs are grounded in the Theory of Planned Behavior (TPB) and the life course perspective. The Theory of Planned Behavior (TPB) and the life course perspective are frameworks used to understand human behavior and development over time. The Theory of Planned Behavior (TPB), developed by Ajzen (18), is a psychological theory that links beliefs and behaviors. TPB posits that an individual's behavior is driven by behavioral intentions, which are shaped by three factors: attitude toward the behavior, subjective norms, and perceived behavioral control. TPB is often used to predict behavioral patterns based on an individual's existing attitudes and intentions. The life course perspective (19) is used in sociology and public health to understand how age, relationships, general life transitions, and social change affect people's lives from birth to death. This theory emphasizes the importance of time, context, and process in understanding people's lives, structural contexts, and social change. The life course perspective examines how various stages of life are interconnected and how early experiences can influence later life. Both theories play an important role in understanding behavior and development, but TPB focuses more on immediate behavioral intentions, whereas the life course perspective provides a broader view of individual development across the lifespan.

Currently, the demand for specialized medical services for old adults is increasing, and nurses' roles in this aging society are emphasized in various aspects. Nevertheless, since most nurses working in hospitals are in their 20s and 30s and are deemed young and relatively in good health, they may not consider old age planning based on their own health beliefs (12). Furthermore, nurses caring for old adults tend to neglect their own health due to unhealthy lifestyle habits and stress caused by the nature and intensity of shift work (13). Existing efforts and interventions to prepare for old age of healthcare professionals caring for the older adults have only provided discounts on medical and screening fees as a welfare service, and in many cases, hospitals or institutions rather encourage early retirement (12, 15). Indeed, nurses caring for old adults need to take a look on their health beliefs and consider whether they are adequately preparing for old age.

However, there have been no prior studies on the health beliefs and preparation for old age of young nurses in their 20s and 30s caring for old adults. Although there have been studies related to preparation for old age in various occupations (20–23), very few addressed the preparation for old age with respect to the health beliefs of young nurses in their 20s and 30s who are currently in charge of caring for old adults in the health care field. At this point, nurses need to exercise their subjective health beliefs about their health and to explore in detail how they prepare and plan for old age. This study aims to provide fundamental data for developing positive measures to prepare for a desirable life after retirement by identifying the current awareness of their health beliefs among young nurses in their 20s and 30s caring for old adults.

The purpose of this study was to examine the influence on the preparation for old age of young nurses in their 20s and 30s who care for older adults in general hospitals. The aims were to (a) identify the general and job-related characteristics of study participants; (b) examine the levels of the preparation for old age and health belief of study participants; (c) examine the differences on the preparation for old age and health belief according to the general and job-related characteristics of study participants; (d) examine the correlation between the preparation for old age and health belief of study participants; (e) examine the factors influencing the level of preparation for old age of study participants.

Methods

Study population

A cross-sectional descriptive design was employed. Study participants were 110 nurses working in general hospitals, South Korea. They were selected using convenience sampling. Inclusion criteria were nurses in their 20s and 30s who had worked in the hospital for more than 3 months, were currently caring for old adults, and understood the purpose of this study. Not included criteria were nurse managers, and new nurses who had worked for less than 3 months based on the reliability of this study because it was judged difficult to provide direct care for old adults.

The sample—110 people—was acquired using the G*Power 3.1.9 program, with a significance level (α) of 0.05, a power ($1\text{-}\beta$) of 0.80, and an effect size of 0.15 (24). Considering that a 10% dropout rate would occur, 123 questionnaires were disseminated. Then, 110 questionnaires were collected (89.43% collection rate) and included in the final data.

Measurements

The measurement tools used in this study were validated for content validity and reliability by two nursing professors, one geriatric medicine professor, and two clinical nurses. Statistical techniques were used to verify the reliability of the measurement tools.

General and job-related characteristics of study participants

A set of general characteristic variables consisted of a total of 12 items including gender, age, marital status, education, religion, total clinical experience, department, current position, annual salary, desired retirement age, preparation for retirement, and chronic disease.

Preparation for old age

To assess preparation for old age, it was an adopted tool from Kang and Yeom (25) who aimed to help nurses pursue a stable life after retirement. This instrument comprises 28 questions, with nine for economic readiness, 10 for physical readiness, and nine for emotional readiness, such as "I save every month for financial deposit for old age," "I train my body through exercise for a healthy life," and "I try not to accumulate stress." This instrument uses a five-point Likert scale, with values ranging from a minimum of 28 to a maximum of 140 points, with higher scores indicating greater preparation for old age. As regarding the preparation scale for old age, in Kang and Yeom's study (25), the reliability of the instrument was Cronbach's $\alpha = 0.90$, but in this study, it was Cronbach's α = 0.87.

Health belief

To assess health belief, it was a modified tool from Lee and Jung (26). The four-subarea instrument includes 22 questions—four about perceived sensitivity, five about perceived severity, six about perceived benefit, and seven about perceived disability. The questions include statements such as "The thought that a chronic disease can occur or worsen frightens me" and "If I manage stress well, I will prevent the occurrence or worsening of chronic diseases." This instrument uses a five-point Likert scale, with values ranging from a minimum of 22 to a maximum of 110 points. The greater the value of the instrument, the higher the health belief. As for the health belief scale, in Lee and Jung's study (26), the reliability of the instrument was Cronbach's $\alpha = 0.80$, while in this study, it was Cronbach's α = 0.87. All of the above tools were verified for content validity by two nursing professors.

Data collection

This study was conducted after receiving approval from the K University Bioethics Review Committee. Prior to data collection, the researcher visited the general hospital in person, asked for cooperation from the nursing department and head nurses, and explained the purpose and content of this study directly. In addition, all nurses were informed in advance of the confidentiality of personal information provision and anonymity. Data collection was conducted from October to November, 2023, and a questionnaire was administered to nurses currently caring for old adults at a general hospital. It took about 30 min for each nurse to complete the questionnaire, and the researcher collected the completed questionnaire after placing it in an envelope and taping it.

Ethical considerations

This study was approved by K University Institutional Review Board (IRB No. KHSIRB-23-471, Approval date October 24, 2023). This study explained the purpose and procedure of the study to nurses who work at general hospitals and currently care for old adults. Afterwards, they were asked to cooperate with the data collection and were told that it would not be used for any purpose other than the study. In addition, they were told that there would be no disadvantages for not participating in the study, and the researcher distributed a questionnaire to those who agreed to participate in the study and had them fill it out themselves. The questionnaire was stored in the researcher's locker with a locker so that no one other than the researcher could access it, and it was stored for 3 years after the end of the study, after which all documents were permanently shredded.

Data analysis

In this study, the collected data were analyzed using the SPSS/WIN 29.0 Program (IBM Corp., Armonk, NY, United States). Descriptive statistics and frequency analysis were used to confirm the general and job-related characteristics of study participants. The level of preparation for old age and health beliefs of study participants were analyzed using the mean and standard deviation. In order to examine the differences in the level of preparedness for old age and health beliefs according to the general and job-related characteristics of study participants, the independent *t*-test, ANOVA, and Scheffe *post-hoc* test was used. The correlation between the level of preparation for old age and health beliefs of study participants was analyzed using Pearson's coefficient correlation. In order to examine the factors influencing the level of preparation for old age of study participants, hierarchical stepwise multiple regression was used for analysis.

Results

General and job-related characteristics of nurses caring for old adults

This study covered 110 nurses who cared for old adults, with five males (4.5%) and 105 females (95.5%). In terms of age, 55 nurses (50.0%) were aged 25–29, followed by 30 nurses (27.3%) aged 30 to 34, with an average age of 29.85 years. The majority of nurses caring for old adults were unmarried 82 nurses (74.5%), and the majority had a college degree (80.9%). Sixty-four nurses (58.2%) had no religious affiliation, whereas 98 nurses (89.1%) had less than 10 years of total clinical experience. The internal medicine ward had the most nurses, totaling 44 (40.0%) among the departments they worked in. Then, general nurses accounted for the majority with 107 (97.3%). Next, 56 nurses (50.9%) aged 50–59 years responded they would like to retire, while 47 nurses (42.7%) stated they were "just planning" to prepare for old age. In this study, 106 nurses (96.4%) caring for old adults were free of chronic diseases (Table 1).

Levels of preparation for old age and health beliefs of nurses caring for old adults

Nurses caring for old adults reported preparation for old age readiness scores ranging from 28 to 140, with a median of 84.00

TABLE 1 General and job-related characteristics of nurses caring for older adults.

Characteristics	N	%
Gender		
Male	5	4.5
Female	105	95.5
Age (year)		
25>	15	13.6
25–29	55	50.0
30–34	30	27.3
35–39	10	9.1
Mean ± SD	29.85 ± 3.93	
Marital status		
Yes	28	25.5
No	82	74.5
Education		
College	13	11.8
University	89	80.9
Attending graduate school	4	3.6
Finish graduate school	4	3.6
Religion		
Buddhism	10	9.1
Christian	25	22.7
Catholic	11	10.0
No	64	58.2
Total clinical experience (year)		
10>	98	89.1
Oct–14	8	7.3
15≤	4	3.6
Department		
Medical ward	44	40.0
Surgical ward	11	10.0
Intensive care unit	10	9.1
Others	45	40.9
Current position		
General nurse	107	97.3
Senior nurse	3	2.7
Annual salary (USD)		
20,300>	11	10.0
20,300–27,000	53	48.2
27,001–33,700	31	28.2
33,701≤	15	13.6
Desired retirement age (year)		
30–39	17	15.5
40–49	12	10.9
50–59	56	50.9
60≤	25	22.7
Preparation for retirement		
Actively preparing	4	3.6
Preparing to some extent	23	20.9
Just making plans	47	42.7
Not prepared at all	36	32.7
Chronic disease		
Yes	4	3.6
No	106	96.4

(Continued)

TABLE 1 (Continued)

and a mean of 85.41 (13.37) points. Economic readiness scores ranged from nine to 45, with a median of 27.00 and a mean of 24.97 (6.04), physical readiness scores from 10 to 50, with a median of 30.00 and a mean of 29.52 (6.09), and emotional readiness from nine to 45, with a median of 27.00 and a mean of 30.92 (4.73). Next, health beliefs scores ranged from 22 to 110, with a median of 66.00 and a mean of 76.85 (6.95). Perceived sensitivity, a subarea related to health beliefs, ranged from four to 20, with a median of 12.00 and a mean of 12.75 (3.55), perceived severity from five to 25, with a median of 15.00 and a mean of 15.68 (4.56), perceived benefit from six to 30, with a median of 18.00 and a mean of 26.39 (3.17), and perceived disability from 7 to 35, with a median of 21.00 and a mean of 22.03 (4.45). In this study, the mean values of nurses caring for old adults for preparation for old age and health beliefs were mostly similar to or higher than the median values. However, the mean values for economic readiness and physical readiness, which are subareas of preparation for old age, were slightly lower than the median values (Table 2).

Differences on preparation for old age and health beliefs according to the general and job-related characteristics of nurses caring for old adults

The preparation for old age of nurses caring for old adults was a statistically significant difference in terms of total clinical experience ($F = 1.58$, $p = 0.049$) and level of preparation for retirement ($F = 10.42$, $p < 0.001$). The result from *post-hoc* test demonstrates that the level of preparation for old age of nurses with a total clinical experience of 15 years or more was higher than them of less than 10 years, or 10–14 years. The level of preparation for old age of nurses caring for old adults was also higher for nurses who claimed they were "actively preparing for retirement" and "preparing to some extent for retirement" compared to those who said they were "not preparing at all for retirement." The level of health beliefs of nurses caring for old adults was a statistically significant difference in terms of their preparation for retirement ($F = 0.76$, $p = 0.048$). The result from *post-hoc* test exhibited that the health beliefs of nurses caring for old adults were higher for nurses who stated they were "preparing to some extent for retirement" compared to those who held they were "just planning for retirement" and "not preparing at all for retirement" (Table 3).

TABLE 2 Levels of preparation for old age and health beliefs of nurses caring for old adults.

Variables	Possible score	Median	Mean ± SD	Variables	Possible score	Median	Mean ± SD
Preparation for old age	28–140	84.00	85.41 ± 13.37	Health beliefs	22–110	66.00	76.85 ± 6.95
Financial preparation	9–45	27.00	24.97 ± 6.04	Perceived sensitivity	4–20	12.00	12.75 ± 3.55
Physical preparation	10–50	30.00	29.52 ± 6.09	Perceived severity	5–25	15.00	15.68 ± 4.56
Emotional preparation	9–45	27.00	30.92 ± 4.73	Perceived benefit	6–30	18.00	26.39 ± 3.17
				Perceived disability	7–35	21.00	22.03 ± 4.45

Correlations between preparation for old age and health beliefs of nurses caring for old adults

This study found a positive correlation between preparation for old age and the health beliefs of nurses caring for old adults ($r = 0.32$, $p < 0.001$). A positive correlation between perceived sensitivity ($r = 0.24$, $p = 0.012$) and perceived disability ($r = 0.41$, $p < 0.001$), which are subareas related to health beliefs, was also observed. In other words, the higher the preparation for old age of nurses caring for old adults, the greater their health beliefs. Specifically, the higher their preparation for old age, the greater their perceived sensitivity and perceived disability in terms of their health beliefs (Table 4).

Impact on preparation for old age of nurses caring for old adults

The impact on the preparation for old age of nurses caring for old adults was analyzed by stepwise hierarchical multiple regression. As a result, the Step-1 regression model with general characteristics was statistically significant. Department ($\beta = 0.29$, $p = 0.005$) was the statistically significant variable in Step 1, and the explanatory power of the Step 1 regression model was 35.1%. In this research, Step 2 included the desired retirement age, the level of preparation for retirement, chronic diseases, and health beliefs, which were the main variables. Department ($\beta = 0.34$, $p < 0.001$), annual salary ($\beta = -0.18$, $p = 0.048$), desired retirement age ($\beta = 0.19$, $p = 0.022$), level of preparation for retirement ($\beta = -0.53$, $p < 0.001$), chronic disease ($\beta = 0.17$, $p = 0.028$), and health beliefs ($\beta = 0.32$, $p < 0.001$) were all statistically significant variables in the Step-2 regression model. Explanatory power increased by 34.1% compared to Step 1. The most impactful and important variable was the level of preparation for retirement, followed by department, health beliefs, desired retirement age, annual salary, and chronic disease. The explanatory power of the final regression model was 69.2% (Table 5).

The assumptions of the regression analysis were tested and proved to be valid, and the assumptions of the regression equation were satisfied. First of all, the tolerance limit of multicollinearity was 0.53–0.92, which exceeded 0.10. The variance inflation factor (VIF) ranged from 1.07 to 1.89. Because the VIF value was not greater than 10, there was no issue of multicollinearity for all variables.

Discussion

In South Korea, due to the aging population and the social culture that requires long-term employment even after retirement, there may be a sense of both the possibility of rest and the burden of having to find work again (8, 21). Given the lack of policies and systems for retirees, Korean cultural norms regarding retirement may be viewed as negative (21, 25). These cultural norms regarding aging and retirement negatively may impact nurses' attitudes and intentions, leading to a lack of proactive behaviors to prepare for old age (8, 25). Particularly, nurses' job stress can be increased not only by emotional labor (27, 28) but also by various structural factors (e.g., staffing ratios, shift length) (25, 29). Factors such as staffing shortages, extended work hours, inadequate promotion or welfare services within the organization, and a negative organizational culture may be all contribute to increased job stress (25, 27, 29). Such job stress may weaken the preparation for old age and health beliefs of nurses in their 20s and 30s (25, 29).

In this study, nurses caring for old adults had levels of preparation for old age and health beliefs that were mostly around or above the median. On the other hand, the mean values for financial and physical preparation, which fall into the sub-areas of preparation for old age, were slightly lower than the median. This study was based on young nurses in their 20s and 30s. It is also reasonable to assume that nurses who believe they still have sufficient time to retire prioritizing emotional preparation above financial or physical preparation in their old age planning. Specifically, it can be inferred that people are filling their lives with emotional preparation such as hobbies, self-development, and friendships as a means to meet the satisfaction of living in the moment, rather than focusing on living costs or health care (30). Based on this, it is necessary to re-identify not only young nurses in their 20s and 30s caring for old adults but also nurses caring for old adults in general by age. This needs to split their financial, physical, and emotional, preparation, and lead to pursuing further studies that consider individual and environmental characteristics.

Next, significant differences in preparation for old age were identified based on total clinical experience and level of preparation for retirement. Health beliefs also significantly differed with preparation for retirement. Those with more than 15 years of clinical experience and those with moderate or more active preparation for retirement were more likely to report higher levels of preparation for old age. Also, those who had some level of preparation for retirement had the highest levels of health beliefs. This suggests that greater clinical experience and greater preparation for retirement are associated with greater interest in retirement, which in turn leads to higher levels of preparation for old age. Also, those who had some level of preparation for retirement may be associated with higher health beliefs. Based on previous research (31) indicating that old-age preparedness is influenced by various factors, it is necessary to examine

TABLE 3 Differences on preparation for old age and health beliefs according to the general and job-related characteristics of nurses caring for old adults.

Characteristics	Preparation for old age		Health beliefs	
	Mean ± SD	*t*-test or *F*- test (*P*) *Scheffe*	Mean ± SD	*t*-test or *F*- test (*P*) *Scheffe*
Gender				
Male	86.00 ± 4.00	−0.01 (0.093)	75.20 ± 3.63	−0.37 (0.192)
Female	86.04 ± 11.10		76.28 ± 6.51	
Age (year)				
25>	88.07 ± 11.17	0.54 (0.790)	77.13 ± 5.05	0.34 (0.882)
25–29	85.00 ± 11.21		76.55 ± 6.91	
30–34	86.03 ± 11.14		75.40 ± 6.71	
35–39	88.70 ± 7.80		75.60 ± 4.53	
Marital status				
Yes	86.43 ± 11.45	0.22 (0.709)	75.50 ± 7.24	
No	85.90 ± 10.73		76.48 ± 6.12	−0.70 (0.621)
Education				
College	85.31 ± 11.54	0.22 (0.913)	65.62 ± 5.98	0.18 (0.905)
University	86.31 ± 10.98		76.20 ± 6.60	
Attending graduate school	86.25 ± 12.84		78.25 ± 7.14	
Finish graduate school	82.00 ± 5.35		76.75 ± 3.77	
Religion				
Buddhism	82.70 ± 13.27	0.79 (0.320)	73.80 ± 7.77	2.11 (0.145)
Christian	86.20 ± 7.24		77.92 ± 7.13	
Catholic	89.91 ± 12.27		79.00 ± 4.43	
No	85.83 ± 11.44		75.47 ± 5.98	
Total clinical experience (year)				
10>	85.57 ± 10.90^{a}	1.58 (0.049*) c > a,b	76.43 ± 6.47	0.57 (0.622)
10–14	87.13 ± 12.11^{b}		75.25 ± 6.48	
15≤	95.25 ± 0.50^{c}		73.25 ± 4.50	
Department				
Medical ward	83.09 ± 8.79	3.68 (0.212)	76.41 ± 6.02	2.25 (0.082)
Surgical ward	82.18 ± 12.79		76.36 ± 6.98	
Intensive care unit	85.90 ± 6.97		80.70 ± 5.38	
Others	89.90 ± 11.94		75.02 ± 6.60	
Current position				
General nurse	85.82 ± 10.89	−1.24 (0.415)	76.21 ± 6.35	−0.21 (0.298)
Senior nurse	93.70 ± 7.64		77.00 ± 9.85	
Annual salary (USD)				
20,300>	85.73 ± 10.75	0.03 (0.998)	74.64 ± 8.16	1.65 (0.344)
20,300–27,000	86.30 ± 10.87		77.36 ± 4.32	
27,001–33,700	85.62 ± 11.77		76.13 ± 7.49	
33,701≤	86.20 ± 10.02		73.60 ± 8.23	
Desired retirement age (year)				
30–39	84.29 ± 11.14	1.15 (0.337)	76.12 ± 6.00	0.13 (0.951)
40–49	81.50 ± 9.41		75.33 ± 6.91	
50–59	86.73 ± 11.27		76.54 ± 5.88	

(Continued)

TABLE 3 (Continued)

Characteristics	Preparation for old age		Health beliefs	
	Mean ± SD	*t*-test or *F*- test (*P*) *Scheffe*	Mean ± SD	*t*-test or *F*- test (*P*) *Scheffe*
60≤	87.84 ± 10.26		76.04 ± 7.78	
Preparation for retirement				
Actively preparing	94.00 ± 1.00^a	10.42 (< 0.001*) a,b > d	74.50 ± 7.00^a	0.76 (0.048*) b > c,d
Preparing to some extent	92.13 ± 8.70^b		77.26 ± 5.68^b	
Just making plans	87.49 ± 9.80^c		75.32 ± 6.32^c	
Not prepared at all	79.25 ± 10.51^d		76.94 ± 6.93^d	
Chronic disease				
Yes	81.50 ± 7.77	−0.85 (0.408)	82.00 ± 6.98	1.86 (0.735)
No	86.21 ± 11.00		76.01 ± 6.31	

*$p < 0.05$; a,b,c,d are the Scheffe test values in post hoc test.

multidimensional influencing factors. Furthermore, comprehensive analysis is needed to develop effective national policies and practical measures to prepare for a super-aged society.

This study discovered that the higher the preparation for old age of nurses caring for old adults, the stronger their health beliefs. Particularly, the higher their preparation for old age, the greater their perceived sensitivity and perceived disability among their health beliefs. These findings corroborate the findings of Ha and Lee (32) who found that increased age-related health beliefs in middle-aged adults positively impact aging perceptions and preparation for old age. This demonstrates that the stronger the subjective health beliefs of nurses caring for old adults, the more likely they are to modify their behaviors to maintain and promote their health. Nurses caring for the older adults need to practice planned behaviors, such as regular health checkups and follow-up care, by strengthening health beliefs to lead more successful lives after retirement. It is necessary to utilize health care education programs that can actively practice this (32). Furthermore, additional studies are needed to identify various factors connected to preparation for old age other than the health beliefs of nurses caring for old adults.

Finally, factors influencing the preparation for old age of nurses in their 20s and 30s caring for the old adults, in order of effect size, were preparation level for retirement, department, health beliefs, desired retirement age, annual salary, and chronic illness. This suggests that preparation level for retirement, health beliefs, socioeconomic status, and health status were significant influencing factors. Also, this study found that higher annual salary and desired retirement age were associated with preparation for old age, suggesting that socioeconomic status plays a role in planning preparation for old age (31). However, while more clinical experience was associated with higher levels of preparation for old age, the impact was not statistically significant. This suggests that higher annual salary, desired retirement age, and clinical experience lead to increased consideration of retirement and, consequently, increased interest in preparation for old age. These results support the qualitative study by Nimrod and Ben-Shem (33), which aimed to elucidate the meaning of successful old-age preparation through the life journeys of older adults aged 65–92. Starting from a young age, practicing various health behaviors related to health beliefs, such as regular physical activity, nutrition, health checkups, retirement preparation according to socioeconomic status, financial ability, religion, and hobbies, is the most important factor in successfully preparing for old age. This finding supports Icek Ajzen's Theory of Planned Behavior (TPB) (18). Behavioral intentions, shaped by three factors: attitude toward behavior, subjective norms, and perceived behavioral control, drive individuals' planned behaviors. Health beliefs can be viewed as these behavioral intentions, leading to planned behaviors like preparation for old age. From a life course perspective (19), this study examines how early experiences can impact later life. This study suggests that young nurses in their 20s and 30s' early experiences caring for the old adults can influence their preparation for the old age, the last period they experience in life. Therefore, maintaining a healthy lifestyle based on health beliefs is not only essential for maintaining current health, but can also enhance preparation for old age, the final stage of life, and serve as a foundation for positive outcomes in maintaining holistic health in old age after retirement.

Implications for practice, policy, and research

Based on the results from this study, it is essential to utilize various educational programs with strengthening their health belief targeting nurses in their 20s and 30s so they can practice healthy behaviors in their daily lives, in addition to the expected behaviors in medical settings and public places. Furthermore, active participation and efforts from national and local communities are essential. Above all, there is a need for better education and training on health beliefs to keep nurses caring for old adults aware of their perceived sensitivity and motivation for preparation for old age (34, 35). To prepare for old age, it is necessary to reinforce education on health awareness, health maintenance, and disease prevention behaviors from the pre-old age stage. It is also important to develop and implement specific nursing intervention programs that can

TABLE 4 Correlations between preparation for old age and health beliefs of nurses caring for old adults.

Variables	Preparation for old age	Financial preparation	Physical preparation	Emotional preparation	Health beliefs	Perceived sensitivity	Perceived severity	Perceived benefit	Perceived disability
	r (*P*)								
Preparation for old age	1								
Financial preparation	0.76 (< 0.001*)	1							
Physical preparation	0.84 (< 0.001*)	0.41 (< 0.001*)	1						
Emotional preparation	0.77 (< 0.001*)	0.34 (< 0.001*)	0.57 (< 0.001*)	1					
Health beliefs	0.32 (< 0.001*)	0.14 (0.158)	0.33 (< 0.001*)	0.29 (0.002*)	1				
Perceived sensitivity	0.24 (0.012*)	0.03 (0.730)	0.31 (< 0.001*)	0.23 (0.017*)	0.28 (0.004*)	1			
Perceived severity	0.18 (0.061)	0.16 (0.098)	0.11 (0.265)	0.17 (0.082)	0.61 (< 0.001*)	0.13 (0.186)	1		
Perceived benefit	0.13 (0.192)	−0.09 (0.327)	0.18 (0.054)	0.24 (0.012*)	0.57 (< 0.001*)	−0.18 (0.054)	0.18 (0.063)	1	
Perceived disability	0.41 (< 0.001*)	0.14 (0.137)	0.53 (< 0.001*)	0.30 (0.002*)	0.32 (< 0.001*)	−0.37 (< 0.001*)	−0.31 (0.001*)	0.14 (0.145)	1

*$P < 0.05$.

TABLE 5 Impact on preparation for old age of nurses caring for old adults.

Variables	Model I					Model II				
	B	SE	*β*	*t*	*P*	*B*	SE	*β*	*t*	*P*
Gender	−0.69	5.13	−0.01	−0.13	0.893	−4.71	4.11	−0.09	−1.15	0.255
Age	−0.26	1.63	−0.02	−0.16	0.975	−2.50	1.34	−0.19	−1.87	0.065
Marital status	−0.39	2.65	−0.02	−0.15	0.884	−1.79	2.11	−0.07	−0.85	0.400
Education	0.24	1.93	0.01	0.13	0.901	1.17	1.54	0.06	0.76	0.447
Religion	0.84	1.00	0.08	0.84	0.401	1.56	0.79	0.15	1.97	0.052
Total clinical experience	3.02	2.83	0.12	1.07	0.287	0.47	2.37	0.02	0.20	0.843
Department	2.30	0.79	0.29	2.90	0.005*	2.68	0.63	0.34	4.25	< 0.001*
Current position	9.22	6.46	0.14	1.43	0.157	2.17	5.17	0.03	0.42	0.676
Annual salary	−1.05	1.41	−0.08	−0.75	0.457	−2.30	1.15	−0.18	−2.01	0.048*
Desired retirement age						2.11	0.91	0.19	2.33	0.022*
Preparation for retirement						−6.92	1.16	−0.53	−5.98	< 0.001*
Chronic disease						10.00	4.49	0.17	2.23	0.028*
Health beliefs						0.54	0.13	0.32	4.16	< 0.001*
Adj R2 = 0.351, *F* = 1.57, *p* = 0.014*						Adj R2 = 0.692, *F* = 6.79, *P* < 0.001*				

B, unstandardized coefficients; SE, standard error; ß, standardized coefficients; t, *t*-test; Adj. R^2, adjust R-squared; *$P < 0.05$.

promote the implementation of health practices (32, 35). Based on research findings, we need to further examine in detail the preparation for old age of nurses caring for old adults by reflecting on South Korea's characteristics to prepare for a super-aged society. In further study, we need to conduct a study comparing the preparation for old age of nurses per nursing department with the preparation for old age of other occupations. In particular, we propose in-depth qualitative research that presents positive causes and situations affecting the preparation for old age of nurses caring for old adults, as well as environmental factors and personal attributes.

Limitations

The above study's findings are significant as they provide invaluable insights into the impact on preparation for old age of nurses caring for old adults through the correlation of their health beliefs, focusing on young nurses in their 20s and 30s in South Korea. However, excluding nurse managers may eliminate valuable insights from those with broader healthcare and aging-related experience. Since the subjects of this study were young nurses in their 20s and 30s caring for old adults only in general hospitals in South Korea, it is difficult to generalize the results of this study as the impacts on the preparation for old age of nurses all in their 20s and 30s caring for old adults in South Korea as a whole. Also, the data collection window (October to November 2023) was relatively short and may miss temporal variations or seasonal influences. Data were collected only from nurses, ignoring patient feedback or institutional policies that may influence behavior. Furthermore, nurses might alter their responses simply because they knew they were being studied. They may be limitations of this study.

Conclusion

In conclusion, the level of preparation for retirement was the most influential on the preparation for old age of young nurses in their 20s and 30s caring for old adults, followed by department, health beliefs, desired retirement age, annual salary, and chronic diseases. Based on this finding, it may be necessary to induce a positive shift in the perception of young nurses in their 20s and 30s caring for old adults to prepare for life after retirement. Additionally, it is imperative to identify and examine various potential predictors of preparation for old age for young nurses caring for old adults. The trend toward an aging society is rapidly increasing the number of old adults; hence, the scope of work of nurses caring for old adults is continuously expanding. Considering such circumstances, the current study on preparation for old age for nurses caring for old adults may be significant and valuable.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Institutional Review Board of Kyung Hee University (IRB No. KHSIRB-23-471, Approval date October 24, 2023). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

SJH: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Validation, Visualization, Writing – original draft, Writing – review & editing. MG: Conceptualization, Formal analysis, Investigation, Methodology, Software, Validation, Visualization, Writing – original draft, Writing – review & editing. SShin: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Resources, Software, Supervision, Validation, Visualization, Writing – review & editing. SSok: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Resources, Software, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

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Influencing factors of home hospice care needs of family caregivers of the older adult with chronic diseases at the end of life in China: a cross-sectional study

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Introduction: With increased life expectancy in the Chinese population coupled with chronic disease the care needs of people at the end of life are attracting much attention. Home hospice care can help the dying older adult achieve comfort and maintain their dignity at home. However, dying at home means great responsibility and challenge for family caregivers, and there are many unmet needs. The study aimed to investigate the home hospice care needs of family caregivers of older adult people with chronic diseases at the end of life in China, and to analyze the influencing factors of home hospice care needs of caregivers.

Methods: In this cross-sectional study, from May to September 2023, 4 community health service centers were selected by stratified sampling from seven administrative districts in Jinzhou City, Liaoning Province, where home hospice care was piloted. Then 224 family caregivers were selected from the communities of seven community service centers by simple random sampling method. A general information questionnaire and the home hospice care needs questionnaire developed by our research group were used to investigate. Univariate analysis was used to compare the differences in the scores of different characteristics, and the factors with significant differences were selected for multivariate linear regression analysis to determine the final influencing factors.

Results: The total score of hospice care needs of family caregivers was 121.61 ± 15.24, among which the end-of-life knowledge need dimension score was 24.04 ± 2.71, the highest score index was 80.13%, while the symptom control need score was 15.58 ± 3.39, the lowest score index was 62.32%. In addition, Caregivers with caregiving experience, dying older adult with longer disease duration, and dying older adult with higher levels of education were the factors influencing the total need for home hospice care among family caregivers, with a variance explained of 22.7%.

Discussion: The needs of family caregivers of the terminally ill older adult are high, and healthcare professionals should implement services to meet their multidimensional needs and improve the quality of care according to the factors affecting their needs.

KEYWORDS

hospice care, cross-sectional studies, older adults, chronic diseases, family caregivers, end of life

1 Introduction

Chronic diseases are defined as non-communicable diseases with long course and slow progress, which are characterized by wide prevalence, high cost, high disability and mortality (1). The most common chronic diseases include stroke, ischemic heart disease, cancer and chronic obstructive pulmonary disease (2). Increasing age is the main risk factor for increasing morbidity and mortality of most chronic diseases (3). China already has the largest older adult population in the world, with approximately 264 million people aged 60 years and older, accounting for 18.7% of the total population (4). It is expected that by 2050 China's total older adult population will reach 400 million, with an aging rate of more than 30% (5). With increased life expectancy in the Chinese population coupled with chronic disease the care needs of people at the end of life are attracting much attention.

Most older adult patients who are dying prefer to get hospice care at home, likely due to the influence of traditional cultural notions in China (6). Home hospice provides palliative and supportive care to terminally ill patients and their families living at home by a team of health-care professionals and social volunteers. Home hospice care allows the dying older adult to achieve comfort and dignity at home, reduces hospitalization time and treatment costs, and improves the quality of death (7). For family caregivers, a death at home involves a great deal of responsibility and challenges. The term "family caregiver" describes the family members who live with the patient and spend the most time caring for the patient or who have the primary responsibility for most of the caregiving tasks, including spouse, child, parent, etc. (8, 9). In the final stages of life, caregivers are in charge of providing the older adult with emotional support, symptom management, and dietary support. Compared with the older adult at the end of life, caregivers lack support, have considerable caregiver burden and many unmet needs. Research indicates that caregivers usually provide care services to patients for ~8 h per day, and when caregiver needs or problems are not met or resolved, it can negatively affect the quality of life of both the patient and the caregiver (10). Therefore, it is of great practical significance to study the home hospice needs of caregivers, and the first step in meeting the needs of family caregivers is to assess their needs.

The research shows that there are many and rich contents on the home hospice care needs of family caregivers in Western countries. The needs of family caregivers include two main aspects: one is the need to take care of dying patients (such as symptom management and end-of-life planning including advanced decision-making and financial planning), and the other is their own physiological and psychological needs when they assume the role of caregivers (such as respite care and psychological counseling) (11–13). Furthermore, Nicolas' systematic scoping review reported that caregivers had the highest unmet needs in the domains of Psychological, Patient Care, and Support (14), and other literature reviews have identified the existence of multiple domains of unmet needs for caregivers, including information needs, and psychological needs (15). In contrast, the development of home hospice care in China has been slow, and research on needs is very limited. Distinct cultural and religious convictions significantly influence hospice needs and the process of making end-of-life decisions (15, 16). Thus, it is necessary to further explore the needs of Chinese family caregivers for home hospice care.

Higher need scores were identified in a cross-sectional study for younger, better educated, and higher household income caregivers (17). Badr et al. hypothesized that poorer physical health of caregivers may increase the unmet needs of caregivers (18). According to Jansma, caregivers with caregiving experience had significantly higher needs for symptom control than those without caregiving experience (19). It is clear that family caregivers' needs for home hospice vary depending on a variety of general information and caregiving-related characteristics. In addition, research has also indicated that factors such as gender, medical burden and self-care ability of terminal cancer patients have an impact on the needs of family caregivers (20), but there are fewer studies on the effects of basic characteristics of older adult terminal patients with chronic diseases on the level of caregiver needs.

This study took the family caregivers of the older adult with chronic diseases at the end of life as the object, and explored its influencing factors based on the survey on the current situation of caregivers' needs, in order to serve as a guide for the community medical staff implementing demand-oriented home hospice interventions.

2 Method

2.1 Design and samples

From May to September 2023, stratified sampling was conducted in seven administrative districts of Jinzhou City, Liaoning Province, where home hospice care pilot units were carried out, and a total of four community health service centers were selected. Then, a simple random sampling method was used to select 235 family caregivers of terminally ill older adult with chronic diseases who met the inclusion and exclusion criteria from the communities of four community service centers. The Jinzhou Medical University College of Nursing Ethics Committee gave its approval to the study (No. JZMULL2023159).

2.2 Inclusion criteria

2.2.1 Older adult with chronic diseases at the end of life

1. Age $\geq$ 60 years.
2. Chronic non-tumor diseases, with 1 or more organs severely impaired in function, no effective means of cure into the terminal stage or patients with malignant tumors into the terminal stage (expected survival $\leq$ 6 months).
3. Choose to die at home (hospice).
4. Clear consciousness, with normal language communication, and understanding ability.

2.2.2 Family caregiver

1. Immediate family members (including parents, spouses, children, siblings, etc.) or primary caregivers (the duration of care was 1 month and above).

2. Age $\geq$18 years old, informed about the condition and involved in nursing decision-making.
3. If there are multiple caregivers taking turns to take care of the patient, the primary caregiver was preferred.

2.3 Exclusion criteria

Caregivers those with a history of mental illness or communication disorders; those who with employment relationships; or those who with recent negative stress events (e.g., loss of relatives, car accidents); not completing the questionnaires or completing them incompletely.

2.4 Instruments

2.4.1 General information questionnaire

Information collected on the dying older adult included demographic characteristics (gender, age, marital status, education level, medical insurance payment method) and their disease status (duration of illness, number of diseases, the type of disease, self-care ability), totaling six items. Family caregivers included demographic information (e.g., gender, age, marital status, education level) and caregiving status (e.g., caregiving burden, relationship with the dying older adult, length of caregiving), totaling 13 items. Demographics of the dying older adult and family caregivers were collected by self-report, and duration of illness and the type of disease were collected from medical record review.

2.4.2 The family caregiver needs assessment questionnaire for home hospice care of the dying older adult

FCNQ was an assessment tool developed by our research group to assess the home hospice care needs of family caregivers of the dying older adult in China. The development phase of the questionnaire consisted of three steps. First, an initial questionnaire containing 48 items was initially developed based on family caregiver interviews and an extensive review of the literature. Second, the initial items developed and compiled by the researcher were reviewed by two rounds of 19 experts (one clinical geriatric medicine, three chronic disease nursing education, four community chronic disease nursing, four community geriatric nursing, six geriatric hospice care, and one community oncology) was revised to 36 items. Finally, 223 family caregivers of terminally ill older adult were selected for questionnaire validation. The validation process consisted of (1) further screening of 34 items using item analysis and (2) psychometric techniques for reliability and validity analysis. The questionnaire has been psychologically validated and found to have good reliability and validity. The Cronbach's alpha coefficient of the total questionnaire was 0.910, the Cronbach's alpha coefficients of the dimensions were 0.888–0.922, and the retest reliability was 0.868. The content validity index of the questionnaire was 0.982, and the content validity indices of the items were 0.83–1.00. For the exploratory factor extraction of the six common factors, the cumulative variance contribution rate was 71.181%. The questionnaire consisted of the following items: symptom control needs (five items), life care needs (seven items), emotional regulation needs (seven items), social support needs (five items), end-of-life knowledge needs (six items) and spiritual care needs (four items), totaling 34 items. Each item was rated on a 5-point Likert scale from "not needed" to "very needed" on a scale of 1–5. The total questionnaire score ranged from 34 to 170, with higher scores indicating a higher level of need. A score of $<$92 was a low need, 92–110 was a medium need, and $>$110 was a high need. Since the number of items in each dimension is different, in order to make them comparable, the score indicator was used for analysis, which was calculated as follows: score indicator = (the actual score of the dimension/the theoretical maximum score of the dimension) × 100% (21).

2.5 Data collection

A research team was set up. The postgraduate tutor was responsible for contacting the community health service center where the survey was conducted and coordinating the time of the door-to-door survey with the community committee. An associate professor was responsible for the quality control of the data collection process, and two PhDs guided the questionnaire design and refinement and were responsible for the training of the questionnaire survey. Two postgraduate students were uniformly trained to collect the questionnaires, and the questionnaires were carried out after passing the training. Before the survey, the purpose and significance of the study were explained to the respondents, and an informed consent form was signed. Then we explained the requirements of filling in the questionnaire and asked the respondents to fill in the questionnaire after they fully understood it. For those with low education levels or unable to answer for other reasons, the researcher read out the questions and options in a uniform way and recorded the actual answers of the respondents. The time limit for answering the questionnaire was 20 min or less.

2.6 Statistical analyses

Epidata 3.1 software was used to input the original values by two people and SPSS22.0 (IBM Corp, Armonk, NY) software was used for statistical analysis of data. The two-sided test level was $\alpha = 0.05$, and the difference was statistically significant at $P < 0.05$.

The frequency and component ratios were used to describe the general information about the older adult with end-stage chronic illness and family caregivers, and the total FCNQ need scores and the scores on each dimension were described by the mean and standard deviation. To analyze differences, first, independent samples *t*-tests (variables were divided into two groups) and one-way ANOVA (variables were divided into three or more groups) were used to initially explore the relationship between the scores on the dimensions of need for home hospice care and general information about study participants. Second, taking the total score and the scores of six dimensions of FCNQ as the dependent variables, the statistically significant independent variables in the single factor analysis were selected for multiple linear regression analyses ($\alpha_{\text{in}} = 0.05$, $\alpha_{\text{out}} = 0.10$) to find out the possible influencing factors of the total needs and the needs of the dimensions.

TABLE 1 General Information of older adult with end-stage chronic disease ($N = 224$).

Characteristics		N	Percentage (%)
Gender	Male	121	54.0
	Female	103	46.0
Age (year)	60–69	94	42.0
	70–79	86	38.4
	≥80	44	19.6
Marital status	Unmarried	3	1.3
	Married/cohabitation	176	78.6
	Divorce	4	1.8
	Widowed	41	18.3
Education level	Primary school and below	127	56.7
	Middle school education	67	29.9
	High school education or technical secondary school	13	5.8
	Junior college and above	17	7.6
Medical insurance payment method	Insurance for urban workers	119	53.1
	New rural co-operative medical system	85	37.9
	Commercial health insurance	6	2.7
	Self-paying	14	6.3
Duration of illness (year)	<1	73	32.6
	1–3	82	36.6
	>3	69	30.8
Number of comorbidities (kind)	1	115	51.3
	2	74	33.0
	≥3	35	15.6
The type of disease	Non-cancer chronic diseases	110	49.1
	Cardiovascular diseases	45	20.1
	Chronic respiratory diseases	30	13.4
	Nervous system diseases	15	6.7
	Cerebrovascular diseases	12	5.4
	Other	8	3.5
	Cancer	114	50.9
	Lung cancer	49	21.9
	Liver cancer	25	11.2
	Colorectal cancer	18	8.0
	Leukemia	9	4.0
	Esophageal cancer	8	3.6
	Other	5	2.2
Self-care ability	Completely capable of	58	25.9
	Most able to	88	39.3
	A part of	50	22.3
	Completely unable	28	12.5

3 Results

3.1 General information

A total of 235 questionnaires were distributed in this study, and 224 meeting the requirements were recovered, with a response rate of 95.3%. Eleven invalid questionnaires were excluded, among which six refused to answer part of the questions in the questionnaire due to personal reasons, resulting in incomplete questionnaires. Five were excluded because the subjects filled in the information incorrectly.

The general information on the older adult dying of chronic diseases and their family caregivers are shown in Tables 1, 2. More than half of the dying older adult were male (54.0%), most of them were aged 60–69 years (42.0%), married/ cohabitation (78.6%), and had an education level of primary school or below (56.7%). The most common type of disease was cancer (54.70%), with a high prevalence of lung cancer (21.9%). Among non-cancer chronic diseases (49.1%), the chronic prevalence of cardiovascular diseases was higher (20.1%).

Most of the family caregivers were female (62.1%), married/Cohabitation (94.6%), educated in junior high school and below (59.4%), and non-religious (92.4%). The highest percentage of caregiver-older adult relationships were with Children (56.5%), nearly half of the caregivers had a per capita monthly household income of <3,000 yuan (42.0%) and had a heavy financial burden of treatment (46.4%).

3.2 Family caregiver home hospice needs score

Family caregivers' home hospice needs had a total score of 121.61 ± 15.24, and the score indicator was 71.54%. The score of End-of-life Knowledge Needs was 24.04 ± 2.71, and its score indicator was the highest (80.13%). Spiritual Care Needs (14.62 ± 2.20) and Emotional Regulation Needs (25.44 ± 4.94) followed with score indicators of 73.10 and 72.69%, respectively. Symptom Control Needs with a score of 15.58 ± 3.39 had the lowest score indicator (62.32%). More detailed information is shown in Table 3.

TABLE 2 General information of family caregiver ($N = 224$).

Characteristics		N	Percentage (%)
Gender	Male	85	37.9
	Female	139	62.1
Age (year)	18–40	58	25.9
	41–59	97	43.3
	≥60	69	30.8
Marital status	Unmarried	10	4.5
	Married/cohabitation	212	94.6
	Divorce	2	0.9
Education level	Junior high school and below	133	59.4
	High school or junior college	45	20.1
	College or above	46	20.5
Health status	Very good	89	39.7
	Normal	71	31.7
	Not good enough	48	21.4
	Poor	16	7.1
Religious belief	No	207	92.4
	Yes	17	7.6
Caregiving burden	No burden of care	33	14.7
	A little burden of care	109	48.7
	Heavy burden of care	82	36.6
Relationship with the dying older adult	Spouse	77	34.4
	Children	126	56.5
	Grandchildren	7	3.1
	Sibling	9	4.0
	Other	5	2.2
Length of caregiving (month)	1–6	112	50.0
	6–12	52	23.2
	>12	60	26.8
Household incomes per capita (yuan)	<3,000	94	42.0
	3,000–4,999	87	38.8
	≥5000	43	19.2
Caregiving experience	No	168	75.0
	Yes	56	25.0
Working condition	Working	116	51.8
	Non-working	108	48.2
Burden of payment for treatment	No burden	15	6.7
	A little burden	56	25.0
	Moderate burden	49	21.9
	Heavy burden	104	46.4

Table 4 lists the five highest scoring items for each dimension. It involved multiple dimensions. The top two need items were "It is hoped that medical staff can share decision-making and discuss advance care planning with family members" (4.42 ± 0.78) and "I hope the older adult die peacefully and with dignity, surrounded by family members" (4.42 ± 0.66).

3.3 Univariate analyses of family caregivers' home hospice needs

After testing the data for normality and homogeneity of variance, we screened for single factors that independently influenced the total FCNQ score and each dimension. The total score of needs showed that the duration of illness, number of comorbidities, self-care ability, age and education level of the dying older adult were statistically significant. Significant differences were also found in the age, relationship with the older adult, length of care, and caregiving experience of family caregivers. More detailed information is shown in Tables 5, 6.

3.4 Multiple linear regression analysis of family caregivers' need for home hospice care

Relationship with the dying older adult (spouse as the benchmark) and Caregiver's marital status (unmarried as the benchmark) of the independent variables were set as dummy variables. Other independent variable assignments are shown in Table 7.

Seven multivariate linear regression analyses were performed to identify significant correlates of total home hospice needs and six dimensions of needs. The diagnostic test independent variables had all variance inflation factor (VIF) values < 10, indicating no multicollinearity issue existed before the analysis was conducted. Furthermore, residual analysis provided support for the equation models' linearity, normality, and homogeneity of variance. Caregivers with caregiving experience ($\beta = 5.794$, $P = 0.010$) as well as dying older adult reporting longer duration of illness ($\beta = 2.664$, $P = 0.042$), and higher levels of education ($\beta = 4.511$, $P = 0.000$) had more total home hospice need for family caregivers, with 22.7% of the variance explained. Caregiver being female ($\beta = 1.303$, $P = 0.003$), longer duration of caregiving ($\beta =$

TABLE 3 Scores for items on dimensions of need for home hospice care for family caregiver.

Dimension	Range of score	Total score ($\bar{x} \pm SD$)	Index of score (%)	Order
Symptom control needs	5–25	15.58 ± 3.39	62.32	6
Life care needs	7–35	24.35 ± 4.33	69.57	5
Emotional regulation needs	7–35	25.44 ± 4.94	72.69	3
Social support needs	5–25	17.58 ± 3.07	70.32	4
End-of-life knowledge needs	6–30	24.04 ± 2.71	80.13	1
Spiritual care needs	4–20	14.62 ± 2.20	73.10	2
Total score	34–170	121.61 ± 15.24	71.54	

TABLE 4 Top five highest scoring items for family caregiver home hospice needs.

Item	Dimension	Score ($\bar{X}\pm$ SD)
It is hoped that medical staff can share decision-making and discuss advance care planning with family members	End-of-life knowledge needs	4.42 ± 0.78
I hope the older adult die peacefully and with dignity, surrounded by family members	Spiritual care needs	4.42 ± 0.66
Hope to help me adjust the fear and sadness caused by the old man's death	Emotional regulation needs	4.40 ± 0.76
Hope to provide me with simple treatment guidance and emergency assistance at home when my condition changes or accidents occur (such as falling down from the bed or choking)	Life care needs	4.40 ± 0.73
It is hoped that institutions and medical staff will provide on-site formal care assistance (such as drug administration, disease monitoring services, and guidance for practical operations).	Social support needs	4.25 ± 0.65

0.780, $P = 0.003$), relationship with the older adult was children ($\beta = 1.723$, $P = 0.000$), and longer duration of illness for the dying older adult ($\beta = 0.771$, $P = 0.004$) were all associated with caregiver symptom control needs, with 18.8% of the variance explained. The influence factors of the other dimensions are shown in Table 7.

4 Discussion

4.1 Family caregivers' home hospice care needs

The results of this study indicate that there is a high level of hospice needs for the family caregivers of the older adult at the end of life with chronic diseases in the home setting. First, in the current study, we found that family caregivers of terminally ill older adult people with end-stage chronic diseases have different levels of needs in all six dimensions. Family caregivers had the highest dimension level of end-of-life knowledge needs, where the highest scoring items corroborate that in China, most of the treatment decisions and advance care planning are made by family members in consultation with medical professionals, consistent with the findings of the study by Gu et al. (22). China has a long history of family-centered collectivist culture, and the family serves the functions of emotional connection, communication, and dealing with life's challenges. Family members are crucial in therapeutic communication considering the physical state and psychological tolerance of the older adult.

Secondly, spiritual care needs are more prominent. Among them, accompanying the older adult peacefully and passing away is considered to be the most important need, which is consistent with the survey of Chinese scholars (23). This means that many family members avoid talking to the patients about their illnesses and cannot truthfully inform the patients of the fact that they have reached the terminal stage. As a result, some patients have unrealistic expectations for how their illnesses will be treated, making it difficult for them to pass away peacefully and dignifiedly.

Thirdly, emotional regulation was also identified as a high need in this study, of which the item of regulating the emotion of fear and sadness was the most important, indicating that the fear and helplessness of the family members increase significantly during the dying period and when the patient's condition deteriorates (16). During the implementation of home hospice care, healthcare professionals should pay attention to the psychological state of family caregivers, provide them with timely psychological support, guide them to cope with negative emotions and establish the correct confidence in caregiving. Symptom control needs have the lowest scores, which belong to the lowest physiological needs in Maslow's hierarchy of needs theory and should be met first (24). This implies that medical professionals in China's existing healthcare system concentrate on managing symptoms. For example, Jing'e team's core service for home hospice is analgesic treatment with guidance on symptom control (25), which shows that the need for symptom control has been largely met.

4.2 Influencing factors of home hospice care needs

Next, we identified several factors related to the home hospice care needs of family caregivers of older adult people with terminal chronic illnesses. We discovered that family caregivers with caregiving experience had high home hospice care needs,

TABLE 5 A univariate analysis of the characteristics of dying older adult with home hospice needs.

Variable	SCN	LCN	ERN	SSN	EKN	SCN	TS
Older adults type of disease							
Non-cancer chronic diseases	15.78 ± 3.53	23.95 ± 4.57	24.99 ± 5.07	16.95 ± 3.06	23.92 ± 2.73	14.63 ± 2.24	120.22 ± 16.15
Cancer	15.39 ± 3.25	24.74 ± 4.06	25.88 ± 4.79	18.18 ± 2.96	24.15 ± 2.69	14.61 ± 2.17	122.95 ± 14.24
t/F	0.873	−1.369	−1.346	**−3.058**	−0.638	0.045	−1.343
p	0.384	0.173	0.18	**0.003**	0.524	0.964	0.181
Older adults duration of illness (year)							
<1	14.58 ± 3.39	23.88 ± 4.48	24.34 ± 5.21	16.62 ± 3.13	23.55 ± 2.84	14.21 ± 2.19	117.16 ± 15.97
1–3	15.67 ± 2.90	24.99 ± 4.21	26.02 ± 4.48	18.27 ± 2.82	24.30 ± 2.20	15.06 ± 2.06	124.32 ± 13.10
>3	16.54 ± 3.67	24.09 ± 4.27	25.91 ± 5.03	17.78 ± 3.05	24.23 ± 3.05	14.54 ± 2.31	123.09 ± 15.96
t/F	**6.258**	1.462	2.737	**6.093**	1.787	**3.050**	**4.891**
p	**0.002**	0.234	0.067	**0.003**	0.170	**0.049**	**0.010**
Older adults number of comorbidities (kind)							
1	15.23 ± 3.29	24.15 ± 4.46	24.91 ± 4.83	17.31 ± 3.10	23.83 ± 2.50	14.43 ± 2.13	119.88 ± 14.38
2	15.58 ± 3.13	24.14 ± 3.82	25.46 ± 5.27	17.54 ± 3.11	23.77 ± 2.82	14.59 ± 2.23	121.08 ± 15.21
≥3	16.71 ± 4.04	25.46 ± 4.83	27.14 ± 4.25	18.54 ± 2.73	25.26 ± 2.84	15.29 ± 2.30	128.40 ± 16.56
t/F	2.590	1.368	2.781	2.193	**4.370**	2.035	**4.393**
p	0.077	0.257	0.064	0.114	**0.014**	0.133	**0.013**
Older adults self-care ability							
Completely capable of	15.16 ± 2.90	24.59 ± 3.95	25.83 ± 4.92	18.22 ± 2.58	24.41 ± 2.34	14.66 ± 2.00	122.86 ± 12.98
Most able to	15.39 ± 3.28	23.58 ± 4.50	24.59 ± 5.08	17.23 ± 3.28	23.74 ± 2.59	14.43 ± 2.21	118.95 ± 15.32
A part of	15.60 ± 3.60	24.56 ± 4.39	25.38 ± 4.41	17.10 ± 3.10	23.36 ± 2.91	14.40 ± 2.00	120.40 ± 14.25
Completely unable	17.04 ± 4.05	25.89 ± 4.10	27.43 ± 5.01	18.21 ± 3.07	25.39 ± 2.91	15.54 ± 2.73	129.50 ± 18.54
t/F	2.152	2.252	2.556	2.081	**4.304**	2.032	**3.765**
p	0.095	0.083	0.056	0.104	**0.006**	0.243	**0.044**
Older adults age (year)							
60–69	15.77 ± 3.48	24.90 ± 4.30	26.07 ± 4.88	18.21 ± 2.97	24.17 ± 2.75	14.69 ± 2.31	123.82 ± 15.42
70–79	15.13 ± 3.27	23.78 ± 4.09	24.44 ± 5.17	17.03 ± 2.98	23.77 ± 2.55	14.42 ± 2.02	118.57 ± 13.53
≥80	16.07 ± 3.39	24.27 ± 4.77	26.05 ± 4.34	17.30 ± 3.23	24.27 ± 2.91	14.86 ± 2.32	122.82 ± 17.23
t/F	1.366	1.535	2.914	**3.638**	0.706	0.678	**2.887**
p	0.257	0.218	0.056	**0.028**	0.495	0.509	**0.047**
Older adults education level							
Primary school and below	15.37 ± 2.99	23.61 ± 4.11	24.87 ± 5.01	17.02 ± 3.07	23.78 ± 2.63	14.37 ± 2.06	119.02 ± 13.93
Middle school education	15.25 ± 3.73	24.33 ± 4.35	25.52 ± 5.03	17.78 ± 2.95	24.15 ± 2.66	14.58 ± 2.34	121.61 ± 16.40
High school education or technical secondary school	17.00 ± 4.47	26.54 ± 4.12	26.31 ± 4.77	18.69 ± 2.87	24.31 ± 3.88	15.31 ± 2.25	128.15 ± 14.75
Junior college and above	17.35 ± 3.45	28.29 ± 3.48	28.71 ± 2.42	20.12 ± 1.97	25.29 ± 2.14	16.12 ± 2.09	135.88 ± 11.38
t/F	2.74	**7.71**	**3.273**	**6.372**	1.705	**3.737**	**7.614**
p	0.104	**0.000**	**0.000**	**0.000**	0.167	**0.012**	**0.000**

SCN, symptom control needs; LCN, life care needs; ERN, emotional regulation needs; SSN, social support needs; EKN, end-of-life knowledge needs; SCN, spiritual care needs; TS, total score. The bold indicated the $p < 0.05$.

particularly for life care needs, social support needs, and end-of-life knowledge needs, which was consistent with the study by Wei et al. (26). Experienced family caregivers witnessed patients suffering from symptoms such as pain, nausea, vomiting, anxiety, and depression, prompting a stronger need for daily life care. They hoped that the care would allow the terminally ill older adult

TABLE 6 A univariate analysis of family caregiver characteristics for home hospice needs.

Variable	SCN	LCN	ERN	SSN	EKN	SCN	TS
Gender							
Male	14.86 ± 3.14	24.11 ± 4.46	25.27 ± 4.85	17.61 ± 3.22	23.98 ± 2.40	14.53 ± 2.11	120.35 ± 15.19
Female	16.02 ± 3.47	24.50 ± 4.25	25.55 ± 5.01	17.56 ± 2.98	24.07 ± 2.88	14.68 ± 2.26	122.37 ± 15.27
t/*F*	**−2.52**	−0.655	−0.406	0.12	−0.256	−0.484	−0.963
p	**0.012**	0.513	0.685	0.905	0.798	0.629	0.336
Age (year)							
18–40	16.3 ± 3.53	24.8 ± 4.58	26.59 ± 4.57	18.05 ± 3.25	24.81 ± 2.39	15.31 ± 2.31	125.88 ± 16.53
41–59	15.1 ± 3.25	24.2 ± 4.40	25.25 ± 4.94	17.64 ± 3.08	23.89 ± 2.71	14.49 ± 1.98	120.59 ± 14.14
≥60	15.6 ± 3.41	24.1 ± 4.03	24.75 ± 5.14	17.10 ± 2.86	23.59 ± 2.85	14.22 ± 2.29	119.45 ± 15.11
t/*F*	2.251	0.445	2.331	1.554	**3.523**	**4.293**	**3.254**
p	0.108	0.641	0.1	0.214	**0.031**	**0.015**	**0.04**
Marital status							
Unmarried	16.10 ± 4.61	25.20 ± 4.66	26.80 ± 5.87	18.10 ± 4.10	25.00 ± 3.16	15.40 ± 2.07	126.60 ± 22.09
Married/cohabitation	15.53 ± 3.34	24.29 ± 4.33	25.47 ± 4.80	17.56 ± 3.02	24.02 ± 2.65	14.59 ± 2.20	121.46 ± 14.91
Divorce	18.00 ± 1.41	26.50 ± 3.54	15.50 ± 6.36	17.50 ± 3.54	21.00 ± 5.66	13.50 ± 3.54	112.00 ± 7.07
t/*F*	0.645	0.46	**4.58**	0.15	1.915	0.902	0.944
p	0.526	0.632	**0.011**	0.861	0.15	0.407	0.351
Education level							
Junior high school and below	15.38 ± 3.08	23.95 ± 4.17	25.49 ± 4.58	17.20 ± 3.04	23.80 ± 2.58	14.37 ± 2.13	120.18 ± 13.93
High school or junior college	15.29 ± 3.42	24.80 ± 4.39	25.04 ± 5.28	17.44 ± 2.96	23.96 ± 2.98	14.93 ± 2.07	121.47 ± 16.19
College or above	16.46 ± 4.09	25.07 ± 4.65	25.70 ± 5.64	18.83 ± 2.97	24.78 ± 2.72	15.04 ± 2.45	125.87 ± 17.32
t/*F*	1.96	1.454	0.211	**5.072**	2.285	2.203	2.416
p	0.243	0.236	0.81	**0.007**	0.104	0.113	0.092
Health status							
Very good	15.42 ± 3.55	24.18 ± 4.32	24.28 ± 5.07	17.16 ± 3.18	24.27 ± 2.43	14.58 ± 2.30	119.89 ± 16.40
Normal	15.65 ± 3.25	25.27 ± 4.40	26.37 ± 4.12	18.06 ± 3.24	24.18 ± 2.99	14.89 ± 2.04	124.41 ± 14.40
Not good enough	15.77 ± 3.40	23.71 ± 4.15	25.90 ± 4.94	17.81 ± 2.62	23.81 ± 2.53	14.58 ± 1.93	121.58 ± 14.24
Poor	15.63 ± 3.38	23.13 ± 4.16	26.44 ± 6.48	17.13 ± 2.73	22.75 ± 3.19	13.75 ± 2.93	118.81 ± 14.41
t/*F*	0.129	1.914	**2.894**	1.352	1.619	1.2	1.364
p	0.943	0.128	**0.042**	0.258	0.186	0.311	0.255
Caregiving burden							
No burden of care	15.58 ± 3.90	23.36 ± 4.37	23.15 ± 6.11	17.27 ± 3.62	24.12 ± 2.95	14.82 ± 2.39	118.30 ± 18.02
A little burden of care	15.76 ± 3.29	24.85 ± 4.54	25.03 ± 4.40	17.83 ± 2.98	24.49 ± 2.49	14.94 ± 1.95	122.89 ± 15.21
Heavy burden of care	15.34 ± 3.34	24.07 ± 3.95	26.91 ± 4.69	17.38 ± 2.95	23.40 ± 2.79	14.12 ± 2.36	121.23 ± 13.99
t/*F*	0.357	1.776	**8.064**	0.692	**3.873**	**3.433**	1.189
P	0.7	0.172	**0.002**	0.502	**0.022**	**0.034**	0.306
Religious belief							
No	15.47 ± 3.22	24.23 ± 4.26	25.43 ± 4.94	17.49 ± 3.02	23.97 ± 2.68	14.53 ± 2.15	121.12 ± 14.63
Yes	16.94 ± 4.93	25.82 ± 4.94	25.59 ± 5.03	18.71 ± 3.46	24.82 ± 2.94	15.71 ± 2.57	127.59 ± 20.90
t/*F*	−1.21	−1.467	−0.125	−1.58	−1.251	**−2.133**	−1.252
P	0.243	0.144	0.902	0.115	0.212	**0.034**	0.227

(Continued)

TABLE 6 (Continued)

Variable	SCN	LCN	ERN	SSN	EKN	SCN	TS
Relationship with the dying older adult							
Spouse	14.66 ± 3.09	23.84 ± 3.77	24.99 ± 5.36	17.12 ± 2.92	23.52 ± 2.70	14.04 ± 2.23	118.17 ± 13.89
Children	16.10 ± 3.55	24.80 ± 4.68	26.04 ± 4.57	17.98 ± 3.11	24.52 ± 2.64	14.98 ± 2.11	124.43 ± 15.90
Grandchildren	14.57 ± 2.88	23.43 ± 3.60	23.14 ± 5.15	17.14 ± 3.39	23.86 ± 1.57	15.43 ± 1.99	117.57 ± 14.67
Sibling	15.89 ± 2.32	23.44 ± 3.71	23.22 ± 5.54	16.44 ± 3.54	22.11 ± 3.52	13.78 ± 2.33	114.89 ± 9.98
Other	17.40 ± 3.51	23.60 ± 4.98	24.60 ± 4.72	17.20 ± 1.79	23.60 ± 1.34	14.80 ± 2.28	121.20 ± 15.82
t/*F*	**2.779**	0.819	1.51	1.36	**2.974**	**2.875**	**2.702**
P	**0.028**	0.514	0.2	0.249	**0.02**	**0.024**	**0.031**
Length of caregiving (month)							
1–6	14.87 ± 2.85	24.21 ± 4.22	25.60 ± 4.20	17.47 ± 3.05	23.93 ± 2.54	14.54 ± 2.04	120.61 ± 13.76
6–12	15.92 ± 3.49	23.29 ± 3.91	24.19 ± 5.39	17.17 ± 2.96	23.81 ± 2.80	14.52 ± 2.11	118.90 ± 14.15
>12	16.62 ± 3.94	25.53 ± 4.63	26.23 ± 5.63	18.13 ± 3.15	24.43 ± 2.92	14.87 ± 2.55	125.82 ± 17.93
t/*F*	**5.79**	**3.977**	2.527	1.511	0.92	0.512	**3.423**
P	**0.006**	**0.02**	0.134	0.223	0.4	0.6	**0.034**
Household incomes per capita(yuan)							
<3,000	15.32 ± 3.14	24.02 ± 3.98	26.22 ± 4.85	17.00 ± 3.09	23.71 ± 2.74	14.35 ± 2.23	120.63 ± 15.07
3,000–4,999	15.71 ± 3.43	24.55 ± 4.50	25.52 ± 4.47	18.10 ± 2.91	24.53 ± 2.55	14.83 ± 2.16	123.24 ± 15.25
≥5,000	15.88 ± 3.86	24.65 ± 4.73	23.58 ± 5.62	17.79 ± 3.18	23.74 ± 2.85	14.79 ± 2.20	120.44 ± 15.64
t/*F*	0.515	0.468	**4.369**	**3.112**	2.394	1.222	0.819
P	0.598	0.627	**0.014**	**0.046**	0.094	0.297	0.442
Caregiving experience							
No	15.24 ± 3.31	23.86 ± 4.25	25.17 ± 4.94	17.24 ± 3.00	23.89 ± 2.56	14.39 ± 2.12	119.80 ± 14.51
Yes	16.59 ± 3.46	25.80 ± 4.27	26.25 ± 4.87	18.59 ± 3.06	24.46 ± 3.08	15.32 ± 2.31	127.02 ± 16.19
t/*F*	**−2.604**	**−2.957**	−1.417	**−2.891**	−1.251	**−2.795**	**−3.129**
P	**0.01**	**0.003**	0.158	**0.004**	0.214	**0.006**	**0.002**
Burden of payment for treatment							
No burden	15.13 ± 3.48	24.27 ± 3.96	21.40 ± 5.99	18.47 ± 2.90	23.60 ± 2.53	14.53 ± 2.26	117.40 ± 14.55
A little burden	16.48 ± 3.92	25.30 ± 4.75	25.04 ± 4.93	18.43 ± 3.08	24.88 ± 2.78	15.48 ± 2.08	125.61 ± 17.22
Moderate burden	15.37 ± 3.23	23.98 ± 4.56	24.82 ± 4.50	17.24 ± 3.19	23.94 ± 2.53	14.69 ± 2.05	120.04 ± 14.75
Heavy burden	15.26 ± 3.10	24.02 ± 4.00	26.54 ± 4.65	17.15 ± 2.94	23.69 ± 2.71	14.13 ± 2.20	120.80 ± 14.18
t/*F*	1.801	1.235	**5.802**	**2.780**	2.559	**4.818**	1.963
p	0.148	0.298	**0.001**	**0.042**	0.056	**0.003**	0.120

SCN, symptom control needs; LCN, life care needs; ERN, emotional regulation needs; SSN, social support needs; EKN, end-of-life knowledge needs; SCN, spiritual care needs; TS, total score. The bold indicated the $p < 0.05$.

to gain somatic comfort. In addition, the older adult dying in this study had comorbidities and 74.1% had self-care deficits. The complexity and variety of older adult conditions made it urgent for even seasoned caretakers to seek professional help. According to Jansma, caregivers who have caregiving experience are mentally ready for the patient's death and want to learn more about end-of-life knowledge in advance so that the deceased can rest in peace and the living can be eased (19). Therefore, the focus of healthcare professionals' knowledge and skills in teaching and instructing also includes caregivers who have experience in caregiving, so that caregivers are able to cope with various emergencies that may arise in family caregiving in an organized manner and meet the needs. However, how healthcare professionals can use different teaching methods and curricula to target caregivers at different levels of care is a topic that needs to be further explored.

This study identified gender as an influential factor in caregivers' symptom control needs. This validates Franchini et al.'s findings (27). With 62.1% of the caregivers in this survey being female, women dominated the role of caregiver due to the Chinese idea that men work hard for a career and women

TABLE 7 Regression analysis of factors influencing total need and need by dimension.

Dimension	Variable[a]	Unstandardized coefficients	Standardized coefficients	Standardized coefficients	R^2	Cumulative R^2	t	p
		β	SE	β				
SCN	Constant	8.385	1.156		0.188	0.158	7.251	0.000
	Relationship with the dying older adult (children)	1.723	0.461	0.253			3.736	0.000
	Caregiver's gender (female)	1.303	0.434	0.187			3.006	0.003
	Length of caregiving (>12 month)	0.780	0.261	0.195			2.988	0.003
	Older adults duration of illness (year)	0.771	0.267	0.181			2.886	0.004
LCN	Constant	19.878	0.999		0.117	0.105	19.889	0.000
	Caregiving experience (yes)	1.620	0.652	0.162			2.483	0.014
	Older adults education level	1.341	0.309	0.278			4.335	0.000
ERN	Constant	21.679	2.313		0.181	0.154	9.373	0.000
	Caregiver's marital status (divorce)	−12.1	3.642	−0.231			−3.322	0.001
	Caregiving burden (heavy burden of care)	1.573	0.560	0.218			2.807	0.005
	Older adults education level	1.102	0.343	0.200			3.210	0.002
SSN	Constant	12.403	1.620		0.209	0.180	7.673	0.000
	Caregiver's education level	0.543	0.255	0.143			2.128	0.035
	Caregiving experience (yes)	1.082	0.433	0.153			2.502	0.013
	Older adults type of disease	1.147	0.471	0.188			2.436	0.016
	Older adults duration of illness (year)	0.879	0.251	0.229			3.501	0.001
	Older adults education level	0.628	0.223	0.184			2.815	0.005
EKN	Constant	24.453	1.144		0.098	0.064	21.373	0.000
	Caregiving burden	0.527	0.265	0.133			1.988	0.048
	Older adults number of comorbidities (kind)	0.622	0.249	0.17			2.495	0.013
SCN	Constant	13.446	1.183		0.165	0.122	11.367	0.000
	Caregiving experience (yes)	0.863	0.325	0.170			2.659	0.008
	Older adults education level	0.446	0.158	0.182			2.821	0.005
TS	Constant	100.368	6.166		0.227	0.183	16.277	0.000
	Caregiving experience (yes)	5.794	2.235	0.165			2.593	0.010

(Continued)

TABLE 7 (Continued)

Dimension	Variable[a]	Unstandardized coefficients	Standardized coefficients	Standardized coefficients	R^2	Cumulative R^2	t	p
		β	SE	β				
	Older adults duration of illness (year)	2.664	1.304	0.14			2.043	0.042
	Older adults education level	4.511	1.07	0.266			4.217	0.000

SCN, symptom control needs; LCN, life care needs; ERN, emotional regulation needs; SSN, social support needs; EKN, end-of-life knowledge needs; SCN, spiritual care needs; TS, total score.

[a]Dummy variables: relationship with the dying older adult (spouse) = 0, Caregiver's gender (male) = 0, length of caregiving (1–6 month) = 0, older adults duration of illness (<1 year) = 0, Caregiving experience (no) = 0, older adults education level (primary school and below) = 0, caregiver's marital status (unmarried) = 0, caregiving burden (no burden of care) = 0, older adults type of disease (non-cancer chronic diseases) = 0, older adults number of comorbidities (1 kind) = 0.

manage the household. Women are more sensitive and thoughtful, more capable of fulfilling the caregiver role and independently accomplishing illness and life care, which leads to their higher needs. In contrast, Lili et al. reported in a stress load survey of primary caregivers of patients with advanced primary liver cancer that women had high load scores (28). Therefore, male family members should be encouraged to actively participate in the care of the older adult by providing guidance and assistance to improve their caregiving skills and quality of care.

The study's caregivers were primarily young and middle-aged, ranging in age from 41 to 59 (43.3%), with most of them being the older adult terminally ill patients' children (56.5%). This group is mostly the economic and spiritual pillars of the family, with jobs and children, and the need to bear the pressure from family, work and study, as well as the task of long-term caregiving with a focus on symptom control. Therefore, the need for caregivers whose relationship with the dying older adult is that of a child and who take care of them for a longer time was higher. In addition, prolonged heavy caregiving is associated with a range of physical and psychological problems, leading to a decline in the quality of care (29). It is fully consistent with the finding of this study that the higher the caregiving burden, the higher the emotional regulation needs and spiritual care needs of caregivers. Consequently, healthcare professionals should pay special attention to the emotional and spiritual states of caregivers in this age group in the process of providing guidance to family caregivers, as well as understand their needs for palliative care in a timely manner and provide professional explanations.

According to this study, family caregivers' needs for home hospice care increased with the length of the older adult patient's illness, especially for symptom control needs, social support needs and spiritual care needs. Oechsle et al. reported that the psychological state of the primary caregiver of a cancer patient worsened as the patient's condition deteriorated and functional status declined (30). Because of the older chronic disease group's longer illness duration and the disease's gradual worsening of symptoms, their carers start to consider matters pertaining to death, which exacerbates emotional distress like anxiety and sadness. The retrospective study by Cengiz et al. also demonstrated that as caregiving grew longer and the patient's condition worsened, the caregiver's needs became more complex and comprehensive, necessitating more medical services to relieve the patient's physical and emotional suffering (31). Patients with malignant tumors confront significant physical, psychological, and spiritual challenges, according to research by Won et al. (32). The vast majority of terminal cancer patients are in critical condition, extremely weak and fatigued, with severely reduced mobility and self-care ability. They require caregiver support even for basic tasks like turning over in bed and defecating (33). However, this survey found that the percentage of those with no caregiving experience was as high as 75.0%, so caregivers are in great need of information and emotional support from family members, especially from other healthcare providers. In line with the findings of this study, family caregivers of terminally ill older adult with cancer had high social support needs.

In this study, caregiver needs were also influenced by education level. Family caregivers' total needs for home hospice care—which include life care needs, emotional regulation needs, social support needs, and spiritual care needs—increased with the terminally ill older adult' educational level. The higher literacy level of the terminally ill means better cognition and higher acceptance of hospice care (34). They have a greater desire to use home hospice care to enhance their quality of life when they are dying. Older adult people and their families live in the same household, and the long time together makes their life concepts and values converge (35). The old person's wishes to die at home will be honored by the caregivers. Additionally, this study also found that the higher education level of caregivers was associated with higher social support needs. Longacre maintained that the more educated the caregivers were, the more they wanted to utilize resources to access health care services and information (36). The reason for this is that highly educated caregivers are more demanding in their work and lives and are strict about improving quality care for their patients. They need to know or learn more information and knowledge, so they need more outside guidance and support. For family caregivers with higher education levels, they can provide more in-depth and professional knowledge about home hospice care, and recommend them to go through professional books, websites and public numbers to increase their rational understanding and participate in hospice care together.

5 Limitations

This study has the following limitations. First, this study was conducted in Jinzhou City, Liaoning Province, which is useful for studies under the same economic and cultural conditions, but whether the conclusions are representative of family caregivers of the chronically dying older adult in other regions needs to be further explored, and future studies could increase the sample size and collect data in different regions to make the findings more generalizable. Second, this study was a cross-sectional survey that investigated the need for and factors influencing home hospice care for this group at a certain point in time. In the future, a longitudinal study could be conducted to investigate the trends in caregivers' needs for home hospice care and the factors that influence them as the conditions of the terminally ill older adult change, so that better clinical guidance can be provided.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by Jinzhou Medical University College of Nursing Ethics Committee. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

LW: Writing – original draft. YL: Writing – original draft. RZ: Writing – review & editing. JL: Writing – original draft. XG: Writing – original draft. HL: Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

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Long-term care based on person-centered care for the older adults in rural Spain: the rural care project

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Introduction and objective: The Rural Care Project is a social and healthcare initiative designed for older adults living in deep-rural areas of the Autonomous Community of Castile and Leon (Spain) who require long-term care (LTC). This intervention program promotes Person-Centered Care (PCC) and active aging to improve quality of life (QoL). The aim of this study is to evaluate the project's effectiveness on QoL by way of a quasi-experimental study.

Methods: A total of 416 Spanish participants were divided into three groups: (a) experimental group ($N = 102$) made up of adults residing in deep-rural areas and receiving targeted home-based support; (b) control: residential care group ($N = 170$) with people receiving extensive formal care; (c) control: at home ($N = 144$), consisting of older adults with clinically identified dependency, disability, or chronic illness, who remained in their homes in rural areas and relied mainly on informal support (family, neighbors, or self-management), receiving little or no formal LTC services. The intervention spanned 18–20 months and included social and psychological support, coordination of care services, and periodic assessments by trained professionals. QoL was assessed pre- and post-intervention using the "World Health Organization Quality of Life" (WHOQOL-BREF) scale. Data were analyzed using repeated measures ANOVA, with *post hoc* tests to explore group differences. Power analysis confirmed adequate sample size to detect medium effects ($\alpha = 0.05$, power $= 0.80$, effect size $= 0.5$).

Results: Participants reported high satisfaction with personal relationships and housing. The experimental group showed significant improvements in physical and psychological health post-intervention, with moderate and small effect sizes, respectively. Improvements in social relationships and environmental context were limited, appearing mainly in the Control: at home group.

Discussion and conclusion: The findings provide evidence that the Rural Care program effectively improves key dimensions of QoL among older adults in deep-rural areas. Recommendations include implementing policy reforms to promote home-based LTC grounded in PCC principles. Prioritizing tailored support to enhance physical health and reduce medical dependency are critical outcomes that should be emphasized. Although the program did not produce significant effects on environmental context and social relationships, observed trends suggest potential benefits if future interventions are expanded to comprehensively address these areas. Thus, future programs should adopt a multifaceted approach, integrating strategies for environmental enhancements and promoting both formal and informal social interactions to empower older adults in decision-making processes.

KEYWORDS

healthcare, quality of life (QoL), long-term care, older adults, person-centered care (PCC), rural care, World Health Organization Quality of Life (WHOQOL-BREF) scale

Introduction

The aging of the population, particularly in rural areas, is one of the most pressing challenges currently faced by European societies. While increased life expectancy is considered a triumph—reflecting advances in healthcare, environment, and social development (1)—it also requires innovative and sustainable long-term care (LTC) models that promote autonomy, quality of life, and social inclusion among older adults. In rural contexts, where demographic aging is more pronounced, the limited availability and uneven implementation of person-centered, home-based LTC models present a significant barrier to adequately addressing the needs of dependent older individuals (2). This study addresses that gap by evaluating the piloting of the Rural Care project—an integrated, Person-Centered Care (PCC) initiative implemented in the rural region of Castile and Leon (Spain). The project's effectiveness is assessed through a quasi-experimental pre-post study comparing outcomes among participants in the Rural Care program and two control groups: one composed of older adults living at home in rural areas, with some degree of dependency, disability, or chronic illness, who relied mainly on informal care or self-management and had little or no access to formal LTC services (Control: at home), and another of care home residents (Control: residential care group).

In 2021, 22.8% of the European Union (EU) population was 65 years of age or older and it is estimated that this figure will reach 29.1% in 2050 (3). As far as rural areas are concerned, all of them have aging populations (4). In Spain in 2022, 20.08% of the population was 65 or older and it is expected that this figure will reach 30.38% in 2050 (5), and the Autonomous Community of Castile and Leon is the worst affected areas, where the greatest demographic aging of Spain's rural areas can be observed. In this region, 47% of local council areas have more than half of their population over the age of 65, with this figure reaching 80% in some councils (6).

The aging of the population in rural areas has significant healthcare implications, including less accessibility to the healthcare system and a greater prevalence of chronic illnesses (7–9) among with significant challenges in terms of emotional and social welfare. Loneliness and social isolation are particularly common due to the lack of infrastructures and services and a lower degree of mobility and social interaction (10–13). This can increase the risk of depression, anxiety and other mental health problems, ultimately leading to a lower quality of life (QoL) among older adults in these areas (14–17).

Long-term care (LTC) is defined as the system of informal and formal care aimed at helping people who cannot completely look after themselves to maintain the best possible QoL in accordance with their preferences (18). This approach is normally employed in combination with PCC, in which social and healthcare professionals work together with users to identify the distinctiveness and uniqueness of each individual (2, 19, 20). Different studies have shown how older adults receiving PPC-based LTC have a better QoL compared with traditional methods of care (21–25). It has also been demonstrated that they are more satisfied with the care they receive (26) and have a greater degree of general satisfaction (27–30).

In Spain the types of LTC available to the older adults include (31): (a) home-based care: enables older adults to receive care in their homes. Services may include personal care (bathing, dressing), meal preparation, and companionship; (b) day centers: Offer social and recreational activities during the day, allowing family caregivers to work or take a break; and (c) care homes (residential facilities): institutional settings where older adults live and receive 24-h care, catering to various needs, including medical, social, and personal care. Various professionals play crucial roles within this system: nurses (provide direct care to LTC recipients, assist with daily activities, administer medications, and monitor health conditions), physicians (oversee medical aspects, diagnose health issues, and prescribe treatments) and social workers (assess social needs, coordinate services, and provide emotional support to LTC recipients and their families).

Some cases of the application of LTC and PPC for older adults in Spain have shown good results in terms of perceived satisfaction, QoL and levels of depression and behavioral problems (32, 33). In spite of the well-known advantages of LTC and PCC, the degree to which they have been implemented in Spain is mixed, with an increase in the number of informal carers (mainly family members) with no specialized training in home care who tend to see a negative effect on their own QoL (34, 35). Regarding the structure of the Spanish healthcare system for LTC, Spain operates a tax-based LTC financing system managed at the regional level, funded by national, regional, and local resources. The system encompasses both community-based and institutional care services.

To achieve the implementation of these national coverages, regional regulation is necessary in each of the autonomous communities. In the region of Castile and Leon, the Individual Care Program *Programa Individual de Atención* (PIA) is currently implemented to provide tailored benefits based on the specific dependency needs of each individual (36) hoping to have benefits. This dependency is classified into three levels: (a) Grade III or High Dependency: when a person requires assistance for multiple basic daily activities several times a day; (b) Grade II or Severe Dependency: when a person needs help with several basic daily activities and need extensive assistance for personal autonomy; and (c) Grade I or Moderate Dependency: when a person requires assistance with several basic daily activities at least once a day or has intermittent or limited needs for support in personal autonomy. Regarding the service catalog, options include dependency prevention, promotion of personal autonomy, telecare, home assistance, day and night care centers, as well as residential centers. These services are managed through the public network of social services of the Autonomous Community, which includes duly accredited public and privately contracted entities.

In terms of economic benefits, options include financial aid for home care, personal assistance, and financial benefits linked to service acquisition. The latter is intended to cover professional services included in the individual's PIA, when adequate public services are not available or when appropriate service choices or benefits are not selected according to the dependency situation.

Rural Care (37) arose as a social healthcare initiative in the region of Castile and Leon to respond to these needs. The programme has been implemented in rural areas with an aging population in need of integrated care. The main objective of the project is to promote PCC and active aging, with the aim of improving the QoL of the older adults and their carers. It is carried out in partnership with different institutions and receives funding from the European Social Fund Plus (ESF+) and the regional health ministry of the Autonomous Community of Castile and Leon (38).

The aim of the present study is to evaluate the piloting of the Rural Care project, analyzing the results of its implementation via a quasi-experimental pre-post study comparing the results of the Rural Care participant group with the two control groups (Control: at home, consisting of people living at home, and Control: residential care group, care home residents).

Method

Participants

The selection of the study groups for the pilot project was conducted in collaboration with the Social Services Management of the regional health ministry of the Autonomous Community of Castile and Leon, which facilitated access to the participant population through its social work staff. This institution is responsible for designing and implementing regional social policy plans and strategies in coordination with public and private entities within the region's Social Services System (36).

Based on the needs and characteristics of the population observed by this public body over the years, 60% of the beneficiaries were women, reflecting the demographic profile of the selected area, which meets the criteria for a Deep-Rural Area. This classification is characterized by low income, significant aging, a predominance of women, and population dispersion.

A total of 416 older adults aged 60–101 years (M = 82.32, SD = 11.56) participated in the study. Of these, 293 (59.55 %) were women and 199 (40.45%) men. Participants were divided into one experimental and two control groups.

- The experimental group (experimental) consisted of 102 individuals receiving home-based support as part of the Rural Care program and living in their community.
- The control group receiving care at home (control: at home; $N = 144$), older adults with clinically identified LTC needs (dependency, disability, or chronic illness) who remained in their rural homes. They relied primarily on informal care (provided by family, neighbors, or through self-management) and had little or no access to formal home-care services.
- The control group of care homes (control: residential care group; $N = 170$), consisted of participants residing in publicly-run care homes.

This distinction is particularly relevant within the Spanish LTC model, where formal services in rural areas are scarce and care depends largely on informal networks. To better capture this variability, participants were also classified using the Home at Risk (HR) system, which stratifies households by degree of dependency and availability of caregivers. The HR classification comprises four levels:

- HR1 corresponds to households with individuals with Grade I dependency with viable caregivers and adequate care.
- HR2 includes households with individuals with Grade I or Grade II dependency accompanied either by adequate care or by fragile caregivers, understood as those who, due to age, physical or mental health limitations, emotional burden, or lack of resources, are unable to provide stable or sufficient care.
- HR3 comprises households with individuals with Grade II dependency with viable caregivers but with insufficient care.
- HR4 encompasses single-person households with individuals with Grade III dependency or with fragile caregivers, as defined above.

This classification system enabled the identification and prioritization of households requiring more intensive support and resources within the regional social services system, ensuring a targeted and structured intervention through the Rural Care program.

Power analysis confirmed adequate sample size to detect medium effects ($\alpha = 0.05$, power = 0.80, effect size = 0.5), and it was consistent to other studies (39). The inclusion criteria for groups experimental and the control: at home group were as follows: (a) living in a deep-rural area; (b) having some kind of dependence, disability or chronic illness; (c) requiring LTC; and (d) remaining at home as their primary residence. For the Control: residential care group, the inclusion criteria were the same with the exception of their usual place of residence being a publicly-run care home. Given the limited number of care homes in rural areas, it was necessary to extend the geographical scope to include urban care homes to meet the inclusion criteria. However, since these were all publicly managed institutions, they operated under the same regulatory standards and care protocols, regardless of their geographic location.

Procedure

The study was developed within the framework of the Programme for Employment and Social Innovation, "EaSI" 2014–2020, in the call for proposals entitled *Call for proposals on social innovation and national reforms (Long-Term Care),* Grant Agreement VS/2020/0290.

A quasi-experimental design was employed to evaluate the effectiveness of the Rural Care program in improving the quality of life among older adults living in deep-rural areas. Participants had previously been assigned to one of three study groups—one experimental and two control groups—based on their existing care conditions and place of residence. As random assignment was not feasible due to contextual and logistical constraints, this study followed a non-randomized, pre-post design, which is a common approach in long-term care intervention research (39, 40).

The intervention was implemented in the experimental group through the Rural Care program, which offered structured home-based support tailored to individual needs. This included assessments, coordination of services, and psychosocial support over an 18–20-month period. In contrast, the control groups continued with their usual care: either extensive formal care in residential facilities or minimal to no formal care at home. The project began in October 2020, with the first assessment being carried out in May 2021 and the last in July 2022. Information about the programme had been disseminated among social healthcare professionals in the field of geriatric care through the regional government of Castile and Leon, SACYL (the regional health service), the provincial government, rural councils and centers and services for innovation in education and healthcare.

Participants were recruited following referral from geriatric care professionals, who served as a link, providing information (either verbally or via an explanatory leaflet) about the existence of the programme to future participants or their immediate family. Subsequently, social workers from the Social Services Department of Castile and Leon conducted follow-up phone calls to confirm participation, provide further information, and schedule home visits. In the case of the Control: residential care group, contact was made through the geriatric professionals directly caring for the participants in the different care homes.

After selection and detailed explanation of the study procedures, and once informed consent and a commitment to participate in the project had been signed, an initial assessment was conducted. The same procedure was performed after a period of 18–20 months, depending on the pace with which the project was carried out. Data collection for both the control and experimental groups was synchronized to ensure consistency in the timing of assessments.

Assessments of all the groups were conducted by two expert assessors (psychologists), specifically trained in the assessment protocol, which included a structured interview with sociodemographic questions and self-administered questionnaires. Each assessment lasted ∼45 min.

Within the experimental group, the HR classification system set the boundaries of potential support agreements with participants, which were reviewed by coordinators and case managers from the Social Services Management. These limits could be adjusted with the proposal of the case coordinator and approval from the project coordinator, provided that the amount contributed to each household did not exceed 50% of the total cost of home adaptations and technical aids. For loans of technical aids, funding was provided at 100%, with no cost to the user.

All HR levels were assigned, at different percentages (36):

- Home adaptation, technical aids and advanced telecare.
- Training and support for non-professional caregivers.
- Personalized social participation program.
- Case manager and reference professional.
- Community relations with a minimum of two actions per day.
- Personal care, as needed, up to 24 h in periods of 2–5 days per month.
- Home healthcare, both scheduled and emergency, according to the service portfolio and chronic and palliative care processes.

Training, selection, and evaluation of the support actions were carried out by staff from the Social Services User Support System (*Sistema de Atención a Usuarios de Servicios Sociales*, SAUSS). The remaining direct care services were provided by "Fundación Personas," a non-profit organization with extensive experience in supporting people with disabilities and other LTC services. Currently, this organization supports 4,000 people in both in urban and rural areas of the region.

Finally, the financial guidelines were (37): for HR4, a maximum of €4,500 per household was financed; for HR3, a maximum of €2,700 per household was financed; for HR2, a maximum of €1,540 per household was financed; and for HR1, a maximum of €680 per household was financed.

In the control groups, the existing LTC services were maintained as they were prior to the start of the project. It is important to note that the conventional LTC programs differ significantly from the model proposed by the Rural Care Project, which prioritizes maintaining the user in their home, adapting services as their needs evolve. The latter prioritizes keeping the user within their own home, adapting the provided aids and services as their needs evolve. This approach contrasts with conventional LTC programs, where users are often moved to care homes when their support needs become extensive or specific. In such facilities, the sense of belonging and connection to their social environment is not as strong as it is in their own home.

Human ethics and consent to participate declarations

In all the procedures, the ethical standards of the institutions, the criteria of the National Research Committee, and the international criteria of the American Psychological Association (APA) (41) and the 1964 Declaration of Helsinki (42) (as well as their subsequent amendments or similar ethical rules), were followed. Within these ethical principles for research involving human subjects, the confidentiality of the data and the pursuit of the benefit of the participants are ensured. The study was approved by the ethics committee and by the European Commission in accordance with Grant Agreement VS/2020/0290.

All participants (or their legal guardians, when applicable) were informed about the aims and procedures of the study and provided written informed consent prior to participation, in line with ethical guidelines.

Variables and tools

Sociodemographic data were collected by asking participants about their sex (male or female) and age. To measure QoL, the "World Health Organization Quality of Life" (WHOQOL-BREF) (43) scale was employing in its Spanish version, adapted by Lucas-Carrasco (44–46). The questionnaire had good psychometric properties both in the original (Cronbach alphas demonstrate good internal consistency for the facets with a range of 0.65–0.93) (43) and Spanish version ($\omega = 0.89$) (45). The WHOQOL-BREF consists of 24 items rated on a Likert-type scale from 1 (completely dissatisfied) to 5 (completely satisfied), focusing on the participants' level of satisfaction regarding various aspects of their QoL in the previous 2 weeks. The scale covers four factors:

a) Physical health (Factor 1—seven items): Referring to pain and discomfort experienced, perceived fatigue and energy levels, and sleep and rest, ranging from the individual's control over their pain to their reluctance or enthusiasm to carry out everyday tasks and sleep problems.
b) Psychological health (Factor 2—six items): Including the presence of positive and negative feelings, aspects relating to thoughts, learning, memory and concentration, self-esteem, body image and appearance.
c) Social relationships (Factor 3—three items): Including company, love and support in personal relationships, as well as the social support provided by friends and family and sexual activity.
d) Environment (Factor 4—eight items); Relating to the degree of physical safety perceived by the person, their place of residence, economic resources, access to social and healthcare, participation in and opportunities for recreational and leisure activities, access to transport and the characteristics of their physical environment in relation to pollution or climate.

Data analysis

A descriptive analysis was conducted of the responses to each block of the questionnaire. Before conducting the main analyses, multivariate outliers were examined using Mahalanobis D^2 distances (with a significance threshold of $\alpha = 0.001$) and Guttman error analysis, in order to detect atypical response patterns. These procedures helped ensure data quality and robustness in the subsequent statistical analyses. Then, the data were analyzed via a repeated measures ANOVA in order to verify the differences between groups and phases. Thus, a mixed design was proposed of repeated measures with an intra-subject factor (the moment of the assessment) and an inter-subject factor (the group). The intra-subject factor has two levels (pretest and posttest), while the inter-subject factor has three. The scores obtained in each of the sub-scales of the WHOQOL-BREF QoL questionnaire were taken as dependent variables. In order to verify the differences between groups, a *post hoc* analysis was performed.

To estimate the necessary sample size, the *pwr* package in R was employed. A significance level of 0.05 was established, along with a statistical power of 0.80 and an effect size of 0.5. This effect size ($d = 0.5$) was selected based on Cohen's (47) conventions for medium effects, as no directly comparable studies reporting effect sizes in similar rural intervention contexts were available.

The calculation of the statistical power indicates that, with a sample size of 30 participants, there would be a probability of 0.80 of detecting an effect size of 0.5. A sample size of 30 participants is sufficient for detecting an effect size of 0.5 with a statistical power of 0.80.

Results

Descriptive analysis

Although the WHOQOL-BREF scoring guidelines (43, 46) do not recommend interpreting individual item responses, item-level results are reported here for exploratory and descriptive purposes. These results aim to offer more detailed insights into participants' perceptions in specific areas of quality of life, particularly relevant in rural intervention contexts. Findings should be interpreted with caution and do not replace domain-level analyses.

First of all, Table 1 shows the relative frequencies obtained in each of the response options for all of the items and the accumulated frequencies and relative frequencies for the higher (four and five) and lower (one and two) values of the scale. In the second phase relating to health (item 2), 28.21% answered that they were dissatisfied or extremely dissatisfied, whereas 35% considered themselves to be quite or extremely satisfied.

More than 70% of the participants considered themselves to be quite or extremely satisfied with their personal relationships (item 20) and with the conditions of their homes (item 23), both in phase 1 and phase 2. Around 50% claimed to feel quite safe (item eight—phase 1 = 51.04%; phase 2 = 56.41%; Table 1).

As far as the two questions of a global nature are concerned (items 1 and 2), the results were divided. In the pretest, around 25% of the participants classified their QoL (item 1) as *normal,* while 37% claimed it was quite or extremely good and another 37% said it was average or extremely bad. In relation to their general state of health (item 2), around 25% classified it as *normal*, with 39% stating that it was good or extremely good and 36%, bad or extremely bad. In the second phase, the results were similar, although for item 1 the percentage of people claiming to have a normal QoL went from 25 to 35%, those who stated that their QoL was extremely bad or average went from 37 to 25 and 39.61% classified it as quite or extremely good compared to the 37% who did so in the pretest. Likewise, as far as the participants' satisfaction with their general health is concerned, around 35% claimed it was *normal* (vs. 25% in the pretest) and another 30% claimed they were quite or extremely dissatisfied (vs. 36% in the pretest).

TABLE 1 Relative frequencies for each response option.

Item	Likert scale										Percentage of responses			
	1 (Not at all)		2 (Not much)		3 (Moderately)		4 (A great deal)		5 (Completely)		% 1–2		% 4–5	
	Pre	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*	*Pre*	*Post*
Physical health														
3r	9.56	3.18	29.41	22.49	13.73	20.29	17.89	19.8	29.41	34.23	38.97	25.67	47.3	54.03
4r	17.4	8.31	0.49	27.14	20.83	32.76	26.23	31.3	8.33	8.31	44.61	27.63	34.56	39.61
10	9.07	3.67	24.75	26.65	34.56	39.61	26.72	25.67	4.9	4.4	33.82	30.32	31.62	30.07
15	14.46	6.11	31.86	30.32	22.79	33.74	15.2	20.29	15.69	9.54	46.32	36.43	30.88	29.83
16	9.56	9.05	18.38	19.8	20.1	22.98	43.63	31.3	8.33	16.87	27.94	28.85	51.96	48.17
17	9.56	2.44	22.79	27.14	31.13	30.56	31.13	28.85	5.39	11	32.35	29.58	36.52	39.85
18	12.75	3.18	19.36	30.07	40.44	32.76	24.51	25.43	2.94	8.56	32.11	33.25	27.45	33.99
Psychological health														
5	22.79	14.67	29.41	30.32	27.21	34.96	19.36	19.32	1.23	0.73	52.21	44.99	20.59	20.05
6	11.27	10.02	18.63	13.69	32.84	37.16	35.78	34.23	1.47	4.89	29.9	23.72	37.25	39.12
7	5.15	5.13	18.87	18.83	28.92	30.07	39.46	29.58	7.6	16.38	24.02	23.96	47.06	45.97
11	6.62	2.44	13.48	13.2	39.71	55.01	37.01	27.63	3.19	1.71	20.1	15.65	40.2	29.34
19	6.13	3.18	13.48	11	27.94	35.7	48.77	45.72	3.68	4.4	19.61	14.18	52.45	50.12
26	5.15	1.22	20.59	18.83	26.23	30.56	30.15	29.83	17.89	19.56	25.74	20.05	48.04	49.39
Social relationships														
20	1.23	0.24	5.15	3.67	20.83	29.1	58.09	60.64	14.71	6.36	6.37	3.91	72.79	66.99
21	35.29	9.54	24.75	26.41	38.48	63.33	1.47	0.73	0	0	60.05	35.94	1.47	0.73
22	2.94	2.44	24.02	25.18	35.54	39.36	27.94	30.32	9.56	2.69	26.96	27.63	37.5	33.01
Environmental context														
8	4.41	0	14.71	14.67	24.26	24.21	53.68	51.1	2.94	10.02	19.12	14.67	56.62	61.12
9	0.49	0	12.5	5.38	58.33	69.19	15.44	24.69	13.24	0.73	12.99	5.38	28.68	25.43
12	4.41	2.44	30.39	21.27	44.85	50.61	18.38	23.96	1.96	1.71	34.8	23.72	20.34	25.67
13	6.37	4.16	15.2	16.63	23.28	30.81	46.08	31.54	9.07	16.87	21.57	20.78	55.15	48.41
14	33.33	25.67	32.11	31.78	24.02	31.05	9.31	11.25	1.23	0.24	65.44	57.46	10.54	11.49
23	1.47	1.47	3.43	4.16	23.77	23.96	55.88	61.37	15.44	9.05	4.9	5.62	71.32	70.42
24	2.94	3.67	9.31	10.76	44.12	40.34	40.2	41.56	3.43	3.67	12.25	14.43	43.63	45.23
25	16.42	3.91	22.3	24.94	52.94	67.73	6.86	3.42	1.47	0	38.73	28.85	8.33	3.42

Items are part of the WHOQOL-BREF questionnaire and rated on a five-point Likert scale (1 = not at all, 5 = completely). “Pre” and “Post” refer to baseline and follow-up assessments. Percentages represent the proportion of responses in each category. The columns “% 1–2” and “% 4–5” indicate the percentage of responses grouped at the lower and upper ends of the scale. Items marked with “r” were reverse-coded according to WHOQOL-BREF guidelines.

Multivariate outliers

Multivariate outliers were analyzed using Mahalanobis D^2 distances, applying a significance threshold of $\alpha = 0.001$ (48). Fourteen observations exceeded the critical value, indicating significant multivariate outliers. The highest D^2 value observed was 228.11. These results are described to support the robustness of the sample prior to the main analyses.

Subsequently, the number of Guttman errors was calculated for each of the observations with the aim of identifying atypical response patterns. The average number of errors was 270.19 (SD = 138.77), in line with the criterion proposed by Zijlstra et al. (49) and by Hubert and Vandervieren (50) for asymmetric distributions. The critical value is 582.5, thus 11 cases with atypical response patterns were identified.

Physical health

Table 2 shows the results relating to physical health on a scale of 0–100. Differences between groups can be observed in the initial assessment, which would later be verified to see whether they were

TABLE 2 Means and standard deviations for WHOQOL-BREF domains.

Domain	Group	Assessment					
		Pre		Post		Overall	
		M	*SD*	*M*	*SD*	*M*	*SD*
Physical health	Experimental	41.28	20.88	53.85	17.14	47.57	20.07
	Control: residential care group	50.97	20.23	56.10	16.99	53.53	18.82
	Control: at home	54.60	17.94	53.87	15.72	54.23	16.84
	Marginal	50.08	20.15	54.64	16.51		
Psychological health	Experimental	47.75	16.61	53.64	15.55	50.69	16.32
	Control: residential care group	56.02	15.06	57.18	15.41	56.60	15.22
	Control: at home	50.78	17.84	52.08	15.34	51.43	16.62
	Marginal	51.85	16.90	54.23	15.54		
Social relationships	Experimental	50.16	14.46	51.88	13.82	51.02	14.13
	Control: residential care group	53.76	12.96	54.28	12.62	54.02	12.77
	Experimental	50.16	14.46	51.88	13.82	51.02	14.13
	Control: at home	46.72	15.99	51.37	12.19	49.04	14.39
	Marginal	50.00	14.91	52.50	12.79		
Environmental context	Experimental	51.32	9.86	52.27	9.17	51.79	9.51
	Control: residential care group	54.01	10.32	55.97	10.31	54.99	10.35
	Control: at home	50.02	10.49	52.44	9.52	51.23	10.07
	Marginal	51.72	10.40	53.62	9.85		

M and SD represent mean and standard deviation, respectively. "Overall" refers to the average (mean and standard deviation) calculated across all groups at each assessment time point (Pre and Post).

significant. On the other hand, an increase can be observed in the mean score relating to physical health in the experimental group (Pre = 41.28; Post = 53.85) and in the Control: residential care group (Pre = 50.97; Post = 56.10) compared with a decrease in the physical health score in the Control: at home group (Pre = 54.60; Pre = 53.87).

An approximately normal distribution can be observed for the physical health scores. The ANOVA shows significant differences among the groups in the pretest for physical health [F (2.413) = 15.11, $p < 0.01$, η^2]. The *post hoc* tests show that the experimental group obtained significantly lower scores on this sub-scale in the pretest than the Control: residential care group ($t = -3.84$, $p < 0.01$) and the Control: at home ($t = -5.45$, $p < 0.01$). No statistically significant differences were observed between the Control: residential care group and Control: at homes ($t = 1.65$, $p = 0.23$).

However, no significant differences were observed between groups in the posttest data analysis [F (2.413) = 0.87, $p = 0.42$]. The repeated measures ANOVA produced a significant interaction effect result between the group (Experimental, Control: at home, Control: residential care) and the phase [Pre vs. Post; F (2.409) = 24.41, $p < 0.01$, $\eta^2 = 0.021$]. Figure 1 shows a graphic representation of the result. It can be observed that there is a significant effect on the experimental ($p < 0.001$, $d = 0.72$) and control groups ($p < 0.001$, $d = 0.3$), with moderate and small effect sizes, respectively. However, there is no significant effect on the Control: at home group ($p = 0.66$).

Psychological health

Table 2 shows the results relating to psychological health on a scale of 0–100. In the initial assessment, differences can be observed among the groups, which would subsequently be verified to see if they were significant. As with the case of physical health, a greater increase in the mean score for psychological health was observed in the experimental group (Pre = 47.75; Post = 53.64) compared to a moderate increase for the control groups (Pre Control: residential care = 56.02; Pre Control: at home = 50.78; Post Control: residential care = 57.18; Post Control: at home = 52.08).

The ANOVA shows significant differences between the groups in the pretest for psychological health [F (2.413) = 7.98, $p < 0.01$, $\eta^2 = 0.038$]. The *post hoc* tests show that the experimental group obtained significantly lower scores in this sub-scale in the pretest than the Control: residential care group ($p < 0.01$). No significant differences were observed between the experimental group and the Control: at home group in the pretest. On the other hand, significant differences were observed between the Control: at home, and Control: residential care group groups in the analysis of the posttest data [F (2.413) = 4.35, $p < 0.05$, $\eta^2 = 0.021$]. In this regard, the Control: at home obtained significantly lower scores than the Control: residential care group ($p < 0.05$). The repeated measures ANOVA produced a significant interaction effect result between the groups and the phase [Pre vs. Post; F (2.409) = 3.93, $p < 0.05$, $\eta^2 = 0.004$]. Figure 2 shows a graphic representation of the result. It can be seen that the increase in the mean score

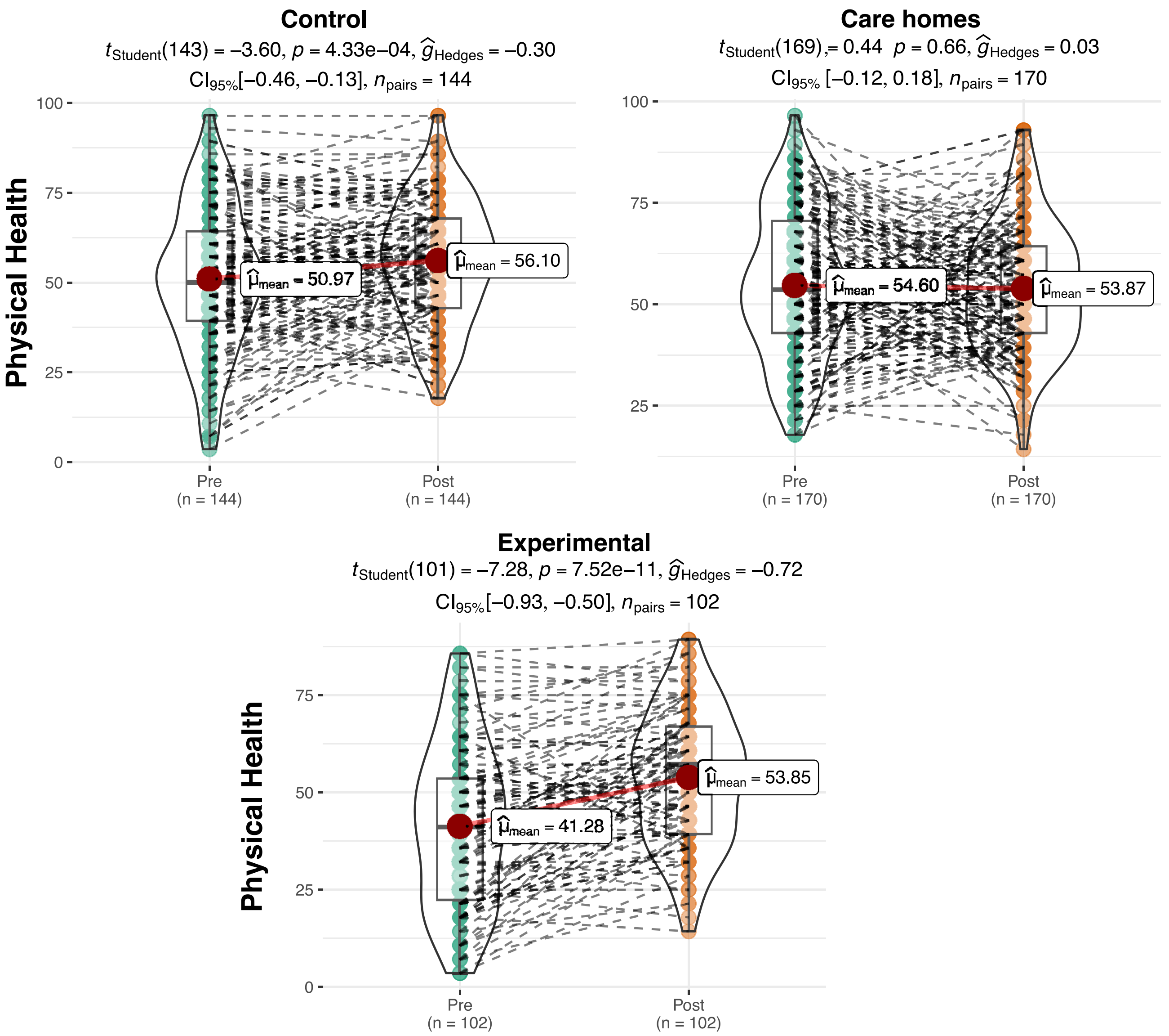


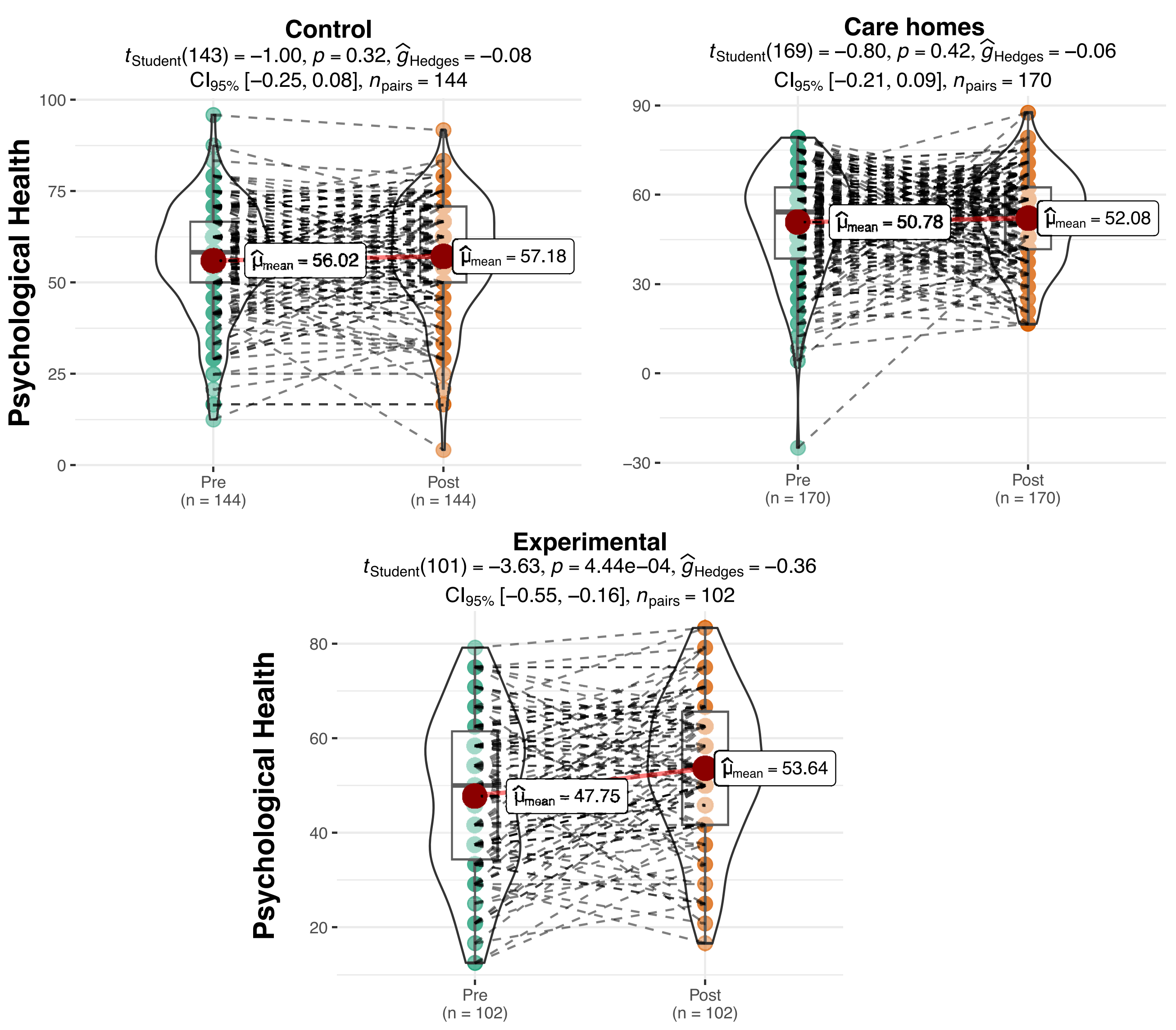
FIGURE 1
Differences in scores for physical health per group and phase. The plots show score density; red dots indicate group means and dashed lines represent individual trajectories.

in the experimental group between the pretest and the posttest is statistically significant ($M_{\text{pre}} = 47.75$, $M_{\text{post}} = 53.64$, $t = 3.63$, $p < 0.001$, $d = 0.360$) with a small effect size. On the other hand, the increase in the mean score in the Control: residential care group ($M_{\text{pre}} = 56.02$, $M_{\text{post}} = 57.18$, $t = 0.997$, $p = 0.32$) and Control: at home ($M_{\text{pre}} = 50.78$, $M_{\text{post}} = 52.08$, $t = 0.802$, $p = 0.424$) groups is not.

Social relationships

Table 2 shows the results relating to the quality of social relationships on a scale of 0–100. Differences were observed among the groups in the initial assessment, which would later be verified to see whether they were significant. A slight increase can be observed in the mean score for social relationships in the experimental group (Pre = 50.16; Post = 51.88) and in the Control: residential care group (Pre = 53.76; Post = 54.28) and Control: at home (Pre = 46.72; Post = 51.37) groups.

The ANOVA showed significant differences among the groups in the pretest in terms of the quality of their social relationships [$F\ (2.413) = 9.05$, $p < 0.01$, $\eta^2 = 0.04$]. In this case, the *post hoc* tests show that the Control: at home obtained significantly lower scores in this sub-scale in the pretest than the control group ($t = -4.25$, $p < 0.01$). On the other hand, no significant differences can be observed among the groups in the analysis of the posttest data [$F\ (2.413) = 2.9$, $p = 0.11$]. The repeated measures ANOVA did not produce significant interaction effect results between the groups and the phase [Pre vs. Post; $F\ (2.409) = 2.46$, $p = 0.087$; Figure 3]. However, the Control: at home improved



Control

$t_{\text{Student}}(143) = -1.00$, $p = 0.32$, $\widehat{g}_{\text{Hedges}} = -0.08$

$\text{CI}_{95\%}$ [−0.25, 0.08], $n_{\text{pairs}} = 144$

Care homes

$t_{\text{Student}}(169) = -0.80$, $p = 0.42$, $\widehat{g}_{\text{Hedges}} = -0.06$

$\text{CI}_{95\%}$ [−0.21, 0.09], $n_{\text{pairs}} = 170$

Experimental

$t_{\text{Student}}(101) = -3.63$, $p = 4.44\text{e}{-04}$, $\widehat{g}_{\text{Hedges}} = -0.36$

$\text{CI}_{95\%}$ [−0.55, −0.16], $n_{\text{pairs}} = 102$

FIGURE 2

Differences in the scores for psychological health per group and phase. The plots show score density; red dots indicate group means and dashed lines represent individual trajectories.

its score significantly for social relationships between the pretest and the posttest ($t = 3.34$, $p < 0.001$, $d = 0.26$) with a small effect size.

Environmental context

Table 2 shows the results relating to the quality of environmental context on a scale of 0 to 100. Differences were observed in the initial assessment among the groups, which would later be verified to see if they were significant. A slight increase can be observed in the mean score for the quality of environmental context in the experimental group (Pre = 51.32; Post = 9.86) and in the Control: residential care group and Control: at homes (Pre Control: residential care group = 54.01; Pre Control: at home = 50.02; Post Control: residential care group = 55.97; Post Control: at home = 53.62).

The ANOVA showed significant differences among the groups in the pretest for the quality of their social relationships [F (2.413) = 5.60, $p < 0.01$, $\eta^2 = 0.028$]. In this case, the *post hoc* tests show that the Control: at home obtained significantly lower scores in this sub-scale in the pretest than the Control: residential care group ($t = -3.43$, $p < 0.01$). No significant differences can be observed between the experimental group and the Control: at homes in the pretest. In the posttest, significant differences were observed among the groups [F (2.413) = 6.43, $p < 0.01$, $\eta^2 = 0.03$], specifically between the Control: residential care group and the experimental group ($t = -2.94$, $p < 0.01$) and between the Control: residential care group and the Control: at home ($t = -3.20$, $p < 0.01$).

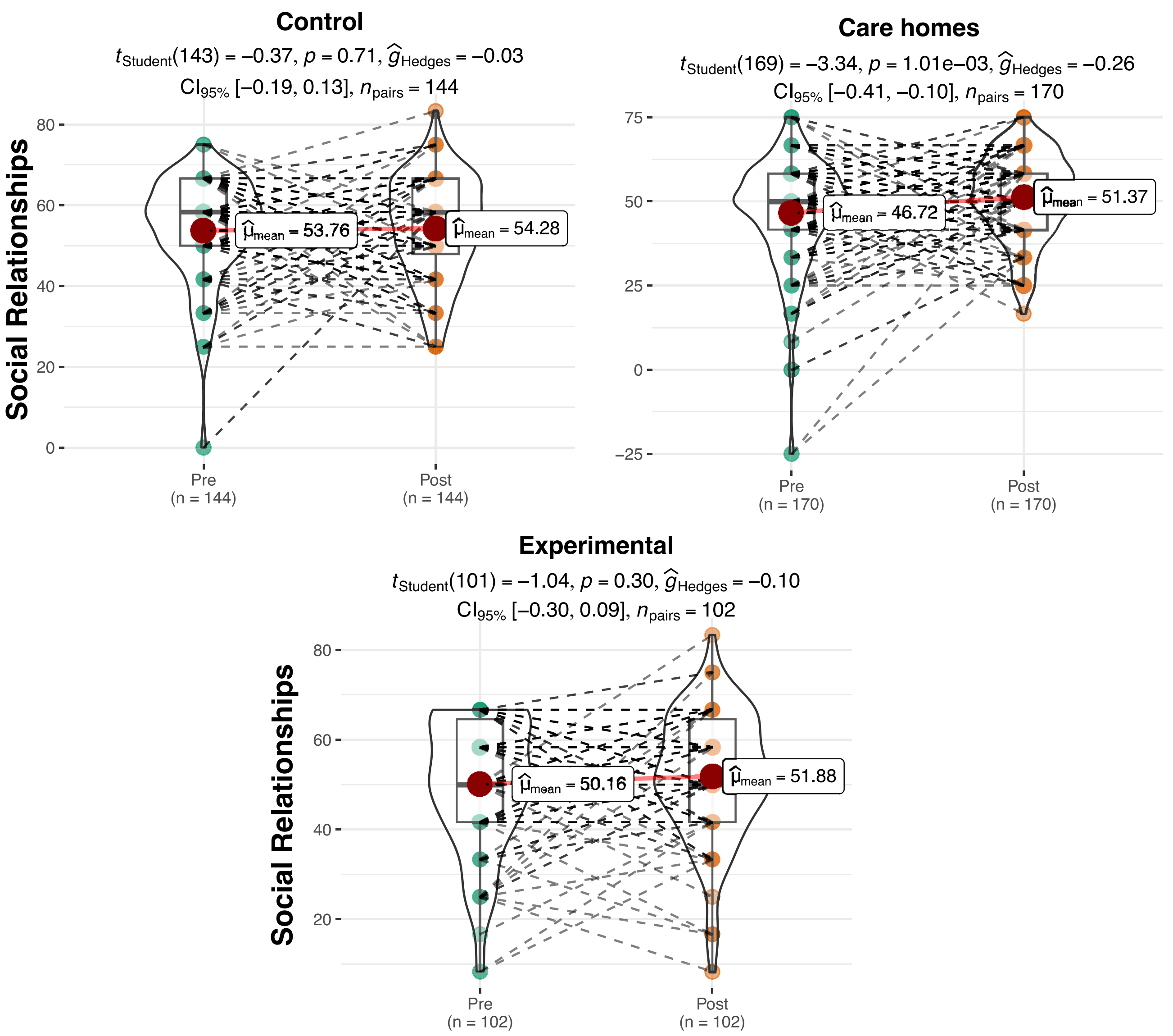


FIGURE 3
Differences in scores for social relationships per group and phase. The plots show score density; red dots indicate group means and dashed lines represent individual trajectories.

The repeated measures ANOVA did not produce significant results for interaction effects between the group and the phase [Pre vs. Post; F (2.409) $= 0.500$, $p = 0.61$]. However, the Control: at home significantly improved its score for environmental context between the pretest and the posttest ($t = 3.34$, $p < 0.001$, $d = 0.26$) with a small effect size (Figure 4).

Discussion

The present study examines the impact of Rural Care, a care model based on LTC and PPC for older adults in deep-rural areas, analyzing its effects on the QoL of the participants. The total average age of the sample studied is 82.32 years, with a higher proportion of women (59.55%).

The results obtained after the application of the Rural Care programme showed, in general terms, improvement in the experimental group in the posttest compared to the pretest for QoL, physical and psychological health. In terms of physical health, the experimental group showed a significant increase in the posttest in comparison of people living at home and in care homes. These results are in line with prior studies, in which improvements in QoL have been found following the application of these types of programmes. In their systematic review and meta-analysis, Kim and Park (51) found that person-centered interventions improved depression and QoL among older adults with dementia. Replicating these results, the systematic review by Chenoweth et al. (52) showed that, after a year of application, LTC had significant effects in improving the QoL of older adults with dementia. Other more recent studies have shown similar results, such as Howard et al. (53)

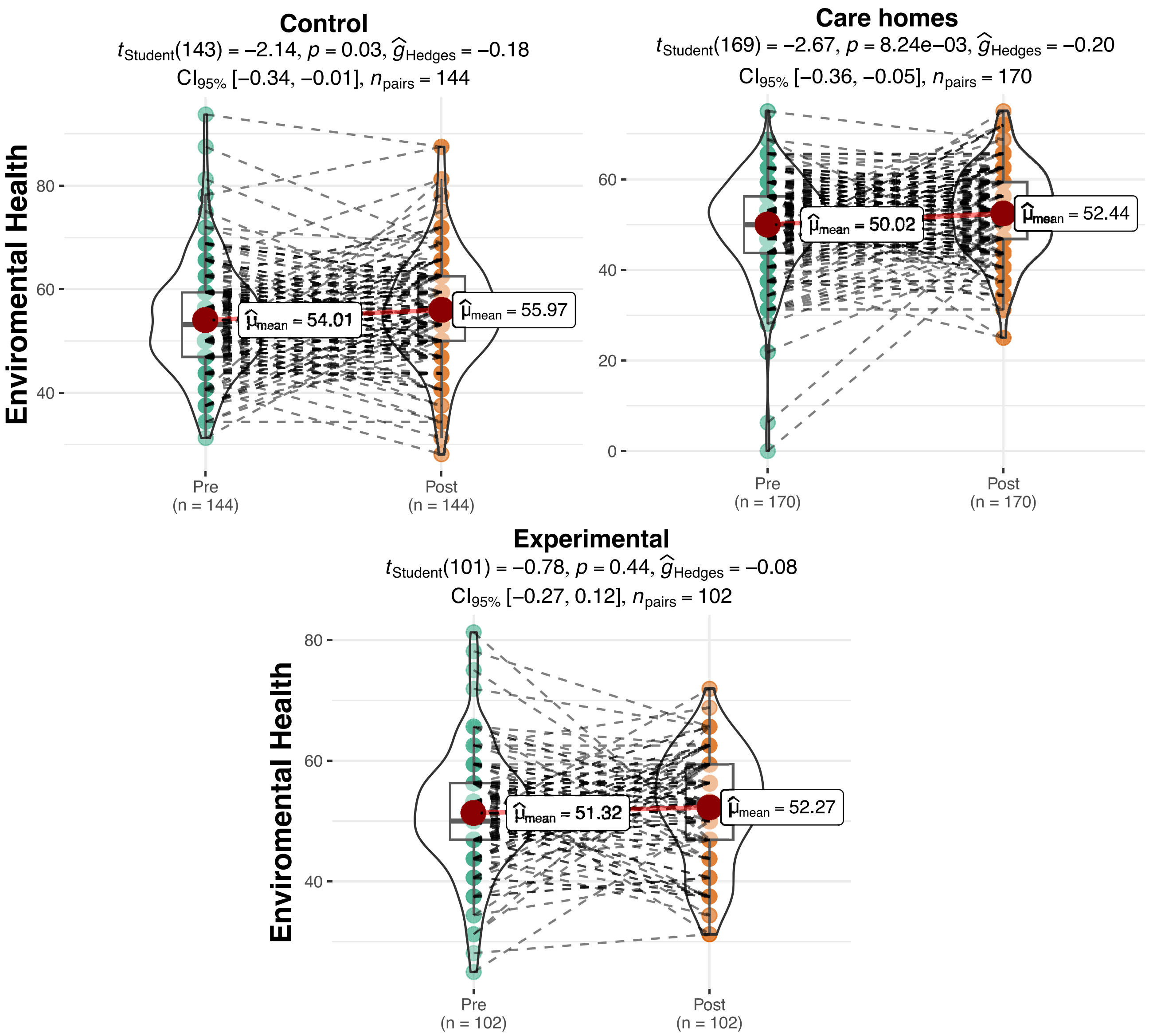


FIGURE 4
Differences in scores for environmental context per group and phase. The plots show score density; red dots indicate group means and dashed lines represent individual trajectories.

and Chen et al. (54), who found that PPC and LTC improve the QoL of older adults.

As for the dimensions of environmental context and social relationships, the results did not show significant effects of the programme, although trends of improvement were observed in the data, both for the experimental group and for the care home residents. This is coherent as Rural Care only contemplated intervention in interpersonal relationships if it had been stated as a need for the person (not in all cases), in accordance with the recommendation of employing a hierarchy of needs in the intervention. This aligns with other research, such as that conducted by Delgado (55), where significant relationships between self-perceived health and QoL, as well as life satisfaction, were observed, but no such relationships between these same variables and social support. Additionally, as Brownie and Nancarrow (56) point out,

> "the introduction of person-centered care is not always incorporated within a wider "hierarchy of needs" structure, where safety and physiological need are met before moving onto higher level needs" (p.1).

Furthermore, the increase in the improvement of social relationships in people living in care homes can also be explained by the fact that the structure of such institutions facilitates social contact, which is often a complex issue in isolated rural areas (57, 58). In short, in rural areas, older adults experience unwanted loneliness due to multiple factors such as the loss of their social circle, the migration of young people and family members to other areas with better services, and the lack of resources (59). Other research (60–62) associates this subjective feeling of loneliness with a higher risk of becoming physically frail, diminished affection toward their emotional bonds, and an increased risk of depression—key elements as a correlation has been found between loneliness and QoL (63).

There was also a positive trend in terms of environmental context for all of the groups, although no significant differences were found. This may be due to the intervention needs of the individual people, which may be covered by both formal and informal care, as pointed out in the previous section (24, 30, 53). Other studies examining LCT and PCC, such as that of Marventano et al. (23), have found an improvement in QoL associated to functional independence, health status and informal social interaction (family, friends and/or neighbors). Furthermore, people receiving LTC at home showed an improvement in intra-psychological skills, such as resilience (59), particularly due to improvements in the infrastructure of the home and its maintenance through homecare services (25). One example is the research by Geigl et al. (64), who show that higher income levels, an internal locus of control, regular exercise, and strong social support are all associated with better physical and mental wellbeing. Consequently, they advocate designing integrated—health and social—interventions tailored to at-risk profiles (advanced age, low social support, or an external locus of control) to reduce inequalities and enhance the quality of life of older adults.

In accordance with all of the above, it can be concluded that interventions should be multifaceted, encompassing environmental improvements and an increase in formal and informal social interactions. This implies changes in terms of LTC programmes and their management, focusing them on the empowerment of older adults in decision-making based on a PCC model (56). However, it should be stressed that there is a need for more research in this field in order to determine the results of this type of programme due to the diversity of results and the consequences of aging.

As Van Malderen et al. (39) point out in their review, high-quality research that comprehensively addresses quality of life in long-term care remains scarce. Multidimensional interventions—those that act simultaneously on physical health, the environment, and social relationships—are the most promising, but they require consensus on which quality-of-life dimensions to include, standardization of measurement tools, and the design of rigorous studies to support evidence-based recommendations. An illustrative example comes from Siqeca et al. (65), who, using an ecological approach with nearly 9,000 older adults in Switzerland, demonstrated how individual determinants (physical health, polypharmacy, educational level), social factors (support network, participation in activities), and macro-level elements (type of health insurance) interact to shape health-related quality of life. Their findings underscore the need for truly integrated interventions capable of simultaneously addressing all these levels to maximize impact.

The present study has certain limitations which imply that the results should be taken with caution. First, due to the nature of the target population, sampling and recruitment proved complicated, making it extremely difficult to achieve the necessary number of participants via random assignment. The lack of randomization between the control and experimental groups is a clear limitation; however, access to rural areas is complex, and in many cases, the characteristics of these regions hinder project dissemination and participant recruitment. Although the project was well received, it was necessary to broaden the inclusion criteria for the Control: residential care group.

Another limitation concerning group assignment is that the experimental group had substantially lower pre-intervention scores in physical and psychological health compared to the control groups in community housing and residential care. Additionally, it showed lower scores in social and environmental dimensions relative to the community housing group, which may have biased the comparisons between groups.

Spasova et al. (66) note that the challenges of the LTC system are common across European countries, but that, in the vast majority, these services lack proper integration between social and health aspects and are organized at different administrative levels: local, regional, and national. Local services are the most affected due to the user-to-service ratio, that is, "the law of supply and demand." Another important point raised by IŽdonaite-MedŽiuniene and Preikšaitiene (67) is that, although there is concern for quality of life, older adults often lack the training and resources needed to turn their intentions into sustainable healthy habits. Therefore, it would be necessary to include specific training in addition to the material supports or social resources provided by programs like Rural Care.

On the other hand, it should be noted that, although the assessments were carried out rigorously by trained assessors using valid, reliable and widely-used tools, QoL is an extremely broad and complex construct, which is difficult to represent with a single tool. In addition, there are very few tools adapted to the older adults, and some items seemed irrelevant to the study population (e.g., assessment of sexual life).

Additionally, it should be noted that, although the WHOQOL-BREF is designed to provide valid scores at the domain level and not for interpretation of individual items, this study included some item-level results for exploratory purposes. This decision aimed to offer more detailed insights into specific aspects of participants' quality of life, particularly relevant in rural contexts. However, we acknowledge that this approach does not strictly follow the instrument's methodological recommendations, and item-level findings should be interpreted with caution and limited to their descriptive value. However, from this perspective, the exploratory review by Arias-Casais et al. (40) warns that comprehensive, high-quality, and homogeneous research remains scarce, and that many initiatives focus on a single determinant when quality of life is, by definition, multidimensional. Furthermore, they note that approaches combining exercise, nutrition, and person-centered care are particularly promising, but require standardization of measures and consensus on quality-of-life dimensions; at the same time, they stress the need to include low-resource interventions, harmonize definitions across different contexts, and conduct more robust effectiveness evaluations to underpin global recommendations.

Furthermore, it is possible that certain biases inherent to self-report questionnaires, such as social desirability, may have also affected the results. On the other hand, it should be noted that the generalizability of the results may be limited due to the specific sociocultural environment where the project was carried out. Finally, although the pre-post longitudinal data have been shown, the project is still ongoing, so another limitation of the study is the lack of long-term follow-up of the results of the intervention. This is a clear line of follow-up research in the future, hoping that a longer-term consolidation of the results and impact of the programme can be shown.

Conclusion

Rural Care highlights the physical and psychological QoL benefits of a person-centered program tailored to rural settings. Providing care that addresses the specific needs of older people in rural areas—while tackling challenges related to accessibility, affordability, quality and sustainability in depopulated rural regions— is essential for promoting dignified aging and safeguarding wellbeing and QoL. The project demonstrates the usefulness of multilevel partnership in care delivery, involving public and private actors and the coordination of social and health services at local, regional and national levels.

Additionally, the continuation of the Rural Care project presents a valuable opportunity to conduct follow-up assessments to evaluate the long-term effects on QoL and the sustainability of observed benefits. Addressing these gaps will yield crucial insights for policymakers aiming to implement integrated care models across diverse socio-cultural and geographical contexts.

Data availability statement

The datasets presented in this article are not readily available because the dataset is subject to several restrictions due to its nature and origin. It contains sensitive health-related information from a vulnerable population, requiring strict confidentiality and ethical considerations. Additionally, as the data is part of a project involving public entities, its access and use are governed by specific legal and regulatory frameworks. Any use of the dataset must comply with applicable data protection laws and ethical guidelines to ensure the privacy and wellbeing of the individuals involved. Requests to access the datasets should be directed to elena.betegon@uva.es.

Ethics statement

The studies involving humans were approved by European Commission in accordance with Grant Agreement VS/2020/0290; and the University of Valladolid (Valladolid, Spain). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

EB: Writing – review & editing, Supervision, Conceptualization, Writing – original draft, Investigation. JR-M: Methodology, Data curation, Investigation, Formal analysis, Writing – original draft. CG-S: Conceptualization, Methodology, Writing – review & editing, Investigation, Writing – original draft. MI: Writing – review & editing, Supervision, Funding acquisition, Project administration, Investigation.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The author(s) declare that no Gen AI was used in the creation of this manuscript.

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Patterns of lifestyle risk behaviors for cardiovascular disease in family caregivers: a latent class analysis

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Introduction: Lifestyle risk behaviors for cardiovascular disease (CVD) often co-occur. However, little is known about their co-occurrence patterns among family caregivers, a high-risk population for CVD. This study aimed to identify distinct latent classes of lifestyle risk behaviors for CVD among caregivers and to examine socio-demographic, health-related, and caregiving characteristics associated with membership in the latent classes.

Methods: We conducted a cross-sectional secondary data analysis of the 2019 Health Information National Trends Survey 5 Cycle 3, involving 643 unpaid family caregivers in the United States. The lifestyle risk behaviors for CVD included current cigarette use, current alcohol consumption, low physical activity, prolonged sedentary time, low fruit intake, and low vegetable intake, as defined by established guidelines. We performed latent class analysis to identify unobserved subgroups based on these multiple lifestyle risk behaviors. Subsequently, we conducted multinomial logistic regression to investigate socio-demographic, health-related, and caregiving characteristics associated with latent class membership.

Results: The majority of participants were females (55.3%) and non-Hispanic white (57.1%), with a mean age of 55 ± 16 years. Three distinct classes were identified: Class 1 (*Physically active caregivers,* 17.1%), Class 2 (*Physically inactive, healthy eaters,* 18.8%), and Class 3 (*Physically inactive, unhealthy eaters,* 64.1%). In unadjusted models, older caregivers (≥65 years) were more likely to belong to Class 2, relative to Class 1, compared to those aged 18–49 years. Caregivers with perceived financial difficulties, psychological distress, low self-efficacy in health management, and poor sleep quality were more likely to belong to Class 3, rather than Class 1, compared to their counterparts. Additionally, dementia care and caregiving ≥ 20 h/week were significantly associated with Class 3 membership. In the adjusted model, psychological distress remained significant. Caregivers reporting psychological distress were more likely to belong to Class 3 rather than Class 1, compared to those without psychological distress.

Conclusion: Our findings reveal the presence of subgroups of caregivers with unique patterns of lifestyle risk behaviors, with most not meeting the recommended levels of health behaviors. Future studies should consider these co-occurring patterns along with the key factors associated with higher-risk lifestyle behavior patterns when developing interventions to promote caregivers' cardiovascular health.

KEYWORDS

health risk behaviors, health promotion, cardiovascular diseases, caregivers, latent class analysis

1 Introduction

The health impact of caregiving represents a significant public health concern, affecting a substantial portion of the population. Currently, nearly 20% of Americans provide unpaid care to family members or significant others with health or functional needs (1). Although caregiving can be fulfilling and rewarding, it can also be extremely demanding, particularly when it involves prolonged and intense care, leading to considerable emotional, physical, and financial strain. Accumulating evidence indicates a link between caregiving and increased risks of cardiovascular disease (CVD) (2, 3). While the mechanisms underlying this connection are not fully elucidated, it is hypothesized that caregivers' limited engagement in healthy lifestyle behaviors, constrained by time, emotional and physical burden, may contribute to this increased risk (4, 5). Caregivers are more likely to encounter lifestyle challenges, such as insufficient exercise or physical activity, sleep disturbances, changes in diet and eating habits, alcohol consumption, and cigarette use, compared to non-caregivers (6–9).

Lifestyle risk behaviors frequently co-occur, with evidence suggesting that a significant proportion (≥60%) of the population engages in multiple risk behaviors (10–13). For instance, physically inactive individuals are also likely to be current smokers and report heavy alcohol consumption and poor dietary quality (10, 14, 15). These behaviors are often interrelated and may exert a synergistic effect on chronic illness and mortality (16, 17). Consequently, targeting a single behavior in an intervention may be less effective than addressing co-occurring behaviors to achieve favorable health outcomes, such as improved cardiovascular health (18, 19). Moreover, the co-occurrence patterns of lifestyle risk behaviors are unlikely to be uniform within a population. Various factors, including demographic, health- or clinical-related, and social factors, can influence the patterns. For example, older women tend to have healthier lifestyle profiles compared to young male adults, and socio-economically disadvantaged groups are more likely to exhibit multiple lifestyle risk behavior patterns than their counterparts with advantageous socio-economic status (20, 21). Psychological health and quality of life were also associated with different health behavior patterns in the general population (14, 22). Thus, subgroups of a population may exhibit distinct configurations of lifestyle risk behaviors.

Understanding the co-occurrence of multiple lifestyle behaviors in a population and the factors associated with these patterns is crucial for developing targeted and effective interventions. Instead of focusing on a single lifestyle risk behavior, such interventions can address a group of lifestyle risk behaviors. While there have been studies on patterns of health behaviors in various populations, including adolescents, middle-aged women, and cancer survivors (23–25), little is known about the co-occurrence of lifestyle risk behaviors among caregivers (26). Given the unique circumstances in which caregivers are prone to various lifestyle challenges and the burdens of caregiving, it is critical to better understand the health behavior patterns and the characteristics of those at higher risk of multiple lifestyle risk behaviors among caregivers. Latent class analysis (LCA) is particularly suited for this purpose as it allows for the identification of distinct subgroups within a population based on their co-occurring behaviors. LCA accounts for the interrelationships among variables to identify subgroups of individuals with similar characteristics, potentially providing an advantage over univariate methods (27). This method may also show a realistic picture of how caregivers engage in lifestyle risk behaviors in their daily lives. To address the knowledge gap in the caregiving literature, therefore, the aims of this study were (1) to identify co-occurrence patterns of lifestyle risk behaviors (i.e., current cigarette use, current alcohol consumption, low physical activity, prolonged sedentary time, low fruit intake, and low vegetable intake) among caregivers using LCA and (2) to investigate sociodemographic, health-related, and caregiving-related factors associated with membership in the identified latent classes.

2 Methods

2.1 Study sample

This study is a cross-sectional secondary analysis utilizing data from the 2019 Health Information National Trends Survey (HINTS), Cycle 3, conducted between January 22 and May 7, 2019. This survey, administered by the National Cancer Institute, is designed to gather information on how non-institutionalized adults in the U.S. use cancer-related information (28). Detailed survey design, sampling and weighting processes are documented in the HINTS 5 Cycle 3 methodology report (29). Briefly, the sample selection procedure involved a two-stage design: first, a stratified sample of addresses was selected from a database of residential addresses using an equal-probability sample. Second, one adult was chosen from each sampled household by the respondents themselves (29). The sampling frame included all non-vacant residential addresses in the U.S., with oversampling in high-minority areas where the population proportion of Hispanics or African Americans was ≥ 34% to increase precision for minority subpopulations (29). The survey was conducted through mailed paper surveys or web-based surveys, using an identical protocol. The overall weighted response rate for the survey was 30.3%. Each iteration of HINTS underwent expedited review approved by the Westat Institutional Review Board and was classified as "not human subjects research" by the National Institutes of Health Office of Human Subjects Research.

Our sample selection is illustrated in Figure 1. In this study, we focused on respondents who identified themselves as caregivers. Of the total HINTS 5 Cycle 3 sample (N = 5,438), there were 203 cases with missing values in caregiving status, and 4,413 respondents indicated they were not caregivers. A total of 822 (15.1%) reported

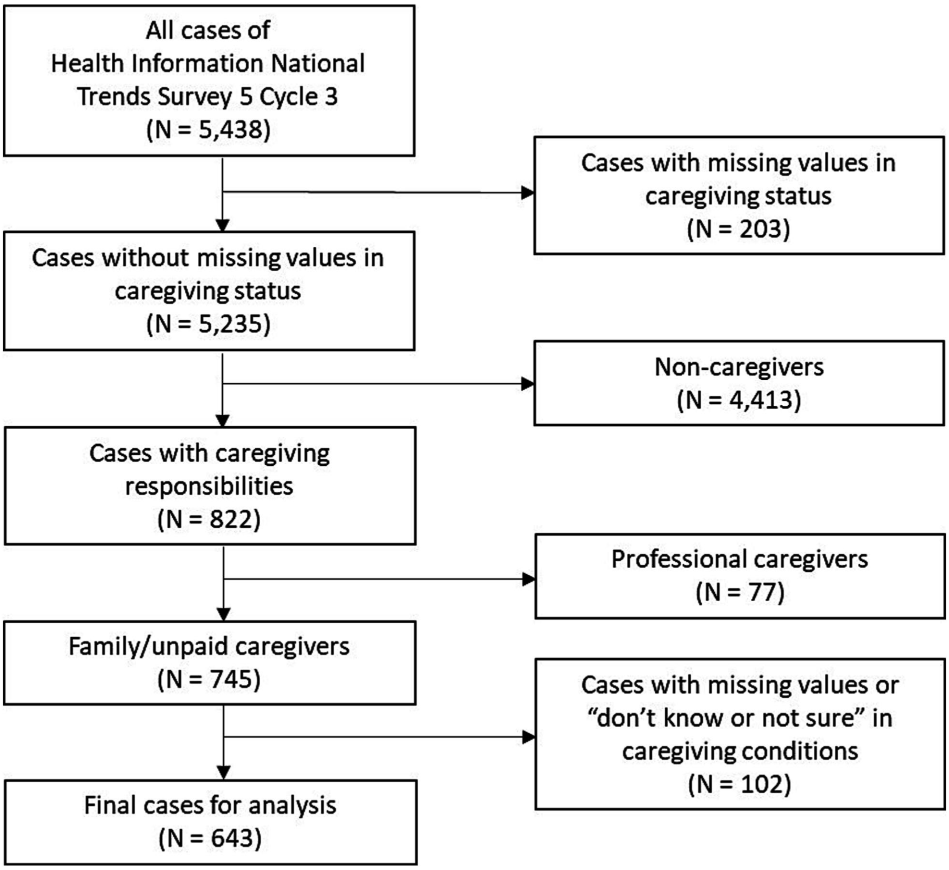

FIGURE 1
Sample selection flow.

that “[they] are currently caring for or making healthcare decisions for someone with a medical, behavioral, disability, or other condition,” specifying the relationship of the care-recipient to them (i.e., child, spouse/partner, parent(s), another family member, or friend/non-relative). To more accurately identify family/informal/unpaid caregivers who were significantly engaged in care, we excluded 77 respondents who provided care as part of a job and 102 respondents who did not know the care-recipient’s main health conditions or did not respond. Ultimately, we included 643 caregivers in our analytic sample for this study (weighted $N = 30{,}253{,}974$).

2.2 Measures

2.2.1 Lifestyle risk behaviors

2.2.1.1 Current cigarette use

Respondents were asked if they had smoked at least 100 cigarettes in their entire life and about their smoking frequency. Based on the responses, cigarette use status was categorized as current vs. never/former user. The use of e-cigarettes was also included.

2.2.1.2 Current alcohol consumption

Respondents reported the number of days per week they consumed at least one alcoholic drink in the past month and the average number of drinks on those days. Using the number of average drinks per week, alcohol consumption was categorized as current drinker (≥1 drink per week) vs. non-drinker (<1 drink per week). Despite the mixed nature of evidence on the health benefits of moderate drinking, we decided to treat current alcohol consumption as a risky behavior following the 2020–2025 Dietary Guidelines for Americans (30). The guidelines recommend that adults who do not drink should not start drinking for any reason, and those who do drink should do so in moderation by limiting intake. However, the guidelines also presented emerging evidence suggesting that even drinking within the recommended limits may still increase the overall risk of death (30). Additionally, a recent meta-analysis study did not show a significantly beneficial association between low to moderate alcohol consumption and reduced risk of all-cause mortality (31).

2.2.1.3 Low physical activity

Respondents indicated the number of days per week they engaged in moderate-intensity physical activity or exercise and the duration of these activities. They also reported the frequency of leisure-time activities for strength training outside of their job. Based on the Physical Activity Guidelines for Americans (moderate exercise≥150 min/week AND strength training≥2 days/week), respondents were categorized into two groups: those not meeting the recommended levels of physical activity (low physical activity) vs. those meeting the recommendation (32).

2.2.1.4 Prolonged sedentary time

Respondents reported their daily sitting time at home or at work. Sedentary behavior was categorized as ≥8 h (prolonged sedentary time) vs. <8 h per day, based on meta-analysis studies that reported the dose–response relationship between sedentary behavior and all-cause and CVD mortality, adjusted for physical activity (33, 34).

2.2.1.5 Low fruit intake

Respondents indicated their daily fruit intake, including 100% pure fruit juice, using the response options ranging from none to 4 or more cups. Based on the 2020–2025 Dietary Guidelines for Americans (≥1–2 cups/day), respondents were categorized into a group not meeting the fruit consumption recommendation (low fruit intake) vs. a group meeting the recommendation (30).

2.2.1.6 Low vegetable intake

Respondents reported their daily vegetable intake, including 100% pure vegetable juice, using the same response options as fruit consumption. Based on the 2020–2025 Dietary Guidelines for Americans (≥2–3 cups/day), respondents were categorized into two groups: those not meeting the recommendation (low vegetable intake) vs. those meeting the recommendation (30).

2.2.2 Sociodemographic factors

Sociodemographic factors included age (18–49, 50–64, ≥65 years), sex (male, female), race and ethnicity (Hispanic, non-Hispanic Asian, non-Hispanic Black or African American, non-Hispanic other [American Indian or Alaska native, Native Hawaiian or other Pacific Islander, multiple races mentioned], non-Hispanic White as pre-specified in the survey data), education (<college [less than high school, high school graduate, some college], ≥college educated [college graduate, postgraduate]), marital status (married or partnered, not married or partnered [single, divorced, widowed, separated]), household income (<\$50,000, \$50,000–\$99,999, ≥\$100,000), perceived financial status (living comfortably, getting by, finding it difficult/very difficult on present income), and rural–urban status by the Rural–Urban Continuum Code per the US Department of Agriculture Economic Research Service (35) as informed by a previous study (36) (rural, urban areas).

2.2.3 Health-related factors

Health-related factors included body mass index (<30 kg/m^2, ≥30 kg/m^2), medical conditions (composite of diabetes, hypertension, heart condition, chronic lung disease, and depression or anxiety disorder; 0–1 condition, 2–5 conditions), self-rated health status (excellent/very good/good, fair/poor), and psychological distress (Patient Health Questionnaire-4; no distress [0–2], mild to severe distress [3–12]). Self-efficacy in health management was asked using a single item, *"Overall, how confident are you about your ability to take good care of your health?"* and was dichotomized as described in a previous study (low [somewhat/a little/not confident], high [very confident/completely]) (37). Sleep duration was categorized as <7 h vs. ≥7 h per night, based on the American Academy of Sleep Medicine's recommended sleep hours for adults (38). Sleep quality was dichotomized into poor (very bad/fairly bad) and good (fairly good/very good).

2.2.4 Caregiving-related factors

Respondents reported the relationship of the care-recipient to them, the care-recipient's health conditions (cancer; Alzheimer's, confusion, or dementia; orthopedic/musculoskeletal issues; mental health/behavioral/substance abuse issues; chronic conditions; neurological/developmental issues; acute conditions; aging/aging-related health issues; other), and caregiving hours per week. Based on previous literature on factors associated with caregiver burden (39), the care conditions and relationships were categorized into dementia care vs. non-dementia care and spousal caregiving vs. non-spousal caregiving, respectively. Caregiving hours were categorized as <20 h vs. ≥20 h per week, as ≥20 h per week represents more intense caregiving (40).

2.3 Statistical analysis

For descriptive statistics of the total sample, we computed frequencies and percentages. We performed LCA using the maximum-likelihood estimation with robust standard errors to identify subgroups of caregivers sharing similar lifestyle risk behaviors. The following six indicators were included in the LCA: current cigarette use, current alcohol consumption, low physical activity, prolonged sedentary time, low fruit intake, and low vegetable intake. We referred to a set of model fit indices to determine the number of classes that best represent the patterns of lifestyle risk behaviors observed in the data. The Akaike information criterion (AIC), Bayesian information criterion (BIC), and sample-size adjusted BIC (SABIC) were used to reflect the balance between model fit and complexity, with lower values indicating better prediction. Entropy was used to assess how well the classes are separated, with values above 0.8 considered acceptable and values closer to 1 preferred (41). The Vuong–Lo–Mendell–Rubin likelihood ratio test (VLMR-LRT) and Lo–Mendell–Rubin adjusted LRT (LMR-LRT) were used to compare the fit of a k-class model to a k-1 class model. The final number of classes was determined by examining both the model fit indices and clinical interpretation.

Multinomial logistic regression analysis was conducted to identify factors associated with latent class membership. Unadjusted regression models were tested on the list of socio-demographic, health-related, and caregiving-related factors. Factors that were significant at $p < 0.05$ in the unadjusted regression models were entered into the adjusted regression model, with age and sex controlled for. Collinearity among the factors included in the model was assessed. Full information maximum likelihood was used to handle missing data in latent class indicators, whereby a survey response contributed to the LCA if data were available for at least one indicator. To address missing data in the multinomial logistic regression analysis, multiple imputation was employed. Specifically, we generated 20 imputed datasets for all socio-demographic, health-related, and caregiving-related factors with missing values (ranging from 0.6 to 9.5%). The specified estimation model was applied to each imputed dataset, and the final estimates were derived by pooling the results across all the imputed datasets. Sample characteristics by latent classes, using both the dataset with missing values and the imputed datasets, for comparisons are presented in the Supplementary Tables. Variance estimation was based on Taylor Series

Linearization to account for the complex sample design of the survey. LCA was conducted using Mplus Version 8 and descriptive and multinomial logistic regression analyses were conducted using IBM SPSS Version 29.

3 Results

3.1 Sample characteristics

Most caregivers (70.4%) were aged 18–64 years, with a median age of 56 years (interquartile range, 45–66). The majority were female (59.3%), non-Hispanic White (57.1%), college-educated (53.5%), and married or partnered (66.6%). About 22% reported financial difficulties. Regarding health-related characteristics, 30.5% experienced psychological distress, 32.2% reported low self-efficacy for taking care of their health, and 14.8% rated their health status as fair or poor. Slightly more than half (50.9%) slept ≥7 h per night on average, with 73.0% rating their sleep quality good. Approximately 20% were spousal caregivers, 29% cared for individuals with dementia, and 36% spent ≥20 h per week caregiving. Other sociodemographic and health-related characteristics of the sample are presented in Table 1. The prevalence rates of lifestyle risk behaviors were as follows: 14.7% current cigarette user, 50.2% current drinkers, 75.4% low physical activity, 43.1% long sedentary time, 50.3% low fruit intake, and 71.2% low vegetable intake.

3.2 Class selection

The model fit indices for the different LCA models for lifestyle risk behaviors are presented in Table 2. A 3-class model was selected given the smallest SABIC and the entropy value greater than 0.8. In addition, the 4-class model had category probabilities below 5 to 10%, suggesting that some categories may lack sufficient representation for meaningful interpretation unless they represent theoretically or empirically significant subgroups (42, 43). Therefore, the 3-class model was determined as the best fitting model.

3.3 Latent classes for lifestyle risk behaviors

For the 3-class solution, conditional item-response probabilities are presented in Figure 2. A total of 17.1% of the sample was expected to belong to Class 1, which had a response pattern characterized by "*Physically active caregivers*." Class 1 consisted of caregivers who had the highest probability for current alcohol drinkers (67.5%) and the lowest probabilities for low physical activity levels (0%), sedentary lifestyle (30.5%), and low fruit consumption (18.4%). Caregivers expected to belong to Class 2 (18.8%), characterized by "*Physically inactive, healthy eaters*." Class 2 membership had the highest probability of low physical activity levels (100%) but had the lowest probabilities for current cigarette use (4%) and low vegetable consumption (0%). Class 3 constituted the largest latent class (64.1%) and was characterized by "*Physically inactive and unhealthy eaters*." Class 3 members have a high probability for low physical activity levels (94.8%) and the highest probabilities for sedentary lifestyle (50.5%) and low fruit (66.1%) and vegetable consumption (100%).

TABLE 1 Sample characteristics (N = 643, weighted N = 30,253,974).

Variable	Category	n (weighted %)
Age group, years		
	18–49	199 (31.0)
	50–64	253 (39.4)
	≥ 65	182 (28.4)
	Missing	9 (1.2)
Sex		
	Male	223 (34.7)
	Female	381 (59.3)
	Missing	39 (6.0)
Race and ethnicity		
	Hispanic	87 (13.5)
	Non-Hispanic Asian	29 (4.5)
	Non-Hispanic Black	77 (12.0)
	Non-Hispanic Other[a]	24 (3.7)
	Non-Hispanic White	367 (57.1)
	Missing	59 (9.2)
Education		
	< College	289 (45.0)
	≥ College graduate	344 (53.5)
	Missing	10 (1.5)
Marital status		
	Married/partnered	428 (66.6)
	Not married/partnered	199 (31.0)
	Missing	16 (2.4)
Household income		
	< \$50,000	233 (36.2)
	\$50,000 to \$99,999	203 (31.6)
	≥ \$100,000	198 (30.8)
	Missing	9 (1.4)
Perceived financial status		
	Living comfortably on present income	247 (38.4)
	Getting by on present income	218 (33.9)
	Finding it difficult or very difficult on present income	143 (22.3)
	Missing	35 (5.4)
Rural–urban status		
	Rural	65 (10.1)
	Urban	578 (89.9)
Body mass index		
	< 30 kg/m^2	382 (59.4)
	≥ 30 kg/m^2	251 (39.0)

(Continued)

TABLE 1 (Continued)

Variable	Category	n (weighted %)
	Missing	10 (1.6)
Medical conditions[b]		
	0–1 condition	430 (66.9)
	2–5 conditions	200 (31.1)
	Missing	15 (2.0)
Self-rated health		
	Excellent/very good/ good	544 (84.6)
	Fair/poor	95 (14.8)
	Missing	4 (0.6)
Psychological distress		
	No distress (PHQ-4 < 3)	433 (67.3)
	Mild to severe distress (PHQ-4 ≥3)	196 (30.5)
	Missing	14 (2.2)
Self-efficacy		
	Somewhat/a little/not confident (low)	190 (32.2)
	Completely/very confident (high)	453 (67.8)
Sleep duration		
	< 7 h/night	301 (46.8)
	≥ 7 h/night	327 (50.9)
	Missing	15 (2.3)
Sleep quality		
	Good	469 (73.0)
	Poor	166 (25.8)
	Missing	8 (1.2)
Dementia care		
	Yes	183 (28.5)
	No	460 (71.5)
Spousal caregiver		
	Yes	126 (19.6)
	No	517 (80.4)
Caregiving hours		
	< 20 h/week	349 (54.3)
	≥ 20 h/week	233 (36.2)
	Missing	61 (9.5)

PHQ-4, Patient Health Questionnaire-4.

[a] The non-Hispanic other category includes non-Hispanic American Indian or Alaska Native, Native Hawaiian or other Pacific Islander, and multiple races mentioned.

[b] Medical conditions include diabetes, hypertension, heart condition (heart attack, angina, or congestive heart failure), chronic lung disease (asthma, emphysema, or chronic bronchitis), depression, anxiety disorder.

3.4 Factors associated with identified class membership

In the unadjusted multinomial logistic regression models of the identified latent classes, age ≥65 years was associated with membership in Class 2, with Class 1 as the reference group (Table 3). Additionally, perceived financial difficulties, psychological distress, low self-efficacy in health management, poor sleep quality, dementia care, and caregiving for ≥20 h per week were associated with membership in Class 3. As there were no high correlations (coefficients range from 0.09 to 0.30) and multicollinearity (all VIFs < 1.2) among these significant factors, all the variables were included in the adjusted multinomial regression model. In the adjusted model, psychological distress remained significant (Table 4). Caregivers reporting psychological distress were more likely to belong to Class 3 rather than Class 1, compared to their counterpart without psychological distress. The fit of the model to the data improved when the predictor variables were added to the intercept-only model (X^2 (18) = 58.25, Nagelkerke $R^2 = 0.122$, $p < 0.001$), and the Chi-Square Goodness-of-Fit test was not statistically significant, which indicates that the model is a good fit for the data (Pearson X^2 (654) = 346.75, $p = 0.206$).

4 Discussion

This study identified three distinct classes of caregivers based on multiple lifestyle risk behaviors among a nationally representative sample of caregivers in the U.S. Notably, the majority (64.1%) were in the class characterized by the greatest number of lifestyle risk behaviors for CVD (i.e., low physical activity, prolonged sedentary time, low fruit and vegetable intake). Caregivers with psychological distress were more likely to fall into this class of "*physically inactive and unhealthy eaters*." These findings underscore the importance of CVD prevention strategies tailored to subgroups and corresponding lifestyle risk behavior profiles in this at-risk population.

To our knowledge, this study is among the few that have investigated the co-occurrence patterns of lifestyle risk behaviors among caregivers, using established guidelines for each behavior through LCA. This approach enabled us to assess caregivers' adherence to recommended levels of health behaviors, providing valuable information for providers working with this population. We found that insufficient physical activity (75.4%) and inadequate vegetable intake (71.2%) were the most prevalent risk behaviors, supporting previous findings that caregivers struggle with exercise and healthy eating due to time constraints (4, 7, 44). A previous study using the Behavioral Risk Factor Surveillance System data reported that 47–53% of caregivers met the recommended level of the aerobic activity, and 27–32% met the muscle-strengthening recommendation (45). Our criteria for physical activity, which are stricter by including both aerobic and muscle-strengthening activities as recommended, resulted in a higher proportion of non-adherent caregivers in the current study. These both studies indicate that over half of caregivers have low levels of physical activity and that only 14–18% of caregivers met dietary recommendations for fruit and vegetables intake (45), highlighting

TABLE 2 **Model fit information for latent class analysis models fit to data.**

Class	AIC	BIC	SABIC	Entropy	VLMR[a]	BLRT[a]	Profile prevalence (%)
2	4413.657	4471.717	4430.443	0.528	0.1386	0.1457	53.7/46.3
3[b]	4398.199	4487.522	4424.023	0.921	0.4608	0.4668	17.1/64.1/18.8
4	4391.779	4512.365	4426.642	0.771	0.4859	0.4906	63.0/7.5/16.2/13.4

AIC, Akaike information criterion; BIC, Bayesian information criterion; BLRT, Bootstrapped likelihood ratio test; SABIC, Sample-size adjusted Bayesian information criterion; VLMR, Vuong-Lo–Mendell–Rubin.

[a] Chi-square statistic for the VLMR and the BLRT, when non-significant ($p > 0.05$), the VLMR and the BLRT test provide evidence that K-1 class model fits the data better than the K-class model.

[b] 3-class model was selected, based on its having the smallest SABIC and the largest entropy (>0.8).

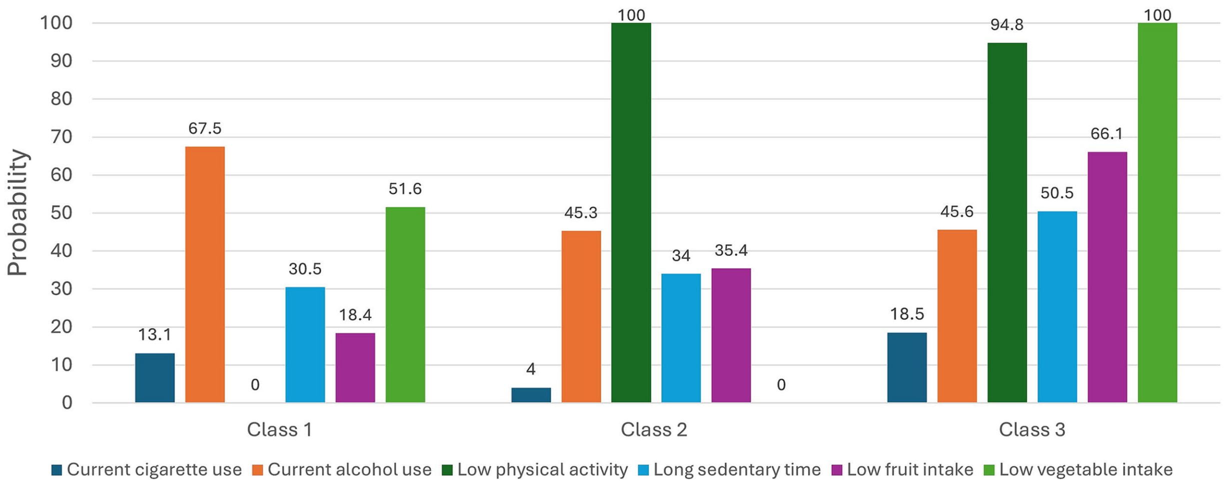

FIGURE 2
Latent classes of lifestyle risk behaviors for cardiovascular disease (CVD) among family caregivers. The figure shows the probabilities of each lifestyle risk behavior for CVD conditional on latent class membership. The proportions of each class: Class 1 (17.1%), Class 2 (18.8%), and Class 3 (64.1%). Class 1 was characterized by *physically active caregivers*, Class 2 by *physically inactive but healthy eaters*, and Class 3 by *physically inactive and unhealthy eaters*.

the need for improvement in caregivers' physical activity and diets. Given the robust evidence linking recommended physical activity levels and vegetable intake with favorable outcomes in CVD mortality and morbidity (46–48), improving these areas is crucial to enhance cardiovascular health among caregivers.

Each identified class exhibited unique behavior configurations. Notably, over 60% of caregivers were characterized collectively by low levels of physical activity, prolonged sedentary time, and low levels of fruit and vegetable intake, while the other two classes were defined by one or two dominant lifestyle risk behaviors. This co-occurring pattern aligns with previous studies in general populations, although the proportion of the class with multiple unhealthy behaviors was higher in the current study of caregivers. For instance, a study of 10,638 Australians found that high-risk lifestyle behaviors, including poor diet quality (i.e., fruit/vegetable intake, soft drink and fast food consumption), physical inactivity, and excessive sitting, co-occurred in 33–40% of the sample, alongside excessive alcohol use and smoking (49). Similarly, a study in the Netherlands identified that 13.2% of the sample exhibited physical inactivity and unhealthy diet, along with current smoking and moderate alcohol consumption (50). In both studies, these behaviors also co-occurred at the favorable end of the spectrum, with a class characterized by low risk or healthy lifestyle behaviors (49, 50). Despite the limitation in making direct comparisons due to different measurements and criteria for the behaviors, it is noteworthy that no class in the current study was free of lifestyle risk behaviors, suggesting significant challenges for caregivers in maintaining healthy behaviors.

Consistent with previous studies (14, 26, 50–52), our findings indicate that caregivers experiencing psychological distress (i.e., depression, anxiety) are more likely to engage in multiple lifestyle risk behaviors, compared to those without such distress. A study of cancer caregivers found that higher levels of caregiver burden and perceived stress were associated with lower engagement in health-promoting behaviors (i.e., health responsibility, physical activity, nutrition, spiritual growth, interpersonal relationships, and stress management) (26). More broadly, risk behaviors, such as smoking, excessive drinking, physical inactivity, and unhealthy diet have been closely linked to poor mental health outcomes (50). In the caregiving context, particularly, psychological distress stemming from caregiving demands may contribute to the adoption of unhealthy behaviors as maladaptive coping mechanisms (53, 54). However, this relationship may be bidirectional. Unhealthy behaviors can also exacerbate psychological distress, potentially creating a self-reinforcing cycle (55). Longitudinal studies in the general population suggest that improvements in health behaviors, such as increased physical activity and greater fruit and vegetable intake, may reduce the risk of

TABLE 3 **Unadjusted multinominal logistic regression of class membership (reference group = Class 1).**

	Class 2		Class 3	
	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)
Age, years				
18–49	Ref.		Ref.	
50–64	0.786 (0.382)	2.194 (0.744, 5.226)	0.504 (0.333)	1.655 (0.859, 3.190)
≥ 65	0.679 (0.495)	**1.972 (1.034, 4.655)**	0.575 (0.414)	1.777 (0.786, 4.018)
Sex				
Male	Ref.		Ref.	
Female	0.524 (0.396)	1.690 (0.774, 3.688)	−0.140 (0.295)	0.870 (0.487, 1.554)
Race/ethnicity				
Non-Hispanic white	Ref.		Ref.	
Non-white[a]	−0.447 (0.462)	0.693 (0.257, 1.588)	0.293 (0.383)	1.340 (0.631, 2.848)
Education				
< College	−0.110 (0.419)	0.896 (0.393, 2.045)	0.171 (0.336)	1.187 (0.612, 2.301)
≥ College	Ref.		Ref.	
Marital status				
No married/partnered	Ref.		Ref.	
Married/partnered	0.330 (0.393)	1.391 (0.641, 3.018)	0.188 (0.313)	1.207 (0.652, 2.237)
Household income				
< $50,000	0.101 (0.487)	1.106 (0.424, 2.884)	0.529 (0.407)	1.697 (0.762, 3.779)
$50,000 - $99,999	−0.282 (0.448)	0.754 (0.312, 1.823)	−0.090 (0.365)	0.914 (0.445, 1.874)
≥ $100,000	Ref.		Ref.	
Perceived financial status				
Living comfortably	Ref.		Ref.	
Getting by	0.031 (0.441)	1.031 (0.433, 2.456)	−0.096 (0.367)	0.909 (0.441, 1.873)
Finding it difficult/very difficult	0.273 (0.489)	1.314 (0.502, 3.443)	0.901 (0.419)	**2.461 (1.079, 5.614)**
Rural–urban status				
Rural	Ref.		Ref.	
Urban	1.237 (0.652)	3.445 (0.954, 12.438)	0.695 (0.473)	2.003 (0.789, 5.087)
Body mass index				
<30 kg/m^2	Ref.		Ref.	
≥30 kg/m^2	0.237 (0.409)	1.267 (0.567, 2.835)	−0.138 (0.345)	0.871 (0.441, 1.719)
Medical conditions				
0–1 condition	Ref.		Ref.	
2–5 conditions	0.102 (0.425)	1.108 (0.479, 2.560)	−0.255 (0.345)	0.775 (0.393, 1.531)
Self-rated health				
Excellent /very good/ /good	Ref.		Ref.	
Fair/poor	0.724 (0.677)	2.063 (0.544, 7.824)	−0.546 (0.529)	0.579 (0.204, 1.641)
Psychological distress				
No distress	Ref.		Ref.	
Mild to severe distress	0.598 (0.445)	1.819 (0.756, 4.373)	1.285 (0.333)	**3.615 (1.878, 6.961)**
Self-efficacy				
High	Ref.		Ref.	
Low	0.442 (0.503)	1.556 (0.578, 4.191)	0.848 (0.397)	**2.336 (1.068, 5.105)**

(Continued)

TABLE 3 (Continued)

	Class 2		Class 3	
	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)
Sleep duration				
< 7 h/night	−0.125 (0.393)	0.883 (0.407, 1.917)	−0.442 (0.316)	0.643 (0.345, 1.199)
≥ 7 h/night	Ref.		Ref.	
Sleep quality				
Good	Ref.		Ref.	.
Poor	0.534 (0.536)	1.706 (0.593, 4.907)	1.206 (0.365)	**3.341 (1.629, 6.851)**
Dementia care				
No	Ref.		Ref.	
Yes	0.540 (0.417)	1.271 (0.560, 2.888)	0.849 (0.308)	**2.336 (1.273, 4.289)**
Spousal caregiver				
No	Ref.		Ref.	
Yes	0.226 (0.506)	1.253 (0.463, 3.393)	0.210 (0.455)	1.233 (0.504, 3.020)
Caregiving hours				
< 20 h/week	Ref.		Ref.	
≥ 20 h/week	0.340 (0.377)	1.405 (0.669, 2.953)	0.767 (0.292)	**2.153 (1.211, 3.829)**

B, regression coefficient; CI, confidence interval; OR, odds ratio; Ref, reference; SE, standard error. Class 1 (*n* = 110) was characterized by physically active caregivers, Class 2 (*n* = 121) by physically inactive but healthy eaters, and Class 3 (*n* = 412) by physically inactive and unhealthy eaters. Bold font indicates statistical significance.

[a]The non-white category includes Black or African American, American Indian or Alaska Native, Asian, Native Hawaiian or other Pacific Islander, and Hispanic or Latino.

TABLE 4 Adjusted multinominal logistic regression of class membership (reference group = Class 1).

	Class 2		Class 3	
	B (SE)	OR (95% CI)	B (SE)	OR (95% CI)
Perceived financial status				
Living comfortably	Ref.		Ref.	
Getting by	−0.046 (0.447)	0.955 (0.396, 2.303)	−0.101 (0.350)	0.904 (0.453, 1.802)
Finding it difficult/very difficult	0.006 (0.564)	1.006 (0.331, 3.059)	0.310 (0.470)	1.363 (0.540, 3.444)
Psychological distress				
Minimal symptoms	Ref.		Ref.	
Mild to severe symptoms	0.409 (0.477)	1.467 (0.573, 3.757)	0.764 (0.354)	**2.173 (1.085, 4.350)**
Self-efficacy				
Completely/very confident	Ref.		Ref.	
Somewhat/a little/not confident	0.473 (0.473)	1.604 (0.632, 4.069)	0.550 (0.363)	1.733 (0.848, 3.542)
Sleep quality				
Good	Ref.		Ref.	
Poor	0.270 (0.623)	1.308 (0.384, 4.464)	0.732 (0.432)	2.079 (0.887, 4.873)
Dementia care				
No	Ref.		Ref.	
Yes	0.015 (0.500)	1.015 (0.379, 2.720)	0.706 (0.370)	2.026 (0.977, 4.202)
Caregiving hours				
< 20 h/week	Ref.		Ref.	
≥ 20 h/week	0.250 (0.387)	1.284 (0.599, 2.749)	0.598 (0.306)	1.819 (0.995, 3.324)

Age and sex controlled for. B = regression coefficient; CI = confidence interval; OR = odds ratio; Ref = reference; SE = standard error. Class 1 (*n* = 110) was characterized by physically active caregivers, Class 2 (*n* = 121) by physically inactive but healthy eaters, and Class 3 (*n* = 412) by physically inactive and unhealthy eaters. Bold font indicates statistical significance.

developing psychological distress (56, 57). On the other hand, in caregiving-specific research, one longitudinal study found that longer caregiving hours predicted poorer health behaviors, but psychological distress and burden did not have additional influences on health behaviors (7). This finding suggests that time constraints, rather than emotional strain, may be a more immediate barrier to engaging in healthy behaviors. Taken together, these findings highlight the complex and potentially reciprocal relationship between psychological distress and lifestyle behavioral patterns in caregivers. To better understand the directionality and underlying mechanisms of this relationship, more longitudinal research, particularly studies that track changes in mental health and lifestyle behaviors over the course of the caregiving trajectory, is needed.

This study underscores the importance of CVD prevention interventions that target co-occurring lifestyle risk behaviors among caregivers. The combined impact of multiple risk behaviors on chronic diseases, including CVD, and mortality, is significantly greater than that of individual behaviors alone (58, 59). A holistic approach to modifying multiple health behaviors, rather than addressing them in isolation, can maximize both the health benefits and cost-effectiveness of interventions (18). Importantly, our findings emphasize the need to address psychological factors when designing behavior change strategies for caregivers. Clinically, these findings suggest that healthcare providers should routinely screen for both psychological distress and lifestyle risk behaviors during clinical encounters. Tailored interventions based on the caregiver's psychological and behavioral profile may be especially effective. For instance, caregivers who exhibit multiple unhealthy behaviors alongside high psychological distress may benefit most from integrated interventions that combine behavioral counseling with psychological support. In contrast, caregivers who maintain relatively healthy behaviors but experience elevated stress may benefit from preventive strategies focused on effective stress management, expanding coping skills, and peer support to sustain resilience and prevent behavioral decline. There is growing interest in mindfulness, mind–body, and positive psychological interventions that focus on emotional and cognitive processes (60). These interventions have shown promise in improving health behaviors, such as physical activity, diet, and medication adherence, and may also contribute to better cardiovascular outcomes (60). Future research should explore the implementation and effectiveness of such interventions in caregivers.

Beyond psychological distress, other health- and caregiving-related factors, including perceived financial difficulties, low self-efficacy in health management, poor sleep quality, dementia care responsibilities, and longer caregiving hours, were associated with membership of the "*Physically inactive, unhealthy eaters*" class, the unhealthiest behavior group in the unadjusted models. These factors should also be considered in identifying high-risk caregivers and designing targeted interventions. Particularly, self-efficacy plays a critical role in health behavior engagement. If one feels confident in their ability to engage in health behaviors, they are likely to commit to their goals and overcome emotional barriers, such as fear of failure (61). Additionally, successfully performing a behavior can further enhance self-efficacy (61). Therefore, improving self-efficacy through achievable goal setting, feedback, and skill-building may be especially effective, given caregivers' challenges in prioritizing their own health needs. Caregiving experiences are dynamic and influenced by various interpersonal and environmental factors, such as the quality of the relationship with care recipients, the level of social support, access to caregiving resources, and cultural norms. These contextual factors may also significantly affect caregivers' capacity to engage in health-promoting behaviors. Therefore, future research should incorporate these dimensions into intervention development to ensure that strategies are comprehensive, context-specific, and responsive to the diverse needs of caregivers.

4.1 Strengths and limitations

Our study has several strengths. To understand patterns of lifestyle risk behaviors among caregivers, we utilized LCA, a person-centered approach that identifies unobserved homogeneous subgroups within a given population based on particular combinations of observed indicators (62). This method is considered superior to variable-centered approaches (e.g., confirmatory factor analysis, regression), which extract generalized trends that apply to all respondents, for evaluating a population with underlying heterogeneous constructs, such as health behaviors (27, 62). Additionally, we used data from a nationally representative sample of caregivers across various conditions, enhancing the generalizability of our findings. By including a wide range of indicators of lifestyle risk behaviors and sociodemographic, health-related, and caregiving-related characteristics, we comprehensively examined the co-occurrence patterns and identified subgroups at higher risk for lifestyle risk behaviors.

Several limitations should be considered when interpreting our findings. First, the cross-sectional study design limits our ability to infer causality and determine directionality. For instance, we cannot ascertain whether psychological distress leads to worse lifestyle risk behavior patterns or if these risk behavior patterns increase the risk for psychological distress. Second, although we utilized nationally representative data, the sample of caregivers included in the analysis was relatively small. Future studies should include larger sample sizes to replicate our findings and enhance the robustness of the results. Third, the use of LCA introduces the possibility of misclassification, as class membership is determined based on probabilistic estimates. This means that individuals may be classified into a latent class even when their behavior patterns are not strongly distinct from those in other classes. Additionally, when the probability of a particular indicator pattern does not vary substantially across classes, that indicator may have limited utility in distinguishing between them (63). For example, in the present study, current alcohol consumption emerged as a relatively non-discriminative indicator. Fourth, the reliance of self-reported survey data for health behaviors introduces potential recall and social-desirability biases, which may impact the validity of our study findings. Future research should consider employing objective measures of health behaviors (e.g., accelerometers) to mitigate these biases. Lastly, we did not include sleep (i.e., sleep duration and quality), which is another lifestyle risk factor for CVD, as an indicator of lifestyle risk behaviors due to poor model fit in initial attempts to incorporate sleep into the LCA modeling. Previous studies have shown that sleep patterns often do not align with other lifestyle behaviors (diet, alcohol consumption, smoking, and physical activity). For example, high-risk sleep patterns can coexist with otherwise healthy behaviors, and low-risk sleep patterns can coexist with high-risk behaviors (49). This suggests that sleep may represent a different construct from other health behaviors regarding the co-occurrence of behaviors. Sleep behavior is often considered less volitional than other health behaviors and is influenced by various intrinsic and extrinsic factors (e.g., emotional distress, daytime behaviors, and sleep environment) (49, 64). Further research is needed to determine the co-occurrence of sleep problems with other lifestyle risk behaviors.

5 Conclusion

Lifestyle risk behaviors may play a critical role in the adverse health outcomes experienced by caregivers. Our study contributes to the growing literature by identifying distinct co-occurrence patterns of CVD-related lifestyle risk behaviors among caregivers. Alarmingly, most caregivers in our sample did not meet recommended guidelines for multiple health behaviors, highlighting a critical area for intervention. These findings underscore the need for holistic, multi-faceted lifestyle approaches that simultaneously address interconnected behaviors. Interventions that integrate mental health support with behavior change strategies may be particularly effective in promoting cardiovascular health in this at-risk population. Future research should explore the longitudinal impact of unhealthy behavioral patterns on cardiovascular outcomes among caregivers, as well as the mechanisms linking psychological distress and lifestyle behaviors.

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: https://hints.cancer.gov/data/download-data.aspx.

Ethics statement

Ethical approval was not required for the study involving humans in accordance with the local legislation and institutional requirement as this study involved the analysis of publicly available de-identified data.

Author contributions

SA: Funding acquisition, Writing – review & editing, Conceptualization, Writing – original draft, Investigation, Formal analysis, Data curation, Methodology. ES: Conceptualization, Methodology, Investigation, Writing – original draft, Writing – review & editing, Formal analysis. MM: Writing – review & editing. JM: Writing – review & editing. YS: Writing – review & editing. CP: Writing – review & editing. LL: Methodology, Investigation, Writing – review & editing, Writing – original draft, Conceptualization, Formal analysis, Supervision.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2025.1593898/full#supplementary-material

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Perceived technology usefulness for caregiving among unpaid caregivers: a National Cross-Sectional Study

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Background: Technological advancements have the potential to improve caregiving quality and alleviate caregiver burden by providing tools for real-time communication, monitoring, and care coordination. To assist with technology adoption among the 53 million unpaid caregivers nationwide, efforts are needed to better understand caregivers' perceptions about the usefulness of certain technologies for caregiving.

Methods: Data were analyzed from a national sample of 483 unpaid caregivers using an internet-delivered questionnaire. All unpaid caregivers were eligible if they provided at least 8 h of weekly care for a care recipient aged 50 years or older. The primary dependent variable was the Perceived Technology Usefulness for Caregiving (PTUC) Scale, which is a composite score of six items ranging from 0 to 100. PTUC item responses were summed and averaged, and the overall PTUC scores were transformed into statistical tertiles (higher scores indicating more perceived technology usefulness for caregiving). An ordinal regression model was fitted to identify factors associated with higher PTUC tertiles.

Results: Across tertiles, unpaid caregivers who were younger (Beta = –0.018, p = 0.030) and male (Beta = 0.422, p = 0.048) reported higher PTUC Scale scores. Compared to non-Hispanic white caregivers, Hispanic/Latino (Beta = 0.779, p = 0.010), African American (Beta = 1.064, p < 0.001), and Asian (Beta = 0.958, p = 0.010) caregivers reported higher PTUC Scale scores. Unpaid caregivers with lower financial insecurity (Beta = –0.010, p = 0.003), higher caregiver strain (Beta = 0.149, p < 0.001), and more satisfaction with the support they receive for caregiving (Beta = 0.009, p = 0.002) reported higher PTUC Scale scores. Unpaid caregivers whose care recipients had less cognitive impairment reported higher PTUC Scale scores (Beta = –0.245, p = 0.048).

Conclusion: Findings indicate caregiver characteristics, caregiving dynamics, and available resources (financial and caregiving support) are associated with perceptions about the usefulness of technology for caregiving. The utility of technology for caregiving may be higher among unpaid caregivers with more caregiver strain or positive experiences with caregiving support.

KEYWORDS

unpaid caregiving, technology, perceived usefulness, older adults, paid caregiving

1 Introduction

There are an estimated 53 million unpaid caregivers in the United States who assist their family members, friends, and neighbors to meet their household, health, and psychosocial needs (1). Unpaid caregivers frequently provide assistance in running errands, attending appointments, and performing activities of daily living. Caregiving tasks are driven by the needs and demands of the care recipient, which can be complicated when care recipients have mobility, sensory, and/or cognitive impairments (2, 3). Further, based on the demands of their care recipients, unpaid caregivers are susceptible to high levels of burden (4) and poor physical and mental health consequences (5, 6). Persisting high levels of caregiver burden are associated with increased depression and anxiety symptoms and greater susceptibility to cardiovascular diseases and hypertension (7). Worse caregiver mental health also predicts greater mortality among persons with dementia, even when accounting for care recipients' age and disease severity (8).

In recent years, there has been a proliferation in technological solutions targeting caregivers (3). These technological advancements are diverse in format and function and can be available in the form of smartphone applications, digital platforms, and wearables (9). Evidence suggests that technology has potential to improve caregiving quality and alleviate caregiving strain or burden by providing tools for real-time communication, monitoring, and care coordination (10). Assistive technology may have mixed benefits for caregivers, impacting emotional, financial, and time-related strain differently. Caregivers have reported that technology can both reduce and increase caregiver-related burden (11, 12). For example, a technology may be used to alleviate worry and anxiety among long-distance caregivers rather than to optimize time spent providing care (10). Studies also show that technology can provide reminder systems to support medication management and activities of daily living; therapeutic activities such as cognitive games, relaxation exercises, and music-therapy; and self-management programs for caregivers to help deal with behavioral change in people with dementia (13–15). Moreover, research suggests that technology can provide more independence for people with cognitive impairment by enhancing social interaction and reducing boredom to support family interactions for the care recipient and unpaid caregiver, especially during extended periods of social isolation (16, 17).

To overcome potential barriers to technology use and assist with technology adoption among unpaid caregivers, efforts are needed to better understand caregivers' perceptions about the usefulness of technology for caregiving. In this context, the purposes of this study were to identify: (a) the degree to which unpaid caregivers perceive technology to be useful for caregiving; and (b) factors associated with higher perceived technology usefulness for caregiving.

2 Methods

2.1 Participants and procedures

Data were collected using a cross-sectional, internet-delivered survey. Participants were recruited from a Qualtrics panel in November 2019. The eligibility criteria to participate in the study required that participants be ages 18 years or older and be a paid or unpaid caregiver of at least one non-institutionalized adult ages 50 years or older. Quota sampling was used to ensure the study sample was diverse in terms of geographic regions across the United States (Northwest, Midwest, West, and South), sex, age, ethnicity, and race. Additional information about the survey and sampling methods are reported elsewhere (18, 19). A total of 626 paid and unpaid caregivers completed the survey; 143 paid caregivers were omitted from analyses given this study's focus on unpaid caregivers. The resulting analytic sample was 483 unpaid caregivers of non-institutionalized adults ages 50 years and older. The study was approved by the Texas A&M University Institutional Review Board (IRB2019-1128 M).

2.2 Measures

2.2.1 Dependent variable

The dependent variable used in this study was the Perceived Technology Usefulness for Caregiving (PTUC) Scale, which was created by study investigators and assessed by summing the responses of six items. PTUC items measured caregivers' perceptions that technology is useful for: (a) easing caregiving burdens; (b) enabling care recipients to live more independently; (c) enabling better quality of life for care recipients; (d) improving relationships with care recipients; (e) communicating with care recipients' family and friends; and (f) communicating with care recipients' healthcare team. Participants rated each item from 0 (not at all) to 100 (a great deal) to indicate the extent to which they perceived technology was useful for caregiving. Items were then summed and divided by six to calculate an average score for the six PTUC items (ranging from 0 to 100%), with higher scores indicating higher perceived usefulness of technology for caregiving. In the current sample of unpaid caregivers, the 6-item PTUC Scale had a single-factor solution using exploratory factor analysis and a Cronbach alpha of 0.924. Because of the positively skewed frequency distribution, statistical tertiles were used to operationalize the PTUC Scale into lowest [range from 0 to 47.17; mean = 28.87; standard deviation (SD) = 13.59], medium (range from 47.50 to 70.33; mean = 58.82; SD = 6.72), and highest (range from 70.50 to 100; mean = 84.80; SD = 9.41) levels, which were used in ordinal regression analyses.

2.2.2 Care recipient characteristics and caregiving situation

Caregivers were asked to report information about their care recipient and caregiving situation. Caregivers indicated their care recipients' age, cognitive status (i.e., healthcare provider ever told that the care recipient has mild cognitive impairment/memory problems or Alzheimer's Disease/Dementia). Caregivers also reported if they lived with their care recipient (i.e., no, yes) and the number of weekly hours they provided care. Caregivers were also asked to rate their satisfaction with the help in caregiving they received from friends, family member, or neighbors in the past month (range from 0 to 100, with higher score indicating greater satisfaction).

2.2.3 Social engagement activities

Caregivers were asked, "in the past 2 weeks, have you participated in in-person organizational gatherings such as: (a) social clubs, resident groups, or committees; (b) community organizations; (c) hobby or interest group organizations; (d) religious group meetings; and (e) coffee or meals with friends." Response choices for each item were "no" (scored 0) and "yes" (scored 1) and summed to create a count variable ranging from 0 to 5. Higher scores for this count variable indicate more social engagement.

2.2.4 Caregiving strain

The Caregiving Strain Scale is a composite score of eight items to assess ways in which caregiving has caused strain in their lives. This scale is a modification of a chronic disease strain scale (20, 21), which the authors tailored to be related to caregiving. Caregivers were asked, "as a result of your caregiving in the past 3 months, have the following situations occurred? (a) had strained family relationships; (b) had strained financial situation; (c) had to reduce social activities; (d) had to cut back on helping family/friends; (e) had to miss work; (f) had to reduce time volunteering in other ways; (g) reduced your usual amounts of exercise; and (h) reduced time on hobbies." Higher scores indicate more caregiving-related strain. In the current sample of unpaid caregivers, the 8-item Caregiver Strain Scale had a single-factor solution using exploratory factor analysis and a Cronbach alpha of 0.809.

2.2.5 Caregiver sociodemographic characteristics

Caregiver's sociodemographic characteristics included age, sex (i.e., female, male), ethnicity (i.e., non-Hispanic/Latino, Hispanic/Latino), race (i.e., White, Black or African American, Asian or Pacific Islander, or Other or Multiple Races), education level (i.e., high school or less, some college or associates degree, college graduate or more), and employment status (i.e., not employed, employed). As a proxy to financial insecurity, participants were asked to report how their "finances usually work out at the end of the month" (i.e., some money left over, just enough money to make ends meet, not enough money to make ends meet), and they also reported their residential rurality (i.e., large metro area, medium metro area, small metro area, urban cluster, small town, or rural area).

2.3 Statistical analyses

All statistical analysis were performed using SPSS version 29.[1] Frequencies and descriptive statistics were generated for all variables of interest and compared across PTUC Scale tertiles. Chi-square tests were used to identify distribution differences across PTUC Scale tertiles for categorical variables. One-way ANOVAs were used to assess the mean differences for continuous and count variables across PTUC Scale tertiles. An ordinal regression model was fitted to assess factors associated with increasing levels of PTUC Scale scores among unpaid caregivers.

3 Results

A total of 483 unpaid caregivers were included in this study. On average, unpaid caregivers had a PTUC Scale score of 56.83 (SD = 25.85). In terms of the individual PTUC Scale items (see Figure 1), unpaid caregivers perceived technology to be most useful to ease caregiving burdens in the future (62.9%), followed by to improve their communication with the care recipients' health care team (60.5%), to enable the care recipient to have a better quality of life (58.7%), and to improve their communication with the care recipients' family and friends (56.2%).

As shown in Table 1, the average age of these caregivers was 60.75 (SD = 12.13) years. Most caregivers were female (74.7%), non-Hispanic/Latino (90.1%), White (74.1%), and not employed (66.3%). Approximately 21% of caregivers had a high school education or less, 36.0% had some college or an associate's degree, and 43.3% had a college degree or graduate-level education. The average age of care recipients was 74.86 (SD = 11.64) years. About 61% of the care recipients did not have cognitive impairment, 22.4% had mild cognitive impairment, and 16.6% had Alzheimer's Disease or dementia. About 2-in-3 caregivers (64.6%) lived with their care recipient. On average, caregivers provided 55.40 (SD = 51.97) hours of care to their care recipients each week.

When comparing sample characteristics across the PTUC Scale tertiles, on average caregivers in the highest PTUC Scale tertiles were younger ($t = 5.90$, $p = 0.003$) and had lower financial insecurity levels ($t = 3.43$, $p = 0.033$). A significantly larger proportion of non-White participants were in the highest PTUC Scale tertile ($\chi^2 = 30.39$, $p < 0.001$). On average, caregivers in the highest PTUC Scale tertile had higher Caregiver Strain Scale scores ($f = 9.49$, $p < 0.001$) and higher satisfaction in the caregiving support they received ($f = 3.62$, $p = 0.027$).

Table 2 presents the ordinal regression model identifying factors associated with PTUC Scale scores among unpaid caregivers. Across tertiles, unpaid caregivers who were male (Beta = 0.422, $p = 0.048$), Hispanic (Beta = 0.779, $p = 0.010$), African American (Beta = 1.064, $p < 0.001$), and Asian or Pacific Islander (Beta = 0.958, $p = 0.010$) reported higher PTUC Scale scores. On average, lower PTUC Scale scores were reported among unpaid caregivers who were older (Beta = −0.018, $p = 0.030$) and those with higher financial insecurity levels (Beta = −0.010, $p = 0.003$). Unpaid caregivers with higher

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[1] https://www.ibm.com/products/spss-statistics

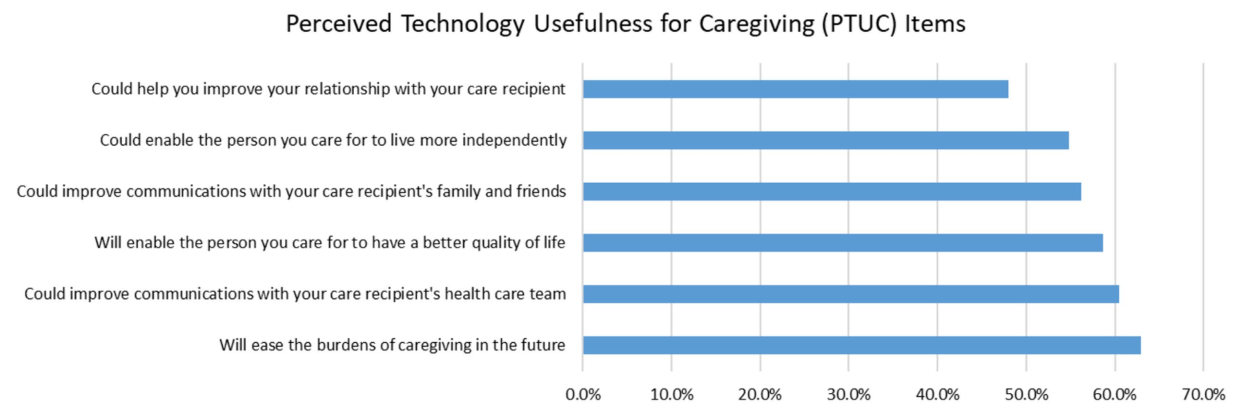

FIGURE 1
Perceived technology usefulness for caregiving (PTUC) items.

caregiver strain (Beta = 0.149, $p < 0.001$) and more satisfaction about support for caregiving from family/friends/neighbors (Beta = 0.009, $p = 0.002$) reported higher PTUC Scale scores. On average, lower PTUC Scale scores were reported among unpaid caregivers whose care recipients had more cognitive impairment (Beta = −0.245, $p = 0.048$).

4 Discussion

The aim of this study was to identify the perceptions of unpaid caregivers on the usefulness of technology for caregiving and the factors that influence their perceptions. We found that unpaid caregivers who were younger and reported more satisfaction with the social support they receive had a higher perception of the usefulness of technology for caregiving. Similarly, unpaid caregivers who had higher caregiving strain also had a higher perception of the usefulness of technology in caregiving. Unpaid caregivers of individuals with more severe cognitive impairment, however, did not find technology for caregiving to be as useful.

In recent years, caregiving technologies have become increasingly prominent, accompanied by a heightened awareness about how their use varies across distinct populations and socioeconomic groups (3). Findings from a national caregiver survey highlighted notable disparities in reported technology usage (e.g., devices and specific functionalities) between caregivers and the individuals they support, as well as the factors linked to various patterns of technology adoption (22). Our study builds upon these findings by examining the perceived usefulness of technological solutions for caregiving, which has potential to influence uptake, duration of use, and overall care quality. Examples of technological innovations for caregiving encompass areas of diagnosis, evaluation and monitoring, functional support, recreational engagement, and overall care coordination (23). While the current study did not examine the perceived usefulness of technology for specific purposes, our study provides insights about the caregiving subgroups and caregiving contexts where such technologies may be more useful.

Age of the user plays a pertinent role in the acceptance of technological assistance in everyday life (24–26). Among unpaid caregivers, older age of the caregiver was associated with significantly lower perceptions of usefulness of caregiving technology. Studies which examined the acceptance and usefulness of caregiving technology among caregivers have consistently shown that younger caregivers are more accepting of caregiving technology (19, 27). Findings from our study suggest that younger unpaid caregivers may have a higher perception of technology's usefulness for caregiving. The utility of technology to improve health outcomes is significantly associated with technology literacy and comfort in navigating digital tools (28). Prior research suggests that compared to younger individuals, older adults have lower technology literacy (25, 26), which could influence the perception of usefulness of these interventions for caregiving. Since the COVID-19 pandemic, older adults' use of technology has increased and diversified (28, 29); yet, there still is persistent digital divide based on age. For example, 2021 Pew Research Center's digital technology survey data showed 35 percentage point difference in the smartphone ownership between those at ages 18–29 years old and older adults at 65 years and older (30). In the current study, relative to their White counterparts, larger proportions of racial/ethnic minority caregivers (e.g., Hispanic, African American, and Asian or Pacific Islander) reported middle and highest PTUC Scale scores (relative to low PTUC Scale scores), respectively. These findings confirm those reported elsewhere (19). While the specific factors contributing to racial/ethnic differences in the perceived usefulness of technology for caregiving remain unclear (e.g., cultural attitudes, familial values), further research is warranted to explore and contextualize these differences.

In our study, perception of technology usefulness for caregiving was higher among individuals facing higher caregiving strain and those more satisfied with the help received from social networks to support their caregiving role. Similar findings have been reported in previous studies (22). Unpaid caregivers facing significant burden from caregiving are more likely to seek support to manage their caregiving roles (31), including being open to using technology to support caregiving. Caregivers reporting high burden and strain are also more likely to be engaged in providing long-term unpaid caregiving (32, 33) and may be in more complex care situations that may require additional skills in caregiving that they are often ill-prepared for (31). In these circumstances, technology to support caregiving may be perceived to be highly useful in supporting their caregiving roles.

TABLE 1 Sample characteristics by PTUC Scale tertiles.

Variables	Total (n = 483)	Lowest (n = 161)	Middle (n = 161)	Highest (n = 161)	χ^2 or f	P
Age	60.75 (±12.13)	63.27 (±11.62)	60.20 (±11.16)	58.78 (±13.15)	5.90	0.003
Sex					1.73	0.420
Female	74.7%	78.3%	73.9%	72.0%		
Male	25.3%	21.7%	26.1%	28.0%		
Hispanic					5.00	0.082
No	90.1%	93.8%	90.1%	86.3%		
Yes	9.9%	6.2%	9.9%	13.7%		
Race					30.39	<0.001
White	74.1%	86.3%	75.2%	60.9%		
Black or African American	14.1%	5.0%	14.3%	23.0%		
Asian or Pacific Islander	6.6%	4.3%	5.6%	9.9%		
Other or multiple races	5.2%	4.3%	5.0%	6.2%		
Education level					4.28	0.369
High school or less	20.7%	21.7%	22.4%	18.0%		
Some college/associates	36.0%	32.9%	40.4%	34.8%		
College degree or more	43.3%	45.3%	37.3%	47.2%		
Employed					1.19	0.553
No	66.3%	69.6%	64.6%	64.6%		
Yes	33.7%	30.4%	35.4%	35.4%		
Financial insecurity level	3.95 (±1.95)	4.24 (±2.09)	3.93 (±1.90)	3.68 (±1.83)	3.43	0.033
Residential rurality	3.11 (±1.43)	3.12 (±1.40)	3.19 (±1.46)	3.01 (±1.44)	0.61	0.544
Care recipient's age	74.86 (±11.64)	76.65 (±12.00)	73.93 (±11.71)	74.00 (±11.04)	2.87	0.058
Cognitive status of care recipient					3.97	0.410
No Impairment	61.1%	55.9%	65.2%	62.1%		
Mild cognitive impairment	22.4%	24.8%	18.6%	23.6%		
Alzheimer's disease or dementia	16.6%	19.3%	16.1%	14.3%		
Lives with care recipient					1.47	0.480
No	35.4%	31.7%	37.3%	37.3%		
Yes	64.6%	68.3%	62.7%	62.7%		
Hours of care given weekly	55.40 (±51.97)	59.62 (±55.20)	49.30 (±45.14)	57.28 (±54.69)	1.75	0.175
Social engagement activities	1.39 (±1.39)	1.24 (±1.30)	1.39 (±1.30)	1.54 (±1.53)	1.94	0.144
caregiving strain scale	3.28 (±2.49)	2.59 (±2.30)	3.60 (±2.50)	3.64 (±2.53)	9.49	<0.001
Satisfaction in caregiving support received	55.84 (±33.61)	53.08 (±36.48)	52.82 (±29.74)	61.63 (±33.71)	3.62	0.027

Caregivers with strong support networks are more likely to have support to address issues that might limit access to, and utility of, technology to support caregiving. Adoption of technology and its use to support caregiving has been shown to be reliant of the caregivers' external sources of information about available technology (34), indicating the role of social networks in increasing uptake of technology for caregiving. Moreover, utility of technology for caregiving is also dependent on the user's technology literacy (16, 35, 36), access to broadband internet, and the affordability of the technology in question (26). Caregivers with robust support networks may be able to navigate these potential barriers more easily.

Additionally, in our study, unpaid caregivers of individuals with cognitive impairment were less likely to perceive technology for caregiving as useful. Studies have identified numerous factors that influence the adoption of technology among caregivers of individuals with cognitive impairment (37–39). For example, the timing and pace of technology introduction, as well as disease progression, are important considerations that may impact the user's level of comfort, familiarity, and ability to adapt to devices (36). Among caregivers of individuals with cognitive impairment, the limitation in their participation in utilizing certain technologies for caregiving may influence the reach and effectiveness of the caregiving technology and often lead to missed opportunities in using technology to support caregiving. Typically, caregivers of individuals with cognitive impairment are most receptive when technology is introduced at earlier stages of disease progression (37).

TABLE 2 Ordinal regression: factors associated with higher PTUC Scale tertiles.

Variables				95% CI	
	B	S.E.	*P*	Lower	Upper
Age	−0.018	0.01	0.030	−0.04	0.00
Male	0.422	0.21	0.048	0.01	0.84
Hispanic	0.779	0.30	0.010	0.19	1.37
Race: White	–	–	–	–	–
Race: Black or African American	1.064	0.29	<0.001	0.51	1.62
Race: Asian or Pacific Islander	0.958	0.37	0.010	0.22	1.69
Race: other or multiple races	0.062	0.40	0.875	−0.71	0.84
Education: high school or less	–	–	–	–	–
Education: some college/associates	0.229	0.25	0.354	−0.26	0.72
Education: college degree or more	0.397	0.26	0.130	−0.12	0.91
Employed	−0.093	0.21	0.654	−0.50	0.31
Financial insecurity level	−0.161	0.05	0.003	−0.27	−0.05
Residential rurality	0.073	0.07	0.263	−0.05	0.20
Care recipient's age	−0.010	0.01	0.256	−0.03	0.01
Cognitive status of care recipient	−0.245	0.12	0.048	−0.49	0.00
Lives with care recipient	−0.266	0.22	0.216	−0.69	0.16
Hours of care given weekly	0.000	0.00	0.803	0.00	0.00
Social engagement activities	0.054	0.07	0.425	−0.08	0.19
Caregiving strain scale	0.149	0.04	<0.001	0.07	0.23
Satisfaction in caregiving support received	0.009	0.00	0.002	0.00	0.01

Nagelkerke $R^2 = 0.181$.

Digital literacy and technology anxiety also contribute to the user's ability to adapt to the technology (38). Caregiving technology may require an initial investment in terms of time and effort to establish and learn the technology. Furthermore, for caregivers caring for those with cognitive decline, the need to communicate about or implement a new technology in a daily routine can be perceived as a challenge, resulting in the lower perception of the usefulness of technology for caregiving. To ensure successful adoption, assistive devices should align with the needs, preferences, and abilities of the user and be capable of adapting to dementia in its different stages (36). Studies have also shown that among caregivers of people with dementia, the perception of the usefulness of technology for caregiving also depends on the type of technology (38). These finding underscore the importance of adequately considering the needs and preferences of the caregiver and individual with cognitive impairment to enhance product utility and use (39).

4.1 Limitations

This study has limitations, which should be acknowledged. Data were cross-sectional; therefore, associations could be identified but causality could not be inferred. Data were collected using an internet-delivered survey from a Qualtrics panel sample. While the quota sampling strategy yielded a large and somewhat diverse national sample of unpaid caregivers, this sample may not be representative of all unpaid caregivers in the United States. Recruiting participants through Qualtrics may have introduced self-selection bias based on topical interest and may have included caregivers with higher digital literacy than the general caregiving population. Although the perceived usefulness of technology for caregiving was identified using the PTUC scale, this study did not directly assess whether the unpaid caregivers were using various forms of technology for specific caregiving purposes. Research does suggest, however, that perceived usefulness of technology contributes to its adoption (10), which may indicate that some participants in the current study were already using technology for caregiving. Perceived usefulness and adoption of technology is impacted by individual level (e.g., cost, time, and adaptability to change) and structural-level factors (e.g., broadband accessibility, technology support, and workplace policies) that may hinder adoption (3). Because perceived usefulness of technology may not always translate into its actual adoption or utilization, future studies should examine the concordance between these two factors while carefully considering contextual influences. This study asked caregivers to report about their care recipients' personal characteristics and their current caregiving situation. However, additional potentially important information may not have been collected, which could better contextualize the perceived usefulness of caregiving technology (e.g., their care recipients' health conditions, diagnoses, impairments, or behavioral risks [e.g., wandering]; whether the caregiver shares caregiving responsibilities with others). The current sample primarily contained caregivers who resided in urban areas. Given caregivers in rural areas may be more susceptible to the digital divide (e.g., less affluence and unreliable internet) and may have unique caregiving-related responsibilities based on geospatial circumstances (e.g., dispersion of health resources, size of residential properties, roles pertaining to property upkeep), rural–urban differences in perceived technology usefulness were anticipated but not observed. Future research should examine the usefulness of technologies from the perspective of caregivers in rural versus urban areas using more geographically diverse samples.

5 Conclusion

This cross-sectional study examined the perceptions of unpaid caregivers on the usefulness of technology for caregiving and the factors that predicted their perceptions. Caregivers reported about the usefulness of technology for caregiving to improve their relationship and communication with the care recipient, help their care recipients live more independently, and ease the burden of caregiving. Experiencing greater caregiver strain, greater satisfaction with the social support received, and lower financial insecurity were associated with higher perceptions of the usefulness of technology for caregiving among unpaid caregivers in terms of needs and perceived benefits. However, caregivers caring for individuals with more severe cognitive decline did not find technology for caregiving to be as useful. This study demonstrates the importance of having caregivers and those being cared for participate more deeply in the design and evaluation of the utility of assistive technologies. By identifying predictors of the usefulness of technology, more targeted and tailored technology interventions can be designed and adopted by diverse unpaid caregivers; thus, improving their quality of life.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Texas A&M University Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The ethics committee/institutional review board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because an information sheet was embedded into the online survey, which participants were required to acknowledge prior to proceeding to the survey.

Author contributions

MS: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. SL: Investigation, Methodology, Writing – original draft, Writing – review & editing. MN: Writing – original draft, Writing – review & editing. DV: Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. JLS: Writing – original draft, Writing – review & editing. ZB: Writing – review & editing. KM: Writing – review & editing. DP: Writing – review & editing. ZR: Writing – review & editing. JSS: Writing – review & editing. J-DB: Writing – review & editing. CK: Writing – review & editing. MO: Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing.

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Conflict of interest

DV was employed by the DVD Associates LLC.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author MO declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

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Place-based, intersectional variation in caregiving patterns and health outcomes among informal caregivers in the United States

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Introduction: Informal caregiving is a critical component of the healthcare system despite numerous impacts on informal caregivers' health and well-being. Racial and gender disparities in caregiving duties and health outcomes are well documented. Place-based factors, such as neighborhood conditions and rural–urban status, are increasingly being recognized as promoting and moderating health disparities. However, the potential for place-based factors to interact with racial and gender disparities as they relate to caregiving attributes jointly and differentially is not well established. Therefore, the primary objective of this study was to jointly assess the variability in caregiver health and aspects of the caregiving experience by race/ethnicity, sex, and rural–urban status.

Methods: The study is a secondary analysis of data from the 2021 and 2022 Behavioral Risk Factor Surveillance System (BRFSS) from the Centers for Disease Control and Prevention. Multivariable logistic regression or Poisson regression models assessed differences in caregiver attributes and health measures by demographic group categorized by race/ethnicity, sex, and rural–urban status.

Results: Respondents from rural counties were significantly more likely to report poor or fair health (23.2% vs. 18.5%), have obesity (41.5% vs. 37.1%), and have a higher average number of comorbidities than urban caregivers. Overall, rural Black male caregivers were 43% more likely to report poor or fair health than White male caregivers (OR 1.43, 95% CI 1.21, 1.69). Urban female caregivers across all racial groups had a significantly higher likelihood of providing care to someone with Alzheimer's disease than rural White males ($p<0.001$). Additionally, there were nuanced patterns of caregiving attributes across race/ethnicity*sex*rural–urban status subgroups, particularly concerning caregiving intensity and length of caregiving.

Discussion: Study findings emphasize the need to develop and implement tailored approaches to mitigate caregiver burden and address the nuanced needs of a diverse population of caregivers.

KEYWORDS

rural health, informal caregiver, disparities (health racial), caregiver health outcomes, effect modification

Introduction

Informal caregiving is a critical component of the United States (US) healthcare system, saving the national economy over $500 billion annually that may otherwise be spent on costly long-term care expenses for older adults with disabilities, cognitive decline, and other chronic conditions (1). Nearly one in six Americans is an informal caregiver (2). Protecting the health and well-being of the 40 million informal caregivers across the US is essential for protecting the care recipients' health and sustaining the healthcare system and the national economy. However, informal caregiving impacts nearly every aspect of the caregivers' life. The extent to which caregiving adversely affects informal caregivers' emotional, social, financial, physical, and spiritual functioning—caregiver burden—is often overlooked. Informal caregivers for older adults face varying degrees of caregiver burden (3–5). The level and type of care provided (6), social support (7), socioeconomic (8), demographic (9), and environmental factors (10) at the individual, community, and organizational levels contribute to and moderate the degree and type of caregiver burden experienced (11).

The type and amount of caregiving provided and the impacts on caregiver health vary across demographic groups (12, 13). There are well-documented disparities in caregiver burden and other consequences of caregiving, including strain and health-related quality of life by sex or gender (14, 15). Furthermore, there are differences in the intensity of caregiving, with female caregivers providing substantially more intensive care than their male counterparts (16, 17). Gender disparities in caregiving intensity only partially explain differences in caregiver burden (18), but more research is needed to understand these complex associations more fully.

Racial and ethnic differences in caregiving intensity and caregiver burden are well documented (19, 20). Black informal caregivers provide substantially higher levels of care than their White counterparts (21). However, Black caregivers do not proportionately report higher levels of caregiver burden and health impacts (22). A study of male informal caregivers determined that the correlates of caregiver burden differed by race/ethnicity, where Black caregivers of the sandwich generation—those with at least one child under age 18 living at home—experienced greater burden compared to those without a child in the home. In comparison, physical pain and fatigue experienced by the caregiver were predictive of higher caregiver burden among Hispanic caregivers (23).

Recent research in informal caregiving has expanded on the study of racial/ethnic and gender differences in caregiver burden and aspects of caregiving by using an intersectional framework to examine the potential for these two factors to impact caregiving jointly and differentially (24). Broadly, intersectionality is a theoretical framework that conceives multiple social categories, such as race/ethnicity and gender, interact to reflect multiple linked systems of privilege and oppression, such as racism and sexism (25). The intersectional framework posits that factors such as race/ethnicity, gender, socioeconomic status (SES), and other social identities create systems of disparities above and beyond the effect of any single factor (26–28). A 2019 study found that Black caregivers spent an average of 28.5 more hours/month caregiving than White caregivers and that Black female caregivers provided significantly higher intensity care than White females and White and Black males (9). However, some research has determined that White female informal caregivers report greater emotional strain than female caregivers of color (29). It has been postulated that these differences in caregiver strain may be partly attributable to differences in resilience across racial and gender groups (30), but further study is needed to clarify these relationships.

Furthermore, there is increasing recognition that place-based or geographic factors contribute to differences in informal caregiving and caregiver health. That is, there are notable differences by rural–urban status. Informal caregiving in rural areas presents unique challenges to the caregiver, including increased distance to, or lack of, caregiving resources and supports (31); increased social isolation (32), decreased access to high-quality health care (33), and farther travel to the care recipient's residence if the care recipient does not reside with the caregiver (34). As a result, rural caregivers face substantial barriers to acquiring and providing caregiving-related support and experience greater difficulty caring for their own health. They are also less likely to have health insurance than urban informal caregivers (35).

To date, no comprehensive assessment of rural caregivers with respect to general health, comorbidities, and aspects of the caregiving experience has been conducted, nor has there been a comparison of existing racial/ethnic and gender-or sex-based disparities across the rural–urban spectrum among caregivers concerning caregiver health and caregiving attributes (36). A vast body of existing research has examined race/ethnicity, gender, and rural–urban status separately. Several studies have investigated the joint effects of two intersecting factors (e.g., race/ethnicity and gender). For example, one study assessed the joint influence of race and gender on creating disparities in caregiving and caregiver health with a sample of rural caregivers (12), but no rural–urban comparisons were conducted. A seminal review of rural health emphasized the need to delve deeper into rural–urban disparities (37). The authors emphasize that to fully understand and improve population health in rural areas, research must consider other structural and intersectional determinants of health within rural communities and compare rural to urban areas. Other studies underscore the need to research the intersections of economic wellbeing and family structure with rural health and aging and how social and physical isolation inherent to rural areas has differential impacts for older adults and their caregivers (38). To date, no studies have assessed the potential for associations between caregiver demographics and caregiving experiences and health outcomes to vary by geography. There is, therefore, a compelling need to identify, understand, and address the potential for these intersecting demographic and place-based factors that result in complex disparities in informal caregiver health, caregiver burden, and overall caregiving experience (26). This study applies and extends the theoretical framework of intersectionality to include not only individual attributes (e.g., race/ethnicity and sex), but also place of residence (rural vs. urban). The primary objective of this exploratory study was to assess potential variability with respect to caregiver health and aspects of the caregiving experience jointly by race/ethnicity, sex, and rural–urban status.

Methods

Data source and analytic sample

This was a secondary analysis of data from the 2021 and 2022 Behavioral Risk Factor Surveillance System (BRFSS), the largest system of health-related telephone surveys administered by the Centers for Disease Control and Prevention (CDC). Respondents were selected and then interviewed through landlines or cell phones. The BRFSS collects data annually from US residents aged 18+ in all 50 states and Puerto Rico regarding their demographics, self-reported health-related risk behaviors, height, weight, chronic health conditions, and use of preventive services. The data collected are widely used for policy and program planning, largely at the state level (39). Each year, between 400,000 and 500,000 interviews are conducted, with a total sample of 438,693 respondents in 2021 and 441,132 in 2022. Response rates for 2021 and 2022 were 44.0 and 45.0%, respectively (40). Data from 2021 and 2022 were combined for statistical analysis for this study.

The BRFSS Caregiver Module is an optional set of nine questions concerning whether the respondent is an informal caregiver. Individual states decide whether to include this module in their annual questionnaire. In 2021, the Caregiver Module was administered in 39 states; in 2022, it was administered in 14 states. Collectively, between the 2 years, the module was administered in 47 states—all except Florida, Montana, and Tennessee. Persons identifying as caregivers complete several questions assessing caregiving, including the type of caregiving, hours per week spent caregiving, and duration of caregiving. The analytic sample for this study was restricted to respondents in either data set who responded “yes” to whether they were informal caregivers. The resultant sample size was n = 74,822 respondents.

Outcome measures

Health and health-related quality of life

Four primary outcome variables on health and health-related quality of life were obtained. Respondents were asked to rate their general health as “excellent,” “very good,” “good,” “fair,” or “poor.” Responses were dichotomized into two categories (fair or poor vs. excellent, very good, and good) (41). Respondents’ self-reported height and weight were used to calculate BMI, which was used to ascertain obesity status. Respondents whose BMI was 30 kg/m^2 or above were classified as having obesity, while those with a BMI below 30 kg/m^2 were classified as not having obesity. The third variable was whether the respondent reported having depressive disorders (yes vs. no). Lastly, a variable containing the sum of major reported comorbidities was calculated from the following measures: diabetes, cancer, hypercholesterolemia, heart disease, myocardial infarction, stroke, hypertension, asthma, chronic obstructive pulmonary disorder, and kidney disease. Comorbidity scores could range from 0 to 10.

Aspects of caregiving

Five aspects of the caregiving experience were examined. The first, a measure of the length of time providing care, was dichotomized into 6 months or more vs. less than 6 months. The second, a measure of hours of caregiving per week, was dichotomized into at least 20 h vs. less than 20 h, in accordance with how intensity caregiving is defined in a recent CDC report (42). The third measure asked whether the care recipient had Alzheimer’s disease (yes vs. no). The last two measures addressed the type of caregiving: whether or not the caregiver provides personal care in the form of activities of daily living (ADLs) to help with tasks such as toileting, eating, bathing, and dressing, and the other about household caregiving, instrumental activities of daily living (IADLs), such as paying bills, medication management, and transportation. Both were dichotomous responses (no ADLs or IADLs vs. at least one).

Exposure measures

Respondents were asked, “Which one of these groups would you say best represents your race?” Eight response options were available: White, Black, Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native, other, do not know, and multiracial. They were also asked if they were of Hispanic ethnicity (yes vs. no). Responses for these two questions were combined into a categorical variable consisting of four categories: White, Black, Hispanic, and Other. The Other category was necessary due to the small sample sizes among respondents identifying as Asian, Native Hawaiian or Other Pacific Islander, American Indian or Alaska Native, other, and multiracial. The other major exposure measure was sex. Each respondent was asked about their sex assigned at birth. This dichotomous variable (female vs. male) was used in the analysis. Lastly, rural–urban status was based on each respondent’s county of residence from the BRFSS data set and was a dichotomous variable (rural vs. urban).

Covariates

Other covariates used were the 5-year age category (except for the first category, which was 18–24), marital status (currently married vs. not currently married), education (less than bachelor’s degree vs. bachelor’s degree or higher), current employment status (currently employed for pay, not employed, retired, or student), and annual household income category (<$50,000, $50,000-99,999, $100,000+, and missing/unknown).

Data analysis

Univariate descriptive statistics were obtained for all study variables—outcomes, exposures, and covariates. Frequencies (N and %) were assessed for all categorical variables and means, and standard deviations were obtained for all continuous and count variables. State-level geographic distributions of each of the nine main outcome measures—health, health-related quality of life, and aspects of caregiving—were assessed through mapping. Chi squared statistics were used to assess bivariate associations between each categorical variable and rural–urban status, and Wilcoxon rank sum tests were used to assess the bivariate association between rural–urban status and the number of comorbidities, a count variable.

Weighted multiple binary logistic regression analyses were used to evaluate the associations between the nine outcome variables and each sex*race/ethnicity*rural–urban status population subgroup, accounting for covariates using the sample weights provided in the BRFSS datasets. Respondents were cross-classified by sex, race/ethnicity, and rural–urban status into one of 16 race/ethnicity*sex*rural–urban indicator variables, as the purpose of this exploratory analysis was to evaluate these three exposures simultaneously. The subgroup of urban White males served as the reference group in all models, and the remaining 15 subgroups were compared to that group. Covariates included in the models were current marital status (reference group = not married), education (reference = less than bachelor’s degree), employment (reference = not employed), age in 5-year intervals, annual income (reference = <

$50,000), and an indicator variable of which year the observation was derived (2021 or 2022). Model fit was assessed using Akaike's Information Criterion (AIC) and the Cox & Snell and Nagelkerke r-squared values. Missing data was assumed to be at random. Statistical significance was set to $p < 0.05$. SAS version 9.4 (Cary, NC) and IBM SPSS version 29 (Armonk, NY) were used for data management and analysis.

Results

Descriptive statistics by rural–urban status for major exposures, covariates, and outcome measures are provided in Table 1. The final analytic sample size was $n = 74,822$, of which 85.9% were from urban counties and 14.1% were from rural counties. Compared to those from urban counties, respondents from rural counties were more likely to be aged 65 and over (38.1% vs. 31.4%), White (84.1% vs. 72.8%), and currently married (63.3% vs. 58.5%) ($p < 0.001$ for all). Respondents from rural counties were less likely to hold at least a bachelor's degree (30.0% vs. 43.5%), be currently employed (46.1% vs. 51.6%), and have an annual household income of $100,000 or more ($p < 0.001$ for all). Respondents from rural counties were more likely to report poor or fair general health (23.2% vs. 18.5%), have obesity (41.5% vs. 37.5%), and have a greater average number of comorbidities (0.69 vs. 0.60) than their urban counterparts. Although rural respondents were significantly less likely to provide personal (48.6% vs. 49.0%) or household (78.3% vs. 79.5%) care than their urban counterparts, they were more likely to have been caregiving for at least 6 months (72.7% vs. 72.1%) and perform at least 20 h per week caregiving (32.0% vs. 31.0%). Urban caregivers were 8.9% more likely to care for someone with Alzheimer's disease than rural caregivers ($p < 0.001$).

The geographic distributions of each of the nine main outcome variables are shown in Figure 1. The percentage of informal caregivers reporting poor or fair health (Panel A) and obesity (Panel B) trended highest in the Southern and lower Midwest states. The highest percentage of caregivers reporting depressive symptoms (Panel C) occurred in Kentucky (33.7%) and Washington (32.5%), with the lowest rates occurring in Hawaii (16.1%), South Dakota (18.6%), and New Jersey (19.2%). Caregivers from Southern states also had some of the highest average number of comorbidities (Panel D), with West Virginia (0.75 average comorbidities), Arkansas (0.75), and Kentucky (0.72) with the highest values. Although there was no clear pattern in the spatial distributions of those providing care for at least 6 months (Panel E), caregivers from the Southern states were more likely to provide at least 20 h per week of caregiving than those from other areas (Panel F). The percentage of caregivers providing care for a patient with Alzheimer's disease was highest in Oregon (18.8%) and South Dakota (18.5%) and lowest in New Jersey (11.6%) and Nebraska (12.2%) (Panel G). The percentage of caregivers providing personal (ADL-type) care was again highest in many Southern states, as well as Nevada and Pennsylvania (Panel H). Simultaneously, there was no discernible spatial pattern for those caregivers providing household care (Panel I).

Figure 2 shows adjusted odds ratios and 95% confidence intervals for the likelihood of reporting poor or fair general health (Panel A), having obesity (Panel B), and reporting depressive symptoms (Panel C), as well as incidence ratios for the number of comorbidities (Panel D). Rural Black male caregivers were significantly more likely to report poor or fair health than White male caregivers (OR 1.43, 95% CI 1.21, 1.69). However, there was no significant association for urban Black male or rural White male caregivers for this general health outcome. Among male caregivers, the likelihood of having obesity was significantly higher among urban Black males (OR 1.14, 95% CI 1.09, 1.19). Similar findings were observed for all rural population subgroups, including White people (OR 1.09, 95% CI 1.04, 1.14), Black people (OR 1.33, 95% CI 1.14, 1.54), Hispanic people (OR 1.20, 95% CI 1.03, 1.40), and people of other races and ethnicities (OR 1.59, 95% CI 1.32, 1.93), compared to White urban people. Similarly, many other population subgroups were significantly more likely to have obesity than urban White male caregivers, most notably urban female Black caregivers (OR 1.77, 95% CI 1.71, 1.83) and rural Black female caregivers (OR 3.49, 95% CI 3.10, 3.93). Compared to urban White male caregivers, Black (OR 0.58, 95% CI 0.55, 0.61), Hispanic (OR 0.87, 95% CI 0.81, 0.92), and Other (OR 0.70, 95% CI 0.67, 0.73) male caregivers in urban areas, along with rural White (OR 0.83, 95% CI 0.78, 0.88), Black (OR 0.41, 95% CI 0.33, 0.52), and Other (OR 0.31, 95% CI 0.22, 0.43) male caregivers in rural areas had significantly lower likelihood of having depressive symptoms. However, most female caregiver subgroups had a significantly higher likelihood of having depressive symptoms than urban White male caregivers, except Black female caregivers from urban (OR 0.91, 95% CI 0.87, 0.94) and rural areas (OR 0.85, 95% CI 0.75, 0.97).

Differences in attributes of caregiving by the examined factors are shown in Figure 3. Among urban male caregivers, Black caregivers were significantly more likely to have provided care for at least 6 months (OR 1.08, 95% CI 1.03, 1.13), at least 20 h of care per week (OR 1.44, 95% CI 1.37, 1,51), and personal (ADL) care (OR 1.21, 95% CI 1.16, 1.27), but significantly less likely to provide household (IADL) care (OR 0.92, 95% CI 0.88, 0.97) than White caregivers. Rural White male caregivers were more likely to have provided care for at least 6 months (OR 1.07, 95% CI 1.02, 1.13) but were less likely to provide ADL care (OR 0.93, 95% CI 0.89, 0.97) or ADL care (OR 0.85, 95% CI 0.81, 0.90) than urban White male caregivers. Among urban female caregivers, nearly all racial/ethnic subgroups were significantly more likely to have provided care for at least 6 months (except for those of the Other race/ethnicity category), provide at least 20 h per week of care, care for a patient with Alzheimer's disease, and provide ADL and IADL care than urban White male caregivers. Similarly, among rural female caregivers, all racial/ethnic subgroups were more likely to provide at least 20 h of care per week and provide ADL care than urban White female caregivers.

Discussion

This study identified substantial differences in the scope and intensity of caregiving, health, and health-related quality of life across demographic groups of informal caregivers. The identified associations were not uniform across the caregiving and health outcomes or race/ethnicity, sex, and rural–urban status. For example, the associations between race/ethnicity and caregiving hours varied notably by sex and rural–urban status, indicating the interdependence of demographic factors in predicting caregiver outcomes.

TABLE 1 Frequencies of major exposure and outcome variables by rural–urban status.

		Urban	Rural	*p*-value
	N (%)	64,304 (85.9)	10,518 (14.1)	
		Weighted %	Weighted %	
Age group	18–39	18.7	15.1	<0.001
	40–64	49.9	46.8	
	65+	31.4	38.1	
Sex	Female	60.7	60.6	0.136
	Male	39.3	39.4	
Race/ethnicity	White	72.8	84.1	<0.001
	Black	10.4	7.7	
	Asian	2.3	0.2	
	Hispanic	9.5	3.2	
	Other	5.0	4.8	
Education	Bachelor's or higher	43.5	30.0	<0.001
	Less than bachelor's	56.5	70.0	
Employment	Currently employed	51.6	46.1	<0.001
	Not employed	18.5	19.6	
	Retired	28.1	33.1	
	Student	1.9	1.3	
Annual income ($)	<50 k	34.5	44.2	<0.001
	50–99.9 k	26.3	25.2	
	100 k+	22.6	12.3	
Currently married	Yes	58.5	63.3	<0.001
	No	41.5	36.7	
General health	Poor or fair	18.5	23.2	<0.001
	Good, very good, or excellent	81.5	76.8	
Has obesity	Yes	37.4	41.5	< 0.001
	No	62.6	58.5	
Has depressive disorders	Yes	25.6	25.4	0.055
	No	74.4	74.6	
Average number of comorbidities	Mean (SD)	0.60 (0.93)	0.69 (1.00)	<0.001
Length of providing care	6 months or more	72.1	72.7	<0.001
	Less than 6 months	27.9	27.3	
Hours of caregiving per week	20 h or more	31.0	32.0	<0.001
	Less than 20 h	69.0	68.0	
Care recipient has Alzheimer's disease	Yes	14.9	13.7	<0.001
	No	85.1	86.3	
Provides personal (ADL) care	Yes	49.0	48.6	<0.001
	No	51.0	51.4	
Provides household (IADL) care	Yes	79.5	78.3	<0.001
	No	20.5	21.7	

Another notable finding highlights the geographic distribution of these caregiving attributes and health outcomes among caregivers across the US. One example is in the prevalence of depressive symptoms identified among informal caregivers: caregivers in Kentucky are more than twice as likely to have depressive symptoms than caregivers living in Hawaii. Likewise, caregivers in many

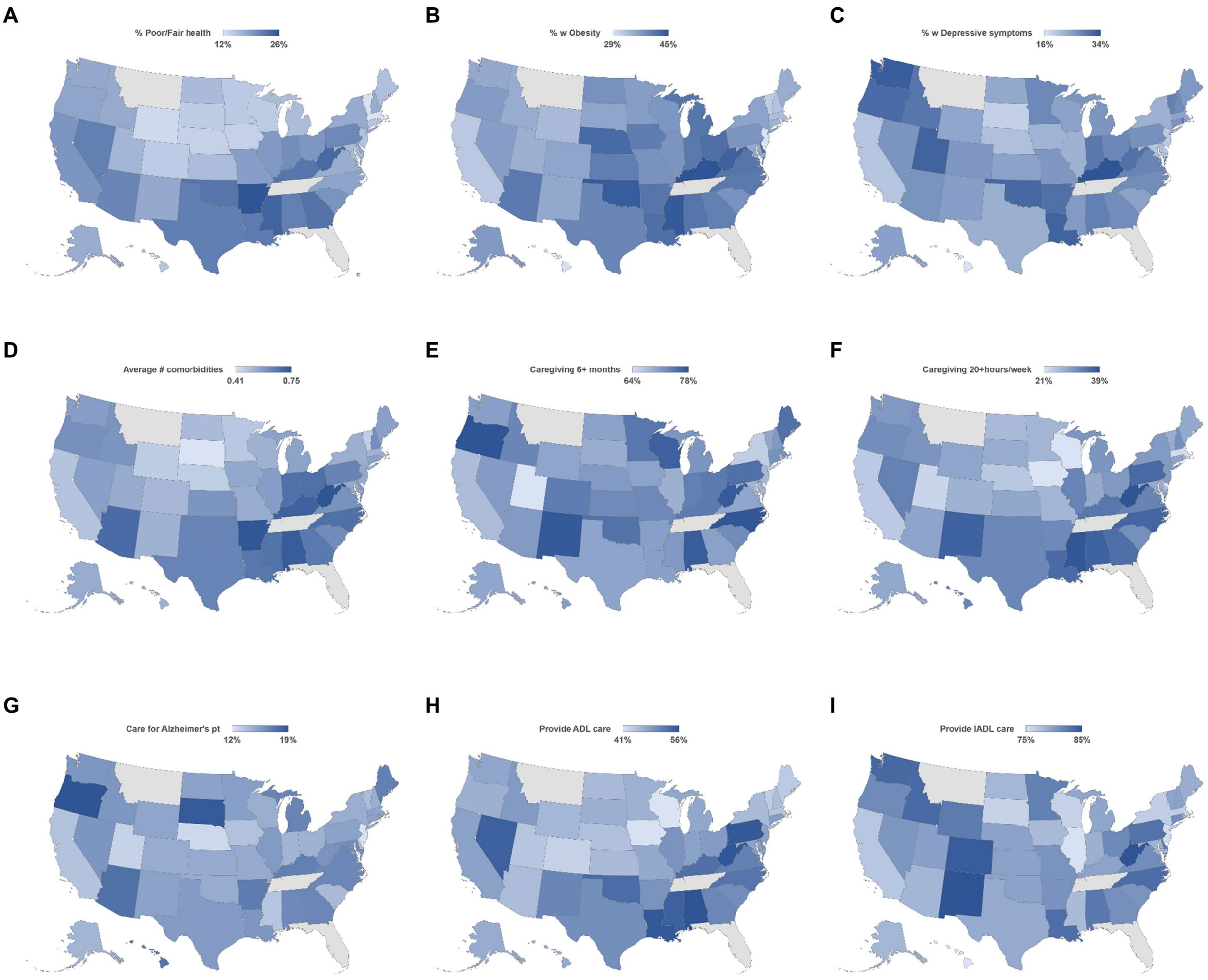

FIGURE 1
Geographic distribution of health issues **(A–D)** and caregiving attributes **(E–I)** by state. Percent with poor or fair health **(A)**, having obesity **(B)**, with depressive symptoms **(C)**, and average number of comorbidities **(D)**; Percent of caregivers providing caregiving for 6+ months **(E)**, providing care for 20+ hours per week **(F)**, providing care to Alzheimer's patient **(G)** providing ADL care **(H)**, and providing IADL care **(I)**.

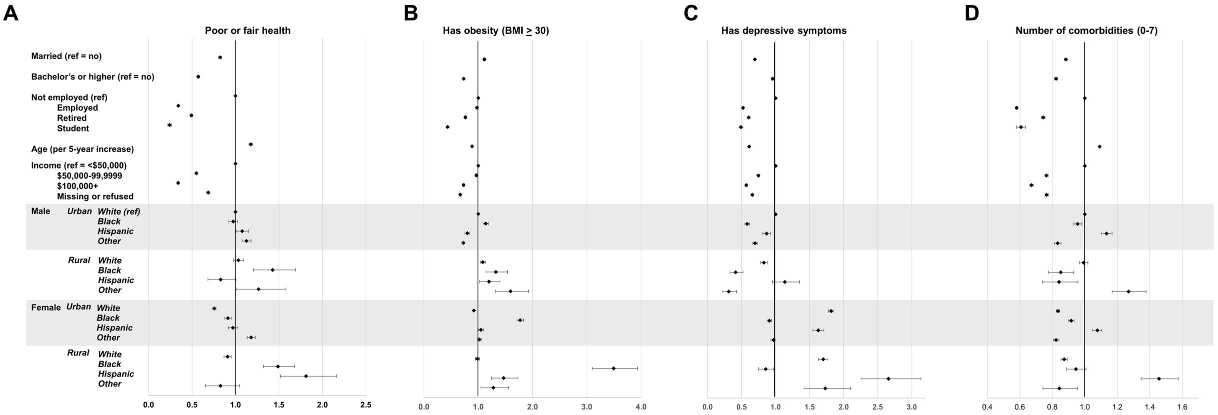

FIGURE 2
Weighted, adjusted odds ratios of health outcomes by race/ethnicity*sex*rural–urban status groupings and covariates. Percent with poor or fair health **(A)**, having obesity **(B)**, with depressive symptoms **(C)**, and average number of comorbidities (prevalence ratio) **(D)**.

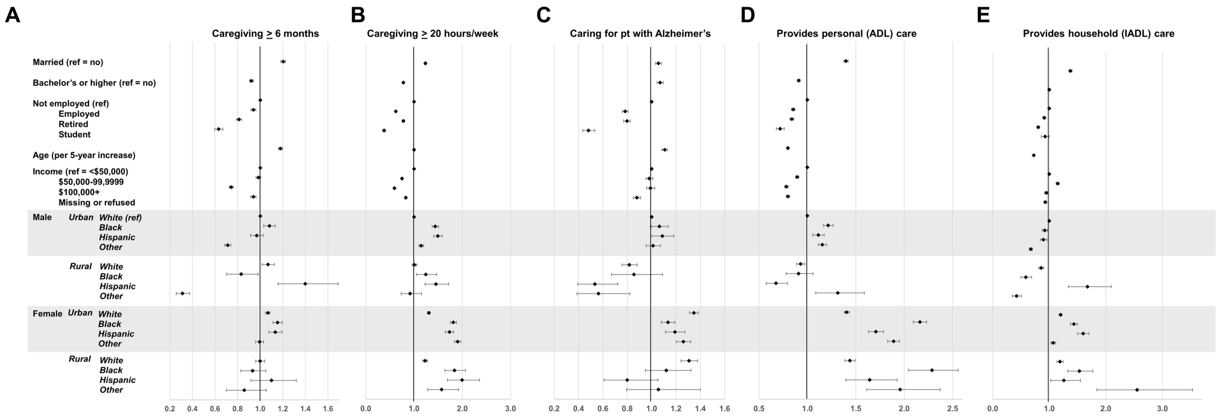

FIGURE 3
Weighted, adjusted odds ratios of caregiver attributes by race/ethnicity*sex*rural–urban status groupings and covariates. Percent of caregivers providing caregiving for 6+ months **(A)**, providing care for 20+ hours per week **(B)**, providing care to Alzheimer's patient **(C)** providing ADL care **(D)**, and providing IADL care **(E)**.

Southern states had higher intensity caregiving with respect to hours per week spent caregiving and provision of ADL care compared to caregivers in other regions. Collectively, the study findings emphasize that the population of 40+ million caregivers in the US is far from a monolith and that the experiences and consequences of informal caregiving vary widely by most of these measures. The potential mechanisms for this deserve further study. That said, variability in state-level policies may contribute to differences in caregiving experience and subsequent health impacts on informal caregivers (43). Cultural attitudes, family norms and expectations, and availability of support and formal care services may also explain some of the observed differences (44). In addition, lack of knowledge related to resources, as well as financial difficulties and poorer overall health both for the caregiver and care recipient may also play a role (45).

One important study finding was that, irrespective of rural–urban status, Black caregivers, particularly women, provide higher intensity caregiving than their White counterparts with respect to caregiving hours and providing ADL and IADL care, which is consistent with previous research (21, 46). It should be noted that the magnitude of these associations varied somewhat between urban and rural caregivers. A seminal paper by Dilworth-Anderson et al. (47) suggests that cultural differences, particularly regarding social roles, may explain the stark and consistent differences in caregiving roles and intensity by race and ethnicity, which persist across geographies. Utilization of paid or formal caregivers is more common among white person than other races (48), possibly due to financial and/or cultural factors (49). Interestingly, there was no clear and consistent pattern of higher prevalences of adverse health outcomes for those populations, supporting the hypothesis of higher resilience in those racial and ethnic groups (30). Social, religious, and cultural factors may help explain the relative resilience these caregivers have, such as familism and filial piety, which may offset the overall psychological toll of caregiving and allow for better coping (50, 51).

Also, urban female caregivers across all racial groups had a significantly higher likelihood of providing care to someone with Alzheimer's disease. These findings were unexpected, given that the rate of Alzheimer's disease and related dementias is 64% higher among Black older adults compared to White older adults (52). There are several possible explanations for these observations. One potential explanation is self-selection. Rural caregivers, regardless of race and ethnicity, have greater logistical (financial and healthcare-related) barriers than their urban counterparts (33) and face substantial barriers to support services (53, 54). Therefore, the rural setting may be less conducive for successful caregiving to Alzheimer's patients, and caregivers may make the decision to move toward more urban or suburban regions to gain access to vital resources and services (45). Furthermore, from 1999 to 2018, mortality due to Alzheimer's disease and related dementias increased nationwide, but this increase was more pronounced in rural areas than in urban areas (55). Other research suggests that underdiagnosis of Alzheimer's disease in rural areas may also contribute to these disparities (56). More research is needed to assess what specific elements of rural vs. urban settings contribute to these disparities.

Another notable set of findings is the more nuanced patterns indicating differences in caregiving attributes simultaneously by race/ethnicity, sex, and rural–urban status. Such findings are evident in long-term (at least 6 months) caregiving. For this attribute, there was strong variation among the 16 race/ethnicity*sex*rural–urban subgroups. Male caregivers of other races/ethnicities in urban and rural settings were significantly less likely than White male urban caregivers to provide care for at least 6 months. However, urban Black male and female caregivers, rural Hispanic male caregivers, and urban Hispanic female caregivers were significantly more likely to have provided at least 6 months of care. Previous research supports these findings (57), underscoring the possibility that cultural factors (58), as well as financial constraints (59, 60) may account for such differences, by race/ethnicity, sex, and geography. Concurrently, there were no associations between the rural female caregiver subgroups for length of caregiving. Similar variability among caregiver subgroups, but slightly different patterns, were observed for personal and household care. Although the reasons for these patterns are unclear, these findings have particular significance in creating efforts to reduce caregiver burden and promote health equity. These findings suggest that any such efforts need to be uniquely tailored to the population subgroups most at risk and address their distinctive set of caregiving patterns that may promote caregiver stress and other negative impacts of caregiving.

There are several important limitations to consider when interpreting the study results. First, since the study used cross-sectional data, it is impossible to assess temporality or causation. Second, one of the three primary exposures was biological sex, not gender. Although the 2021 and 2022 BRFSS data sets do contain a variable on gender, it was contained in an optional module and, therefore, was only asked of approximately 61% of all BRFSS respondents. If gender is incorporated in the complete survey asked in all states in future BRFSS data sets, that variable could be used instead of biological sex in subsequent studies. A third limitation is the measure of rural–urban status. The dichotomous variable may mask more nuanced attributes in the rural–urban continuum (61) and may impact the observed associations between rural and urban caregivers (62). Furthermore, there is no universal measure of rural–urban status in the population health and gerontological literature (63). There is evidence that the current array of rural–urban status measures available will provide differing estimates of associations depending on which measure is used (64) and which of the many attributes of rural–urban status are emphasized in each measure (65, 66). Also, due to the limited questions on caregiving in the BRFSS module, subjective caregiver burden can not be assessed, which may complement the more objective measures used to provide a more thorough picture of the caregiving experience with respect to resources, cultural attitudes, and social support. Lastly, the present study was limited to the variables available in the BRFSS data and is based on self-report. Although several attributes of caregiving experiences, health, and health-related quality of life were assessed, it was not possible to examine other aspects of caregiving, such as caregiver burden, burnout, and socio-emotional strain, based on the use of these data.

The study has several notable strengths, as well. First, it is one of the first studies to incorporate intersections of multiple demographic factors, along with rural–urban status, a key place-based determinant of health, into evaluating their associations with aspects of caregiving and caregiver health using a large, nationally representative sample of informal caregivers. In addition, since the Caregiver Module was administered in 47 US states, the generalizability of the findings to US caregivers is robust. The states that are not represented—Florida, Montana, and Tennessee—are not centralized in one region. Future studies could examine data from previous BRFSS samples to determine if caregiving in those states varied substantially from the other 47 states. Although the analysis only addressed nine outcomes, four health and health-related quality of life measures, and five attributes of caregiving, it included many outcomes, many of which are policy actionable.

Study findings show substantial variability with respect to the caregiver's race/ethnicity and sex, as well as where the caregiver lives with respect to many aspects of the caregiving experience and health conditions. Such results emphasize the need to address caregiver needs through effective policies, programs, and interventions on a highly granular level to reduce disparities and promote health equity. What may be effective in one population may not be effective in another. Further research can identify the specific, policy-actionable mechanisms that drive the observed differences in caregiving attributes and caregiver health and quality of life. Identifying and addressing these factors may have additional benefits not only to informal caregivers but also to the larger population who are subject to the same factors (e.g., race/ethnicity, sex, SES, place-based characteristics) that also promote other types of health disparities. As the demand for informal caregivers will continue to grow as the population continues to age, the need to develop and implement effective strategies to mitigate caregiver burden and address the nuanced needs of a diverse population of caregivers, with the ultimate goal of protecting and supporting this critical component of the healthcare system.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

Ethics statement

The studies involving humans were approved by University of Rhode Island Institutional Review Board. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

SC: Writing – original draft, Writing – review & editing. CN: Data curation, Project administration, Software, Writing – review & editing. MG: Formal analysis, Supervision, Visualization, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

Publisher's note

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The evaluation and enhancement strategies of core competencies for older adult caregivers in integrated medical and older adult care institutions

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The study aimed to understand the main skills of older adult caregivers and find ways to improve these skills. We selected participants using a method called random cluster sampling, where caregivers from 17 different medical and nursing care facilities across seven districts in Hangzhou were chosen. We collected 492 valid questionnaires and conducted interviews with 150 people. To analyze the data, we used T-tests and Analysis of Variance (ANOVA) to identify what factors affect caregivers' skills. We also performed multiple regression analysis to explore these factors in more depth. The analysis showed that age ($p = 0.041$), annual income ($p < 0.001$), and having a training certificate ($p < 0.001$) significantly influence the skills of older adult caregivers. Specifically, caregivers' age and whether they had a training certificate were linked to how competent they were, with income being a very strong factor. The study highlighted a gap between the caregivers' current skills and the skills needed for high-quality care. This gap shows the need for training programs that are specifically tailored to the caregivers' diverse needs and cultural backgrounds. Medical and eldercare facilities should adjust their work and educational programs accordingly. It's also important to look at how caregivers are paid to make sure their salary reflects their skills and the quality of care they provide. Finally, it's crucial to integrate a comprehensive training program that leads to certification within eldercare organizations.

KEYWORDS

nursing care, caregivers, eldercare, aging, IADL

1 Introduction

By 2022, there will be 771 million people aged 65 and over, accounting for nearly 10% of the global population. This demographic group is expected to increase to 16% by 2050, when there will be about 1.5 billion people aged 65 and over globally (1, 2). According to data from the Seventh National Population Census released by the National Bureau of Statistics, as of November 1, 2020, the older adult population aged 60 and above, and 65 and above in China is substantial, constituting 18.7 and 13.5% of the population, respectively (3). With the burgeoning older adult demographic, there is a concurrent rise in the prevalence of chronic conditions detrimental to their quality of life, such as hypertension, diabetes, and coronary heart disease. This uptick is in stark contrast to the lagging traditional models of eldercare, revealing a profound discrepancy between the escalating needs of the aging populace and the existing caregiving frameworks.

The rapid development of integrated medical and eldercare institutions is a response to this demographic shift. These institutions, as their designation suggests, are equipped with both medical and caregiving capabilities, offering a range of services including psychological comfort, daily life care, palliative care, and medical assistance to the older adult (4). They mitigate to some extent the societal pressures brought about by population aging. Older adult caregivers, individuals who provide services such as daily living and hygiene care for the older adult, serve as one of the primary workforces in these integrated facilities. Their core competencies are crucial to the effective functioning of integrated medical and eldercare institutions in China and significantly influence the quality of eldercare services (5). There is a general lack of older adult care staff in various institutions in China. Older adult care staff are generally older adult and have lower levels of education, and their overall core competencies are relatively low. The most lacking professional medical and mental care skills are exactly what the older adult need the most (6). Therefore, the systemic evaluation and enhancement of caregiver competencies transcend operational considerations and constitute a societal mandate. Nonetheless, there is an evident gap in comprehensive research that specifically addresses the assessment and improvement of these competencies within the Chinese context.

Scholarly investigations into family caregiving dynamics reveal a taxonomy of care necessity, ranging from no need—where the older adult individual is fully independent—to maximum need, necessitating full-time caregiver involvement (7). Research elucidates that the efficacy of respite care—a service that offers temporary relief to primary caregivers—is substantially bolstered by a constellation of factors. These encompass the caregiver's senior age (65 years or older), marital status (currently married), chronic health conditions, current and deteriorating health status, along with a long-term commitment to caregiving, spanning a decade or more. Furthermore, the health condition of the older adult care recipient and their proficiency in Instrumental Activities of Daily Living (IADL) scores are also pivotal to the success of respite interventions (8). Strategies aimed at fortifying caregivers' confidence in their care recipients' ability to function independently may decelerate the trajectory of functional decline in elders receiving home care (9). While extant literature has shed light on the care demands of the older adult and has pinpointed factors that amplify care effectiveness, there remains a conspicuous gap in comprehensive explorations focused on augmenting the foundational competencies of older adult caregivers—a crucial element for advancing the quality of eldercare.

The cultivation of a high-quality, professional workforce of eldercare caregivers has emerged as a focal point of scholarly interest in recent years. Hangzhou, the capital of Zhejiang Province, plays an important role in China's economic and social development, and has always been at the forefront of integrating modern healthcare and older adult care systems to meet the needs of an aging population. By focusing on Hangzhou, this study aims to utilize the insights of this city to showcase the challenges and progress of older adult care, provide a template, and provide information for broader practices and policies across China. This study will take Hangzhou as a case in point and commence by examining the "core competencies of older adult caregivers," assessing the current working conditions of caregivers within integrated medical and eldercare institutions in Hangzhou. It aims to summarize the challenges encountered in their roles, analyze the underlying causes, and investigate pertinent influencing factors. Based on the findings, the study will propose viable pathways for enhancing the core competencies of these vital care providers.

2 Methods

2.1 Research subject

Using a random cluster sampling method, a survey was conducted from July to August 2021, involving a total of 17 medical and older adult care institutions in seven districts of Hangzhou City, including Gongshu District, Binjiang District, Xiaoshan District, Shangcheng District, Qiantang New District, Fuyang District, and Xihu District. The survey targeted the caregivers working in these institutions. This study distributed a total of 500 questionnaires, excluded 8 invalid ones, and collected 492 valid questionnaires, resulting in an effectiveness rate of 98.4%. Using random sampling, a subset of older adult caregivers was selected for semi-structured interviews in addition to the questionnaire survey of older adult caregivers. A total of 150 interviews were conducted. A total of 2 university professors and 6 college students conducted on-site surveys, conducting one-on-one interviews with older adult care workers, collecting questionnaires on site, and reviewing the validity of the questionnaires on the same day. Two college students simultaneously used epidata 3.1 software to perform dual track data entry and proofreading, ensuring the authenticity and reliability of the data.

2.2 Research instruments

The survey questionnaire was adapted based on the "Competency Assessment Index System for Nursing Staff in Medical and Older Adult Care Institutions" developed by scholars such as Che et al. (10). Ultimately resulting in the "Core Competency Survey Questionnaire for Nursing Staff in Medical and Older Adult Care Institutions in Hangzhou." It comprises five sections, including general demographic information, nursing skills, personal qualities, caregiving knowledge, and occupational evaluation.

The general demographic information section includes 10 items, such as the respondent's hometown, marital status, education level, certification for the position, annual income, duration of training, and years of experience as a caregiver, etc. The caregiving knowledge dimension comprises six items, including knowledge related to the prevention of chronic diseases, safe medication guidance, observation and care of common older adult ailments, knowledge about infectious disease prevention, older adult care-related laws and regulations, and end-of-life care-related knowledge. The nursing skills dimension encompasses 13 items, including skills related to older adult hygiene and sanitation care, older adult nutrition and dietary skills, older adult sleep care, older adult excretion care, pain relief and care for the older adult, hot and cold compress care, nursing skills (use of assistive devices, etc.), basic first aid knowledge and skills (hemostasis, etc.), disinfection and isolation skills, end-of-life care skills, knowledge and skills related to writing nursing records, basic knowledge of traditional Chinese medicine consumption, and methods for preparing Chinese herbal decoctions, as well as the use of healthcare and older adult care apps, totaling 13 items. The personal qualities dimension covers eight items, including an understanding of the psychological characteristics of the older adult, mastery of communication skills with the older adult, respect for and protection of the interests of the older adult, possession of good professional ethics and personal qualities, having good interpersonal relationships and teamwork spirit, having a sound sense of right and wrong, life values, and worldviews, having a rigorous work style, self-discipline, and strong execution capability, and possessing a sound personality. The occupational evaluation section includes three items, which assess aspects such as compensation and benefits, workload, and overall job satisfaction.

Each dimension has three options: complete mastery (2 points), partial mastery (1 point), no mastery (0 points). The care knowledge dimension has a full score of 12 points; the nursing skill dimension has a full score of 26 points; the personal quality dimension has a full score of 16 points. The sum of scores from these three dimensions is the core competency score. A higher score indicates stronger core competency in nursing staff. The Cronbach's alpha coefficient for the entire questionnaire is 0.916, while the Cronbach's alpha coefficients for the various dimensions range from 0.788 to 0.867. The overall content validity index (S-CVI) of the questionnaire is 0.902, and the item-level content validity indices (I-CVI) range from 0.779 to 0.871.

The interview outline consists of four questions: (1) How long have you been working as a caregiver? (2) Did you receive any relevant training before officially taking up the position? What was included in the training? (3) How many hours do you work per day? Do you have weekends and holidays off? (4) What are the biggest difficulties and confusions you encounter at work?

2.3 Research methodology

The collected data was coded and analyzed using SPSS25.0 software. Descriptive analysis was performed on the demographic data of the survey participants. The scores of the older adult caregivers' various dimensions and core competencies were subjected to descriptive statistics. *T*-tests and one-way ANOVA were used to explore the factors affecting core competencies. Multiple regression analysis was employed to further analyze the factors influencing the core competencies of older adult caregivers.

3 Results

3.1 General demographic data of older adult caregivers

Among the participants, there were 98 males (19.92%) and 394 females (80.08%). The majority of the older adult caregivers fell within the age range of 50–60 years, comprising 308 individuals (62.60%). A significant proportion of them came from rural areas, accounting for 448 individuals (91.06%). Marital status indicated that 479 individuals were married (97.36%), while 13 individuals were not married (2.64%). The overall educational attainment of eldercare caregivers is currently at a low level, 286 individuals had attained a primary school education or below (58.13%), and 202 individuals had completed middle school or higher (41.06%). The majority of participants reported an annual income within the 3–5 thousand range, constituting 304 individuals (61.79%). A large portion of the respondents had undergone training, with 454 individuals having received training (92.28%). Among those, 306 individuals had obtained training qualification certificates (62.20%). For the duration of training, 192 individuals received training for less than 7 days (39.02%). Regarding work experience, the highest proportion had more than 36 months of work experience, totaling 266 individuals (54.07%) (Table 1).

3.2 Scores on older adult caregiver dimensions and core competencies

The analysis results indicated that the core competencies of older adult caregiver in the surveyed medical and older adult care institutions have an average score of 41.21 ± 8.88, with a maximum score of 54 and a minimum score of 13. Within the three surveyed dimensions: caregiving knowledge, nursing skills, and personal qualities, the dimension with the highest score is personal qualities, with an average score of 15.04 ± 1.63. In this dimension, the maximum score is 16, and the minimum score is 7. For the other two dimensions, caregiving knowledge has an average score of 7.93 ± 3.03, while nursing skills have an average score of 18.24 ± 5.28 (Table 2).

3.3 Univariate analysis of older adult caregivers core competencies under general demographic data

Independent sample t-tests and one-way analysis of variance (ANOVA) were used to conduct differential analysis on variables including gender, age, educational level, household registration, annual income, marital status, possession of a training certificate, participation in training, training duration, and years of work. According to the results, age, annual income, possession of a training certificate, participation in training, and training duration all exhibited significant differences ($p < 0.05$) (Table 3).

3.4 There is a positive correlation between individual quality and job satisfaction of older adult caregivers

One-way analysis of variance (ANOVA) was employed to conduct differential analysis on salary and compensation assessment, workload evaluation, and job satisfaction assessment. The statistical results revealed that there were no significant differences in salary and compensation assessment and workload evaluation ($p > 0.05$). However, there was a significant difference in job satisfaction assessment ($p < 0.05$) (Table 4).

3.5 Multivariate regression analysis of factors influencing older adult caregivers core competencies

Multiple regression analysis was conducted using the total score of older adult caregiver core competencies as the dependent variable, and the factors that showed statistical significance in the independent sample t-tests and one-way analysis of variance as independent variables: age, annual income, possession of a training certificate,

TABLE 1 General demographic data of older adult caregivers in Hangzhou integrated healthcare and older adult care facilities (*n* = 492).

Basic information	Group	Number of cases	Proportion (%)
Gender	Male	98	19.92
	Female	394	80.08
Age	Under 50 years old	80	16.26
	Aged 50 to 60 years	308	62.60
	Above 60 years old	104	21.14
Household registration	Rural area	448	91.06
	Urban area	44	8.94
Marital status	In marriage	479	97.36
	Non-in marriage	13	2.64
Educational level	Elementary school and below	286	58.13
	Middle school (junior high, senior High, and vocational school)	202	41.06
	College degree, bachelor's degree, and higher	4	0.81
Annual income	Less than 30,000	19	3.86
	30,000 to 50,000	304	61.79
	50,000 and above	169	34.35
Training qualification certificate	Yes	306	62.20
	No	186	37.80.
Receiving training	Yes	454	92.28
	No	38	7.72
Number of days of training	Less than 7 days	192	39.02
	8 to 15 days	120	24.39
	More than 16 days	180	36.59
Years of employment	Less than 36 months.	226	45.93
	More than 36 months	266	54.07

participation in training, and training duration, as outlined in Supplementary Table S1. The statistical results indicate that age, annual income, and possession of a training certificate are the primary influencing factors on older adult caregiver core competencies (Table 5).

3.6 Interview results of older adult caregiver

In response to the question "What is your biggest challenge in your current job?" the most common answers include: low educational level and inability to write; limited rest time; insufficient sleep; lack of understanding from older adult individuals and their families; lack of support from management; occasionally neglecting personal health due to caring for older adult individuals with limited mobility; and difficulties in dealing with older adult individuals with irritable temperaments.

4 Discussion

The analysis reveals that caregivers in Hangzhou's eldercare sector possess an average care knowledge proficiency score of 7.93 out of a potential 12. This suboptimal performance is influenced significantly by the caregivers' educational backgrounds, primarily those from rural areas with limited formal education. Such a deficit is particularly problematic in managing chronic diseases, a critical area in geriatric care. These findings suggest a pressing need for educational programs tailored to bridge knowledge gaps, particularly in chronic disease management, to enhance caregiver competencies. Another layer of complexity is added by the caregivers' origins—predominantly from provinces like Anhui and Henan—where distinct linguistic and cultural norms may interfere with the effectiveness of current training modalities. The presence of such barriers indicates that training programs must not only be informative but also culturally and linguistically adapted to the caregivers' backgrounds to improve learning outcomes and care quality. The variance in nursing skills, with scores ranging from 5 to 26 out of a possible 26, underscores a significant inconsistency in the mastery of essential nursing techniques. While routine daily care tasks are generally well-managed, there is a notable deficiency in more complex medical procedures, such as the application of hot and cold compresses or the execution of emergency first aid. This gap highlights the necessity for more rigorous and specialized training that aligns with the medical needs of the older adult, ensuring better preparedness among caregivers to handle diverse healthcare scenarios (11). The perception of older adult caregiving within traditional Chinese culture—as a low-skill and low-status occupation—further complicates talent recruitment and retention in this sector (12). This cultural view diminishes the

TABLE 2 Scores on various dimensions and core competencies of older adult caregivers.

Dimensions	Number of items	Full score	Mean ± standard deviation	Maximum value	Minimum value
Caregiving knowledge	6	12	7.93 ± 3.03	12	0
Caregiving skills	13	26	18.24 ± 5.28	26	5
Individual attributes	8	16	15.04 ± 1.63	16	7
Core competencies	27	54	41.21 ± 8.88	54	13

profession's appeal to potentially skilled workers and perpetuates a cycle of underqualification (13). Addressing these occupational stereotypes and promoting caregiving as a respected and essential profession are vital steps toward attracting and retaining higher-quality talent, which is crucial for improving the overall standard of older adult care.

Our study highlights significant differences in core competencies among eldercare caregivers across various age groups, revealing that those above 60 years of age exhibit the highest competencies. This observation aligns with prior research indicating that older caregivers often report higher self-efficacy ($\beta = 0.215$, 95%CI 0.139–1.027) (14). This raises important questions about the factors contributing to this age-related disparity in skills and knowledge. Caregivers within the 50–60 age range often face a dual burden of responsibilities. They not only provide care in integrated medical-eldercare settings but also tend to familial obligations, including the care of their own older adult parents and grandchildren. This multiplicity of roles may dilute their ability to focus entirely on their professional responsibilities, potentially leading to lower competency scores. This phenomenon suggests that life-stage pressures can significantly impact professional capacity. Conversely, caregivers over the age of 60, often retirees, are likely to have fewer family obligations and a closer affinity with the elder demographic. Their life experiences and proximity in age may foster a deeper empathy and commitment to their caregiving roles, enhancing their effectiveness and competencies in eldercare. This demographic's unique position presents an opportunity for optimizing care practices within professional settings. Given the impact of age on caregiver competencies, it is crucial for integrated medical-eldercare institutions to tailor work assignments and training modules to suit the diverse needs and capabilities of caregivers at different life stages. By doing so, institutions can enhance the overall quality of care and ensure that caregivers are supported in balancing personal commitments with professional development (15). Future training programs and organizational policies must consider these demographic differences to optimize caregiver efficacy and sustain high standards of care across all age groups.

Our study investigates the significant intersection between income remuneration and core competencies among eldercare caregivers. Empirical data demonstrate a direct correlation between caregivers' annual income and their skills essential for high-quality geriatric care. Caregivers earning higher incomes tend to display a broader array of core competencies, which aligns with previous research indicating that income rewards are linked to positive attitudes and professional growth in caregiving roles ($\beta = 0.214$, 95%CI: 0.117–1.461) (14).The findings suggest that income satisfaction plays a crucial role in fostering caregivers' dedication and enthusiasm for their roles. Higher earnings are correlated with a greater willingness among caregivers to engage in ongoing professional development and skill enhancement. This inclination toward lifelong learning is critical in the dynamic field of eldercare, where evolving standards require continuous educational engagement. The relationship between income satisfaction and the pursuit of professional excellence underscores the need for equitable and motivating compensation strategies. These strategies should not only ensure a decent living wage reflecting the complexity of caregiving tasks but also aim to improve the overall standard of care provided to the older adult. It is imperative for eldercare institutions and policymakers to invest in their workforce through fair compensation practices. In light of these insights, it is critical for eldercare service providers to reassess their current pay structures. Implementing salary scales that reflect the caregiver's level of expertise and the quality of care they provide could initiate a virtuous cycle (16)· Enhanced caregiver competencies, driven by better income incentives, could lead to higher-quality eldercare services, justifying further income and attracting a more skilled and motivated workforce to the sector.

Our research demonstrates the profound impact of structured training programs and subsequent certification on the competencies of eldercare caregivers. Those who have undergone formal training and obtained certification exhibit markedly higher competency levels compared to their untrained peers. This correlation between certification and enhanced professional acumen underscores the value of formal education processes in the eldercare sector. The diversity of both caregivers and the older adult population in integrated medical-eldercare institutions poses unique challenges. Caregivers come from various backgrounds, ranging from domestic roles to professional careers, which can lead to potential misunderstandings and interpersonal conflicts (17, 18). Targeted training that encompasses both technical skills and soft skills such as effective communication and conflict resolution is crucial to address these challenges. Caregivers with prolonged experience in the field tend to develop and refine their skills continuously, enhancing their ability to manage emergencies and complex caregiving situations. This experiential enhancement of practical skills is essential for improving the overall quality of care. The advantages of certification extend beyond technical caregiving competencies. Certified caregivers are better equipped to navigate social interactions and foster harmonious relationships within the caregiving environment, contributing to a more peaceful and supportive setting for the older adult. The synthesis of vocational skills and interpersonal adeptness is crucial for the superior performance of certified caregivers in eldercare. Given the clear benefits of structured training and certification, eldercare institutions should consider integrating robust training programs with a clear certification pathway into their operational models. Such strategic investments not only enhance caregiver competencies but also improve the overall quality of eldercare. Additionally, the potential integration of artificial intelligence in training programs could further enhance these outcomes by improving the efficiency and adaptability of caregiving practices (19, 20). Investing in caregiver education and

TABLE 3 Univariate analysis of core competencies of older adult caregivers under general demographic data.

Variables	Group	Core competencies (Mean ± SD)	t/F	P
Gender	Male	40.97 ± 8.96	−0.298	0.765
	Female	41.27 ± 8.88		
Age	Under 50 years old	40.35 ± 7.57	7.411	0.001
	Aged 50 to 60 years	40.43 ± 8.66		
	Above 60 years old	44.14 ± 9.78		
Household registration	Rural area	41.38 ± 9.04	1.673	0.100
	Urban area	39.51 ± 6.80		
Marital status	In marriage	41.21 ± 8.93	−0.049	0.961
	Non-in marriage	41.33 ± 7.02		
Educational level	Elementary school and below	40.65 ± 9.16	1.896	0.151
	Middle school (junior high, senior high, and vocational school)	42.08 ± 8.51		
	College degree, bachelor's degree, and higher	37.50 ± 3.70		
Annual income	Less than 30,000	47.95 ± 7.54	7.237	0.001
	30,000 to 50,000	41.44 ± 9.06		
	50,000 and above	40.03 ± 8.30		
Training qualification certificate	Yes	44.23 ± 8.56	11.251	<0.001
	No	36.25 ± 7.00		
Receiving training	Yes	41.56 ± 8.96	3.775	<0.001
	No	37.08 ± 6.84		
Number of days of training	Less than 7 days	40.08 ± 7.93	3.378	0.035
	8 to 15 days	42.73 ± 8.28		
	More than 16 days	41.41 ± 9.98		
Years of employment	Less than 36 months.	42.05 ± 9.61	3.790	0.052
	More than 36 months	40.49 ± 8.13		

TABLE 4 Univariate analysis of occupational appraisal and older adult caregivers individual quality dimensions.

Variables	Group	Individual quality dimensions (Mean ± SD)	t/F	P
Salary and compensation assessment	High	13.50 ± 0.92	0.921	0.399
	Moderate	13.21 ± 1.39		
	Low	13.06 ± 1.63		
Workload evaluation	Heavy	13.36 ± 1.10	1.455	0.234
	Moderate	13.11 ± 1.54		
	Light	13.25 ± 1.65		
Job satisfaction assessment	Satisfied	13.38 ± 1.18	7.415	0.001
	Neutral	12.96 ± 1.67		
	Dissatisfied	12.20 ± 2.15		

certification is not just an institutional requirement but a strategic approach to elevating the standards of eldercare. By embracing comprehensive training models and supporting continuous professional development, eldercare institutions can better meet the complex needs of the aging population and ensure high-quality care.

TABLE 5 Results of multivariate regression analysis on factors influencing older adult caregivers core competencies.

Independent variable	β	95%CI	t	P
Age	1.210	0.039 to 2.379	2.047	0.041
Annual income	2.632	−3.965 to −1.318	3.904	<0.001
Obtaining a training certificate	8.042	−9.493 to −6.522	10.658	<0.001
Receiving training	0.158	−2.924 to 2.551	0.113	0.910
Number of training days	0.463	−0.355 to 1.275	1.117	0.264

Our research explores the significant correlation between job satisfaction among eldercare caregivers and enhancements in their personal quality dimensions. Caregivers with higher job satisfaction demonstrate superior understanding of the older adult's psychological characteristics and adhere more closely to professional ethics. This positive relationship underscores the importance of job satisfaction in fostering personal growth and ethical professional conduct. Job satisfaction in eldercare is influenced by a variety of factors including remuneration, work assignments, interpersonal relations among staff, and the work environment. These factors collectively impact caregivers' motivation and their ability to provide high-quality care. It is well-established that job satisfaction is a critical buffer against job burnout, which can manifest as reduced enthusiasm, decreased interaction with the older adult, and a shift toward self-interest at the expense of care recipients' wellbeing (21). Understanding the link between job satisfaction and burnout provides a pathway for enhancing caregivers' personal qualities. Institutions play a pivotal role in this process by proactively addressing factors that contribute to job satisfaction. Measures that improve job satisfaction can lead to reduced burnout and enhanced personal and professional qualities among caregivers, ultimately improving the quality of care provided to the older adult. Recent advancements in technology, especially the integration of artificial intelligence in eldercare, offer significant potential to support caregivers. By reducing the workload and automating routine tasks, AI can help caregivers focus more on personalized care aspects, enhancing job satisfaction and retention (22). This technological support is not just a tool for efficiency but also a strategic asset in improving the caregiving environment and staff wellbeing. The evidence suggests that eldercare institutions must engage in active reforms aimed at bolstering caregiver satisfaction. Such reforms might include policy changes, improved communication channels, and a supportive work environment that fosters a sense of value and belonging among caregivers. By investing in caregiver wellbeing, institutions indirectly enhance the quality of care provided to the older adult, with substantial implications for the future of eldercare services.

5 Conclusion

The disparity between the skills that are necessary for effective eldercare and those currently exhibited by caregivers not only impacts the quality of care but also highlights the critical need for specialized and culturally attuned training programs. The effectiveness of caregiver training programs greatly depends on their relevance to the specific demands of the caregiving role and the cultural context in which care is provided. Moreover, given the significant influence of a caregiver's age on their core competencies, it is imperative for integrated medical-eldercare institutions to develop role-specific training that considers the life stage and career phase of each caregiver. Compensation is another critical factor influencing caregiver performance and retention. Eldercare providers need to reassess their existing pay structures to ensure they are aligned with the caregivers' skill levels and the quality of care they are capable of delivering. The strategic importance of well-defined training and certification paths in eldercare cannot be overstated. Institutions must adopt robust training programs that culminate in certification, thereby assuring a standard level of competency across all caregivers. In addition, the incorporation of technology and modern educational methodologies, such as the use of artificial intelligence in training programs, can further enhance these outcomes by improving the efficiency and adaptability of caregiving practices.

5.1 Limitations and implications

This study has the following limitations. Firstly, random cluster sampling may increase sampling error. Individuals within each cluster often exhibit high similarity, while there may be significant differences between clusters. As a result, this method may not represent the overall population as effectively as simple random sampling. Secondly, in this study, a cross-sectional survey was conducted to investigate the core competencies of older adult caregivers in integrated medical and older adult care institutions. The conclusions drawn from this approach are limited in their ability to infer causality. This study has the following implications. Firstly, customized training programs. Institutions should develop and implement training programs that are customized to the life stages and cultural backgrounds of caregivers. This approach not only enhances caregiver competencies but also improves job satisfaction and retention. Secondly, revision of compensation structures. Based on the findings, eldercare services should revise their compensation structures to better align with the skills and the quality of care provided by caregivers. This would motivate caregivers to pursue further professional development and improve the quality of care. Lastly, technological advancements in caregiving. Practical application of AI and other technologies can reduce the physical and cognitive load on caregivers, allowing them to focus more on the interpersonal aspects of care. Institutions should consider investing in such technologies to enhance the efficiency and effectiveness of caregiving.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Medical Ethics Committee of Zhejiang Chinese Medical University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

CR: Conceptualization, Data curation, Writing – original draft. Q-HW: Investigation, Writing – review & editing. H-YX: Writing – review & editing, Validation. MC: Conceptualization, Formal analysis, Writing – original draft. LZ: Formal analysis, Writing – review & editing. R-RX: Conceptualization, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2024.1407496/full#supplementary-material

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Problem-solving training to improve caregiver burden and depressive symptoms among dementia caregivers: personal and clinical factors of responders vs. non-responders

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Introduction: Metacognitive strategy training interventions, like Problem-Solving Training/Descubriendo Soluciones Juntos (PST/DSJ), have efficacy for improving caregiver burden and depressive symptoms. We previously demonstrated that PST/DSJ improved caregiver burden and depressive symptoms among caregivers of adults with Alzheimer's Disease and related dementias (ADRD), regardless of the number of sessions or boosters received. However, these results did not examine factors characterizing those who responded (improvement in caregiver burden or depressive symptoms) or did not respond to the intervention.

Objective: To identify key personal and clinical factors associated with response to PST/DSJ. Personal factors included age, gender, race, Hispanic ethnicity, education, and employment status. Clinical factors included care recipient diagnosis and dementia severity, caregiver problem-solving skills at baseline, caregiving experiences (caregiver life social support, satisfaction and resentment with the caregiving role, anger toward the care recipient, and care recipient aggressive, depressive, and forgetful behaviors), and social disconnection, caregiver burden, and depressive symptoms.

Method: We conducted a 2 × 2 randomized controlled optimization trial to test remotely delivered PST/DSJ to ADRD caregivers (NCT04748666). Primary outcomes were caregiver burden, measured by the Zarit Burden Interview (ZBI), and depressive symptoms, measured by the Patient Health Questionnaire-8 (PHQ-8). Response to PST/DSJ was defined for each primary outcome as a clinically important change (defined as ≥1 point on ZBI and ≥3 on PHQ) from baseline to 6-month follow-up.

Results: Ninety-one caregivers were included in responder analysis, with 55 (60.4%) demonstrating a clinically meaningful improvement in caregiver burden and/or depressive symptoms. No personal factors were associated with being a Responder (vs. Non-Responder). Clinical factors associated with being a Responder were greater care recipient dementia severity (FAST score, $p < 0.01$), lower baseline caregiver life satisfaction ($p = 0.05$), higher baseline caregiver overload ($p = 0.05$), higher baseline caregiver burden ($p = 0.01$), and more baseline depressive symptoms ($p < 0.01$).

Conclusion: Most caregivers demonstrated a clinically meaningful improvement in caregiver burden and/or depressive symptoms after receiving PST/DSJ. Notably, those who responded had higher symptoms of distress, including caregiver burden and overload and depressive symptoms and lower life satisfaction, and had care recipients with more severe dementia, indicating that those benefiting from the intervention were those most in need of this support.

Clinical trial registration: ClinicalTrials.gov, identifier is NCT04748666.

KEYWORDS

caregiver, dementia, Alzheimer's disease and related dementia, problem-solving, Spanish language, dementia care, psychosocial intervention, metacognitive strategies

Introduction

Alzheimer's disease or related dementias (ADRD), including vascular dementia, Lewy Body dementia, and other dementias, represent a substantial public and personal health burden. Informal caregivers—typically spouses, adult children, or other family members – provide day-to-day support to individuals with ADRD, totaling approximately 18.4 billion hours of unpaid care per year (based on 2023 data) with an estimated value of $346.6 billion (1–4). Over 11 million individuals are currently informal caregivers of a person with ADRD (4). Being an informal caregiver to someone with ADRD can lead to depression, health problems, increased alcohol use, caregiver burden, and poorer quality of life (5–10). Caregiver distress also affects the health and well-being of care recipients (11), with caregiver burden emerging as a direct predictor of institutionalization and of care recipient behavioral and psychological symptoms (11). Moreover, caregiver burden is substantial in the underserved US Hispanic/Latino population, with few available linguistically and culturally appropriate resources (12) despite the higher likelihood of developing dementia for older Hispanic/Latino adults (4, 13).

To date, most interventions for dementia caregivers are primarily focused on providing them with education about ADRD and providing support to manage the needs and behaviors of their care-recipient (14–16). There is growing evidence that interventions focused on emotional support and stress management for caregivers may help in reducing or managing caregiver burden (17, 18). This highlights the importance of evidence-based interventions to support caregivers in managing their own needs and stressors, including ones focused on enhancing problem-solving skills, rather than just the needs of their care-recipients (16).

Even when interventions are shown to improve caregiver outcomes, knowing who is most likely to benefit from these interventions and who may need additional support or intervention adaptations to benefits remains unclear. Very few studies identify factors that contribute to response (i.e., meaningful improvement in outcomes) vs. non-response after caregiver support interventions. One study evaluating factors affecting change in depressive symptoms after a stroke caregiver intervention found that responders generally had a more active coping style and were less reliant on the counseling relationship (19), suggesting the importance of intervention components that promote self-efficacy and self-management. Further, non-responders more frequently endorsed a history of psychologic disorder and had higher levels of anger compared to responders (19), so those with more psychological distress (and arguably in most need of support) may be less likely to benefit. A qualitative study that surveyed non-responders and interventionists about a caregiver support intervention identified specific supports to meet the needs of non-responders: providing more support specific to caregiving, spending more time processing the caregiver's emotions, providing skills and psychoeducation materials based on the caregiver's needs, and working with caregivers to identify ways they can ask for help or strengthen interpersonal relationships (20).

Problem-Solving Training (PST)/Descubriendo Soluciones Juntos (DSJ) is an evidence-based, bilingual strategy training intervention that promotes proactive coping skills and self-efficacy by teaching a simple, systematic approach to problem-solving, including thorough problem assessment, generating and selecting solutions for specific self-identified goals, developing detailed plans of action, and evaluating and adapting plans as needed to support goal achievement (21–33). PST has been translated and culturally adapted for Spanish-speaking caregivers (DSJ) (34) and caregivers can receive the intervention via telephone or videoconference (23, 35, 36), circumventing many known barriers to caregiver support. PST has demonstrated efficacy in improving caregiver burden and reducing mood symptoms (22, 24, 27–30, 37) and negative problem-solving orientation (38, 39). We previously demonstrated that PST/DSJ led to improvements in caregiver burden and depressive symptoms among caregivers of adults with ADRD, regardless of the number of sessions or boosters received (39). However, these results examined participants in aggregate and did not examine factors characterizing those who responded or did not respond to the intervention, which is important to understand for personalizing intervention approaches and providing the best support to all who need it.

The objective of this study was to identify key personal and clinical factors associated with response to PST/DSJ, defined as improvement in caregiver burden and/or improvement in depressive symptoms, among ADRD caregivers. Personal factors included age, gender, race, Hispanic ethnicity, education, and employment status. Clinical factors included care recipient diagnosis and dementia severity, caregiver social problem-solving skills at baseline (pre-intervention), caregiving experiences, and baseline caregiver burden and depressive symptoms.

Materials and methods

Design

The CaDeS study was a 2×2 factorial design randomized controlled trial to test differential effects of number of sessions and booster sessions of PST/DSJ on caregiver burden and depressive symptoms among English- and Spanish-speaking caregivers of adults with ADRD (NCT04748666). Details about the study design and methods are provided in the published study protocol (40) and in the primary outcomes paper (39). Participants were randomized to receive 3 or 6 sessions with or without booster sessions. As reported in the published results for the primary trial aim, we found a main effect of time (improvement in both caregiver burden and depressive symptoms from baseline to 6-months post-baseline) with no significant difference for number of sessions or presence of booster sessions (39). Therefore, for the aim of this study to examine differences in those who did and did not respond to PST/DJS, we pooled all participants across study arms and categorized them based on improvement in the two primary outcomes, regardless of group assignment.

Participants

Participants ($n = 91$) were informal caregivers of persons with ADRD. Inclusion criteria were that the participant identified as a caregiver (i.e., a family member, spouse/partner, or friend) with more than a 1-year relationship with the care recipient, spoke English or Spanish, was over 18 years old and able to self-consent, and endorsed some depressive symptoms and/or caregiver burden symptoms (scoring ≥2 on the PHQ-2 and/or ZBI-4). The PHQ-2 assesses the two hallmark symptoms of depression (41), with scores ranging from 0 to 6 and a score ≥2 validated as a cut-off for potential depression. The ZBI-4 is a short screener for caregiver burden with a score of ≥2 validated as a cut-off for notable caregiver burden (42).

We determined that a sample size of 26 per arm ($n = 104$ total) would achieve 80% power at a significance level of 0.05 to detect the improvements between any two arms of 30% vs. 65, 40% vs. 75, 50% vs. 83, and 60% vs. 90%, accounting for 10% attrition (40). We consented $n = 106$ participants, but randomized $n = 104$ (2 withdrawn prior to randomization), and 7 (6.7%) were lost prior to the intervention beginning. Of the $n = 97$ who started the intervention, 6 were lost to follow-up by the 6-month assessment (6.2%), leaving us with $n = 91$ participants to include in responder analysis. The percentage of participants who completed 100% of sessions ranged from 82.1 to 95.2% across study arms.

Intervention

PST/DSJ teaches individuals a simple step-by-step process, to solve problems and achieve goals. A trained coach teaches participants the PST/DSJ strategy and then guides them through iterative practice applying it to goals of their choosing (34, 39, 40, 43). The strategy employs an easy to remember mnemonic: A = Assess the problem/ A = Analice el problema; B = Brainstorm solutions/ B = Buscar soluciones; C = Consider solutions and Choose one/ C = Considere y escoja; D = Develop a plan and Do it/ D=Desarrollar un plan y ¡Desempeñelo!; E = Evaluate/E = Evaluar y Evolucionar; F = Flex. Sessions were conducted by telephone or Microsoft Teams by Coaches with master's level training. Detailed description of the 3- and 6-session versions of PST/DSJ are provided in the published protocol. Briefly, both versions included training participants how to use the ABCDEF strategy, with the six session version allowing more sessions for coach-supported iterative practice applying the strategy (26). During booster sessions, which occurred monthly for 6 months if assigned, participants followed up with their coach about progress they had made using the strategy, received extra supported practice, and discussed opportunities for using PST/DSJ in the future. Intervention fidelity, assessed using our established fidelity protocol (27), was excellent at 95%.

Outcome measures

We collected:

1. Demographic data: age, gender, race, Hispanic ethnicity, education (≤ High School vs. > High school), and employment status (full-time or part-time vs. retired or unemployed).
2. Caregiver personal factors: social problem-solving skills [Social Problem-Solving Skills Inventory (44)] and social disconnectedness [Upstream Social Interaction Risk Scale (45, 46)].
3. Caregiving-related information: care recipient diagnosis (Alzheimer's disease vs. Other), care recipient dementia severity [Functional Assessment Staging Tool (47) for dementia score], and family caregiving experiences (48), comprising caregiver life satisfaction, social support, overload, satisfaction and resentment with the caregiving role, anger toward the care recipient, help needed by and provided to the care recipient, and care recipient aggressive, depressive, and forgetful behaviors.
4. Clinical outcome measures: caregiver burden [Zarit Burden Interview (49, 50)] and depressive symptoms [Patient Health Questionnaire (41, 51)].

Primary outcomes were caregiver burden, measured by the Zarit Burden Interview (ZBI), and depressive symptoms, measured by the Patient Health Questionnaire-8 item version (PHQ-8). The ZBI (49, 50) consists of 22 items and measures self-reported caregiver burden with included items covering overall well-being, social and family life, finances, perceived control, and emotional health. ZBI scores range from 0 to 88. The PHQ (41, 51) is a depression screening tool based on the DSIM-IV-TR symptoms of a major depressive episode. Scores range from 0 to 24 for the 8-item version.

Response to the intervention was defined for each primary outcome as a clinically important change from baseline to 6-month follow-up (final follow-up, 3 months post-end of intervention). For ZBI, we used a distribution-based method (52), defining Responders as those who improved by ≥1 point, equivalent to 1 standard error of the mean (SEM) of the sample (53) vs. Non-responders who did not. For PHQ, we based our definition of response on consensus-methods (52), which ranged from 2 to 3 points. We defined Responders as those who improved by ≥3 points (54) vs. Non-responders who did not.

Statistical analysis plan

We calculated the percentage of responders for each outcome and overall (Responder for Caregiver Burden AND/OR Depressive symptoms vs. Non-responder for both). We first descriptively present differences between Responders and Non-Responders on all covariates. Next, we conducted bivariate analyses, including Mann–Whitney U tests and Chi-squared tests, to determine statistically significant differences between Responders and Non-Responders for all covariates. We used the overall Responder variable (improvement in either outcome) as our primary indicator of response to intervention, as inclusion criteria for the study were a positive screen for caregiver burden OR depressive symptoms (ZBI-4 or PHQ-2 scores) rather than both. A *p*-value of ≤ 0.05 was deemed statistically significant, and all tests were two-sided.

Ethics statement

All research procedures were in accordance with the Declaration of Helsinki, and all participants provided informed consent. The UT Southwestern Medical Center's Institutional Review Board (IRB) served as the single IRB for the study, with other sites as reliance sites. Protocols were established for managing any crises that arose in the context of intervention delivery, and there were no serious adverse events. This trial is registered to ClinicalTrials.gov Identifier: NCT04748666.

Results

Ninety-one participants completed the 6-month follow-up assessment (88% retention of those who consented) and were included in these analyses (39). Based on initial screening, all participants (100%) met the criterion cut-off on the ZBI-4, and 27 participants (29.7%) met the criterion cut-off on the PHQ-2. The mean change in ZBI for all participants was −3.0 (SD = 9.2, Cohen's d = 0.33) and for PHQ was −1.1 (SD = 3.6, Cohen's d = 0.31).

For caregiver burden, there were 51 (56.0%) participants who improved by 6-month follow-up and 40 (44.0%) who did not improve. For depressive symptoms, there were 27 (29.7%) who improved and 64 (70.3%) who did not improve. Of these 64 who did not improve on the PHQ-8, almost all had stable depressive symptoms, with many not meeting the initial screening criteria for depressive symptoms (i.e., they did not have meaningful depressive symptoms to improve). Close to two-thirds of the sample (60.4%, $n = 55$) showed meaningful improvement on at least one of the outcomes (Responders), with a little over one-third of the sample (39.6%) not showing meaningful improvement for either caregiver burden or depressive symptoms (Non-Responders). Table 1 shows the cross tabulation of Responders and Non-Responders across both outcomes. Notably, among those whose depressive symptom scores improved, only 4 (14.8%) did not also improve for caregiver burden. Figure 1 shows the distribution of change scores for the ZBI and PHQ for Responders and Non-Responders.

TABLE 1 Cross tabulation of responders and non-responders for caregiver burden and depressive symptoms.

Caregiver burden	Depressive symptoms		Total
	Responder	Non-responder	
Responder	23	28	51
Non-responder	4	36	40
Total	27	64	91

*Responder is defined as a decrease in the outcome (≥1 point on the Zarit Burden Interview for caregiver burden; ≥3 points on the Patient Health Questionnaire for depressive symptoms) from baseline to second follow-up (6 months post-intervention). All 91 participants screened positive at baseline for caregiver burden, whereas only 27 (29.7%) screened positive for depressive symptoms (59 did not).

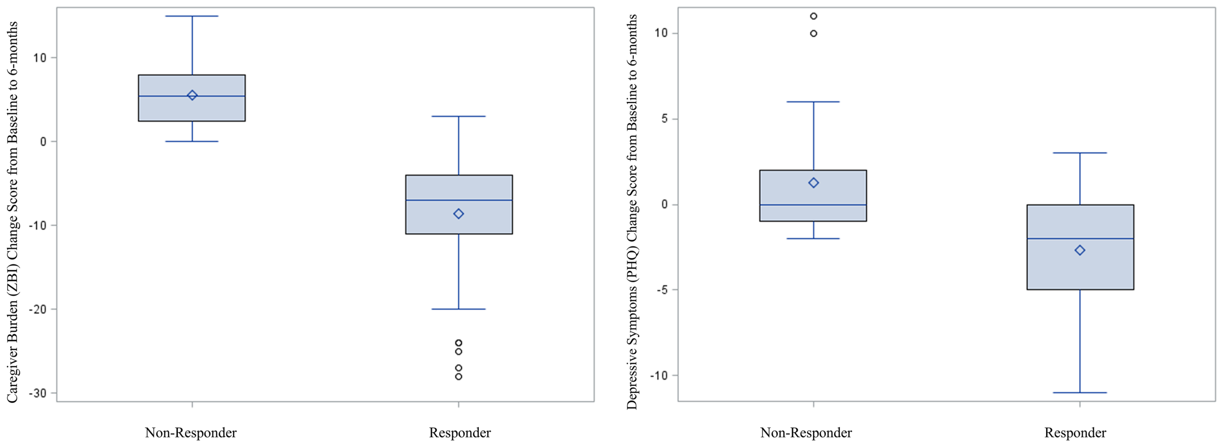

FIGURE 1
Boxplots comparing change in caregiver burden and depressive symptoms between responders and non-responders; positive scores indicate worsening symptoms; negative scores indicate improving symptoms.

Table 2 presents personal and clinical characteristics for all participants ($n = 91$) and descriptive and bivariate analyses between the combined Responder vs. Non-Responder groups. Statistically significant differences between groups for bivariate analyses were observed, with Responders reporting lower Caregiver Life Satisfaction ($p = 0.05$) and more feelings of Caregiver Overload ($p = 0.05$), more Caregiver Burden ($p = 0.01$), and greater Depressive Symptoms ($p < 0.001$) at baseline compared to Non-Responders. Responders had care recipients with higher FAST scores (dementia severity, $p < 0.01$) compared to their Non-Responder counterparts, with respective median scores of 6 (IQR = 5.7) indicating moderately severe dementia, vs. 5 (IQR = 4.6), indicating midstage dementia (see Table 2).

We also assessed differences in Responders vs. Non-Responders for caregiver burden and for depressive symptoms separately. Participant characteristics and group comparisons for each outcome are presented in Supplementary Table 1 (Caregiver Burden Responders) and Supplementary Table 2 (Depressive Symptom Responders).

Discussion

This study aimed to transcend outcome evaluation by examining the factors associated with treatment response among caregivers enrolled in a problem-solving intervention. We compared those achieving clinically significant improvement (i.e., Responders) with those who did not improve (i.e., Non-Responders) after PST/DSJ among 91 ADRD caregivers. Almost two-thirds of the sample were Responders ($n = 55$, 60.4%), supporting the benefits of PST/DSJ for dementia caregivers. Research on similar interventions has not always found statistically significant changes in burden/depression (55–57), and there is a paucity of dementia caregiver studies evaluating clinically, as opposed to just statistically, meaningful response to treatment (58).

In the current study, no personal characteristics of caregivers were associated with being a Responder (vs. Non-Responder). This suggests that the content of PST/DSJ was appropriate for caregivers in different situations and from different backgrounds and cultures, indicating success in our efforts to culturally translate the intervention while maintaining all evidence-based effective PST principles. Clinical factors associated with being a Responder (vs. Non-Responder) included providing care for individuals with greater dementia severity (moderately severe vs. midstage dementia) and, at baseline, reporting lower caregiver life satisfaction, higher caregiver overload, higher caregiver burden, and more depressive symptoms. This emphasizes that caregivers with greater need for intervention and support were also more likely to benefit from PST/DSJ.

This is contrary to a similar study in stroke caregivers who completed a cognitive-behavioral problem-solving and coping skills intervention that found that non-responders more often had a history of psychologic disorder and reported higher levels of anger than responders (19). Two notable differences between these studies may explain these somewhat discrepant findings. First, stroke and ADRD are notably different in their onset and progression, and participants in the stroke caregiver study were in their first year of caregiving. It may be that during this time of adjustment to a new, unexpected, and sudden-onset role, stroke caregivers experiencing the most emotional distress were not ready to engage in this kind of intervention. Second, related to the nature of the intervention, though both taught adaptive problem-solving based coping skills, cognitive behavioral approaches focus more on self-reflection and changing internal thoughts about a situation to improve emotional well-being, whereas PST/DSJ focuses only on the step-by-step applied process for goal setting and goal achievement known to have downstream effects on emotional health. Direct comparative studies of these different approaches may be warranted to best target interventions to caregivers' needs and individual circumstances.

While the demand for caregiving interventions is growing alongside the rates of ADRD diagnoses and unpaid caregivers in the US (59, 60), the nature of caregiving demands, as well as feelings of burden and depression, may hinder caregivers from seeking out or participating in available and accessible interventions (61, 62). Additionally, although caregivers of care recipients with more severe dementia may be more likely to respond to intervention, the complexities of their caregiving situations and circumstances (and feelings of being overwhelmed and overburdened) may prevent them from engaging in multi-session interventions (63). The virtual delivery modality of PST/DSJ may overcome some of these barriers, as it is conducive to remotely reaching and serving caregivers with limited time and the inability to leave their care recipients alone while they travel to in-person interventions (39). Notably, though not statistically significant, a higher proportion of participants in the Responder group were employed (50% vs. 36%), lending support to the idea that those with the most demanding schedules may benefit the most from flexible and remotely delivered interventions.

This study is an important step to understanding differences between those who do and do not respond to interventions, which can provide insight into targeted recruitment strategies and adaptations for greater effectiveness. In the clinical trial from which this study was drawn (40), we employed brief screeners for caregiver burden and depression to ensure caregivers could potentially benefit from the intervention. As such, large proportions of caregivers engaged in the intervention had modifiable risk factors addressed by PST/DSJ, which may indicate why the intervention was generally successful across intervention doses and personal characteristics. While many studies have used this approach to recruit and engage appropriate participants (64–66), this strategy is recommended for future research and practice to avoid 'floor effects' (i.e., participants do not have risk at baseline and may not benefit from the intervention) and/or engaging participants with too high of risk at baseline, which may signal the need for advanced intervention with clinical professions (i.e., beyond the anticipated and feasible benefits participants can receive from the offered intervention) (67).

Given the smaller, yet considerable, proportion of caregivers categorized as Non-Responders to the intervention in the current study, there are clear opportunities to adapt or complement PST/DSJ to better meet the diverse and complex needs of caregivers. In these analyses, all participants across intervention arms were combined into a single group, thus not accounting for dose–response in the analyses. This is justified by the non-superiority effect of session number and booster sessions in a previous PST/DSJ publication (39); however, if all caregivers received the same dose, or if dose was more individually targeted to individual need, a larger proportion may have been Responders to the intervention. This may support future pragmatic trials that uniformly serve caregivers to assess clinical benefits in care burden and depression. While not all caregivers responded to the

TABLE 2 Differences in personal and clinical characteristics between responders and non-responders to problem-solving training for either caregiver burden or depressive symptoms.

	All	Responders[±]	Non-responders	*p*-value
	N = 91	*N* = 55	*N* = 36	
A. Personal factors				
Age years (median [IQR])	61, [52, 72]	59, [52, 71]	65.5 [52, 73]	0.6
Gender				0.56
CIS-Female	77 (86%)	48 (87%)	29 (83%)	
CIS-Male	13 (14%)	7 (13%)	6 (17%)	
Employment				0.12
Yes (Full-time or Part-time)	42 (46%)	29 (53%)	13 (36%)	
No (Retired or Unemployed)	49 (54%)	26 (47%)	23 (64%)	
Diagnosis of care recipient				0.16
Alzheimer's Disease	56 (62%)	37 (67%)	19 (53%)	
Other*	35 (38%)	18 (33%)	17 (47%)	
Fast score (median [IQR])	6 [4, 7]	6 [5, 7]	5 [4, 6]	**<0.01**
Education				0.69
≤High School	9 (10%)	6 (11%)	3 (8%)	
> High School	82 (90%)	49 (89%)	38 (92%)	
Hispanic ethnicity				0.64
Non-Hispanic	71 (78%)	42 (76%)	29 (81%)	
Hispanic	20 (22%)	13 (24%)	7 (19%)	
Race				0.78
White	71 (78%)	42 (76%)	29 (81%)	
Black	13 (14%)	9 (16%)	4 (11%)	
Other race	7 (8%)	4 (7%)	3 (8%)	
B. Clinical factors (median [IQR])				
Social problem-solving skills				
Positive problem orientation	13 [10, 15]	13 [10, 15]	13 [10, 14]	0.67
Negative problem orientation	4 [2, 7]	5 [2, 7]	3 [1, 5.5]	0.16
Rational problem solving	10 [8, 12]	10 [8, 12]	10 [8, 12]	0.82
Impulsive/carelessness style	2 [1, 5]	2 [1, 4]	2.5 [1, 5]	0.66
Avoidance style	5 [3, 7]	5 [3, 7]	5 [3, 6]	0.18
Family caregiving (caregiving experience)				
Caregiver life satisfaction	20 [17, 24]	19 [17, 23]	22.5 [18, 25]	**0.05**
Caregiver social support	25 [23, 27]	26 [23, 27]	24 [23, 27]	0.39
Caregiver overload	11 [9, 12]	11 [9, 13]	10 [7, 12]	**0.05**
Satisfaction/love for caregiving role	27 [25, 30]	27 [25, 30]	26.5 [24, 30]	0.46
Resentment for caregiving role	14 [11, 17]	15 [11, 17]	14 [10.5, 16.5]	0.35
Anger toward care recipient	9 [6, 11]	9 [6, 11]	8.5 [6, 11]	0.44
Care recipient aggressive behaviors	11 [6, 15]	11 [8, 15]	10 [4.5, 15.5]	0.33
Care recipient depressive behaviors	6 [4, 8]	6 [5, 8]	7 [3, 8]	0.31
Care recipient forgetfulness/confusion	9 [8, 11]	9 [8, 11]	9 [8, 11]	0.41
Caregiver burden (ZBI)	37 [30, 46]	39 [32, 47]	32.5 [24, 42]	**0.01**
Depressive symptoms (PHQ-8)	6 [2, 8]	6 [3, 10]	3.5 [1, 6]	**<0.01**
Social disconnectedness (U-SIRS-13)	6 [3, 10]	7 [4, 10]	5 [2, 9]	0.07

[±] Responder = decrease (improvement) of 1 pt on ZBI equivalent to 1 SEM OR 3 + points on PHQ8. *Other diagnoses include Lew body dementia Vascular dementia Mild cognitive impairment and Mixed etiology and other Dementias.

P-values are bold when they are statistically significant at *p* <= 0.05.

intervention in terms of caregiver burden and depression, other subjective benefits may have been obtained by these caregivers (and those who were responders to the intervention). Therefore, future research should assess other measures to document other benefits of PST/DSJ, such as relationship quality, perceived care quality, shared decision making, resilience, social connection, loneliness, and participants' perceptions of benefit (68).

Finally, some among the Non-Responders may require additional or different intervention. PST/DSJ teaches a problem-solving strategy that provides a concrete adaptive coping skill for proactive problem solving and goal attainment. The downstream benefits of PST/DSJ on emotional outcomes like depressive symptoms likely result from enhance self-efficacy, goal attainment, and behavioral activation (55, 69–71). However, this may not be sufficient to address more severe depression that may require psychotherapy or pharmacological intervention. For caregiver burden, the skills learned in PST/DSJ help caregivers better manage their daily tasks and achieve goals that are important to them (55, 71), but this does not necessarily lessen the overall burden they still experience by the demands of caregiving and the potential lack of support available. Community-level interventions that provide tangible and instrumental support to caregivers are still needed to lessen these demands (14, 68).

Limitations and future directions

Though baseline assessment of caregivers in this study was robust, multiple factors that could contribute to treatment response were not measured, including access to resources, socioeconomic factors, and social support. Our sample was somewhat homogenous with regard to demographics (predominantly White care partners) and geography, which may introduce bias and limit generalizability. Additionally, though PST/DSJ is offered in both English and Spanish, there were not enough Spanish-speakers to examine whether response differed by language of delivery, which is an important direction for future research. Though care recipients had several different dementia diagnoses, most had AD, and the amount and nature of caregiving help provided was not captured in detail. Lastly, as previously noted, we only measured two common outcomes for caregivers: depressive symptoms and caregiver burden. However, PST/DSJ does not target any specific outcome and may have conferred unmeasured benefits for both caregivers and their care recipients.

Future work is needed to identify other potential benefits and to further determine for whom PST/DSJ would be most beneficial. Participants in the Non-responder group reported less severe symptoms of caregiver burden and depression compared to Responders, suggesting perhaps these were not outcomes for which they needed intervention. However, dementia caregivers experience a range of other challenges, from social participation restrictions to loneliness to anger and resentment, to name a few. Follow-up qualitative studies could reveal outcomes that are most meaningful and could benefit from PST/DSJ. Some in the Non-responder group actually reported worsening symptoms, indicating a need for more targeted and/or intensive intervention to address these potentially more serious emotional symptoms. Additionally, there are other approaches to operationalizing "response" to intervention, such as the participant's perspective of whether they improved or not, which may yield different results.

Conclusion

This study is an important step in identifying the drivers of intervention response among caregivers of people living with ADRD. As seen in our study, most caregivers demonstrated a clinically meaningful improvement in caregiver burden and/or depressive symptoms after receiving PST/DSJ. Notably, those who responded to the intervention had higher symptoms of distress, caregiver burden, overload, and depressive symptoms; had lower life satisfaction; and had care recipients with more severe dementia. These results indicate that those benefiting may also be those most likely in need of this support. Additional studies are needed to drive adaptations and complementary support services to effective caregiver interventions to improve recruitment and increase impact.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by University of Texas Southwestern Medical Center University of Texas Rio Grande Valley Texas A&M University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

SJ: Investigation, Funding acquisition, Conceptualization, Resources, Writing – review & editing, Project administration, Supervision, Formal analysis, Methodology, Writing – original draft. MS: Conceptualization, Funding acquisition, Investigation, Writing – original draft, Resources, Writing – review & editing, Methodology. KW: Writing – review & editing, Writing – original draft, Project administration. BW: Writing – review & editing, Writing – original draft. GH: Validation, Writing – review & editing, Methodology, Formal analysis, Writing – original draft. CS: Writing – original draft, Conceptualization, Funding acquisition, Project administration, Writing – review & editing. GM: Writing – review & editing, Project administration, Funding acquisition, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

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Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2025.1682373/full#supplementary-material

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Caring under pressure: economic social determinants of health influence family caregivers

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Health disparities, the unequal onset, severity, and treatment of chronic health conditions, are differentially experienced by adults living in different geographic locations in the United States. Coupled with an earlier onset and more severe symptomatology among patients, family care partners may also experience increased stress related to other place-based disparities, including limited access to care and increased economic challenges. Using data from the 2023 Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System, we examine the influences of caregiver resources, caregiving demands, and place-based factors in a structural equation model aimed at understanding caregiver physical and emotional health. Data from 5,432 family caregivers (Mean age ~ 66 yrs.; ~60% female; 10% rural) who provide a range of assistance with personal care tasks (49%) and household tasks (78%) were used in a multigroup analysis examining the unique contributions of rurality to this model of caregiver stress. Although rurality does not differentially increase psychological wellbeing challenges among caregivers, rural caregivers did experience exacerbation of physical health challenges when compared to their urban counterparts. *Post hoc* analyses are conducted in order to isolate this effect and to inform policy and program recommendations.

KEYWORDS

caregiving, behavioral risk factor surveillance system, stress, well-being, social determinants of health

Introduction

Relative to their non-caregiving counterparts, family caregivers may experience lower emotional wellbeing, which is often attributed to the stresses of providing care. Fifty years of caregiving research have documented the emotional, physical, social, financial, and space constraints that exacerbate caregiving stresses (1). Building on these important foundations, more recent work has begun to examine the influence of pre-caregiving stressors on families (2). Other work takes a more nuanced approach to identify the specific aspects of caregiving that might give rise to threats to caregiver wellbeing (3). The purpose of the current study is to examine the potential effects of caregiving stressors within a broader framework of stressors that include one's economic context.

General stress as the linchpin in the caregiving-wellbeing nexus

Broadly defined, stress is a process whereby stimuli evoke a physiological and/or emotional reaction (4, 5). These responses, particularly in the face of ongoing and chronic exposure, may result in decreased physical and emotional wellbeing. Although researchers and clinicians may ask domain-specific questions about experienced stress, it is unclear whether most adults are able to decompose their experienced stress into its constituent parts. For example, Luo and colleagues (6) recently used two samples from the Health and Retirement Study to examine the factor structure of general versus domain-specific stress. They focused on the domains of family/interpersonal stress, job-related stress, racial discrimination, and neighborhood changes. General stress at time 1 predicted health at time 2 (4 years later), with only the neighborhood domain emerging as a unique domain-specific predictor. Thus, although adults are able to identify sources of stress across domains, it is the general stress factor which seems to underly physical health outcomes. Of note, individual characteristics were associated with higher perceived general stress, including younger ages, female sex, non-white racial identity, higher neuroticism, and more recent exposure to stressors. These same characteristics are often associated with family caregivers.

Although more than half of caregivers report experiencing stress while providing care (7), it is unclear whether this relates to an individual propensity for experiencing stress, the nature of the care tasks, or other environmental demands. Data from the HRS (2) were used to investigate pre-caregiving and post-caregiving trajectories among 4,812 adults who reported the physical and cognitive decline of their mother. Results suggested that it was not caregiving, per se, that was associated with increased depression among these adult caregivers, but rather, being exposed to the health declines of a family member served as a salient stressor. Among these adults providing care to their aging mothers, dementia and functional disability was especially challenging and these challenges increased threats to wellbeing over time among the caregiving adult children (2). Similarly, recent work by Smith et al. (3) identified aspects of caregiving that resulted in increased threats to emotional wellbeing. Whereas care receiver characteristics were associated with demands on caregiver time, the difficulty of performing those care tasks was associated with increased depression. Thus, a more nuanced approach to understanding pre-existing patterns and resources, as well as current care demands, may be informative.

eSDOH and family caregiving

Among non-caregivers and caregivers alike, there are multiple sources of stress in an adult's life, including economic challenges and other Social Determinants of Health (SDOH) (8). SDOH include environmental conditions that affect one's health and quality of life, such as where people work, live, and age. Other non-demographic SDOH incude access to health care, education, food, and preventative health behaviors (9). Economic social determinants of health (eSDOH), may include loss of employment, difficulty with finances, and difficulty with transportation. That such financial strain is associated with increased depression is not surprising (10).

Indeed, the effects of financial strain on caregivers have been studied for decades. However, such challenges have not been examined using SDOH frameworks. It is clear that when the caregiving context requires, many caregivers reduce their paid employment to accommodate (11), but such options are not available to all families. The strains that financial stress may add to caregiving have not been adequately studied.

The current study focuses on the contributions of the caregiving context and specific eSDOH to experienced stress and emotional wellbeing. Caregivers face many stressors. Disentangling the sources of the stress, including those experienced by non-caregivers, has the potential to provide a better understanding of wellbeing and to potentially guide interventions. Thus, we sought to examine whether the effects of caregiving and eSDOH differentially influence experienced stress and ultimately wellbeing.

Methods

Data source

Data for these analyses were provided by adults who completed the 2023 Behavioral Risk Factor Surveillance System (BRFSS), released by the Centers for Disease Control and Prevention in September 2024 (12). The BRFSS is a national interview administered annually to assess a variety of health risks, health behaviors and general health status among adults ages 18 + living in the community in all 50 US states and three US territories. More than 420,000 adults participated in the 2023 survey. All participants were asked: "During the past 30 days, did you provide regular care or assistance to a friend or family member who has a health problem or disability?" (12). A total of 11,502 responded in the affirmative (22.6%). The 2023 BRFSS included an optional module about economic social determinants of health (eSDOH) (12). About half of the caregivers answered these items. Thus, the following analyses are based on responses from 5,432 caregivers who provided answers to all of the items of interest in the current study. Finally, we note that we acquired the data in September 2024. Some items (i.e., eSDOH) in our analyses may no longer be available to the public.

Participants

Among the 5,432 caregivers in the current sample, the average age was 57.5 years (SD = 16.4; range 18 to 80+). Approximately 40% identified as male. The optional caregiving module was offered by only five states in the 2023 BRFSS. Specifically, the module was offered in: Arizona, Arkansas, Hawaii, Idaho, and Louisiana. Approximately 11.4% of the current sample resided in rural areas. The analytic sample was less racially diverse than the US as a whole (13). Within the current sample, 66.7% identified as white non-Hispanic (64%), 6.5% identified as Black non-Hispanic (12%; US Census), and 8.8% identified as Hispanic (16%) (13). Additionally, 11.1% of the current sample identified as a member of another non-Hispanic group, and 6.9% identified as multiracial. The median annual household income was in the $25,000 to $35,000 range. More than half (61.2%) were married or part of a long-term couple, but 2.3% were separated from their spouse, 13.1% were divorced, 8.5% were widowed, and 14.4% were single, never married. The sample was well-educated, with 95.2% having earned a high school diploma or equivalent. About 40% had earned a 4-year college degree.

Among the caregivers, 1,535 (28.3%) were providing care to parents or parents-in-law. An additional 1,302 were caring for a spouse or partner (24%). A third group included 1,578 adults (29.1%) who were providing care to another relative, including a child ($n = 565$), grandchild ($n = 54$), sibling ($n = 434$), grandparent ($n = 185$), and other relative ($n = 358$). A fourth group of 1,017

(18.7%) were providing care to a friend. Reasons prompting the need for care varied, but included physical health conditions (23.2%) such as kidney or lung diseases, cancer (8.4%), developmental disabilities such as Down Syndrome (5.5%), emotional illness and substance abuse (4.7%), injuries like broken bones (7.2%), "old age" or general frailty (16.5%), and other conditions (34.4%).

Measures

To test the model depicted in Figure 1, we examined indices of the caregiving context, economic SDOH, stress, and emotional wellbeing. Each is described below.

Caregiving context

Caregiving context was assessed using three indicators. Caregivers were asked whether the care recipient had dementia or other cognitive impairment, to which 16.7% replied in the affirmative. Functional ability of the care recipient was indexed by the sum of two items, which queried whether the caregiver assisted with personal care tasks (49.3%) or household tasks (79.7%). The two dichotomous items were summed, and the mean was used in subsequent analyses ($M = 1.29$; SD = 0.72). A third index was formed based on the number of hours per week caregivers assisted. The categorical responses were recoded to the midpoint, and included less than or equal to 8 h (53.9%, recoded to 4 h), 9 to 19 h per week (14.0%, recoded to 14), 20 to 39 h per week (12.0%, recoded to 30), and 40 or more hours per week (20.1% recoded to 40).

eSDOH

Participants reported whether during the past year, they received food stamps (11.3%), were unable to pay their bills (12.6%), had their utilities disconnected for failure to pay (8.9%), had their work hours reduced or were terminated from their job (11.8%), and whether lack of reliable transportation was a problem (9.3%). Although most (69.7%) reported none of these economic SDOH, 16.8% experienced one and 13.6% reported two or more. Thus, despite the range being 0 to 5 ($M = 0.54$, SD = 1.0, $\alpha = 0.66$), the count measure operates as a dichotomous variable.

Daily stress

Daily stress was assessed using a single item, "Stress means a situation in which a person feels tense, restless, nervous, or anxious, or is unable to sleep at night because his/her mind is troubled all the time. Within the last 30 days, how often have you felt this kind of stress?" Most reported never (29.6%) or rarely (28.0%) feeling such stress. However, 25.4% reported sometimes, 9.2% reported usually, and 7.8% reported always feeling such pervasive stress. Responses were recoded such that higher scores reflected more frequent experiences of stress, resulting in a sample mean of 2.38 (SD = 1.22).

Caregiver wellbeing

Caregiver wellbeing was indexed using three items. Caregivers were asked the number of days in the past 30 days during which their mental health was poor. Including the 53% who responded that they had zero poor mental health days, the sample mean number of poor mental health days was 5.71 (SD = 9.4; range 0 to 30). Exploratory analyses examined whether a log transformation was needed, given the potential for zero-inflation. Results with the raw and transformed index were essentially the same, so we report raw scores herein. Caregivers also reported whether they had ever been diagnosed with depression, a depressive disorder, or anxiety, with 26% responding in the affirmative. Finally, participants were asked, "In general, how satisfied are you with your life?" Higher scores reflect more dissatisfaction, such that 1.4% were very dissatisfied, 4.6% were dissatisfied, 51.1% were satisfied, and 42.9% were very satisfied. The item mean was 1.64 (SD = 0.64).

Analyses

Preliminary analyses

Bivariate associations for the sample were examined using Pearson correlation coefficients for continuous variables and Spearman correlations for categorical variables. Due to the large sample used in the current study, smaller magnitude correlations reached statistical significance. Thus, we focus on those coefficients with magnitudes

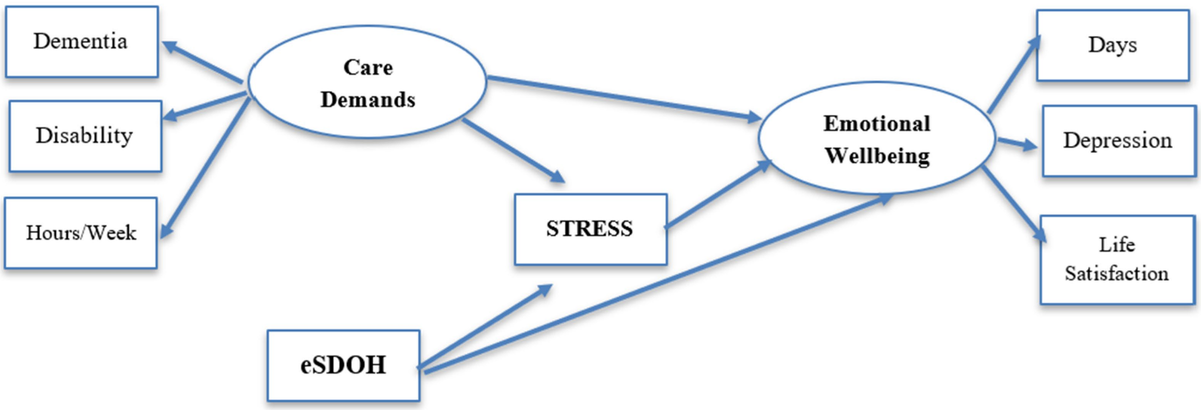

FIGURE 1
Conceptual model.

greater than 0.20 and p-values smaller than 0.001. Coefficients are presented in Table 1.

The model represented in Figure 1 was tested in AMOS v. 29.0.0. AMOS uses maximum likelihood procedures to simultaneously estimate measurement and structural paths in the model. Individual paths are tested for statistical significance using the Critical Ratio (CR), for which values greater than 2.16 are significant at $p < 0.01$ and CR > 3.29 are significant at $p < 0.001$. Because the chi-squared statistic is sensitive to small deviations between the tested and inherent models in larger samples, we relied on additional indices of fit. We used the comparative fit index (CFI), for which values greater than 0.90 suggest an acceptable fit, but values greater than 0.95 being preferred. We examined the Tucker-Lewis Index (TLI), for which values greater than 0.90 indicate an acceptable fit. We also used the root mean square error of approximation (RMSEA), for which values less than 0.08 are considered acceptable, and values less than 0.05 indicate a close fit of the model to the data (14, 15).

As shown in the upper portion of Table 2, the three indices of Wellbeing loaded well onto the latent construct. The lower portion of the table displays the individual regression paths. Results of the analysis suggest a close fit of the model to the data, X^2 (DF = 17; $N = 5{,}432$) = 168.09, $p < 0.001$; CFI = 0.977; TLI = 0.961; RMSEA = 0.040. The model accounted for 55.6% of the variance in wellbeing and 13.1% of the variance in stress. When inspecting individual regression paths, it is important to remember that due to the large sample size of the current study, relatively small beta weights resulted in statistically significant effects. All regression paths were significant.

As shown in Table 2, poorer wellbeing was associated with more stress ($\beta = 0.63$, $p < 0.001$) and more eSDOH ($\beta = 0.23$, $p < 0.001$), but not directly linked with caregiving demands ($\beta = 0.03$, $p = 0.085$). Both caregiving demands ($\beta = 0.13$, $p < 0.001$) and eSDOH ($\beta = 34$, $p < 0.001$) directly contributed to stress. We examined the indirect effects of caregiving demands and eSDOH on wellbeing through their association with stress. In both cases, stress mediated the effects on wellbeing. The specific indirect effect of caregiving demands on wellbeing through stress ($\beta = 0.079$) was significant (bias-corrected 95% CI = [0.064, 0.105], $p = 0.004$). Similarly, the indirect effect of eSDOH on wellbeing via stress ($\beta = 0.214$) was significant (bias-corrected 95% CI = [0.198, 0.231], $p = 0.007$). We note that the CI do not overlap, with a stronger effect of eSDOH on wellbeing than caregiving demands on wellbeing.

Moderation testing

In order to examine whether the relationship to the care recipient altered the associations within the model, we conducted a multigroup moderation analysis comparing model functioning across caregivers to parents, spouses, other relatives, and friends. Table 3 presents standardized direct and indirect effects for these four groups of caregivers. As shown in Table 3, only small differences in the strength of associations were observed across the four groups.

Discussion

Decades of research show that family caregivers often experience struggles in caring for their family members (1). More recent studies expand attention to include the broader context in which family caregiving occurs. To that end, we examined the influences of caregiving demands and economic demands on stress and wellbeing among caregivers. Using data from the 2023 CDC, we are able to assess these effects in a large sample of adults.

By including both caregiving demands and economic SDOH in a single model, we are able to directly assess their associations with both experienced daily stress and longer-term emotional wellbeing. Moreover, we are able to compare their direct effects on wellbeing and their indirect effects on wellbeing via experienced stress. Results of our

TABLE 1 Descriptive statistics and correlations for study variables.

	1	2	3	4	5	6	7	8	9	10	11
1. Age	—										
2. Sex †	0.00	—									
3. Relationship †	0.13**	0.02	—								
4. MH days	−0.25**	−0.09**	0.01	—							
5. Satisfaction with life	−0.14**	0.00	−0.011	0.37**	—						
6. Depression †	−0.18**	0.12**	−0.01	0.46**	−23**	—					
7. Stress	−0.29**	0.12**	−0.033*	0.52**	0.39**	0.39**	—				
8. eSDOH	−0.31**	0.03**	0.03*	0.32**	0.29**	0.25**	0.27**	—			
9. CR Disability	−0.05**	−0.07**	0.05**	0.08**	0.06**	0.09**	0.09**	0.10**	—		
10. CR Dementia †	0.03*	0.04**	−0.04**	0.04**	0.04**	0.05**	0.06**	0.01**	0.12**	—	
11. Hours/week	−0.09**	−0.02	0.07**	0.07**	0.07**	−0.45**	0.11**	0.10**	0.84**	−0.12**	—
Mean	57.13	1.60	2.38	5.71	1.64	0.26	2.38	0.54	0.49	0.17	1.29
Standard deviation	16.37	0.49	1.08	9.45	0.64	0.44	1.22	1.00	0.50	0.38	0.72

† Spearman's ρ used.
$*p < 0.05$, $**p < 0.01$.

TABLE 2 Results of SEM testing (*N* = 5,432).

	b	β	S. E.	C. R.	*p*
Measurement model					
Poor mental health days←Wellbeing	1.0	0.732			
Life Satisfaction←Wellbeing	0.048	0.517	0.002	31.30	***
Depression←Wellbeing	0.036	0.559	0.001	33.44	***
Dementia←Care Demands	1.0	0.155			***
Functional Disability←Care Demands	8.73	0.701	1.20	7.29	***
Hours per Week←Care Demands	145.63	0.571	17.71	8.23	***
Structural model					
Wellbeing←Stress	3.566	0.629	0.089	40.03	***
Stress←Care Demands	2.622	0.125	0.453	5.79	***
Wellbeing←Care Demands	3.608	0.030	2.098	1.72	0.085
Stress←eSDOH	0.410	0.340	0.015	26.81	***
Wellbeing←eSDOH	1.591	0.233	0.098	16.28	***

X^2 (DF = 17; $N = 5{,}432$) = 168.09, $p < 0.001$; CFI = 0.977; TLI = 0.961; RMSEA = 0.040.
R^2 Stress = 0.131; R^2 Wellbeing = 0.556.
***$p < 0.001$.

TABLE 3 Relationship to care receiver moderation analyses.

Betas and CI	Care-receiver is:			
	Parent (*n* = 1,535)	Spouse (*n* = 1,302)	Other family (*n*= 1,578)	Friend (*n* = 1,017)
Standardized direct effects (β)				
Wellbeing←Stress	−0.643***	−0.605***	−0.670***	−0.567***
Stress←Care Demands	−0.080**	−0.142***	−0.140***	−0.093*
Wellbeing←Care Demands	−0.039 ns	0.020 ns	0.074*	0.055 ns
Stress←eSDOH	−0.343***	−0.330***	−0.298***	−0.410***
Wellbeing←eSDOH	0.240***	0.269***	0.168***	0.294***
X^2 (DF = 68) = 299.09, $p < 0.001$; CFI = 0.964; TLI = 0.941; RMSEA = 0.025				
R^2 Wellbeing	0.549	0.564	0.564	0.554
R^2 Stress	0.129	0.109	0.109	0.176
Standardized indirect effects (β)				
Care Demands→Stress→Wellbeing	0.051**	0.086**	0.094**	0.052**
eSDOH→Stress→Wellbeing	0.221*	0.199*	0.200*	0.232*

*$p < 0.05$, **$p < 0.01$, ***$p < 0.001$.

omnibus structural model were profound: although caregiving demands exert indirect effects on wellbeing through their association with experienced stress, caregiving demands, per se, did not directly result in threats to wellbeing. In contrast, economic SDOH exerted strong direct and indirect effects on wellbeing. When comparing the standardized beta weights, the effect for eSDOH was nearly three times that of caregiving demands. This finding is particularly disturbing because the measure of eSDOH is somewhat crude and was operating much like a dichotomous variable. Adults who expressed nearly any difficulty paying their bills, had their utilities disconnected, were challenged to obtain sufficient food, or did not have reliable transportation were at an especially high risk for threats to their wellbeing. Caregiving clearly adds to stress and likely exacerbates the effects of eSDOH on wellbeing.

Thus, although consistent with the general stress factor identified in the HRS data (6), our results extend beyond the identification of a pervasive stress factor. Given the strong effects of economic burdens, social safety nets like Medicaid and other sources may become critical for supporting families who are providing care amidst other financial challenges. Moreover, although we had thought that the strength of predictors within the model might vary as a function of different relationships to the care-receiver, that was not the case. Across relationships, having difficulty paying one's bills, experiencing food insecurity, and lacking reliable transportation was associated with more stress and ultimately, poorer emotional wellbeing. These results fit well with the nuanced investigation by Han (2), suggesting that experienced stresses among caregivers is exacerbated by specific contextual influences. For Han (2), dementia and functional disability in the care receiver were the primary stressors. Our analyses suggest that caregiving research must expand to include broader contexts, including economic challenges.

Strengths, limitations, and implications

This is a novel and critical study that brings forth a more accurate understanding of informal caregiving within the context in which it occurs. Recognizing that experienced stress has a variety of potential causes, and thus, interventions may help us to better support family caregivers.

Although prior work has acknowledged that caregiving may affect several domains, including finances and employment (1), and it is reasonable to assume that poor emotional wellbeing outcomes among caregivers are associated with the care they provide, our analyses suggest a more holistic view is appropriate. Specifically, caregiving tasks added to experienced stress, but they did not directly affect wellbeing. However, the daily financial hardships that families were experiencing did exert both direct and indirect effects on wellbeing. This finding suggests that public health may be well-served by broader financial safety nets for caregivers and non-caregivers alike. Moreover, alleviating such daily sources of stress might result in improved care-receiver outcomes, as well. Finally, reciprocal effects between stress and wellbeing across different contexts must be examined. However, these hypotheses are best tested using more sophisticated caregiving data that includes longitudinal examinations.

We examined the experiences of caregiving adults using public access health surveillance data from the CDC's BRFSS. Thus, as a secondary data set, we did not control the breadth or depth of caregiving items posed. In addition, the caregiving module is an optional module in the BRFSS. As such, only five states included it in 2023. It is likely that local resources in Arizona, Arkansas, Hawaii, Idaho, and Louisiana differ from other areas in the United States. Geographic differences are likely to be key factors shaping the relation among economic SDOH, stress and other stressors. However, the caregiving module was selectively launched by states and the 2023 BRFSS does not allow a rigorous examination of these regional differences in caregiving experiences. Similarly, because it is a surveillance survey, the BRFSS module includes only a handful of items. For example, although the number of hours per week and tenure of caregiving are queried, only three ADL/IADL tasks are included. Other items that could inform this research, such as emotional closeness and specific caregiving burden, are not included. These data also do not provide information about whether caregiver status is voluntary or whether there are other caregivers who support the car receiver.

Despite these limitations, our study adds to the literature on family caregiving. Specifically, our study is among the first to examine caregiving demands within the context of other daily stressors. By situating caregiving in this way, we are able to begin to disentangle the effects of economic stresses and caregiving stresses on overall emotional wellbeing. Therefore, it would be helpful to conduct a longitudinal study with interventions included and ask more focused caregiving questions. This can allow us to pinpoint caregiver stress changes over time and identify variables and interventions that may influence those changes in a positive way.

Conclusion

The significant direct influences of experienced stress and eSDOH on caregivers' wellbeing reinforce the need for public health intervention programs to support caregivers and those who are struggling with eSDOH threats.

Data availability statement

Publicly available datasets were analyzed in this study. These data can be found here: BRFSS 2023 data are available: https://www.cdc.gov/brfss/annual_data/annual_2023.html.

Ethics statement

The studies involving humans were approved by West Virginia University #2107363352. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from the participants or the participants' legal guardians/next of kin in accordance with the national legislation and institutional requirements.

Author contributions

PR: Conceptualization, Writing – original draft, Writing – review & editing. SB: Writing – review & editing. JP: Data curation, Methodology, Conceptualization, Writing – original draft, Supervision, Formal analysis, Resources, Writing – review & editing, Software.

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The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Gender differences in spousal caregiver strain and paid service use among dementia caregivers in rural Appalachia

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Spousal caregivers of persons living with dementia (PLwD) often experience high overload and loneliness due to the intensive and ongoing nature of caregiving for their partner. Paid in-home services, such as assistance with daily household tasks, respite care, or personal care, might help ease caregivers' physical strain; however, it is unclear if these in-home services effectively address loneliness and overload and whether their benefits differ by gender. Guided by the Stress Process Model, we analyzed structured interview data from 61 spousal caregivers living in rural Appalachia. Although husbands reported significantly lower loneliness and overload than wives, the overall use of paid services was similar across husbands and wives. Among those experiencing high stress, however, a higher percentage of husbands used in-home paid services than wives. Logistic regression analyses revealed that greater emotional strain (overload and loneliness) and higher functional impairment of the PLwD were independently associated with increased likelihood of paid service use. Our findings underscore the need for programs and policies to acknowledge emotional strain as a legitimate criterion for eligibility for paid services.

KEYWORDS

caregiver burden, loneliness, in-home care services, help-seeking behavior, gender norms, Stress Process Model, informal support, activities of daily living

1 Introduction

Family caregivers play a critical role in supporting the quality of life of persons living with dementia (PLwD), often preventing or delaying placement in assisted living facilities or nursing homes. Among these caregivers, spouses often assume the most sustained and intensive responsibilities, placing them at heightened risk for emotional and physical burden (1, 2). The daily demands of caregiving often constrain spousal caregivers' ability to leave their home or pursue self-care, especially when their partner cannot be left alone. These constraints, compounded by physical fatigue from hands-on care and managing household tasks and emotional exhaustion from managing dementia-related behavioral symptoms, can take a cumulative toll on caregivers' physical, emotional, and social wellbeing (3).

Two forms of emotional strain are especially prevalent among spousal caregivers: caregiver overload and loneliness. Prior research has consistently documented high levels of caregiver overload marked by constant vigilance, fatigue, and limited opportunities for personal time (4). Loneliness is defined as the subjective distress that arises when one's social relationships are perceived as deficient in quality and quantity. Contemporary researchers categorize loneliness into three interconnected facets: emotional loneliness (lack of close attachments), social loneliness (absence of a supportive network of friends and family), and existential loneliness (a feeling of meaninglessness) (5). For spousal caregivers, loneliness may manifest as feeling isolated, cut off from others, and a diminished sense of belonging. Both overload and loneliness are linked to poor mental and physical health, which in turn may compromise spouse caregiver's ability to provide care (6).

To cope with these challenges, some spousal caregivers turn to paid in-home services such as assistance with activities of daily living (ADLs), homemaking, personal care, respite, and rehabilitative therapies. These in-home care services can provide meaningful relief to caregivers by easing the physical and emotional demands of caregiving and creating opportunities for rest and social engagement with others. However, many caregivers, especially in rural regions, avoid or delay using paid care due to financial barriers, lack of awareness of available services, unavailability of services in their area, or discomfort with allowing outsiders into the home (7).

While paid in-home services may help relieve caregiving stress, their potential to alleviate emotional strain, particularly caregiver loneliness, remains less understood. Most research examines how paid services affect older adults with functional limitations, not caregivers specifically. For example, Arsenijevic and Groot, using SHARE data from nine European countries, found no association between reduced government-supported household help and increased loneliness among older adults (8). Conversely, drawing on the China Health and Retirement Longitudinal Study (CHARLS), researchers reported that using home- and community-based services was associated with lower loneliness among Chinese older adults with physical limitations (9). Whether in-home services confer similar emotional benefits for spousal caregivers of PLwD remains an open question.

In addition to emotional strain, caregivers' decision to seek support are shaped by gendered norms (10). While both men and women spousal caregivers of PLwD report elevated levels of caregiving strain, wives were more likely to report poorer mental health outcomes, including higher levels of depression and social isolation (11). These differences reflect not only personal risk factors but also broader social expectations, structural norms, and constraints. Women are more likely to be the primary caregivers, provide more hours of care, and receive less help from others (12). Connidis and McMullin's concept of *structured ambivalence* (13) highlights the internal conflict many women caregivers experience, where cultural expectations of care, combined with limited financial and social resources, can create conflicting pressures and emotional strain even when caregiving is deeply valued (14).

Despite well-established gender differences in caregiver burden, findings on gender and use of paid services are inconclusive. Vipperman et al. report no significant gender difference in paid service utilization among rural dementia caregivers (7). Others have found that differences depend on the type of service. For example, Sun et al. (15) found that men were more likely to use in-home care, while women were more likely to use transportation services; no differences were found in the use of day care and support groups. Qualitative studies offer more nuanced insights into how men and women engage with services (16). For example, Brown et al. (17) noted that husband caregivers often seek help earlier and adopt a managerial approach to caregiving, while in another paper (18), they noted that wife caregivers tend to minimize problems they experience and are more likely not to seek help because they believe they are not too difficult to handle. These patterns suggest that caregiving strain may prompt different help-seeking responses across genders.

The current study is guided by the Stress Process Model, which conceptualizes caregiving stress as arising from both primary demands (e.g., care tasks) and secondary strain (e.g., emotional distress) and emphasizes the role of coping resources, such as paid services, as potential buffers of stressors (19). Within this framework, gender is treated as a contextual factor that influences not only caregivers' exposure to stress but also their access to, and use of, paid support.

Building on this model, our study has two primary objectives:

1. To examine the association between spousal caregivers' experiences of loneliness and overload and their use of paid in-home care services.
2. To assess whether these associations differ by gender.

We hypothesize that the use of paid in-home services will be associated with lower levels of loneliness and overload, particularly among husband caregivers. We further anticipate that these associations will be weaker for wives, who may be experiencing greater internalized caregiving norms and therefore not seeking assistance. By addressing both emotional stress of caregiving and gendered service use patterns, this study aims to contribute to a more nuanced understanding of how to support the wellbeing of spousal caregivers in the context of dementia care.

2 Methods

2.1 Study design and participants

This study draws from a larger mixed-method, two-phase investigation (FACES-AD) that examined the caregiving experiences of family members providing care to PLwD in rural Appalachian counties of Virginia (20). A total of 539 screening calls yielded 233 eligible family caregivers, of whom 183 consented to participate. Twenty caregivers subsequently withdrew after consenting, primarily due to time constraints or acute health problems for the caregiver or PLwD, resulting in a final sample of 163 family caregivers. For the current analysis, we focused on Phase 1 structured telephone interview data of spousal caregivers.

Participants were included if they were (a) the spouse of a person diagnosed with dementia, (b) the primary caregiver involved in day-to-day care, and (c) residing in one of the 23 designated Appalachian counties in Virginia. Additional inclusion criteria included English fluency, telephone access, and a minimum of 10 years of residence in the region. Of the initial sample, 74 spouse caregivers participated (30 husbands, 41%; 44 wives, 59%), and after applying inclusion criteria specific to the current study's analysis, 61 caregivers (23 husbands, 38%; 38 wives, 62%) comprised the final analytic sample.

2.2 Recruitment and procedures

Caregivers were identified through clinical referrals from a large health care system and through local Area Agencies on Aging serving the targeted counties. Recruitment followed a two-step procedure. First, families were mailed study information and were given the option to decline participation. Subsequently, those who did not opt out were contacted by trained interviewers by telephone to confirm eligibility, obtain consent, and schedule the interview. Trained research assistants conducted structured telephone interviews. Each interview lasted ∼60 min and asked questions about caregiving roles, service use, stress, and wellbeing. Data were collected between 2017 and 2019. Institutional Review Boards of [anonymous] Clinic (IRB #19-627) and [anonymous] (IRB#16-776) approved this study.

2.3 Sample characteristics

The sample of spousal caregivers ($M_{\text{age}} = 72$ years, SD = 9.39, Range = 43–89 years) was predominantly White (98%), consistent with regional demographics, and represented long-standing marriages ($M = 43$ years, SD = 17.32, Range = 6–69 years). The majority of caregivers had a high school diploma/GED or some college education (46%), with ∼38% having an associate's, bachelor's or advanced degree. Most caregivers (57%) had annual household incomes under $40,000, and a majority (89%) were not actively employed, being either retired, homemakers, or on disability. Approximately one-third (28%) of participants reported having "just enough money, with none left over," indicating financial strain. The caregiving duration ranged from 3 months to 15 years, with nearly two-thirds (61%) providing care for three or more years.

2.4 Measures

We used key constructs from the Stress Process Model, focusing on caregiving stressors and the use of in-home paid services. We explain these measures below.

2.4.1 Caregiving stressors

Two indicators of secondary stressors, overload and loneliness, were assessed. Overload was measured using the average of three items capturing physical and emotional exhaustion and limitations on personal time, including statements such as "Felt exhausted when you go to bed at night," "Felt that you had more things to do than you can handle," and "Felt that you did not have time just for yourself." Caregivers responded on a four-point Likert-type scale (1 = Never, 4 = Often), with higher scores indicating greater overload ($\alpha = 0.81$) (19). Loneliness was assessed with two of the original three items from the validated three-item UCLA Loneliness scale (21)—"How often do you feel left out?" and "How often do you feel isolated from others?"—plus one item we slightly adjusted for our rural caregivers, "How often do you feel lonely?" We substituted this wording for the original "How often do you feel that you lack companionship" after pre-testing feedback showed that the latter phrasing was unclear to caregivers. Together, the three questions capture the social (left out, isolated) and emotional (lonely) facets of the loneliness definition, but not the existential facet. Caregivers rated these items on a four-point Likert-type scale (1 = Never, 4 = Often), with higher average scores indicating greater loneliness ($\alpha = 0.80$). Caregivers were classified into *'high-stress'* and *'low-stress'* groups using median splits based on the sample distributions. Specifically, caregivers scoring at or above the median (50th percentile) were categorized as *'high-stress'* (overload: scores ≥ 2; loneliness: scores ≥ 1.667), whereas those below these medians were categorized as *'low-stress'* (overload: scores < 2; loneliness: scores < 1.667). The sample mean and standard deviation were 1.95 (SD = 0.88) for overload and 1.63 (SD = 0.92) for loneliness. Caregivers with scores above the median on only one of the variables were not included in the analyses ($n = 13$).

2.4.2 In-home paid care

The primary outcome was the use of in-home paid care, defined as receipt of any formal assistance with activities of daily living (ADLs) provided at home. Caregivers reported whether they used specific services. The proportion of caregivers who reported using each service was as follows: 43% used respite care, 25% used homemaker assistance, 25% used personal care services, 15% used home health nursing, and 5% used meal delivery. A binary variable was created to indicate the use of in-home paid care, coded as 0 for caregivers who did not use any in-home paid services, and 1 for those who used at least one of these services.

2.4.3 Covariates

Two covariates were included to account for contextual influences on caregiver stress and service use. The functional status of the PLwD was assessed using the caregiver's report of their limitations in ADLs, including self-care tasks such as bathing, dressing, eating, grooming, toileting, and transferring in and out of bed. Each activity was rated on a five-point scale (1 = does not need help, 2 = needs reminders or a little help, 3 = needs a lot of help, 4 = cannot do on their own, and 5 = never did or not applicable). This variable represents a primary stressor within the Stress Process Model, capturing the intensity of daily care demands. Responses coded as '5' were treated as missing, and the remaining items were reverse-coded and summed, with lower scores reflecting poorer functioning and greater need for assistance ($\alpha = 0.93$) (22).

Perceived informal support was assessed using eight items reflecting the caregiver's perception of support from family members (23). Items captured both positive (e.g., "How much can you rely on them to help if you have a serious problem?") and negative (e.g., "How often do they let you down when you are counting on them?") aspects of support. Caregivers responded on a four-point Likert-type scale (1 = Not at all, 4 = A lot), with higher scores indicating more perceived support, which represents an enabling resource that may reduce reliance on paid care ($\alpha = 0.80$).

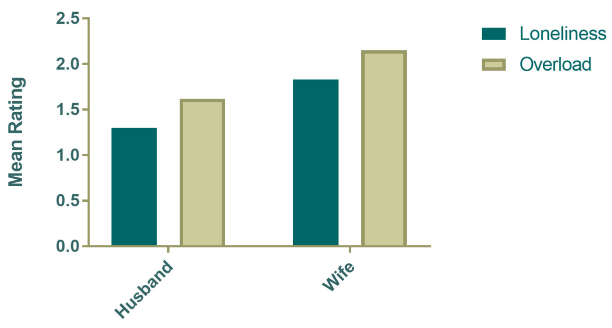

FIGURE 1
Gender differences in caregiver loneliness and overload among spousal dementia caregivers.

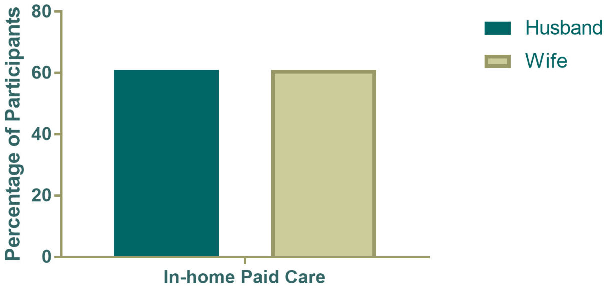

FIGURE 2
Use of paid in-home services by gender of spousal dementia caregivers.

2.5 Analytic strategy

T-test statistics were used to examine gender differences in overload, loneliness, and use of in-home paid services. A subgroup analysis was also conducted to compare service utilization among spousal caregivers classified as high-stress vs. low-stress using Fisher's exact test. The Firth logistic regression model, which is a highly effective method for handling rare events and small sample sizes (24), was used to estimate the odds of using in-home paid services by husband and wife caregivers classified into low- and high-stress groups. Husband caregivers in the low-stress group served as the reference category. The model also included ADL limitations of the PLwD and caregivers' perceived support from family members as covariates. Variance inflation factors (range: 1.17–1.97, all $<$10) indicated no multicollinearity. Parameter estimates, standard errors, and odds ratios (OR), and 95% confidence intervals (CI) are reported. All analyses were conducted using Stata 18.

3 Results

3.1 Gender differences in caregiving stress and in-home service use

As shown in Figures 1 and 2, husbands reported significantly lower levels of loneliness ($t = -2.25$, $p = 0.03$) and caregiver overload ($t = -2.35$, $p = 0.02$) than wives. However, in-home service use did not differ by gender: 61% of husbands and 61% of wives reported using paid in-home services.

3.2 Stress patterns and in-home service use

Among the full sample of spouses, 35 caregivers (57%) were classified as experiencing high levels of both overload and loneliness. Among this high-stress group, 71.43% reported using in-home services (not shown), with 81.8% of high-stress husbands and 66.7% of high-stress wives reported using in-home care services (Figure 3). Although the proportion was higher among men, the difference was not statistically significant (Fisher's exact test, $p = 0.45$).

3.3 Logistic regression model

Results from the Firth logistic regression model are presented in Table 1. Compared to low-stress husbands, high-stress husbands were significantly more likely to use in-home services (OR = 14.33, $p = 0.04$). High-stress wives were also more likely to use in-home services (OR = 8.01, $p = 0.03$). Caregivers who perceived more support from family and friends were more likely to use in-home services (OR = 1.24, $p = 0.03$), suggesting that informal and formal resources may function synergistically. Functional limitations in activities of daily living were a significant predictor of in-home service use. Specifically, caregivers were more likely to use in-home support when the PLwD had greater functional impairments (OR = 0.82, $p = 0.002$). The wide confidence intervals for some interaction terms reflect the small sample size and rare event distribution.

4 Discussion

This study examined the associations among caregiver stress, gender, and the use of paid in-home care services among spousal caregivers of PLwD in rural Appalachia. Consistent with previous research (10, 11), wives reported significantly higher levels of caregiver overload and loneliness than husbands. The overall rates of in-home service use, however, were comparable for husbands and wives. More importantly, among caregivers classified as experiencing high emotional strain marked by elevated loneliness and overload, a higher percentage of husbands reported using paid in-home services compared to wives; however, the difference was not statistically significant, possibly due to small subgroup sample size. Nevertheless, these findings suggest gendered nuances in how emotional strain influences help-seeking behavior.

A key finding of this study was that both the subjective experience of caregiver stress (overload and loneliness) and objective caregiving demands (ADL limitations) were independently associated with in-home service use. Similar to previous research (25) and current eligibility criteria for paid care services in many states (26), caregivers in our study were more likely to use paid support when the PLwD had greater functional limitations. We also found that high levels of emotional strain, regardless of functional impairment, were strongly related to service utilization. This underscores the

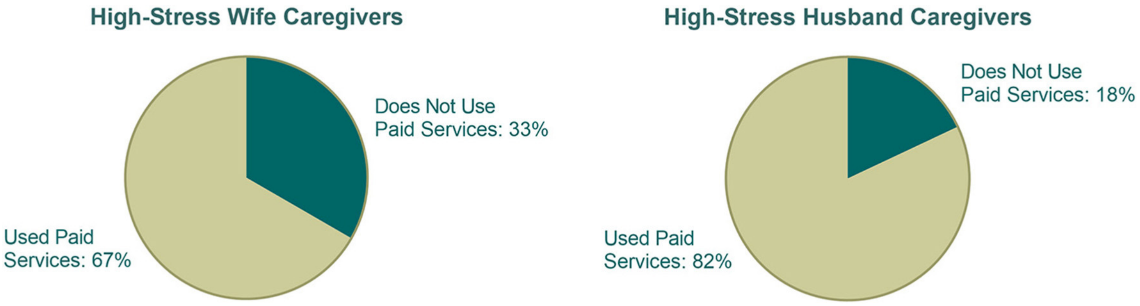

FIGURE 3
Use of paid in-home services by gender among high-stress caregivers.

TABLE 1 Firth logistic regression predicting use of in-home care services by spousal caregivers.

Predictors	*b* (S.E.)	OR	95% CI	*p*-value
Activities in daily living	−0.20 (0.06)	0.82	0.73 – 0.93	0.002
Family support	0.22 (0.10)	1.24	1.03 – 1.50	0.026
Overload/loneliness by gender				
Husbands, low overload/loneliness	Ref.	Ref.	Ref.	Ref.
Wives, low overload/loneliness	0.59 (0.93)	1.80	0.29–11.11	0.525
Husbands, high overload/loneliness	2.66 (1.33)	14.33	1.07–192.46	0.045
Wives, high overload/loneliness	2.08 (0.95)	8.01	1.26–51.10	0.028
Constant	−3.07 (2.71)	0.05	0.0002–9.38	0.257

b, Coefficient; S.E., Standard error; OR, Odds ratio; CI, Confidence interval; Ref., reference group. Model fit: Penalized log-likelihood = −22.33, Wald $\text{Chi}^2(5) = 13.30$, $p = 0.021$. Wide confidence interval for interaction terms reflect small sample size and rare events.

significance of secondary stressors such as caregiver loneliness and overload as meaningful indicators of caregivers' need for assistance from others.

The gender differences in service use, particularly within the high-stress subgroup, align with previous qualitative studies, suggesting that gender of the caregiver shapes service use (16–18). As suggested by these studies, men may be approaching caregiving tasks more pragmatically or managerially, viewing paid assistance as a logical resource to delegate tasks they feel ill-equipped or unwilling to handle. Women, on the other hand, may be internalizing cultural norms around caregiving, and therefore delaying the use of formal support despite experiencing high emotional strain. Although our study shows that many high-stress wives used in-home services, their usage was relatively lower to high-stress husbands, although not statistically significant, suggesting potential internal barriers, such as concerns about giving up caregiving responsibilities—albeit temporarily, discomfort with in-home workers, or guilt related to seeking external help. These results provide empirical support for Connidis and McMullin's *structured ambivalence* framework, highlighting that gendered caregiving expectations may heighten emotional stress, particularly among women caregivers (13, 14).

Our findings have implications for developing gender-sensitive interventions and policies. Current criteria for paid care services are primarily based on care recipients' functional impairments; our results argue for expanding these criteria to incorporate caregiver wellbeing, particularly emotional strain indicators such as loneliness and overload. Such a change could help better align service eligibility with caregivers' lived experiences and potentially mitigate caregiving-related emotional distress that could exacerbate poor health outcomes for the caregiver and unmet needs among PLwD. Additionally, community outreach and marketing efforts should acknowledge gender-specific service-use pathways. Educating men about the practical, task-oriented nature of the paid services might enhance timely uptake. For women, normalizing help-seeking, addressing guilt or stigma associated with asking for assistance, and ensuring services feel culturally acceptable, trustworthy, and aligned with personal caregiving standards may resonate more.

Several limitations warrant caution. We had a modest sample size recruited from a single geographic area, which limits the generalizability of our findings beyond rural Appalachia. Although our loneliness measure demonstrated good internal consistency, we did not use the full, unmodified three-item UCLA Loneliness Scale. Consequently, our scores may not be directly comparable with studies that use the unaltered instrument. Moreover, the cross-sectional design restricts conclusions about the directionality of observed associations between stress and in-home service use. Lastly, we conceptualized service use as a binary variable in this study. Future studies could incorporate more nuanced service utilization measures, such as service use intensity, attitude toward service use, and caregiver satisfaction with services, to get to a deeper understanding of service utilization among high-stress spousal caregivers.

In summary, this study underscores the complexity of spousal caregiving, highlighting the significant role of overload, loneliness, and gender in shaping caregivers' use of paid care services. Tailoring services and outreach to better address gendered caregiving norms and emotional strain can improve the accessibility and uptake of supportive care services by spousal caregivers in rural, under-resourced regions. Future research is essential to further disentangle these relationships and inform targeted interventions to enhance caregiver wellbeing and sustainability.

Data availability statement

The study data are not available because the primary investigators have not completed their original work with the dataset. Requests to access the datasets should be directed to JS, JSavla@vt.edu.

Ethics statement

The studies involving humans were approved by Carilion Clinic (IRB #19-627) and Virginia Tech's Institutional Review Boards (IRB#16-776). The studies were conducted in accordance with the local legislation and institutional requirements. The Ethics Committee/Institutional Review Board waived the requirement of written informed consent for participation from the participants or the participants' legal guardians/next of kin because informed consent and interviews were conducted over the telephone. Before the informed consent was obtained on the telephone, copies of consent forms were mailed to participants. Opting-in and opting-out information was provided in the mailed documents.

Author contributions

JS: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft. KR: Conceptualization, Data curation, Funding acquisition, Project administration, Validation, Writing – review & editing. LF: Conceptualization, Data curation, Investigation, Visualization, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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The author(s) declare that no Gen AI was used in the creation of this manuscript.

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Utilization of home- and community-based services among rural family caregivers of persons with dementia: the role of the area deprivation index

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Background: Dementia significantly impacts rural communities in the U.S., presenting unique challenges for family caregivers due to limited access to essential support services. This study examines the influence of area-level factors on the utilization of home- and community-based services among rural caregivers.

Methods: Using Andersen's extended behavioral model of health services utilization, baseline data (n = 361) from family caregivers participating in a national randomized trial evaluating the *Building Better Caregivers* workshop were analyzed. Participants completed an online survey assessing home- and community-based support services and caregiving aspects. Area-level factors were measured using the Area Deprivation Index (ADI) and U.S. Census region, linked to respondents ZIP+4 code and state. Multivariable logistic regression analyses assessed the relationship between area-level factors and support service utilization.

Results: About 65% of caregivers used at least one support service, with 52% utilizing home-based services and 52% community-based services. Caregivers in the most deprived rural areas were significantly less likely to use any support services (OR = 0.45; 95% CI [0.23, 0.89]) and community-based services (OR = 0.26; 95% CI [0.26, 0.86]) compared to those in the least deprived rural areas. No significant associations were found between Census region and any type of support service utilization.

Conclusion: Service utilization differences within rural areas highlight the need for nuanced, area-specific interventions to enhance support service accessibility for caregivers in deprived rural areas, improving caregiving outcomes. Future research should further investigate area-level variations and their interactions with individual factors to better understand barriers faced by rural caregivers.

Trial registration: https://clinicaltrials.gov/ct2/show/NCT04428112, identifier NCT04428112.

KEYWORDS

social network, socially connected, activities of daily living, area-level factors, neighborhood atlas

1 Introduction

Dementia affects a growing number of individuals in the United States (U.S.), posing significant challenges for family caregivers who are essential in managing the complex needs of people with dementia (PwD). Home- and community-based support services, such as respite care, home health aides, and specialized medical care, have been shown to improve the quality of life for both caregivers and PwD (1, 2). These services, defined as person-centered care delivered in the home and community to individuals with functional limitations who require assistance with daily activities (3). Despite the benefits of these services, many caregivers, particularly those in rural areas, report low levels of utilization (4).

Rural caregivers face unique challenges compared to urban counterparts, including fewer healthcare resources, reduced access to services, and diminished infrastructure to support caregiving (4). Area-level characteristics such as geographic isolation, transportation barriers, and socioeconomic conditions significantly shape access and use in rural settings (5). Understanding these challenges requires a comprehensive approach to identify specific individual- and area-level factors associated with support service utilization in varied rural settings.

Rural areas vary widely in economic conditions, health and social service infrastructures, natural amenities, and capacity to address economic and environmental stressors (6, 7). While some areas struggle with persistent poverty, high unemployment, out-migration, and poor health, others experience transformative demographic and economic changes driven by new industries and innovation (8). The Area Deprivation Index (ADI), a composite measure of socioeconomic deprivation (9), provides a granular lens for examining differences within rural areas. Capturing area-level factors such as poverty, education, housing, and employment (9), the ADI offers an alternative to broad rurality measures like the Urban Influence Code and Rural Urban Continuum Code, making it particularly relevant for understanding rural variability and its impact on support service utilization.

Existing research has examined support service utilization in relation to area-level factors, including U.S. Census region (4), Urban Influence Code (10), Rural Urban Continuum Code (11), residence in a specific rural area (e.g., Appalachia) (12–15), and county-level socioeconomic status (16). However, these broad measures often lack the granularity required to capture the nuanced intersection of socioeconomic deprivation and service utilization. The ADI allows for a more detailed understanding of how rural area-level factors impact support service utilization, filing an important gap in existing literature. While the ADI has been applied in studies investigating home-and community-based services use among veterans (17) and other types of services (18, 19), its application in the context of caregiver support services in rural areas remains novel. By leveraging the ADI at the ZIP+4 code level alongside U.S. Census regions, this study aims to offer a better understanding of rural variability and its influence on support service utilization.

Regional disparities in support service utilization further complicates this picture (4). The U.S. Census Bureau defines four regions: Northeast, Midwest, South, and West. Each region includes states with diverse demographic, economic, and healthcare infrastructure characteristics, which influence service availability and utilization. While regional comparisons provide helpful insights, they fail to account for rural-specific variability within regions. The ADI enables a more detailed analysis of area-level socioeconomic status, offering a multifaceted approach to understanding rural variability and its influence on support service utilization. Understanding these dynamics can inform targeted resource allocation and evidence-based policy development to improve caregiver support services for rural settings across the U.S.

This study is guided by Andersen's extended behavioral model of health services utilization (20), which accounts for both individual- and area-level factors (what Andersen refers to as community-level factors in the model) influencing service use. Predisposing factors, such as demographic characteristics, influence individuals' propensity to utilize services; need factors relate to health issues requiring care; and enabling factors, such as income, facilitate service use (21). Andersen's extended model emphasizes that individual-level factors operate within broader area-level contexts, making it well-suited for analyzing the role of area-level deprivation and Census region in shaping service utilization (20).

Using data from a national randomized controlled trial (RCT) of rural caregivers of PwD, this study investigates the relationship between area-level socioeconomic status, geographic region, and the use of home- and community-based support services among caregivers of PwD residing in U.S. rural areas. We hypothesize that caregivers residing in most deprived rural areas (defined by higher ADI scores) or intermediate deprived rural areas will report lower support service utilization compared to those residing in the least deprived rural areas. We also hypothesize that rural caregivers residing in non-West U.S. Census regions (Midwest, Northeast, or South) will report lower utilization than those residing in the Western region (West), based on evidence suggesting higher service utilization in the West compared to other regions (4).

2 Methods

2.1 Study design and participants

This study is a cross-sectional secondary data analysis of baseline data from a national RCT evaluating an online skills-building workshop, *Building Better Caregivers*, for rural caregivers of PwD ($n = 409$). The parent RCT procedures and intervention are described elsewhere (22). Briefly, participants were recruited in collaboration with rural-serving community organizations. Inclusion criteria consisted of: adult self-identifying as living in a U.S. rural, farming, or small-town area; providing at least 10 caregiving hours per week to a family member or friend with dementia; reporting a stress level of 4+ on a 10-point scale (23); having internet access; and having English proficiency. Participants completed a baseline online survey that included assessments of home- and community-based support services and caregiving aspects. The study protocol was approved by the University of California, San Francisco Institutional Review Board.

This secondary analysis excluded caregivers who were non-relatives ($n = 48$). We focus on family caregivers ($n = 361$) because they may have access to family-based resources that are not available to non-relatives, such as shared housing or financial resources, that may influence support service utilization.

2.2 Measures

2.2.1 Dependent measures

The dependent variables are self-reported current use of home- and community-based support services by caregivers or the PwD they assist. Home-based services include: homemaker assistance, non-medical personal care, home healthcare (e.g., nursing, hospice), and respite care (e.g., overnight respite). Community-based services include: meal delivery, transportation, adult day care, and use of informational services from a case manager/social worker or legal or financial services representative. Respondents answered "yes" or "no" to each service. For each service, "yes" responses were counted. If the count was 1 or greater, then the service was classified as 1 indicating use; otherwise, they were classified as 0. To determine use of any support service, respondents who answered "yes" to any type of service were classified as 1 indicating use; otherwise, they were classified as 0.

2.2.2 Independent area-level measures

Independent variables were area-level factors: socioeconomic deprivation status and geographic Census region. Socioeconomic deprivation status was assessed using the Area Deprivation Index (ADI), a validated composite ranked index (9, 24) based on 17 indicators from the American Community Survey: educational distribution (percentage of population with less than 9 years versus 12 or more years of education), median family income, income disparity, occupational composition, unemployment rate, family poverty rate, percentage of population with income below 150% of the federal poverty level, single-parent household rate, home ownership rate, median home value, median rent, median monthly mortgage, household crowding, and percentages of households without access to plumbing, telephone, or motor vehicle (9). Respondent mailing address Zip+4 code was linked to the 2020 ADI ranking retrospectively. ADI rankings range from 1 to 10, with higher values indicating the most deprived areas (9). Respondents were classified into three groups: those living in the most deprived areas ($ADI \geq 7$), those in intermediate deprived areas ($4 \leq ADI \leq 6$), and those in the least deprived areas ($1 \leq ADI \leq 3$). Geographic region was determined by caregiver state of residence and categorized according to U.S. Census regions: Midwest, Northeast, South, and West.

2.2.3 Individual-level measures

Models adjusted for individual-level predisposing, need, and enabling factors.

Predisposing factor measures included caregiver age in years categorized as younger (18–64 years) or older (65 + years), gender (woman, man, refused), caregiver race or ethnicity (White, Black/African American, Latino/Hispanic, Native American/American Indian/Alaska Native, Asian/Asian American, Native Hawaiian/Other Pacific Islander, mixed race, other race) and education (high school or less, technical school or associate's degree/some college, college graduate or higher), relationship to the PwD (parent, spouse), and co-residence with their PwD (co-reside, do not co-reside). Respondents also reported the age and gender of the PwD.

Need factor measures were the everyday cognition level of the PwD, PwD functional limitations, and care burden. *Everyday cognition* was assessed using the 12-item Everyday Cognition (ECog-12) measure (25). The ECog-12 score was created by averaging items. Scores ranged from 1 to 4. Higher scores indicate more cognitive impairment.

Functional limitations of PwD was measured using a checklist of activities of daily living (ADLs). The 6-item ADL checklist included needing help getting out of bed, getting across a room, dressing, toileting, bathing, and eating. Responses were summed, with scores ranging from 0 to 6. ADL scores were categorized as meeting nursing home placement criteria ($score \geq 3$) and not meeting criteria ($score < 3$) (26).

Caregiver burden was assessed with the 12-item Zarit Burden Inventory short form (27). Responses were summed, with scores ranging from 0 to 48. Scores were categorized as high burden ($score > 20$) or none-to-moderate burden ($score \leq 20$).

The *enabling factor* measure was caregiver *social network,* assessed using the 6-item Lubben Social Network Scale (28). A total score was the sum of items, with scores ranging from 0 to 30. Scores were categorized as socially connected ($score \geq 13$) or not socially connected ($score < 12$) (28).

2.3 Statistical analysis

Descriptive statistics of measures were obtained to summarize the data. Categorical variables are expressed as number of subjects and percentage. Continuous variables are presented as mean and standard deviation (SD). Analysis of variance (ANOVA), t test, and chi-squared test were, respectively, used to assess whether continuous and categorical variables differed by area deprivation levels and Census regions separately (tables not shown). Correlations between the different types of support services (any, home- and community-based), area-level factors, and individual-level factors (table not shown) were examined for multicollinearity and deemed multicollinear if the Variance Inflation Factor (VIF) exceeded 5. No multicollinearity was detected. To assess associations between area-level factors and support service utilization, we first conducted bivariate analysis for the area-level factors (e.g., area deprivation levels, Census regions) with the utilization of each type of support service using chi-squared tests and univariate logistic regression. Then, we conducted multivariable logistic regression analyses on the associations between area-level factors and support service utilization while controlling for individual level variables (predisposing, need, and enabling factors). Predisposing factors, caregiver race or ethnicity and education, were excluded from the analysis due to limited variability. Unadjusted and adjusted odds ratio (OR), 95% confidence interval (CI), and *p*-values were calculated. Statistical significance was defined at $p < 0.05$. Analyses were conducted using SAS 9.4.

3 Results

As shown in Table 1, among 361 family caregivers, the mean age was 63.4 (SD = 10.4). The majority were women (83%) and self-identified as White (87%). Over half (57%) had completed a college degree or higher. Fifty percent of caregivers provided care to a spouse, while the remaining 50 % cared for a parent. The majority (80%) co-resided with their PwD. A little less than two-thirds (64%) of caregivers reported being socially connected. Among PwD, the average age was 79.1 (SD = 9.5) and 52% were women.

TABLE 1 Descriptive characteristics of family caregivers and persons with dementia and key study variables ($N = 361$).

Mean (SD; range)	Total
Caregiver	
Age	63.4 (10.4; 30–86)
Gender, *n* (%)	
Women	299 (83%)
Men	58 (16%)
Prefer not to answer	4 (1%)
Race or ethnicity, *n* (%)	
White	315 (87%)
Black or African American	13 (4%)
Hispanic or Latino	13 (4%)
American Indian/Alaska Native	6 (2%)
Other[a]	14 (3%)
Education, *n* (%)	
Less than college graduate	156 (43%)
College graduate with bachelor's degree or higher	205 (57%)
Relationship to person with dementia, *n* (%)	
Spouse	180 (50%)
Parent	181 (50%)
Co-resides with person with dementia, *n* (%)	
Yes	288 (80%)
No	73 (20%)
Care burden, *n* (%)	
None to moderate	129 (36%)
High	232 (64%)
Socially connected, *n* (%)	
Yes	231 (64%)
No	130 (36%)
Area deprivation level, *n* (%)	
Least deprived rural areas	75 (21%)
Intermediate deprived rural areas	102 (28%)
Most deprived rural areas	184 (51%)
U.S. Census region, *n* (%)	
West	124 (34%)
South	88 (24%)
Midwest	80 (22%)
Northeast	69 (19%)
Person with Dementia	
Age	79.1 (9.5; 52–100)
Gender, *n* (%)	
Women	188 (52%)
Men	173 (48%)
Level of cognitive impairment[b]	3.3 (0.7; 1.2–4.0)
Needs assistance with ≥3 activities of daily living, *n* (%)	
Yes	133 (37%)
No	228 (63%)
Support services utilized	
Any service, *n* (%)	234 (65%)
Home-based services[c], *n* (%)	189 (52%)
Community-based services[d], *n* (%)	187 (52%)

SD refers to standard deviation.

[a] Other includes Asian/Asian American, Native Hawaiian/Other Pacific Islander, mixed race, and other race.

[b] Cognitive impairment, possible range 1–4, higher = worse.

[c] Home-based services include: homemaker services, non-medical personal care, respite care, and home health care.

[d] Community-based services include: meal delivery, transportation, adult day care, and informational services from a case manager/social worker or legal or financial services representative.

The average level of cognition was 3.3 (SD = 0.7) indicating moderate or greater impairment, and 37% needed assistance with 3 or more ADLs. Almost two-thirds (64%) of caregivers reported high care burden.

Over half (51%) of caregivers lived in the most deprived rural areas, 28% lived in intermediate deprived areas, and 21% lived in the least deprived areas. Caregivers were represented across all four Census regions: 34% West, 24% South, 22% Midwest, and 19% Northeast.

Approximately two-thirds (65%) of caregivers used at least one service (Table 1), and an equal percentage of caregivers utilized home-based services (52%) and community-based services (52%).

3.1 Bivariate results

In bivariate analysis, we examined any support service use based on area deprivation level and Census region. As shown in Figure 1, caregivers in the least deprived rural areas reported the highest use of any service (76%), followed by those in intermediate deprived areas (63%) and those in the most deprived areas (61%). A statistically significant difference was observed between the least and most deprived rural areas (76% vs. 61%, $p = 0.026$). Caregivers residing in the most deprived areas had significantly lower odds of using any support service (OR = 0.48, $p = 0.0201$) compared to those residing in the least deprived areas.

For home-based services, caregivers in the least deprived rural areas reported the highest usage (60%), compared to similar rates in the intermediate deprived (49%) and most deprived (51%) areas. However, no statistically significant differences in the use of home-based services were found between the three deprivation groups (see Figure 1).

For community-based services, caregivers in the least deprived rural areas had the highest usage (60%), followed by those in areas with intermediate deprivation (56%) and those in the most deprived areas (46%). A statistically significant difference in the use of community-based services was observed between the least and most deprived rural areas (60% vs. 46%, $p = 0.0449$, see

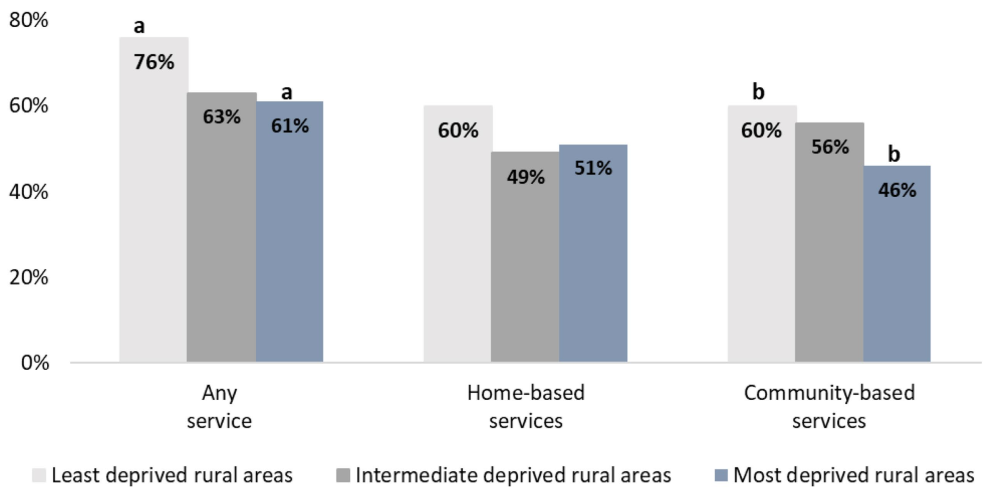

FIGURE 1
Support services utilized among family caregivers and persons with dementia by area deprivation index (N = 361). [a,b]There is a statistically significant difference between the least and most disadvantaged areas for these services, with a $p < 0.05$. Home-based services include: homemaker services, non-medical personal care, respite care, and home health care. Community-based services include: meal delivery, transportation, adult day care, and informational services from a case manager/social worker or legal or financial services representative.

Figure 1). Caregivers residing in the most deprived areas (OR = 0.53, p = 0.0270) had significantly less odds to use community-based support services compared to those residing in the least deprived areas.

As shown in Figure 2, caregivers in the Northeast region of the U.S. reported the highest use of any service (71%), home-based (61%), and community-based (59%) compared to all other regions. However, no statistically significant differences were found between the regions for utilization of each type of support services.

3.2 Multivariable results

Table 2 displays results from the adjusted multivariable logistic models on caregiver self-reported use of different types of support services.

3.2.1 Utilization of any support service

In adjusted models, caregivers residing in intermediate deprived rural areas (OR = 0.39, p = 0.014) and those residing in the most deprived rural areas (OR = 0.45, p = 0.021) both had significantly lower odds of utilizing any support services compared to caregivers in the least deprived areas. The odds of utilizing any support service was not associated with any Census region. Among individual-level factors, the odds of using any support service were lower for women (OR = 0.46, p = 0.029) compared to men and those co-residing with their PwD (OR = 0.47, p = 0.049) compared to those not co-residing. Caregivers caring for a parent (OR = 2.67, p = 0.004) compared to those caring for a spouse had significantly higher odds of using any support service. Similarly, caregivers caring for a PwD requiring assistance with 3 or more ADLs (OR = 3.09, p = 0.0001) compared to those supporting a PwD requiring assistance with < 3 ADLs had significantly higher odds of using any support service. Caregivers socially connected (OR = 1.80, p = 0.025) compared to those not socially connected had significantly higher odds of using any support service.

3.2.2 Utilization of home-based support services

In adjusted models, utilizing home-based support services was not associated with either area-level deprivation or any Census region. Among individual-level factors, the odds of using home-based support services were lower for women (OR = 0.36, p = 0.003) compared to men. Caregivers caring for a parent (OR = 3.04, p = 0.001) compared to those caring for a spouse had significantly higher odds of using home-based support services. Caregivers caring for a PwD requiring assistance with 3 or more ADLs (OR = 3.81, p < 0.0001) compared to those supporting a PwD requiring assistance with < 3 ADLs had significantly higher odds of using home-based support services. Caregivers socially connected (OR = 1.94, p = 0.011) compared to those not socially connected had significantly higher odds of using home-based support services.

3.2.3 Utilization of community-based services

In adjusted models, caregivers residing in the most deprived rural areas (OR = 0.48, p = 0.015) had significantly lower odds of using community-based support service compared to those residing in the least deprived rural areas. The odds of utilizing community-based support services was not associated with any Census region. Among individual-level factors, the odds of using community-based support services was lower for caregivers co-residing with their PwD (OR = 0.44, p = 0.015) compared to those not co-residing. Caregivers caring for a parent (OR = 2.05, p = 0.022) compared to those caring for a spouse had significantly higher odds of using community-based support services. Caregivers caring for a PwD requiring assistance with 3 or more ADLs (OR = 1.74, p = 0.033) compared to those supporting a PwD requiring assistance with < 3 ADLs had significantly higher odds of using community-based support services. Caregivers

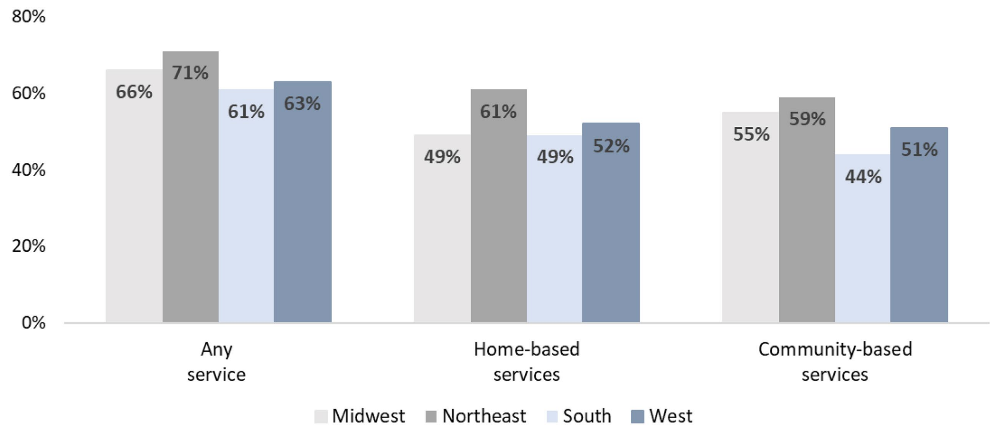

FIGURE 2
Support services utilized among family caregivers and persons with dementia by U.S. Census region (N = 361). Home-based services include: homemaker services, non-medical personal care, respite care, and home health care. Community-based services include: meal delivery, transportation, adult day care, and informational services from a case manager/social worker or legal or financial services representative.

socially connected (OR = 1.72, p = 0.027) compared to caregivers not socially connected had significantly higher odds of using community-based support services.

4 Discussion

Our study investigated the utilization of home- and community-based support services among rural caregivers of PwD, focusing on the influence of area-level factors: socioeconomic deprivation status and geographic Census region. Findings highlight significant variation in service utilization across rural areas. Caregivers residing in the most deprived rural areas were substantially less likely to use any support services and community-based services compared to those in the least deprived rural areas. These results align with our hypotheses, underscoring the crucial relationship between area-level deprivation status and successful utilization of services. While area-level deprivation did not predict the utilization of home-based support services, the observed effect size suggests a potentially meaningful relationship that warrants further investigation.

Contrary to initial hypotheses, our study found no significant association between geographic Census region and support service utilization, which contrasts with previous research (4). This suggests that socioeconomic status within rural areas is a more critical determinant of service utilization than regional Census location. Our use of ADI offered a detailed measure of area-level socioeconomic status, enabling a more nuanced understanding of its impact on service utilization. Additionally, focusing on granular-level data, such as ZIP+4 codes, rather than larger regions, provides a more accurate depiction of rural area-specific disparities. Our findings align with previous research on hospital utilization suggesting that utilizing smaller geographic levels enhances measurement precision and may result in targeted policies that more effectively address rural disparities (29). Future research should delve deeper into specific area-level variations and their interactions with socioeconomic factors to better understand the complex barriers faced by rural caregivers.

Our analysis further underscores the complexity within rural classifications, demonstrating that not all rural areas face the same level of deprivation. Rural areas vary significantly in terms of health and social service infrastructures, economic conditions, and natural amenities (6, 7). The current analysis suggests that caregivers in the most deprived rural areas face heightened barriers to accessing support services, likely due to persistent poverty, high unemployment, and limited healthcare resources (8). In contrast, caregivers in the least deprived rural areas have access to better infrastructure and more services. Examining other area-level factors such as local healthcare infrastructure and community resources could provide further insights into improving support service accessibility, especially for communities most in need.

At the individual-level, several factors were significantly associated with support service utilization. Women were less likely to use both any support services and home-based support services compared to men. This may reflect gender differences in caregiving roles and perceived need for external support (6, 30). Additionally, caregivers who co-resided with PwD were less likely to use services, which might be due to practical challenges (e.g., transportation issues, time constraints) in accessing services or a greater reliance on informal care within the household.

Caregivers providing care to parents, those caring for individuals needing assistance with three or more ADLs, and those who reported being socially connected were more likely to use support services. Prior studies have found that caregivers reporting having a social network, family support, or social support were more likely to utilize services early in the dementia trajectory (12, 31, 32). Our findings are similar in that the presence of social connectedness was associated with higher service utilization. However, other studies have noted that social networks diminish as dementia progresses, resulting in underutilization of support services (33, 34). Although our study did not assess the duration of dementia, more than half of PwD in our study exhibited moderate–severe cognitive impairment, indicating they were in the later stages of disease and may have needed assistance with three or more ADLs. These findings highlight the importance of social support networks and degree of cognitive impairment as drivers

TABLE 2 **Unadjusted and adjusted odds ratio (OR) of using any, home-based, or community-based services among family caregivers of persons with dementia (*N* = 361).**

Characteristic	Any service		Home-based services		Community-based services	
	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)	Unadjusted OR (95% CI)	Adjusted OR (95% CI)
Intermediate deprived rural areas (ref. Least deprived rural areas)	0.54 (0.28, 1.05)	0.39 (0.19, 0.82)*	0.65 (0.35, 1.19)	0.52 (0.26, 1.03)	0.86 (0.47, 1.58)	0.68 (0.36, 1.32)
Most deprived rural areas (ref. Least deprived rural areas)	0.48 (0.26, 0.89)*	0.45 (0.23, 0.89)*	0.64 (0.37, 1.21)	0.63 (0.34, 1.19)	0.53 (0.30, 0.93)*	0.48 (0.26, 0.86)*
Northeast region (ref. West)	1.47 (0.78, 2.80)	1.04 (0.50, 2.14)	1.42 (0.78, 2.59)	1.00 (0.50, 1.99)	1.48 (0.81, 2.71)	1.15 (0.59, 2.24)
South region (ref. West)	0.88 (0.50, 1.56)	0.71 (0.37, 1.35)	0.84 (0.48, 1.46)	0.62 (0.33, 1.16)	0.70 (0.40, 1.22)	0.61 (0.33, 1.12)
Midwest region (ref. West)	1.06 (0.58, 1.94)	1.04 (0.50, 2.14)	0.82 (0.46, 1.46)	1.00 (0.50, 1.99)	1.05 (0.59, 1.86)	0.94 (0.50, 1.76)
≥ 65 years old (ref. 18–64 years old)	–	1.60 (0.87, 2.92)	–	1.11 (0.62, 1.97)	–	1.52 (0.86, 2.67)
Women (ref. Men)	–	0.46 (0.23, 0.93)*	–	0.36 (0.19, 0.71)**	–	0.57 (0.31, 1.06)
Parent (ref. Spouse)	–	2.67 (1.37, 5.18)**	–	3.04 (1.59, 5.80)***	–	2.05 (1.11, 3.80)*
Co–resides with person with dementia (ref. Does not co–reside)	–	0.47 (0.22, 0.99)*	–	0.78 (0.40, 1.52)	–	0.44 (0.23, 0.85)*
Cognitive impairment	–	1.38 (0.93, 2.02)	–	1.43 (0.97, 2.11)	–	1.20 (0.83, 1.74)
Person with dementia needs assistance with ≥3 ADL (ref. Needs assistance with < 3 ADLs)	–	3.09 (1.73, 5.53)***	–	3.81 (2.22, 6.56)****	–	1.74 (1.05, 2.90)*
High care burden (ref. None to moderate burden)	–	1.08 (0.65, 1.81)	–	0.91 (0.55, 1.52)	–	1.58 (0.98, 2.56)
Socially connected (ref. Not connected)	–	1.80 (1.08, 3.01)*	–	1.94 (1.17, 3.24)*	–	1.72 (1.06, 2.78)*

CI, confidence interval; ref, reference; ADLs, activities of daily living.

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$; ****$p < 0.0001$.

Home-based services include: homemaker services, non-medical personal care, respite care, and home health care.

Community-based services include: meal delivery, transportation, adult day care, and informational services from a case manager/social worker or legal or financial services representative.

of service utilization. Interventions aimed at enhancing social connectivity and addressing caregiving burdens related to cognitive impairment may improve service use.

Our study did not measure factors such as falls, hospitalizations, or other clinical indicators that may prompt clinician orders for home-based services. These orders, often tied to insurance (e.g., Medicare) benefits, could promote access to supportive services, particularly in areas of deprivation. As such, our findings indicating that persons requiring assistance with three or more ADLs had greater odds of using any supportive service should be interpreted with caution. Future research should include clinical variables, along with insurance coverage criteria, to better understand their impact on service uptake.

This study underscores the complex interplay between individual-level and area-level factors in shaping the utilization of support services among rural caregivers. The findings have important implications for research and practice. Longitudinal studies are needed to understand how changes over time in ADI-level socioeconomic conditions influence support service utilization patterns. Additionally, qualitative research could provide deeper insights into caregiver social connectivity, burden, and perceptions of support services. These findings could inform more targeted interventions, such as content for online caregiver support programs or mobile app-based solutions. Tailored approaches that account for individual caregiver characteristics and needs may improve service utilization and enhance the quality of life for both caregivers and PwD.

To address disparities in service utilization, the ADI can be leveraged to identify caregivers in high-deprivation areas and help connect them with accessible resources. Promoting support services through local media (e.g., radio, newspapers) can increase visibility and engagement. Additionally, outreach initiatives, such as distributing informational flyers, posters, and newsletters through local businesses, community organizations, schools, and healthcare providers, can further enhance awareness of available services. Strengthening referral systems is a critical step in this effort. Healthcare systems and local aging services organizations can maintain up-to-date directories of local services, including home health aides, transportation assistance, meal delivery programs, and caregiver support groups, to provide timely and accurate referrals. ADI data can also be used to identify regions with high levels of deprivation and determine whether or not existing home- and community-based support services serve those areas, which would allow resources to be more effectively targeted to areas of greatest need.

This study included a geographically diverse sample of rural caregivers but has limitations to consider. The cross-sectional design of the study precludes the ability to infer causality between area-level factors and support service use. The parent RCT was not powered to detect possible differences among different service utilization factors. Caregivers who participated in the parent RCT may differ from those who did not enroll with respect to service utilization patterns, ability to complete an online survey, cultural differences, health status, or other unmeasured characteristics. Participants were not asked to report additional details about the services they received, e.g., agency providing service, service duration, reason for utilizing service (dementia versus other reason), or insurance eligibility. Self-reported utilization was not independently confirmed. This study did not assess the number or accessibility of services in caregivers' geographic area. Future research could benefit from using in-person recruitment methods, expanding the range of variables influencing service utilization, conducting qualitative interviews to explore caregiver experiences with service utilization, and mapping service availability in rural communities to better capture the realities of caregiving in rural areas.

Our study provides valuable insights into the disparities in support service utilization among rural caregivers of PwD, highlighting the significant associations between area deprivation level and service use. Addressing these disparities through targeted research and area-specific interventions is crucial for improving the quality of life for both caregivers and PwD in rural areas. By focusing on variations in area deprivation within rural regions, future efforts can more effectively bridge the gap in service utilization and support the needs of caregivers in rural areas.

Data availability statement

The data analyzed in this study is subject to the following licenses/restrictions: The data that support the findings of this study are available from the corresponding author upon reasonable request. Requests to access these datasets should be directed to Jasmine Santoyo-Olsson, jasmine.santoyo-olsson@ucsf.edu.

Ethics statement

The studies involving humans were approved by University of California, San Francisco Institutional Review Board (#18-25814). The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

JS-O: Writing – original draft, Conceptualization, Software, Writing – review & editing, Funding acquisition, Project administration, Formal analysis, Methodology, Visualization, Data curation. KC: Writing – review & editing, Investigation, Formal analysis, Project administration, Data curation, Methodology. JC: Formal analysis, Methodology, Project administration, Data curation, Investigation, Writing – review & editing. DG: Project administration, Writing – review & editing, Investigation, Data curation, Formal analysis, Methodology. VY: Writing – review & editing, Conceptualization, Investigation, Funding acquisition, Supervision, Resources, Validation, Data curation, Project administration, Methodology, Formal analysis.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Older caregivers' responsibilities and strategies for their cohabiting partners living at home—a qualitative systematic literature review

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Background: Ageing-in-place policies have increasingly shifted elder care responsibilities onto family members. Among older cohabiting couples, one's partner's illness significantly impacts the other's daily life and well-being.
Aim: To explore the responsibilities and strategies of caregiving partners in older cohabiting couples from the perspectives of cohabiting caregivers.
Methods: A qualitative systematic literature review was conducted across seven databases, following PRISMA guidelines and registered in PROSPERO (CRD42025632103). Sixty-five studies were included based on predefined inclusion and exclusion criteria using Covidence. Quality was assessed using the Critical Appraisal Skills Programme (CASP) checklist for qualitative studies. Data were synthesised through descriptive numerical summaries and thematic analysis.
Results: The studies, conducted in 20 countries, primarily used individual interviews for data collection. Three overarching themes emerged: (1) strategies directed towards the partner, (2) strategies to maintain personal identity and space, and (3) strategies for navigating formal care systems. Cohabiting caregivers often assumed daily responsibilities despite emotional and physical strain. They relied on both informal and formal support to care for their partner and preserve time for themselves. However, formal care involvement led to issues such as broken agreements and inadequate services.
Conclusion: Older cohabiting caregivers constantly balance and adapt their caregiving roles in relation to their partner, themselves, and formal care providers. This shift in responsibility results in an often invisible, morally-driven labour that remains under-recognised in Ageing-in-place policies. The study highlights the need for policy frameworks and interventions that acknowledge caregivers' moral labour, enhance the quality of formal care, and support caregiver autonomy.
Clinical trial registration: https://www.crd.york.ac.uk/PROSPERO/view/CRD42025632103, identifier (CRD42025632103).

KEYWORDS

ageing-in-place, caregiver burden, cohabiting partners, older adults, qualitative systematic literature review, responsibilities, roles

Introduction

Healthcare services are continuously evolving due to advancements in knowledge, changes in the population's health conditions, and demographic shifts, creating a substantial and continuous influence on global population dynamics (1). As part of this evolving landscape, there is a shift away from institutional care as the conventional standard for older adults and contemporary trends indicate a growing preference for and acknowledgement of older adults' preference for living at home into advanced age, also called 'Ageing-in-place' (1–3). In many western countries, governments have outlined Ageing-in-place policies that shift the responsibility of elder care from health professionals to family members (4–6). Ageing-in-place is generally presented as beneficial for the well-being and autonomy of older adults, given that remaining in familiar surroundings can improve quality of life and foster a sense of security and dignity (7–9). However, it can carry implicit expectations about life at home in old age (10, 11) that shape societal perceptions as to what a 'good' life means in old age (12, 13). Hence, concerns have arisen regarding the impact of discourses on successful, active, and healthy ageing on older adults (14), which often impose expectations on how older adults should lead their lives (11, 14) and overlook the fact that old age is not a homogeneous experience (15, 16).

Ageing-in-place policies also have complex implications, particularly as they increasingly rely on partners and other family members to provide necessary support (4, 17, 18, 126). Partners often serve as the primary source of care in later life (19, 20). The interaction between older couples and their environments influences how they experience and adjust to old age at home, creating a dynamic that is personal, social, and physical (21, 22). For instance, research highlights that couples often frame their frailty and health issues differently, depending on their collective outlook and shared memories, as they prepare for future possibilities, including end-of-life (23, 24). While many partners willingly assume caregiving responsibilities, it cannot be assumed that they are all enabled or willing to do so (25). In couples with low quality relationships, partners may not want to provide care (26). In addition, traditional gendered expectations significantly affect caregiving, where providing care for a partner is viewed as a feminine role for the wives rather than husbands (19, 27, 28). However, this is not always the case, as a study from the Netherlands found no gendered differences in the likelihood of older adults to receive care from their partner, rather it was influenced more by other factors such as the partner's ability to provide care or relationship quality (29).

Frailty in one partner often leads to transformation in the partners' relationship, where caring becomes integral to everyday life and is influenced by their unique life courses and histories together (30). Older couples frequently adapt to challenges through shared routines and mutual support, relying on long-standing companionship to help maintain each other's wellbeing (27). Rather than restricting fulfilment, this shift in roles can deepen connection and purpose between partners, challenging assumptions about loss of independence (30–32). Partner caregiving often entails a dual role, as caregivers must also manage their own age-related health challenges (19, 33). This underscores the diverse ageing experiences, with the past and future continuing to shape partners' care roles (23, 34). While caregiving can be deeply meaningful, it presents distinctive physical, emotional, and social strains, especially as both partners experience the ageing process individually and together. Many older adults depend on their partners for support, whether by choice or financial necessity, creating a unique caregiving dynamic where both partners may confront similar physical or cognitive limitations (22, 27, 28), though to varying extents as one is able to fully or partially care for the other at home.

Recent literature reviews characterise informal caregiving for frail or ill older adults, such as those living with dementia, multimorbidity, or undergoing cancer treatment, as a demanding and often burdensome job (18, 27, 35–39). Caregivers manage daily activities, face a gradual erosion of reciprocity in their relationships, and risk social isolation. At the same time, they are often required to provide instrumental, preventive, and emotional care, frequently at the expense of their own well-being and personal routines. While some studies highlight positive aspects, such as personal growth, enhanced relational closeness, and family cohesion, the literature remains fragmented, particularly regarding how cohabiting partner caregivers understand and manage their responsibilities and sustain caregiving in everyday life. This reveals a significant knowledge gap concerning the everyday practices and strategies of cohabiting caregivers navigating these complex roles. Through a review of the existing literature, this study aims to explore the responsibilities and strategies of the caregiving partners in older couples living at home, from the perspectives of cohabiting older adults.

Method

This study carried out a qualitative systematic review to synthesise insights from qualitative studies, following a method adapted from Bettany-Saltikov and McSherry (40). It is conducted in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (41), and the review protocol is registered with PROSPERO (registration number CRD42025632103).

Identifying the research questions

This review aimed to answer the following three research questions:

1. What are the well-being and health conditions of cohabiting older adults living at home?
2. What responsibilities did cohabiting caregivers have for their partner and themselves in daily life?
3. What strategies did cohabiting caregivers use to make daily life work for themselves and their partner?

Inclusion and exclusion criteria

The inclusion criteria were: (1) Studies about responsibilities and strategies of the caregiving partners in older couples living at home, (2) Perspectives of older cohabiting caregivers and care receivers at home, age 60 + years old, (3) Qualitative studies or qualitative sub-studies in mixed method studies, (4) Published in English, French, or Scandinavian languages, and (5) Published between 1 January 2015–28 January 2025 to align with the latest evidence related to the study's aim. The review excluded: (1) Systematic literature reviews, (2) Intervention studies, (3) Editorials/commentaries, (4) Dissertations/theses, and (5) Guidelines/recommendations. Old age is defined differently across academic traditions and countries, with thresholds ranging from 50 to 70 years. For this study, we included studies involving adults aged 60 and older, as our preliminary literature search identified this age range as the most used definition.

Searching, selecting, appraising, and extracting relevant data

A search was performed in the PubMed, EMBASE, CINAHL Complete, Eric, SocINDEX, and PsycInfo databases with support from an experienced librarian (Last search: 28 January 2025). Inclusion and exclusion criteria were defined according to the Population, Exposure, and Outcome (PEO) model. The PEO model was selected because it offers a structured approach to framing research questions and organising data, which aligns effectively with qualitative methodologies (40, 42). The search strategy followed the building block approach structured around the PEO model (Table 1).

Search terms within each block were tailored to suit the specific requirements of each database. Details of the search strategies are provided in Table 2.

The initial search yielded 9,404 publications, which were imported into Covidence software for screening. Two authors (SG and HX) jointly conducted the title and abstract selection process, and three authors (SG, HX and RJAG) the full text screening. To identify additional relevant studies beyond those retrieved using the current search strings, a citation pearl search was conducted in the Web of Science database (Last search: 5 March 2025). This process involved two approaches: (1) examining the reference lists of the included articles to identify further relevant publications, and (2) exploring newer publications that cited the included articles to assess their relevance for inclusion in the current literature review. For any disagreements during screening, full-text review, or pearl search, discussions were held with the co-authors until consensus was achieved. If the two authors (SG and HX) disagreed or were in doubt about a publication's relevance in the initial screening process, the publication was included in the full-text screening. In cases of disagreement during full-text screening, a third author (RJAG) read the articles and a consensus decision was reached. No disagreements remained regarding final inclusion or exclusion, as discussions mainly concerned articles that addressed the study's aim only partially in their results. Finally, the third author (RJAG) read and assessed all included publications and supported their inclusion. A PRISMA flow diagram (Figure 1) details the study selection process, with the 65 included publications.

TABLE 1 Populations, exposures, and outcomes (PEO).

Population (P)	Exposure (E)	Outcome/ Theme (O)
Older caregivers caring for their partners	Home care environment in primary care	Responsibilities and strategies of the caregiving partners from the perspectives of cohabitant older caregivers and partners

The quality of the included publications was evaluated using the Critical Appraisal Skills Program (CASP) qualitative study checklist (43), ensuring the review's findings were based on credible, high-quality evidence and reflecting a commitment to methodological rigor. Its use was supported by the Cochrane Qualitative and Implementation Methods Group (44). This checklist comprised 10 questions that assess various aspects of the studies, such as their aims, methodology, design, recruitment strategies, data collection, data analysis, findings, and overall research significance, as detailed in Table 3. The quality appraisal aimed to ensure the robustness of the evidence in addressing our research question.

Analytical strategy

The data analysis strategy comprised a descriptive numerical summary analysis, titled 'Characteristics of the Studies,' and a reflexive thematic analysis, inspired by Braun and Clarke's (45) approach. Initially, the publications were read multiple times to ensure thorough familiarisation with the material (45). The following data were extracted by all the authors: (1) Authors, (2) Location, (3) Journal, (4) Study period, (5) Study design, (6) Sample size, (7) Target group and context, (8) Theory/concepts, (9) Results, and (10) Limitations. The focus of data extraction was on the qualitative findings pertinent to the review's aim and research questions (40). The included studies span a range of contexts and countries, each with distinct cultural and healthcare system characteristics. To manage this diversity, we focused on extracting data relevant across various settings while acknowledging contextual differences. This process was guided by the study's aim and research questions, and did not require standardized data extraction forms. SG, HX and RJAG verified the extracted data for accuracy and ensured that all relevant results were extracted, and discussed with each other, if they were in doubt. A selection of the extracted data is presented in Table 4.

The result sections of the publications were initially coded and then reorganised to align with the review's research questions (45). From these codes, preliminary themes were developed by examining patterns of similarity and difference. Codes with similar meanings were clustered together to form overarching themes. The themes were reviewed and refined through a collaborative process among the authors. This involved multiple iterations, where the themes were revisited alongside the empirical data and research questions to ensure that the themes accurately reflected the data (45). In the final stage, each main theme and its sub-themes were clearly defined, refined, and named. They were thoroughly reviewed to ensure they were both succinct and sufficiently descriptive (45). The resulting themes and subthemes are presented in Figure 2.

Results

Characteristics of the studies

The studies were conducted in Sweden (*n* = 12), United Kingdom (*n* = 12), Norway (*n* = 7), China (*n* = 6), United States of America (*n* = 5), Canada (*n* = 4), Australia (*n* = 3), Finland (*n* = 3), Iceland (*n* = 2), Netherlands (*n* = 2), New Zealand (*n* = 2), Brazil (*n* = 1), Iran (*n* = 1), Ireland (*n* = 1), Israel (*n* = 1), Italy (*n* = 1), Japan (*n* = 1),

TABLE 2 Search strategies.

Search line #	Search terms	Results
PubMed		
#1	Aged[Mesh]OR aged[Title/Abstract] OR old[Title/Abstract] OR older[Title/Abstract] OR elder[Title/Abstract] OR older adults[Title/Abstract] OR senior[Title/Abstract] OR seniors[Title/Abstract] OR octogenarian*[Title/Abstract] OR pensioner*[Title/Abstract] OR dementia*[Title/Abstract]	5,634,835
#2	caregiv*[Title/Abstract] OR care giv*[Title/Abstract] OR care provid*[Title/Abstract] OR care staff[Title/Abstract] OR community care[Title/Abstract] OR partner*[Title/Abstract] OR spouse*[Title/Abstract] OR cohabit*[Title/Abstract] OR "co-habit*"[Title/Abstract] OR relative*[Title/Abstract] OR famil*[Title/Abstract] OR sibling*[Title/Abstract] OR sister*[Title/Abstract] OR brother*[Title/Abstract] OR general practitioner*[Title/Abstract] OR GP[Title/Abstract] OR GPs[Title/Abstract] OR occupational therapist*[Title/Abstract] OR physiotherapist*[Title/Abstract] OR informal carer*[Title/Abstract] OR couple*[Title/Abstract]	3,996,244
#3	"Home Nursing"[Mesh]OR home care[Title/Abstract] OR home nursing[Title/Abstract] OR care home*[Title/Abstract] OR ordinary hous*[Title/Abstract] OR ordinary accommodation*[Title/Abstract] OR living at home[Title/Abstract] OR Ageing in place[Title/Abstract] OR togetherness[Title/Abstract] OR relational turbulence[Title/Abstract]	42,645
#4	#1 AND #2 AND #3	10,280
#5	Filters: Danish, English, Norwegian, Swedish, from 2015 to 2025	4,337
Embase		
#1	'aged'/exp OR aged:ti,ab,kw OR 'old age':ti,ab,kw OR 'old adult*':ti,ab,kw OR 'old people':ti,ab,kw OR older:ti,ab,kw OR elder:ti,ab,kw OR older adults:ti,ab,kw OR senior:ti,ab,kw OR seniors:ti,ab,kw OR octogenarian*:ti,ab,kw OR pensioner*:ti,ab,kw OR dementia*:ti,ab,kw	5,547,282
#2	'caregiver'/exp OR caregiv*:ti,ab,kw OR 'care giv*':ti,ab,kw OR 'care provid*':ti,ab,kw OR 'care staff':ti,ab,kw OR 'community care':ti,ab,kw OR partner*:ti,ab,kw OR spouse*:ti,ab,kw OR cohabit*:ti,ab,kw OR 'co-habit*':ti,ab,kw OR relative*:ti,ab,kw OR famil*:ti,ab,kw OR sibling*:ti,ab,kw OR sister*:ti,ab,kw OR brother*:ti,ab,kw OR 'general practitioner*':ti,ab,kw OR gp:ti,ab,kw OR gps:ti,ab,kw OR 'occupational therapist*':ti,ab,kw OR physiotherapist*:ti,ab,kw OR 'informal carer*':ti,ab,kw OR couple*:ti,ab,kw	4,993,175
#3	'home care'/exp OR 'independent living'/exp OR 'home care':ti,ab,kw OR 'home nursing':ti,ab,kw OR 'care home*':ti,ab,kw OR 'ordinary hous*':ti,ab,kw OR 'ordinary accommodation*':ti,ab,kw OR 'living at home':ti,ab,kw OR 'ageing in place':ti,ab,kw OR togetherness:ti,ab,kw OR 'relational turbulence':ti,ab,kw	123,613
#4	#1 AND #2 AND #3	19,034
#5	#4 AND 'conference abstract'/it	2,788
#6	#4 NOT #5	16,246
#7	#6 AND ([danish]/lim OR [english]/lim OR [norwegian]/lim OR [swedish]/lim)	14,780
#8	#7 AND (2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py OR 2020:py OR 2021:py OR 2022:py OR 2023:py OR 2024:py OR 2025:py)	7,802
#9	#8 AND [embase]/lim	843
CINAHL		
#1	(MH "Aged+") OR TI (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*) OR AB (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*)	1,376,792
#2	(MM "Caregivers") OR TI (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*) OR AB (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*)	1,082,693
#3	((MM "Aging in Place") OR (MM "Home Nursing") OR (MM "Home Health Nursing")) OR TI ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence") OR AB ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence")	33,342
#4	#1 AND #2 AND #3	9,362
#5	Publication Date: 20150101-20251231; Language: Danish, English, Norwegian	4,403
PsycInfo		
#1	MM "Older Adulthood" OR TI (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*) OR AB (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*)	719,214

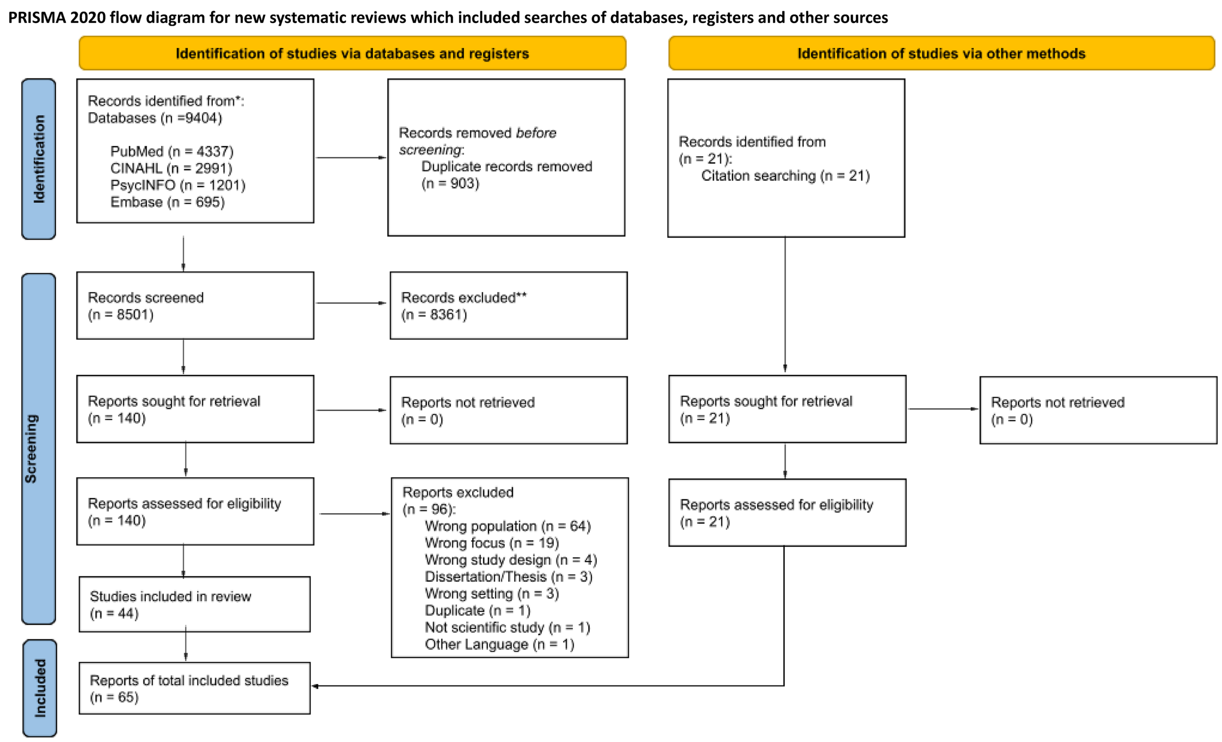
(Continued)

TABLE 2 (Continued)

Search line #	Search terms	Results
#2	DE "Caregivers" OR TI (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*) OR AB (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*)	1,194,982
#3	DE "Home Care" OR TI ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence") OR AB ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence")	17,014
#4	#1 AND #2 AND #3	5,950
#5	Publication Year: 2015-2025; Language: Swedish, English	2,567
ERIC		
#1	DE "Older Adults" OR TI (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*) OR AB (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*)	112,890
#2	(DE "Caregivers") OR TI (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*) OR AB (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*)	283,419
#3	TI ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence") OR AB ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence")	2,079
#4	#1 AND #2 AND #3	384
#5	Published Date: 20150101-20241231; Language: English	64
SocIndex		
#1	((DE "OLDER people") OR (DE "OLDER men" OR DE "OLDER women")) OR TI (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*) OR AB (aged OR old OR older OR elder OR older adults OR senior OR seniors OR octogenarian* OR pensioner* OR dementia*)	174,008
#2	(DE "CAREGIVERS" OR DE "OLDER caregivers" OR DE "CAREGIVERS -- Social aspects") OR TI (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*) OR AB (caregiv* OR "care giv*" OR "care provid*" OR "care staff" OR "community care" OR partner* OR spouse* OR cohabit* OR "co-habit*" OR relative* OR famil* OR sibling* OR sister* OR brother* OR "general practitioner*" OR GP OR GPs OR "occupational therapist*" OR "physiotherapist*" OR "informal carer*" OR couple*)	449,204
#3	DE "HOME care of older people" OR TI ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence") OR AB ("home care" OR "home nursing" OR "care home*" OR "ordinary hous*" OR "ordinary accommodation*" OR "living at home" OR "Ageing in place" OR togetherness OR "relational turbulence")	6,285
#4	#1 AND #2 AND #3	1,763
#5	Publication Date: 20150101-20251231; Language: Swedish, Danish, English	656

Germany ($n = 1$), Switzerland ($n = 1$), and Taiwan ($n = 1$). Almost all studies were conducted in one country, and two studies were conducted in two countries. A total of 1,103 participants took part in the included studies, distributed as 682 cohabiting caregiver partners, 164 older care receiving adults, 175 other relatives, 66 healthcare professionals and 16 stakeholders. All studies used qualitative methods, where most studies ($n = 50$) used individual interviews, eight studies used focus group interviews, and one study used video recordings. Six studies used both observations and interviews. Ten different analytical methods were used where 26 studies conducted thematic analysis, 12 used content analysis, 11 applied a phenomenological analysis, five used a grounded theory analysis, four applied a hermeneutic phenomenological analysis, two used a hermeneutic analysis, and five used other analytical methods, see Table 4.

The older care receivers were described as living with dementia ($n = 31$), chronic diseases ($n = 14$), disabilities ($n = 6$), and other mixed medical diagnosis ($n = 14$). Twenty-seven studies focused primarily on older partner caregivers. Ten studies included both the cohabiting caregiver and the care receiver. Nineteen studies included other family members as well as the older partner caregiver and/or the care receivers. Other eight studies also included healthcare personnel. The articles were published in journals with a specific focus on health(care) science ($n = 17$), dementia ($n = 10$), gerontology/



*Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers).
**If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools.

Source: Page MJ, et al. BMJ 2021;372:n71. doi: 10.1136/bmj.n71.

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FIGURE 1
PRISMA 2020 flow diagram for new systematic reviews which included searches of databases, registers and other sources. *Consider, if feasible to do so, reporting the number of records identified from each database or register searched (rather than the total number across all databases/registers). **If automation tools were used, indicate how many records were excluded by a human and how many were excluded by automation tools. Source: Page et al. (41). This work is licensed under CC BY 4.0. To view a copy of this license, visit https://creativecommons.org/licenses/by/4.0/.

geriatrics ($n = 15$), nursing ($n = 8$), psychiatry or mental health ($n = 3$), and others ($n = 11$). The impact factor of the journals ranged from 0.27 to 7.5, see Table 4.

According to the authors' assessment using the CASP checklist (43), all selected publications demonstrated appropriate methodological rigour (Table 3). Overall, CASP scores ranged between 8/10 and 10/10, and the majority of included studies had scores of 9 or higher (56 studies out of 65), suggesting excellent quality. One common area of limitation was the relationship between researchers and participants (Criterion 6), either unclear or unreported in 28 out of 65 studies, followed by the recruitment strategy (Criterion 4), insufficiently described in six studies (Table 3).

The cohabitation committed—caregivers' strategies towards the other

Declaration of intent—adapting roles and responsibilities in caregiving for better or worse

Several caregivers described a commitment to fulfil the moral obligation of the partnership whilst adopting a strategy to manage their emotions and feelings, and work on them and change them in alignment with certain ideals and perceived marital expectations (46–55, 127). They revealed shifts in household and care responsibilities following illness or disability, with many cohabiting caregivers commonly experiencing the need to adapt to new roles and expanded duties (46–51, 53, 55–72, 127).

Several cohabiting caregivers found evident shifts in domestic tasks, with caregivers taking over tasks previously managed by their partners, including cooking, grocery shopping, home maintenance, and financial responsibilities (46–51, 53, 55–70, 72, 127). For many male cohabiting caregivers, the traditional gendered divisions of household was altered and they had to learn and perform activities traditionally associated with female roles, however their strategies drew upon using skills as leadership and problem-solving, gained through prior life challenges and work experiences (46, 49–51, 56, 58, 61, 62, 73). In addition to household tasks, many caregivers transitioned into more professional roles, including medication management, monitoring health conditions, assistance with mobility and hygiene, and interactions with health and social care systems (46–51, 53, 55–72, 74–77, 127).

Some caregivers used Information and Communication Technology (ICT) for medical documentation, health tracking apps to help train the memory, and care coordination, acting as experts without necessary support from the health care system (127). Other caregivers described the need for close follow-up to remind their partners to use their assistive technologies such as portable alarms, GPS-tracking, phones and other safety measures (59). Some cohabiting caregivers developed strategies of being present and able

TABLE 3 **Qualitative study appraisal.***

Author(s), years	Section A: are the results valid?						Section B: what are the results?			Section C: will the results help locally?	Scores
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	
Abulaiti et al., 2022 (88)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Aaltonen et al., 2021 (74)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Andréasson et al. (127) (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Atler et al., 2016 (82)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9/10
Backhouse et al, 2024 (128)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Bendixen et al., 2018 (75)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Cao et al., 2022 (83)	Yes	Yes	Yes	Yes	Yes	Yes	yes	Yes	Yes	Yes	10/10
Carabante et al., 2017 (84)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8/10
Cash et al., 2019 (46)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Cheng et al., 2024 (92)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Chistell et al., 2023 (89)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Clark et al., 2019 (47)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10

(Continued)

TABLE 3 (Continued)

Author(s), years	Section A: are the results valid?						Section B: what are the results?			Section C: will the results help locally?	Scores
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	
Cole et al., 2022 (56)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Compton et al., 2020 (99)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Cooper and Pitts, 2022 (80)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8/10
Donnellan et al., 2015 (81)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	10/10
Greenwood et al., 2019 (100)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Guo et al., 2023 (103)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Hale et al., 2020 (57)	yes	yes	yes	yes	yes	No	yes	yes	yes	yes	9/10
Hammar et al., 2021 (48)	yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8/10
Hellström et al., 2017 (58)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Hemberg et al., 2018 (129)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Hochwald et al. 2022 (96)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Horsfall et al., 2016 (90)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9/10

(Continued)

TABLE 3 (Continued)

Author(s), years	Section A: are the results valid?						Section B: what are the results?			Section C: will the results help locally?	Scores
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	
Häikiö et al., 2019 (59)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Häikiö et al., 2020 (101)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Jarling et al., 2020 (60)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
LaManna et al., 2024 (61)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Larsson et al., 2020 (104)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Lethin et al., 2016 (62)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9/10
Melilla et al., 2024 (49)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Merrick et al., 2016 (50)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Meyer et al., 2016 (63)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Miller et al., 2024 (51)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Munkejord et al., 2020 (85)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
MusgraveTakeda et al., 2022 (64)	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes	10/10

(Continued)

TABLE 3 (Continued)

Author(s), years	Section A: are the results valid?						Section B: what are the results?			Section C: will the results help locally?	Scores
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	
Olivier et al., 2017 (52)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8/10
Papa and Lamura, 2019 (65)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9/10
Pedreira et al., 2017 (66)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Pejner and Brobeck, 2018 (106)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	9/10
Pickering et al., 2022 (97)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Read et al., 2023 (98)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	9/10
Redley et al., 2025 (102)	Cannot tell	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	8,5/10
Riekkola et al, 2019 (93)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9/10
Riekkola et al, 2024 (67)	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9/10
Rodger et al., 2015 (130)	yes	yes	yes	yes	yes	yes	no	no	yes	yes	8/10
Rykkje and Tranvåg, 2019 (73)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9,5/10

(Continued)

TABLE 3 (Continued)

Author(s), years	Section A: are the results valid?						Section B: what are the results?			Section C: will the results help locally?	Scores
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	
SadeghiMahalli et al., 2024 (68)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9,5/10
Schaepe and Ewers, 2018 (105)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9.5/10
Shiff et al., 2025(53)	Yes	Yes	Yes	Cannot Tell	Cannot Tell	Yes	Yes	Yes	Yes	Yes	9/10
Smith and Shaw, 2017 (78)	Yes	Yes	Yes	Cannot tel	Yes	Cannot tell	Yes	Yes	Yes	Yes	9/10
Stefánsdóttir et al., 2022 (69)	Yes	Yes	Yes	Cannot tel	Yes	Cannot tell	Yes	Yes	Yes	Yes	9/10
Sun et al., 2021 (76)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Tatangelo et al., 2018 (94)	Yes	Yes	Yes	Cannot tell	No	Cannot tell	Yes	Yes	Yes	Yes	9/10
Thomas et al., 2018 (86)	Yes	Yes	Yes	Cannot tell	Cannot tell	Cannot tell	Yes	Yes	Yes	Yes	8,5/10
Tolhurst et al., 2023 (70)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9,5/10
Turjamaa et al., 2020 (87)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Turner et al., 2016 (54)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	8/10

(Continued)

TABLE 3 (Continued)

Author(s), years	Section A: are the results valid?						Section B: what are the results?			Section C: will the results help locally?	Scores
	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	
Tyrrell et al., 2019 (71)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9,5/10
Vos et al., 2020 (95)	Yes	Yes	Yes	Yes	Yes	Cannot tell	Yes	Yes	Yes	Yes	9.5/10
Wammes et al., 2021 (79)	Yes	Yes	No	No	Yes	Yes	Yes	Yes	Yes	Yes	8/10
White and Palmieri, 2024 (55)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Yang et al., 2021 (91)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Yang et al., 2023 (77)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10
Zhang et al., 2020 (72)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	10/10

*Conducted in accordance with CASP Qualitative study checklist (43).

TABLE 4 Study characteristics.

Author(s), Year of Publication (Country)	Journal (year: impact factor)	Study aim	Design; study population; recruited from; analytical method	Study period
Aaltonen et al., 2021 (74) (Finland)	Dementia (2023: 2.92)	To detect different ways people with memory disorders and spousal carers strive and are able to influence formal care. To recognize situations where their influence on care is described as restricted or even nonexistent.	Semi-structured in-depth life-course interviews (13 dyad/8 individual); 15 older care receiving adults, 19 cohabitant older partners; at home (trough two organisations); Thematic analysis inspired by Braun and Clarke.	October 2018–March 2019
Abulaiti et al., 2022 (88) (China)	Frontiers in Psychiatry (2023: 3.3)	To describe the dyadic care experiences of older adults individuals with disabilities and their caregivers from the perspective of family resilience.	Semi-structured, in-depth interviews; 9 older care receiving adults, 3 cohabitant older partners, 6 other relatives; 4 communities and 2 hospitals; Descriptive phenomenological study, thematic analysis inspired by Colaizzi method and using NVivo 11.0	August 2020–February 2021
Andréasson et al. 2023 (127), (Sweden)	Journal of Family Studies (2023: 1.4)	To explore how the notion of couplehood and family life is understood and negotiated in everyday life by older carers and their spouses.	Ethnographic study with interviews, observations and informal conversations; 7 older care receivers; 9 cohabitant older partners (age: 65+); in and outside couple's home; abductive, thematic analysis, methodically inspired by Emerson, theoretical informed by Morgan's sociologically informed theory and conceptualization of family practices and the doing of families/family life.	December 2018–June 2019
Atler et al., 2016 (82) (United States of America)	Physical & Occupational Therapy in Geriatrics (2023: 0.7)	To explore the lived experiences of spousal caregivers providing care to their partners with cognitive changes.	Phenomenological approach by description of the Daily Experiences of Pleasure, Productivity, and Restoration Profile, recording activities over a 24-h period + individual semi-structured interviews + focus group interview; 3 cohabiting older adults (age: 70–83), 2 other relatives; local caregiver support group; thematic analysis	
Backhouse et al, 2024 (128) (United Kingdom)	The Gerontologist (2023: 4.6)	To examine features of personal care interactions between care-home staff and family carers (henceforth collectively termed as caregivers) and people with advanced dementia to understand how care may be improved and inform the development of caregiver educational resources	Naturalistic observation study using one-off video-recorded observations of 26 separate personal care interactions were video recorded hereof 12 interactions from five family caregiver/relative with dementia dyads; 2 cohabitant spouses; 21 other relatives; 16 care-home staff, 42 older care receiving older adults; observational video coding to determine the frequency of actions of people with dementia and qualitative content analysis for in-depth examination	2019
Bendixen et al., 2018 (75) (Norway)	Scandinavian Journal of Caring Sciences (2023: 2.70)	To describe family members' experiences of attending to an old person with diabetes receiving home care services, including their interaction with the formal caregivers.	Individual semi-structured interviews; 3 co-habitant partners, 5 other relatives; Home care services nurse; Content analysis inspired by Graneheim and Lundman.	May–August 2015
Cao et al., 2022 (83) (China)	Frontiers in public Health (2022: 5.18)	To explore the factors that influence risk perceptions and responses by informal caregivers of older adults with disabilities.	Semi-structured interviews; 5 cohabitant older spouses, 11 other relatives; 6 public organizations having connections with older adults with disabilities; Deductive content analysis based on a socio-ecological framework, using NVIVO	October 2020–February 2021
Carabante et al., 2017 (84) (Sweden)	Scandinavian Journal of Occupational Therapy (2023: 2.74)	To explore and describe how older adults spousal caregivers experience and discuss participation in everyday life when living in shifting contexts due to the use of respite care.	Repeated focus group interviews; 12 cohabitant older partners (10 women, 2 men, age 65–83); A respite care center. Analysis was inspired by a grounded theory approach.	Q1 + Q2, 2014.

(Continued)

TABLE 4 (Continued)

Author(s), Year of Publication (Country)	Journal (year: impact factor)	Study aim	Design; study population; recruited from; analytical method	Study period
Cash et al., 2019 (46) (Australia)	Australasian Journal on Ageing (2019; 1.2)	To explore how expectations of informal care impact spousal caregivers in later life.	Interpretive qualitative design using in-depth interviews; 10 cohabitant older caregivers (age 65–84); Regional Australia. Thematic analysis informed by interpretive qualitative methodology.	Not specified
Cheng et al., 2024 (92) (China)	International Journal of Mental Health Nursing (2024): not published yet. (2023: 5.16)	To elucidate on the experiences of caring and explore the experiences and perceptions of family caregivers in supporting older adults with multimorbidity living in the community to cope with loneliness.	Semi-structured interviews; 3 cohabiting partners, 8 other relatives; a non-government organization (NGO) in Hong Kong, providing community support and home care services; Reflexive thematic analysis inspired by Braun and Clarke.	Not specified
Chistell et al., 2023 (89) (Switzerland)	BMC Nursing (2023: 3.47)	To record and analyse the experience of loneliness among CRs of chronically ill people. Specifically, the aim is to develop a conceptual model based on the concepts of social, emotional, and existential loneliness.	Narrative semi-structured interviews; 10 cohabiting spouses, 3 other relatives; Outpatient care service organizations in Rhaeto-Romanic and German-speaking Switzerland + a regional hospital in Rhaeto-Romanic Switzerland; Thematic analysis, inspired by Saldaña and using MAXQDA software (Analytics Pro 2020).	September 2020–January 2021
Clark et al., 2019 (47) (United Kingdom)	Dementia (2023: 2.92)	To explore the dyadic perspective of dementia within a couple relationship.	Individual semi-structured interviews; 6 cohabiting spouses, 6 partners with dementia; through mental health services for older people within a NHS Foundation Trust; Interpretative phenomenological analysis	Not specified
Cole et al., 2022 (56) (United Kingdom)	Dementia (2022: 2.4)	To investigate the experiences of people living with dementia and their main family carer (family dyad) when managing intimate continence care at home and explore whether this type of care affected their dyad relationship	Semi-structured interviews; 1 older care receiving adult; 7 cohabitant older partners, 6 other relatives; Health and social care organisations, and community organisations supporting people living with dementia; Phenomenological analysis.	Not specified
Compton et al., 2020 (99) (Canada)	Canadian Journal on Aging (2023: 1.7)	To explore the experiences of clients and family caregivers with the services and support provided by Home First, given the complex needs of older adults who want to remain in their home over time.	Semi-structured interviews; 8 older care receiving adults, 8 cohabitant partners, 3 other relatives; 'First Home' programme; Thematic analysis inspired by Thorne and Morse.	Not specified
Cooper and Pitts, 2022 (80) (United States of America)	Journal of Social and Personal Relationships (2024: 2.3)	To gain insight into caregiving spouses' experiences of relational uncertainty and influence from their partner across the prolonged relational transition of Alzheimer's disease or related dementia (ADRD).	In-depth interviews; 16 cohabitant older partners (9 women, 7 men, age 62–88), 2 other relatives; 3 were widowed; Local memory care center, local Alzheimer's caregiver support groups, Facebook group; Thematic analysis inspired by Braun and Clarke and relational turbulence theory	January–March 2020
Donnellan et al., 2015 (81) (United Kingdom)	Aging & Mental Health (2014: 2.8)	To assess how spousal dementia carers can achieve resilience and highlight assets and resources they draw on to facilitate or hinder resilience	Individual in-depth semi-structured interviews; 17 cohabitant partners, 2 were widowed and another had their partner admitted in a nursing home; 2 dementia support groups and one care home in North West England; Grounded theory analysis.	Not specified
Greenwood et al., 2019 (100) (United Kingdom)	Maturitas (2019: 3.2)	To explore the experiences of older carers and to understand, from their perspectives, whether their experiences were similar or different to those of younger adult carers.	Qualitative study using five focus groups; 44 cohabitant caregivers (age 70–87); Greater London; Thematic analysis.	Not specified

(Continued)

TABLE 4 (Continued)

Author(s), Year of Publication (Country)	Journal (year: impact factor)	Study aim	Design; study population; recruited from; analytical method	Study period
Guo et al., 2023 (103) (China)	BMC Geriatrics (2023: 3.57)	To explore the interaction experience between family caregivers and community nurses for disabled older adults people at home, so as to provide reference signifcance for future related research.	Semi-structured interviews; 2 cohabitant older partners, 5 other relatives, 5 professionals; Linshanzhai Community Health Services Center in Zhengzhou City, Henan Province; Directed content analysis	March–June 2022
Hale et al., 2020 (57) (New Zealand)	The Gerontologist (2020: 5.3)	To report carers' perceptions of: (a) their role caring for a family member with cognitive decline, (b) the skills and attributes they used to perform this work, and (c) enablers and barriers to achieving their care goals.	Qualitative study using semi-structured interviews; 15 cohabitant caregivers (age 63–89); Community settings in New Zealand; Thematic analysis.	Not specified
Hammar et al., 2021 (48) (Sweden)	Dementia (2023: 2.92)	To explore spouse carers' experiences of caring for a partner with dementia, their everyday life as a couple and their support needs.	Semi-structured interviews; 9 cohabitant older partners (age 65–94); 2 memory clinics and 2 local support groups of a dementia organisation Latent content analysis inspired by Graneheim and Lundman.	Not specified
Hellström et al., 2017 (58) (Sweden)	Scandinavian Journal of Caring Sciences (2018: 4.6)	To describe how older Swedish men approach the caregiver role of a wife with dementia over time.	Semi-structured interviews; 8 male cohabitant caregivers; Memory clinics; Secondary thematic analysis.	Not specified
Hemberg et al., 2018 (129) (Finland)	Scandinavian Journal of Caring Sciences (2018; 4.6)	To explore and understand experiences of suffering from loneliness in older adults receiving home care.	Hermeneutical inspired individual interviews; 6 cohabitant older adults (aged 72–95), 11 older care recipients living alone; Primary care, Municipality of Ostrobothnia; Latent content analysis inspired by Graneheim and Lundman, informed by a 'caring science' theoretical framework.	Not specified
Hochwald et al. 2022 (96) (Israel)	Dementia (2022: 2.5)	To unpack family caregivers' emotional coping and the emotional-strategies they use; and to place family caregivers' emotion work within the appropriate Israeli cultural context.	Qualitative phenomenological study using semi-structured interviews; 50 cohabitant caregivers (19 men, 31 women); Home hospice and home care units in Israel; Thematic content analysis.	Not specified
Horsfall et al., 2016 (90) (Australia)	Health and Social Care in the Community (2023: 2.24)	To understand how carers made decisions to accept or reject support as part of the caring journey and to inform policy makers, service managers and providers about how to develop and promote culturally appropriate support services, and negotiate them with carers and care recipients in a timely way	Focus group and individual interviews, standardised tests; 12 cohabitant older partners (age 68–87, the Greek community), 19 healthcare professionals, 6 community leaders; St. George Migrant Resource Centre (SGMRC); Thematic analysis inspired by Braun and Clarke.	2012–2013
Häikiö et al., 2019 (59) (Norway)	BMC Health Services Research (2019: 3.9)	To examine family carers' perspectives on how to prevent different forms of harm to those living with dementia while receiving community-based services, and how their efforts to alleviate those risks might affect and interact with health professional's activities in this regard.	Semi-structured qualitative interviews and a consultation of a panel of people with personal or professional experiences; 11 cohabitant older partners, 12 other relatives; A range of health services, institutions or organizations; Thematic analysis inspired by hermeneutic/phenomenological approaches.	June–October 2017
Häikiö et al., 2019 (101) (Norway)	BMC Geriatrics (2020: 4.2)	To explore family carers experiences with, perspectives on, contributions to, and interactions with healthcare services provided to older adults living with dementia.	Qualitative study using semi-structured in-depth interviews; 23 cohabitant caregivers (17 women, 6 men); Healthcare personnel (e.g., dementia coordinators), social media (Facebook), and snowball sampling across Norway (urban and rural areas); Four-step thematic analysis informed by hermeneutic and phenomenological methodology.	June–October 2017

(Continued)

TABLE 4 (Continued)

Author(s), Year of Publication (Country)	Journal (year: impact factor)	Study aim	Design; study population; recruited from; analytical method	Study period
Jarling et al., 2020 (60) (Sweden)	Scandinavian Journal of Caring Sciences (2020: 1.98)	To describe the life situation when family caregivers are imposed responsibility for an older person with complex care needs in their own home.	Individual interviews (a reflective lifeworld research design); 8 cohabitant older partners, 2 other relatives; Primary healthcare; Phenomenological analysis	2017
LaManna et al., 2024 (61) (United States)	Geriatric Nursing (2024: 1.5)	To describe lived experiences of men who engaged in later-life caregiving.	Streubert's phenomenological qualitative unstructured interview method; 8 older caregivers (age 66–83); Older adult learning communities, caregiver support groups, churches, health fairs, and snowball sampling in Florida, USA; Phenomenological qualitative analysis.	June 2019–January 2020
Larsson et al., 2020 (104) (Sweden)	International Journal of Qualitative Studies on Health and Well-Being (2020: 2.1)	To explore spouses' existential loneliness when caring for a frail partner later in life	Multi-stage focus group interviews; 5 cohabitant partners, 5 widows; Primary healthcare; Hermeneutical analysis inspired by Dahlberg et al.	August–October 2018
Lethin et al., 2016 (62) (Sweden)	Scandinavian Journal of Caring Sciences (2026: 1.46)	To investigate family caregivers' experiences of formal care when caring for a person with dementia, through the stages of the disease.	Focus group interviews; 13 cohabitant older partners, 10 other relatives; recruitment via dementia nurses in four municipalities; Content analysis inspired by Graneheim and Lundman and Meleis' transition theory.	October 2011
Melilla et al., 2024 (49) (Norway)	BMC Health Services Research (2024: 3.9)	To understand the health-promoting experiences of older family caregivers who care for their home-dwelling spouses receiving home-care services	Narrative unstructured interviews; 10 cohabitant older partners (aged 79–91); Primary healthcare; Narrative thematic analysis, inspired by Riessman.	June 2021
Merrick et al., 2016 (50) (United Kingdom)	Dementia (2016: 2.5)	To contribute to our understanding of the experience of dementia from a relational perspective.	interview; Interpretative phenomenological analysis; 7 cohabitant partners (5 men and 2 women); Local branches of the Alzheimer's Society in the UK; Interpretative phenomenological analysis	Not specified
Meyer et al., 2016 (63) (Sweden)	British Journal of Community Nursing (2016: 0.45)	This study aimed to describe spouses' experiences of living with a partner affected with dementia	Life-world interviews; 7 cohabitant older partners (4 men, 3 women aged 69–92); recruited via an association for relatives of people affected with dementia; Descriptive phenomenological approach based on a reflective life-world perspective.	Not specified
Miller et al., 2024 (51) (Canada)	Canadian Journal on Aging (2024: 1.5)	To examine husbands whose wives have dementia and how they provide care and construct their sense of self.	Constructivist Grounded Theory using semi-structured interviews; 11 older caregivers (age 61–88); Caregiver and memory support organisations, clinics, social media, and snowball sampling in Ontario, Canada; Constant comparative analysis.	May–June 2021
Munkejord et al., 2020 (85) (Iceland and Norway)	International Practice Development Journal (2020: 1.79)	To provide a deeper understanding of the struggles, suffering and unmet needs of care partners by listening to the voices of older women living with and caring for a spouse with severe cognitive decline.	In-depth open-ended interview; 11 older partners (some still cohabiting, some widowed); Primary care (Norway), nursing home (Iceland), private persons through advertisement in a newspaper Norway; Thematic analysis.	2018–2019
Musgrave-Takeda et al., 2022 (64) (Japan)	Dementia (2022: 2.4)	To identify the experience of being the spouse of a person with dementia in the context of their marital relationship	Observation and semi-structured interviews; 7 cohabitant older partners (4 male and 3 female); recruited from managers at home nursing facilities; hermeneutic Heideggerian phenomenological analysis.	Not specified
Olivier et al., 2017 (52) (New Zealand)	Scandinavian Journal of Caring Sciences (2017: 0.37)	To explore the lived experience of three stroke family members during the 18 months following a first-ever stroke.	Stand-alone case study; individual conversational style interviews at 6 weeks, 12 months and 18 months; 1 cohabitant older partner, 2 other relatives; Hospital; Thematic phenomenological analysis following van Manen	September 2011-September 2013

(Continued)

TABLE 4 (Continued)

Author(s), Year of Publication (Country)	Journal (year: impact factor)	Study aim	Design; study population; recruited from; analytical method	Study period
Papa, and Lamura, 2019 (65) (Italy)	Journal of Gerontology and Geriatrics 2019 (2019: 0.27)	To provide evidence of informal caregivers pivotal role in care provision	Semi-structured face-to-face in-depth interviews; 2 cohabitant older partners (age 72 and 80), 4 other relatives; the Italian National Institute of Health and Science on Ageing; Framework Analysis	November–December 2017
Pedreira et al., 2017 (66) (Brazil)	Journal of Clinical Nursing (2017: 3.2)	To understand the lived experience of older Brazilian carers.	Semi-structured interviews; 3 cohabitant older partners (73–84 years old), 3 other relatives (63–78 years old); public home-care programme in Salvador (north-eastern Brazil); hermeneutic phenomenological analysis.	January–February 2016
Pejner and Brobeck, 2018 (106) (Sweden)	Home Health Care Management and Practice (2018: 0.8)	To describe how couples in need of home care services experienced the received support from care professionals	Focus groups; 8 cohabitant older partners, 8 older care receiving persons (couples) aged between 65–80 years old, 2 nurses; Relative Association (nonprofit for family caregivers) and home care of the municipality; content analysis.	Not specified
Pickering et al., 2022 (97) (Canada)	Health & Social Care in the Community (2022: 2.5)	To explore the transnational systems of support that Canadian spousal caregivers use to provide care while living seasonally in the United States as international retirement migrants.	in-depth semi-structured dyad interviews; 20 cohabitant partners (age > 60); Facebook groups for Canadians in Yuma and postcards on Canadian-plated cars; Thematic analysis.	January 2019
Read et al., 2023 (98) (United Kingdom)	Parkinson's Disease (2023:2.1)	To facilitate an in-depth exploration and further comprehend the lived experience of caregiving for late-stage Parkinson's and the perception of service needs and provision from the family-caregivers' perspective in England.	Semi-structured interviews; 6 cohabitant older partners, 5 other relatives; the English cohort of the European "Care of Late-Stage Parkinsonism" (CLaSP) study with help from general practitioners' (GPs) surgeries, NHS hospital outpatient clinics, Parkinson's charities, and specialist neurologists in and within Greater London; Thematic analysis inspired by Braun and Clarke.	2016
Redley et al., 2025 (102) (United Kingdom)	Healthcare (2023: 1.95)	Explore how family caregiver experience input from a team managing crises in dementia (TMCD)	Semi-structured interviews; 4 cohabitant older partners, 3 other relatives; Primary health care; Thematic analysis	Not specified
Riekkola et al, 2019 (93) (Sweden)	Journal of Aging Studies (2019: 1.54)	to explore how older adults couples, who are in need of social services in the community, act and reason over time regarding their everyday togetherness	Shared interviews and participant observations; 3 female co-habitant spouses and their 3 male ill partners (age 66–78); Recruited by a caregiver counselor at one municipality; Data analysis followed Polkinghorne's description of the paradigmatic analysis of diachronic narrative data.	November 2016–February 2018
Riekkola et al, 2024 (67) (Sweden)	Journal of Aging Studies (2024: 2.24)	To explore and describe the experiences and reasoning of spousal carers, healthcare professionals, and stakeholders regarding possibilities for older couples to age in place.	Focus groups; 12 cohabitant older partners (age 65–83, 10 women, 2 men), 18 healthcare professionals, 16 stakeholders; Residential respite care facility in a municipality; Constant comparative methodology inspired by Charmaz	Not specified
Rodger et al., 2015 (130) (Ireland)	British Journal of Community Nursing (2015: 0.4)	To explore the experiences of informal carers in Ireland and to identify supports required in caring for older adults at home	Unstructured interviews; 1 cohabitant older partner (80 years old), 5 siblings or children; outpatient clinic in an older person service in Ireland; Morse and Field's 4-step Heideggerian hermeneutic phenomenological analysis.	2009
Rykkje, and Tranvåg, 2019 (73) (Norway)	SAGE Open (2023: 2.0)	To explore the experiences of husbands engaged in caregiving for their home-dwelling spouse with dementia.	Qualitative individual interviews; 5 cohabitant husbands (age 72–82 years); 2 hospital memory clinics; Exploratory design founded upon Gadamer's philosophical hermeneutics, a four-step hermeneutical analysis	Not specified

(Continued)

TABLE 4 (Continued)

Author(s), Year of Publication (Country)	Journal (year: impact factor)	Study aim	Design; study population; recruited from; analytical method	Study period
Sadeghi-Mahalli et al., 2024 (68) (Iran)	Geriatric Nursing (2023: 2.5)	To explore the support process for older spousal caregivers of people with Alzheimer's disease.	Semi-structured, in-depth interviews; 10 cohabitant older partners, 3 other relatives, 3 healthcare providers; One memory clinic and one care center; Grounded theory analysis inspired by Corbin and Strauss's method, using Word software.	2022–2023
Schaepe and Ewers, 2018 (105) (Germany)	BMC Nursing (2023: 3.1)	The study aims to explore family caregivers in Home Mechanical Ventilation (HMV) safety experiences and how safety is perceived by them in this context; it seeks to understand how family caregivers contribute to the patients' and their own safety in HMV and what kind of support they expect from their health care team.	Exploratory semi-structured interviews; 6 cohabitant older partners, 3 other relatives; Nursing care providers, respiratory care center, a health care insurance company, personal contacts and organizations; Thematic analysis, inspired by Braun and Clark among others, using the software MAXQDA 11	June 2014–June 2015
Shiff et al., 2025 (53) (United States of America)	Journal of Applied Gerontology (2023: 2.2)	We sought to explore dementia caregiving experiences from the perspective of spouses/partners; identify common motivating factors and greatest challenges associated with how and why spouses/partners provide in-home care for their loved one living with dementia.	Mixed methods longitudinal from 2 studies (validated tools, interviews, observations); 15 older care receiving adults, 15 cohabitant partners (aged 65–90); recruitment site not specified in San Francisco, CA; Secondary data analysis using Thematic Analysis inspired by Braun and Clarke.	Study 1: 2018–2020 Study 2: 2021–2024
Smith and Shaw, 2017 (78) (United Kingdom)	Medicine, Health Care and Philosophy (2023: 2.3)	To explore family members' lived experience of Parkinson's disease and their opportunities for well-being.	In-depth interviews; 4 older care receiving adults, 5 older cohabitant partners; One Parkinson's support group; Interpretative phenomenological analysis.	Not specified
Stefánsdóttir et al., (69) (Iceland and Norway)	Scandinavian Journal of Caring Sciences (2023: 1.9)	To shed light on couplehood changes as experienced by men caring for wives with dementia.	Individual in-depth interviews; 8 cohabitant husbands (67–92 years); Primary care; Constructivist grounded theory study, data analysis inspired by Charmaz, using NVivo software	2018–2019
Sun et al., 2021 (76) (Canada)	Geratric Nursing (2023: 2.5)	To gain a better understanding of the relationship between client's therapeutic self-care ability and homecare safety outcomes, and the role of self-care and caregiving activities in supporting homecare safety in relation to chronic disease management.	One-on-one, in-depth, semi-structured interviews; 15 older care receiving adults 65 + and 15 cohabitant older partners (15 dyads); One homecare organization in Ontario; Qualitative description/naturalistic inquiry and thematic analysis inspired by Patton.	Not specified
Tatangelo et al., 2018 (94) (Australia)	International Journal of Nursing Studies (2023: 7.5)	To examine the health needs of partner and offspring caregivers of older people with dementia, including the barriers they experience in meeting their needs.	Semi-structured interviews; 12 cohabitant older partners (aged 62–89), 12 other relatives; [Setting unknown]; Thematic analysis approach, using NVivo software.	Not specified
Thomas et al., 2018 (86) (United Kingdom)	Palliative Medicine (2023: 3.6)	To illustrate the relevance of 'relevant background worries' in family carers' accounts of caring at home for a dying adult	Qualitative cross-sectional observational (in-depth semi-structured interviews); 30 caregivers; General practitioner (GP) practices; Narrative analysis presented as 4 case studies (3 cohabitant older partners and 1 daughter)	2011–2012
Tolhurst et al., 2023 (70) (UK)	Healthcare (2023: 2.5)	To explore how couples negotiate relationships and care following a dementia diagnosis, with a focus on the perspectives of male caregivers.	Semi-structured interviews; 10 female older care receivers adults, 10 male cohabitant partners (aged 62–86); 2 dementia support groups and one church organisation; A thematic analysis founded upon a constructivist and interpretivist framework.	Not specified

(Continued)

TABLE 4 (Continued)

Author(s), Year of Publication (Country)	Journal (year: impact factor)	Study aim	Design; study population; recruited from; analytical method	Study period
Turjamaa et al., 2020 (87) (Finland)	Healthcare (2020: 1.6)	To describe the individual experiences of older caregivers who were looking after a spouse with a memory disorder	Thematic individual interviews; 10 older co-habitant partners (6 women, 4 men, age 69–86); One memory clinic at a health center; Inductive content analysis	During spring 2016
Turner et al., 2016 (54) (United Kingdom)	Age and Ageing (2023: 6.0)	To explore the experiences of the 'oldest carers' in caring for a dying spouse at home.	In-depth interviews; 17 cohabitant older partners (aged 80–90); Primary care in the North West (Lancashire and Cumbria) and South West (East Devon) of England; Thematic analysis inspired by Braun and Clarke, Ritchie and Spencer, and Reissmann.	2011–2013
Tyrrell et al., 2019 (71) (Sweden)	Dementia (2023: 2.4)	To describe spouses' experiences of living with partners who have developed neuropsychiatric symptoms related to dementia in a community setting.	Semi-structured interviews; 14 cohabitant older partners (aged 64–85); Older adult clinics, one older adult psychiatry unit, one dementia support organisation; Content analysis inspired by Krippendorff.	November 2014–November 2015
Vos et al., 2020 (95) (The Netherlands)	Health and Social Care in the Community (2023: 2)	This study aims to explore older adults' experiences of changes in their social networks and to understand the impact of these changes on their lives.	Focus Groups; 14 cohabitant older partners (aged 65+); Four home-care organisations; Grounded Theory analysis.	April–May 2017
Wammes et al., 2021(79) (Netherlands)	Alzheimer's and Dementia (2021: 4.9)	To prioritize care characteristics for community-dwelling persons with dementia and informal caregivers using innovative-mixed-methods approach	Focus groups with a quantitative ranking exercice; 10 cohabitant carers, 7 children, 2 relatives and 1 close friend; 5 day-centers across the Netherlands and a dementia-support organization; thematic analysis through Braun and Clarke's approach.	December 2019 to March 2020
White and Palmieri, 2024 (55) (United States of America)	International Journal of Qualitative Studies on Health and Wellbeing (2024: 2.6)	To describe the lived experience of women caregivers of male spouses living at home with Parkinson's disease	Semi-structured interviews; 12 female cohabitant carers aged between 60 and 83; recruited from the Colorado Parkinson Foundation; phenomenological analysis using Colaizzi's seven-step process.	Not specified
Yang et al., 2021 (91) (China)	International Journal of Nursing Practice (2023: 1.9)	This study aimed to explore the experiences of family caregivers interacting with people with dementia.	Descriptive phenomenological qualitative inquiry using semi-structured interviews; 5 cohabiting older partners, 5 other relatives; Department of Neurology and Mental Health in Hangzhou in Zhejiang Province; Thematic analysis inspired by Braun and Clarke, using NVivo9	June–September 2018
Yang et al., 2023 (77) (Taiwan)	The Journal of Nursing Research (2023: 2.4)	The aim of this study was to explore the care experiences of FCs caring for older family members with cancer at home.	In-depth interviews; 5 cohabitant older partners, 17 other relatives; Chemotherapy outpatient setting of a medical center in northern Taiwan; Content analysis inspired by Graneheim and Lundmann.	January–December 2019
Zhang et al., 2020 (72) (China)	Dementia (2023: 2.4)	This study aims to explore the meaning of family supported home care in China from the perspectives of people with dementia and family caregivers.	In-depth, semi-structured individual interviews; 10 care receiving older adults, 5 cohabitant older partners, 9 other relatives; Shandong Mental Health Centre; Thematic analysis inspired by Braun and Clarke.	August 2016–January 2017

to adapt to shifting needs and tailor their support, finding assistive technologies helpful, as they promoted independence (59, 78, 79). However, some caregivers reported that these roles were often accompanied by a lack of familiarity and formal guidance and thus led to uncertainty and confusion (56, 59, 62, 64, 76, 80).

Many caregivers experienced emotional and identity challenges as they adjusted to expanded responsibilities (46–51, 53, 55–65, 67–72, 127). With the progression of illness, caregivers' responsibilities grew while their personal freedom diminished. Some caregivers linked their current situation to serving a prison sentence (65, 81), or a loss of freedom (60). Cohabiting caregivers and care receivers emphasised the need for constant presence and supervision as key strategies to prevent harm, such as falls or accidents (54, 59, 60, 70, 82–87). However, such responsibility with ongoing presence and supervision often led to emotional exhaustion and a sense of being overburdened among caregivers, especially when care receivers resisted help in an effort to preserve independence (59, 60, 82, 84, 85, 88).

Balancing couplehood while negotiating support and care

Many cohabiting caregivers expressed that caregiving shifted the dynamics of couplehood, which led to their relationships characterised by mutual vulnerability, where both partners beared physical and emotional burdens and uncertainty in face of illness and caregiving

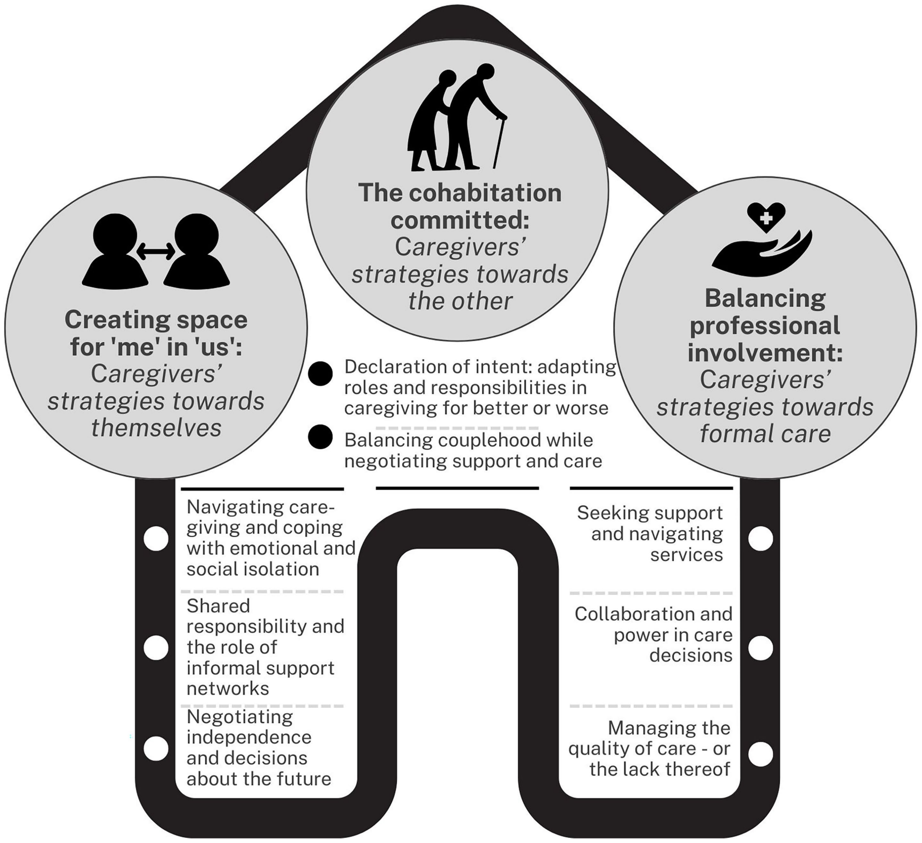

FIGURE 2
Themes and subthemes.

(46, 48, 50, 55, 59, 60, 62, 64, 70, 73, 81, 82, 89, 90, 127). They experienced tensions between their roles as being a partner and a caregiver, describing a strategy of taking a more pragmatic and task-oriented approach to the situation and the practicalities that needed to be done (47, 56, 58, 60, 74, 127). Many highlighted the tension between respecting their partner's independence and the increasing need to intervene for safety and well-being (55, 59, 70, 82, 127).

Caregivers often engaged in emotional work to preserve their partners' dignity and identity, actively striving to maintain the marital relationship instead of letting illness and dependency completely redefine it (46–48, 50, 53, 55, 57–59, 64, 69, 70, 127). There were examples of caregivers that might balance the act of being a lover and being a caregiver, reminiscing the important and good times, and receiving small verbal and non-verbal gestures seemed to be a coping strategy for the change in the attentiveness of their partner (47, 49, 53, 64, 80, 89). A common strategy mentioned was keeping a positive climate between the partners, avoiding triggering anger or hostility, often by putting their own needs second (48, 57, 59, 91). Doing so seemed to get easier when understanding the disease and its different symptoms and how it affected the person they cared for (59, 70, 86). However, the overwhelming responsibilities sometimes caused caregivers to put their lives on hold to focus on caring for the other, at the expense of their own social and emotional needs (49, 66, 89).

A strategy used by some cohabiting caregivers was to redefine responsibility, viewing their new roles and tasks as a privilege that brought purpose to their changed circumstances and to life more broadly (54, 56, 87, 90). Despite noticeable changes in reciprocity between partners, some caregivers adopted the strategy of focusing on the positive aspects of the relationship during caregiving as a way to cope and support their own well-being (50, 71). However, there seemed to be a diversity in the need for maintaining an active life outside of caregiving, providing pleasure, productivity and restoration while others chose to use their time with the care receiver (69, 82).

Creating space for 'me' in 'us'—caregivers' strategies towards themselves

Navigating caregiving and coping with emotional and social isolation

Caregivers often paused their own lives to dedicate themselves to caring for the other, at the expense of taking care of their own illnesses and physical ailments (52, 54, 65, 66, 79, 83–86, 90, 92–95) and their own social and emotional needs (49, 66, 89). Loneliness was closely tied to caregivers' internalised sense of responsibility, often leading to extended isolation and hopelessness, as well as feelings of frustration, resentment, and guilt directed at the care receiving partner (64, 65, 82, 87, 89).

Caregivers employed myriad strategies to reduce loneliness and preserve normalcy, emphasising self-care, meaningful activities, and relationships beyond their caregiving role to support their wellbeing (48, 49, 73, 84, 87, 89, 91, 95). Often this included socialising, engaging in hobbies and activities, and using technology to stay connected. In some cases, pets offered relief from loneliness (89). Many caregivers sought social contact outside of their relationship with friends and family (55, 57, 61, 84, 87, 90, 91, 127), such as caregiver support groups to bond over shared experiences (48, 79, 82). Others carved out time for skill-based classes, outdoor physical activities or leisure/hobbies, or to read or watch television programs on their own (49, 55, 64, 77, 82, 84, 87, 89). Some caregivers found relief in their faith and spirituality (55, 77). Some caregivers even opted to include their partner during activities rather than miss out on the opportunity to participate (73, 78) or found time for themselves by maintaining activities in their partners' lives by keeping them engaged in enjoyable pastimes despite their declining condition (81).

Use of social technology was also a strategy utilised by caregivers to both get a break from caregiving activities and to socially and emotionally connect with others. It was a way to find new online friendships (127). In some cases, when care recipients spent time on the computer, caregivers could also take a break from caregiving and run errands (127). Social media sites and apps (e.g., Facebook, Instagram) provide opportunities to connect with people in similar caregiving situations (48) and stay in touch with friends and family (93, 127). Some caregivers noted that video calling apps (i.e., Zoom) seemed too impersonal of a platform for sharing their situation (55). Technology such as smartphones and tablets offered a variety of distracting app-based games, some of which had an embedded social element played virtually with others. A shared interest of, e.g., watching boats and the use of a boat information app provided entertainment and connection to beloved pastimes aided by technology during in-person interactions (127).

However, some caregivers adopted emotional distancing or passive endurance as a strategy, or because of a result of a lack of external support (48, 58, 88, 89, 96). In some cases, caregivers became apathetic, stating there was 'nothing they could do' or they were 'fed up' (88). Loneliness even manifested as a physical pain for some caregivers (89). The overwhelming responsibilities associated with caregiving had some partners wishing for death on themselves (48) or their partners to relieve the suffering of both partners (48, 96). Yet at the same time, caregivers also expressed fear of the loneliness they will feel when their partner dies, which was deemed worse than the burden of caregiving itself (96). Few caregivers opted for divorce (58, 96).

Shared responsibility and the role of informal support networks

Many caregivers adopted a strategy of actively seeking support from family, friends and neighbours to manage their daily lives as caregivers (49, 54, 55, 60, 62, 68, 83, 84, 87, 90, 93, 97, 98). Such support consisted of assisting with household maintenance (98), preparing of food (97), helping with the physical and emotional care of the ill partner (55, 85), emotional support of the cohabiting caregiver (7, 49, 97), and enabling outdoor activities for the cohabiting caregiver (84). The support also consisted of advice and information provision (65, 83, 98). Some caregivers benefitted from having a close family member being a health professional (57), or a retired health worker as neighbours who could address medical complications (97). Others were struggling to find the right information and support (65). The amount of support received from family and friends differed greatly. Cohabiting caregivers recognised factors such as travel distance (84), family obligations, and health issues limited the support they received from family and friends (54). Support from others could ease the cohabiting caregiver's burden by creating a sense of shared responsibility (60). However, some received little support and had to beg for help (67), while others feared becoming a burden (84). Other cohabiting caregivers first assessed a person's ability and willingness to provide effective support before asking for help (68). Some caregivers also viewed faith communities as part of their informal support network (98).

Connecting with caregiver support groups was another strategy to manage daily life (48, 55, 59, 68, 70, 79, 81, 82, 87, 97). Caregiver support groups offered help through the sharing of experiences (55, 68, 70, 79, 81, 97), benefitting from knowing other people who were experiencing similar situations (55), easing feelings of guilt and helping to normalise their feelings (48, 59), sharing information (68, 70, 79, 81, 97). Several caregivers were happy to be able to share the information they had compiled (55, 68), giving them a feeling of becoming experts (81). They were more likely to use informal support networks if they could offer social support to others in the same situation encouraging independence and "giving back" rather than dependence (81). However, support groups did not necessarily suit everybody and were described as helpful to a certain point (48). Some cohabiting caregivers got anxious when the amount of information was impossible to digest (87). Other caregivers received support from other people in similar circumstances on the internet if they were not able to leave the house (48). Others again did not have experiences with caregiver support groups but asked for the opportunity to join one (85).

Negotiating Independence and decisions about the future

The utilization of respite care constituted a deliberate strategy by caregivers to manage their caregiving responsibilities, safeguard their own well-being, and facilitate the continued residence of the care recipient in the home environment for as long as feasible (48, 58, 63, 67, 84, 87, 93). Respite care enabled caregivers to complete tasks such as grocery shopping (48) and gardening (58), regaining their energy (93), emotional and physical recovery, engaging in meaningful activities, and maintaining essential social relationships (67). It also offered time to grieve, reflect on life's changes, and consider future living arrangements (84). Others hesitated to use respite care because they were reluctant to send their partner away from home (87), or feared the emotional consequences of doing so (84, 93).

While the use of respite care represented one aspect of the caregiving strategy, the decision to transition the care recipient to a nursing home was a considerably more consequential and emotionally fraught choice (56, 63, 68, 85, 89, 90, 99), especially when the care recipient refused (85, 89, 99), or when cohabiting caregivers believed that care homes offered inferior care or could even pose a fatal risk to their relative (56). Cohabiting caregivers frequently encountered significant uncertainty regarding the trajectory of the care recipient's condition and the implications for their own caregiving role (47, 55, 62, 63, 65, 78, 91). This uncertainty often centered on concerns about disease progression (65, 78), the caregiver's capacity to maintain their responsibilities over time (62, 65, 94), and the anticipated disruption of shared daily life with their partner (47, 63). In response, caregivers employed various strategies to manage the psychological and practical demands of their role. Some engaged in proactive planning, while others adopted a present-focused approach, deliberately avoiding long-term considerations as a means of emotional self-regulation (91). For certain individuals, the recognition of inevitable decline led to a strategic emphasis on the present moment, reflecting a perceived lack of control over future outcomes (80).

Balancing professional involvement—caregivers' strategies towards formal care

Seeking support and navigating services

Seeking and navigating care services were central and often challenging aspects of life for caregivers in a cohabiting couple. As a result of shifting responsibilities, many caregivers had to be more proactive in identifying and accessing formal support, with home care services playing a key role in sustaining ageing at home (46, 47, 54, 56, 58, 59, 62, 67, 70, 74, 79, 84, 90, 92, 99–102). Other caregivers demonstrated a reluctance to accept public services, reflecting personal preferences and societal expectations of independence (46, 73, 74). Some caregivers found formal care easily accessible (46, 99, 101), but this was not a straightforward process. Some caregivers had to fight for services, switch to new, lower-quality products (e.g., incontinence aids), navigate opaque bureaucratic systems, manage financial matters like reimbursements, and deal with shifting regulations (56, 62, 67, 74, 79, 99–101). Access to formal care was not taken for granted by caregivers, knowing that overuse could affect others' access or reflect negatively on their caregiving abilities (99). Cultural and linguistic accessibility was also viewed by some caregivers as key to comfort and communication through care navigation (90). In some cases, caregivers described using social leverage, through other family members or appealing to higher authorities, to obtain needed care (101).

While caregivers frequently performed many tasks themselves, formal services like home care support helped with essential activities of daily living, such as dressing, medication adherence or practical challenges, like incontinence (e.g., (49, 54, 69, 79)), which enabled them to attend to their other needs or responsibilities (79, 99). Beyond home care support, caregivers collaborated with other health professionals, including physical and occupational therapists, district nurses, general practitioners, and palliative care nurses (54, 92, 99). Some caregivers also recognised the importance of professional input for their own well-being, expressing a desire for greater involvement of doctors or social workers in addressing issues like loneliness and fatigue (92) and rationalising their life situation (47, 62). In other cases, caregivers were left entirely unsupported, having to beg for help or deal with inexplicable service withdrawals (67). Other caregivers sought alternative treatments through personal research and online purchases when conventional support felt limited (70). While some caregivers found creative ways to engage with services, others struggled with barriers that left them feeling isolated and overwhelmed.

Collaboration and power in care decisions

When balancing their responsibilities, several caregivers asserted their desire to be involved in decision-making (103) and to maintain control over the delivery of care and the cohabiting couples' daily living (56) while avoiding intrusion in their intimacy and routines (84). However, they often faced challenges in establishing trustful relationships and collaboration with formal care providers (49, 56, 62, 66, 74, 84, 85, 99, 103). Some caregivers described feeling disempowered when formal caregivers dismissed their input and observations (49, 55, 69, 74, 87, 100, 103). Uncertainty about receiving support at a specific time disrupted some caregivers' daily routines, often leaving those caregivers to resort to carrying out the tasks themselves (84) or to conclude that it would have been simpler without (74). Often, caregivers recognised that most attention by formal care was around the older care recipients, where the needs and responsibilities of caregivers themselves were not recognised or considered; for example, the need for their own daily schedule to be synchronised with the delivery of home care services and caregivers' well-being (48, 49, 55, 66, 69, 87, 103). When responsibilities became overwhelming (49) or when disease-related complications occurred (85, 103), caregivers recognised the value of formal care (49, 62, 74, 89, 99, 100, 103), especially when the scope of tasks was overwhelming (49) or when they lacked knowledge about disease-related complications (85, 103).

To avoid repeating past suboptimal care experiences (59), some caregivers strove for more control over the care provision as a result of mistrust (59, 61, 74). The presence of formal caregivers might also be experienced as an intrusion in the home, which became a contested space, both physically (e.g., bedrooms) and relationally (56) and re-allocating of rooms (e.g., bedrooms) (86). Some caregivers found this intrusion difficult, to the point of limiting or rejecting formal support, even when needs were extensive (84). In some cases, involvement of formal carers was perceived as a threat to their caregiving role (90), leading to feelings of judgment or exclusion or 'not fitting in' (48, 56). In other cases, caregivers viewed the company of the health professionals as a way to reduce their potential loneliness (89, 90). The continuous dialogue with health professionals was essential to adapt strategies when previous ones failed (59, 84). Other caregivers feared being displaced by professionals or other family members, signalling an assertion of their authority within the dyad (74, 104). Struggling between being decision-makers and the ones left behind, caregivers often faced morally conflicting decisions (74), where revealing symptoms, such as aggressive behaviours (48), could unintentionally mean exposing their partner to harm or institutionalisation (104).

From the perspective of some caregivers, building trust with 'allied' staff members became a vital strategy for gaining influence, others also relied on private communications with professionals to convince them of their views on the care situation (74). This happened when professionals included family carers as part of the team (99, 105). Many caregivers found that a strong relationship with formal care professionals, marked by mutual recognition of roles, compassionate communication, and information sharing, could improve service responsiveness (62, 103), particularly in urgent situations (99). Such relationships were seen as key to the success of own caregiving strategies (57, 62, 63, 75, 98, 100, 103, 105).

Managing the quality of care—or the lack thereof

Successful collaboration with formal care providers was associated with quality of care when professionals demonstrated competence, continuity and accommodation to the reality of caregivers, offering problem-solving support and social interaction (48, 49, 57, 62, 63, 67, 75, 82, 98, 99). Such collaboration was highly dependent on the invisible labour of informal caregivers, involving advocacy efforts, coordination, and monitoring (49, 55, 74, 86, 101, 105). Some caregivers preferred not to make all decisions (104) and took a more hands-off role (81), mainly monitoring daily care (59).

This invisible labour was applied specifically to fill systemic gaps and failures resulting from under-resourcing and fragmented services (68, 86, 99, 101). Caregivers often described needing to advocate persistently or persuade professionals to adapt care to their lived reality (74). Some caregivers filled in where formal services failed, for example, by providing hands-on care in hospitals (66), preparing for emergencies (105), and coaching professionals (105). In some cases, the trust in professionals was so low that caregivers preemptively trained staff to ensure safe care delivery (105) or preferred doing the care themselves (48, 66). Frequent changes in staff (86) and limited number of home visits (67) as well as inadequate transfer of information (e.g., discharge notes) created burdens for some caregivers who had to ensure care continuity (48, 101). Other resources like respite care were perceived as inconsistent with caregivers' desire to maintain normalcy and avoid stigmatisation, e.g., being labelled as part of another generational group (57). The act of 'surrendering' a partner to others' care was experienced as both necessary and devastating, fraught with doubt, grief, and the fear of abandonment (104).

Sometimes, caregivers strategically withheld information to steer decisions (74), revealing underlying tensions between the perceived expertise of professionals and caregivers' intimate knowledge (106). Some caregivers weighed the risk of deteriorating relationships with service providers against the potential benefits of advocating for better care (101). Strategic efforts were deployed to maintain person-centredness in a context of heavy care standardisation (71, 106) and professionalisation (56), which often was translated into levelling down care quality by ignoring individual needs and emotional aspects (48, 71, 85, 101). As such, managing care quality was not just about ensuring appropriate medical treatment; it was an active and often moral engagement with a system that frequently fell short.

Discussion

The discussion focuses on two main findings, namely a role transition from being a partner to being a caregiver and the new responsibilities and strategies associated with it, and how the strategy of involving formal care at home combined practical, moral, and emotional labour of the older cohabiting caregivers to ensure good care for their partner. Furthermore, the method's strengths and limitations are discussed.

The findings revealed a role transition from being a cohabiting partner to becoming both a partner and a primary caregiver that brought new responsibilities and strategies with it. According to van Gennep (107), a transition process often begins with a phase of separation. This involves a gradual detachment from the familiar, shared identity as equal partners. Typically triggered by the onset of illness, frailty, or disability, the caregiving partner becomes increasingly aware that their relationship is no longer defined solely by mutuality but is now shaped by new roles, responsibilities and dependencies. This stage may be marked by emotional turmoil, including a sense of loss and anticipatory grief, as the couple's previous balance begins to dissolve and the structures that supported their shared life begin to shift (108, 109). Following separation, van Gennep (107) describes a liminal phase in the transition, which is defined as an ambiguous space characterised by uncertainty and ambivalence. In this state, the individual is no longer simply a partner, but not yet fully identified with the caregiving role, capturing the in-betweenness of this experience. The findings showed how the caregiving partner inhabits a dual role, navigating the emotional demands of intimacy and companionship alongside the practical and moral demands and responsibilities of care. This role is often unstable and fraught with internal tensions. At the same time, they are engaged in an ongoing moral negotiation about what they owe their partner, how much they can realistically give, and how their own needs and well-being fit into the equation. Liminality is not only experienced individually, but can also affect the couple's shared identity, as they renegotiate what it means to be together in a context of increasing asymmetry (110). Over time, the caregiving partner may reach a stage of incorporation (107), wherein they re-enter the social world with a newly stabilised identity with the development of strategies that work as well as possible for the balance of the partnership and for the individual caregiver partner. At this point, they may begin to self-identify as a caregiver and receive external recognition in that role. This incorporation was, as shown in the findings, reinforced through strategies of social activities, participation in support groups, engagement with health and social services, or adjustments in daily life and routines. However, incorporation is not always a neat or complete process. The nature of long-term caregiving means that roles continue to evolve, and the balance between care and companionship often remains in flux. Even so, as the findings revealed, many caregivers found strategies to integrate elements of their former partnership, such as shared rituals, emotional closeness, or mutual recognition, into this new phase of life, resulting in a layered and complex sense of identity. The shift from partner to caregiver is not merely practical but is a significant social and moral transformation (111). It involves crossing multiple thresholds in terms of identity, relationship, and social status, including changed responsibilities within partnership and the development of new everyday strategies. As the findings pointed out, the transition towards being a caregiver was also a question about the health conditions of the cohabiting caregiver. In many older cohabiting couples, both partners are ill or frail (112, 113). However, the neoliberal governance of care support at home often assumes that the less ill partner can take responsibility and act on behalf of the couple (114). Yet unlike traditional rites of passage, this transition is often unmarked by formal rituals or societal recognition, making it an invisible yet deeply consequential process in the lives of ageing couples, including responsibility and role distribution. Traditional gendered roles typically push women to take on caregiving roles more often than men, and those caring for older adults are less likely to be paid for their labour, which paradoxically restricts their availability for paid work (115). The overlapping roles of caregiving and couplehood leaves little room for self-care, leisure, and even paid work, thereby reinforcing social isolation, marginalisation and undermining health and economic security (116). As it often occurs in private households, informal caregiving remains hidden from policy frameworks or formal systems of support, uncaptured through conventional institutional measurements (117). To better support caregivers in these transitions to older couplehood and ageing-in-place, future studies should explore the rites of passage in older cohabiting couples when life conditions change and new roles and responsibilities emerge.

Furthermore, the findings showed different strategies in which informal caregivers actively engaged with formal care systems to maintain their life at home. Caregivers often walk a thin line between self-reliance and institutional dependency, continually reassessing what is ‘enough,’ ‘acceptable,’ and ‘possible’ in the shifting landscapes of care. As shown in the findings, caregivers frequently described navigating services as a continuous and often burdensome responsibility and strategy. Funk (118) shows that navigation supports remain fragmented and condition-specific, leaving many older adults and caregivers struggling to access care. At political and provider levels, this calls for patient-centred strategies, including improving information, expanding public support, and integrating services (118). The support of home care services, particularly for tasks such as personal hygiene, mobility, and medication management, was acknowledged as essential to sustaining ageing-in-place. However, access to these services was rarely straightforward or reliable. Instead, caregivers were required to become strategic agents, continuously evaluating, combining, and supplementing formal resources to meet complex and evolving care needs. This suggests a form of practical-moral reasoning, wherein carers make judgments not only about what is possible, but about what is right and necessary in their particular circumstances (119). Seeking support is not merely a logistical task; it is an ongoing moral practice shaped by care ethics, social inequalities, emotional strain, and systemic (dis)function, as also shown by Lilleheie et al. (120). For some, accepting help from outside the family represents a failure of moral responsibility or a breach of relational commitment. For others, particularly those navigating progressive care needs, it is a necessary, even urgent, adaptation to protect both themselves and their partners. Care systems require caregivers to become ‘moral entrepreneurs’ (121), who must advocate, argue, and even battle for access to support (122). The findings highlighted that cohabiting caregivers expressed frustration with inconsistent or absent follow-up from services, necessitating a proactive stance just to obtain basic help. This reveals a troubling dynamic. Even when caregivers formally ‘belong’ to the care system, they are expected to demonstrate their worthiness or urgency through persistence, suggesting a system that implicitly delegates responsibility onto the very people it is meant to support (123, 124). At the same time, caregivers’ efforts to navigate and coordinate services also reveal forms of agency, creativity, and resilience. The results suggested that some found ways to integrate different supports, combining formal rehabilitation with respite care or learning techniques from professionals to better manage behavioural symptoms. These practices can be understood as situated acts of moral repair (119) in which caregivers attempt to restore a sense of order and coherence amid fragmented care environments. However, the emotional toll of this work is significant. The burden of constant form-filling, follow-up calls, and struggles for consistency was not only exhausting but demoralising, as shown in the findings. Caregivers sometimes felt ignored or unheard, and when services were subpar, it was experienced not just as a failure of quality, but as a violation of the personhood and dignity of the person cared for. Such failures represent a breach in the moral fabric of care, undermining the trust and mutuality that caregivers strive to uphold. Older cohabiting caregivers operate within care systems that are at once enabling and limiting, requiring them to negotiate ethical tensions between duty, exhaustion, and systemic inadequacy (119). The unevenness of support thus reflects not only structural fragmentation but also a failure to recognise the moral significance of caregivers’ knowledge, efforts, and experiences. This pointed to the need for more responsive, relationally attuned services that do not just provide care, but actively support the moral labour of caregiving itself. These findings call for Ageing-in-place policies that explicitly recognise the invisible, morally-driven labour undertaken by cohabiting caregivers. To ensure the relevance and responsiveness of national and local eldercare strategies, caregivers’ perspectives must be considered in the design and evaluation of care programmes. In addition, it is important that policymakers address issues such as broken agreements and inadequate support by implementing stronger quality assurance mechanisms and accessible complaint procedures, also bridging formal and informal care systems. Future studies about the moral labour of caregiving are needed to understand the contextual and relational complexities in the encounters between informal and formal caregiving when ageing-in-place.

The study’s strengths and limitations

The study has several strengths and limitations. For pragmatic reasons, the results were based on articles that included cohabiting partners aged 60 and above. However, the notion that age can be reduced to a mere number oversimplifies the complexity of human experience, biological diversity, and the social influences that shape the ageing process. Firstly, biological ageing is not uniform. Individuals of the same chronological age can differ significantly in physical health, cognitive function, and overall vitality. Secondly, the social construction of age imposes rigid expectations. Society assigns roles, privileges, and limitations based on chronological age, from birth to death. Yet, these categories are often arbitrary and fail to reflect individual capabilities. Moreover, emotional and psychological ageing do not always align with numerical age depending on the lived lives. Defining a person’s stage of life solely by the number of years lived disregards these nuances. While using age as a numerical measure may be convenient, it is an inadequate and overly simplistic representation of the ageing process (30). As with most literature reviews, it was not possible to cover the full range of conditions experienced in relation to caregiving, with nearly half of our studies focusing on dementia (31 out of 65 studies). Whereas dementia brings complex relational challenges greatly affecting the caregiving experience, this overrepresentation might also be the result of a sampling limitation, where more demanding conditions are more frequently reported than other, less demanding ones. Our qualitative interpretation, combined with the detailed context of each study, supports the transferability of our findings, thus addressing this limitation, and future studies focusing on a broader range of experiences are encouraged.

While our results touched upon the gendered aspects of caregiving, a more explicit focus could have illuminated critical nuances in this review and enriched our interpretations, and these should be addressed in future studies. The review covers studies published between 2015 and 2024, spanning pre- and post-COVID-19 contexts. Although the pandemic likely intensified challenges such as isolation, reduced service access, and increased moral labour, these dynamics were unevenly addressed across studies. Future research could more directly examine how caregiving roles shifted during and after the pandemic. The included studies also span 20 countries with diverse healthcare systems, welfare models, and cultural understandings of family care. Such heterogeneity shapes how caregiving is supported and experienced, for instance, strong formal care infrastructures may ease family responsibilities, whereas family-based systems place greater demands on relatives (125). Cultural norms around gender, ageing, and obligation further influence how moral labour is perceived and enacted. While this diversity enriches the current review, it limits direct transferability of findings. Future research should investigate how systemic and cultural factors mediate caregiving experiences to inform context-sensitive policy and practice. Furthermore, only relevant articles in English were found. It appears that the formal search did not lead to articles in French or Scandinavian languages; even the Pearl Search did not locate such articles. Yet, articles do exist; for example, Vedsegaard and Wind (112). However, many lower-ranked journals are not indexed in the major scholarly databases. In addition, English has become the leading language in academia, the lingua franca (126), which is why most research is published in English-language journals. We used the Web of Science database to ensure the inclusion of newer publications that cited these articles, assessing their relevance for the current literature review. It seems that the initial search was not precise enough, as about a third of the included articles were found through pearl search. One explanation is that articles that did not use the term ‘older adults’ to describe this group of people have been difficult to capture in the search. For example, Aaltonen et al. (74) did not use the term ‘old*’ or ‘older adults’ but used the term ‘people with memory disorders.’ A subsequent review of the articles found through pearl search also reveals that other articles could have been found by adding keywords such as ‘family living’ and/or ‘couplehood’ to the primary searches, e.g., Andréasson et al. (127). However, the first author subsequently discussed the uncaptured articles with the expert university librarian involved, concluding that the extensive pearl search had successfully identified the articles missed in the initial search. Furthermore, the search found a lot of articles related to the aim, but many of the articles did not separate older adults from other caregivers in the results. All articles where it was not possible to distinguish cohabiting older adults (caregivers) from other caregivers were excluded. This means that the results clearly represent this group, but at the same time, additional knowledge about this group may be present in the excluded studies, which could not be differentiated in this literature review.

Conclusion

Focusing on the perspectives of cohabiting older caregivers, the results showed that when transitioning from their roles as partners to that of caregivers, cohabiting older adults transformed the couple’s relationship to enact new responsibilities. Caregivers took responsibility for both their partner and for holding together fragile systems of care. Their work was driven not just by necessity, but by a commitment to sustaining relationships, honouring personhood, and doing what they understood to be ‘the right thing,’ even when systems failed to adequately support them. This pointed to the need for more responsive, relationally attuned services that do not just provide care, but actively support the moral labour of caregiving itself. This also calls for user-involving research and participatory designs within home care, with the aim of supporting the needs of older adult cohabiting couples in a time when political trends advocate for ageing-in-place.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Author contributions

SG: Supervision, Methodology, Writing – review & editing, Conceptualization, Formal analysis, Writing – original draft, Project administration. HX: Writing – review & editing, Methodology, Writing – original draft, Formal analysis. R-ES: Writing – review & editing, Writing – original draft, Formal analysis. CS: Writing – original draft, Writing – review & editing, Formal analysis. GW: Writing – original draft, Formal analysis, Writing – review & editing. RG: Writing – review & editing, Writing – original draft, Methodology. P-LT: Writing – review & editing, Formal analysis, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Correction note

A correction has been made to this article. Details can be found at: 10.3389/fpubh.2025.1734743.

Generative AI statement

The author(s) declare that Gen AI was used in the creation of this manuscript. AI was used as a support tool for language translations.

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Correction: Older caregivers' responsibilities and strategies for their cohabiting partners living at home—a qualitative systematic literature review

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A community-based participatory approach to delivering the *Dealing with Dementia* program to Black caregivers

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Background: Alter is a community-based program created to address gaps in dementia awareness and caregiving support/resources for Black and faith communities. The Rosalynn Carter Institute for Caregivers (RCI) collaborated with Alter to adapt the existing *Dealing with Dementia* (DWD) program [$\text{DWD}_{\text{Alter}}$] to better reach and meet the needs of Black families through relevant dementia education and practical caregiving strategies.

Context: Faith-based partnerships were identified as a trusted place to start to deliver the pilot $\text{DWD}_{\text{Alter}}$ Program. Four focus groups were conducted with Black faith leaders, their congregants who identified as caregivers, and other community members to inform the adaptation of the program. RCI's original agency-based DWD model was modified using the principles of Community-Based Participatory Research.

Programmatic elements: Input from the focus groups shaped the $\text{DWD}_{\text{Alter}}$ protocol, which included: (a) facilitator "toolkit," (b) program assessments, (c) procedure manual, and (d) a community recruitment plan. To test the pilot $\text{DWD}_{\text{Alter}}$, 22 Black community members were trained as facilitators, including 10 (45%) from rural Georgia communities. Between June and August 2024, 15 facilitators conducted 27 $\text{DWD}_{\text{Alter}}$ sessions using these new materials. Outcomes of this pilot initiative include an assessment of participant demographics and program satisfaction (acceptability). Two hundred and sixty-four persons attended the sessions, 95% of whom identified as Black or African American. Seventy-nine percent were family caregivers for individuals living with dementia, and 83% strongly agreed that the program met their caregiving needs. Evaluation of program effectiveness, specifically changes in caregiving self-efficacy and dementia knowledge before and after participation, will be conducted at a later time.

Discussion: While program acceptability was high, delivery challenges included limited facilitator availability, a 2.5-month grant period, and outreach barriers in Black rural communities. Following the pilot field test, a sustainability plan was co-developed with community facilitators to support continued implementation and ensure that resources spent on $\text{DWD}_{\text{Alter}}$ were not lost.

KEYWORDS

dementia, Alter, community participatory research, caregivers, Georgia, churches

Introduction

Caregiving is a nearly universal experience, but the intersection of race, culture, and social inequities can make it especially demanding for Black dementia caregivers. Black caregivers face not only the general challenges of caregiving but also unique stressors shaped by cultural norms, socioeconomic barriers, and institutionalized disparities (1). For example, research indicates that compared to White caregivers, Black caregivers are more likely to provide intensive care, over 40 h each week (54% vs. 39%), and are also more often caring for someone living with dementia living below the federal poverty line (32% vs. 12%) (2). They also report higher use of supportive services than White caregivers (33% vs. 25%) (2). Such disparities extend beyond care hours and service use—they also include inequities in access to healthcare, financial resources, and reliable social support. While the literature on dementia caregiving is extensive, less is known about the needs of caregivers in rural communities, as most research reflects urban settings.

Rural caregivers of persons living with dementia can face unique challenges, including limited access to healthcare, transportation barriers, and a shortage of affordable support services (3). Even when services exist, geographic isolation, economic disadvantage, and weak community infrastructure create additional barriers (3). Demographic trends further heighten these challenges. With younger adults leaving for education and employment, rural areas are aging more rapidly than urban ones (3). In the United States (U.S.), 17.5% of rural residents are aged 65 years and older compared with 14.9% nationwide, and nearly three-quarters of rural older adults live in the South (4). As this population ages, the risk of developing dementia and demand for caregiving will continue to rise (5). Currently, about one in five caregivers (20%) live in rural communities (6). Yet, within the already limited research on rural dementia caregiving, the specific needs of Black rural caregivers remain especially overlooked (3). According to the 2020 Census, approximately 4.5 million Black individuals lived in rural areas of the U.S., accounting for 7.4% of the rural population. Although this number has declined in recent years, the proportion of Black rural residents remains highest in the South (4). Research further indicates that Black caregivers represent about 6% of reported rural caregivers, yet they have higher odds of experiencing unmet needs in rural areas compared with their White counterparts (7). Given that Black caregivers often encounter racial and ethnic disparities, when combined with the structural disadvantages of rural environments, these overlapping burdens place rural Black caregivers at the intersection of multiple inequities, underscoring the need for targeted resources and interventions.

Based in Americus, Georgia, for nearly 10 years, the Rosalynn Carter Institute for Caregivers (RCI) has been a leader in providing resources to dementia caregivers through the delivery of its *Dealing with Dementia* (DWD) program (8). DWD was developed out of a recognized need for family caregivers to have practical guidance when caring for persons living with dementia. As part of the DWD program, caregivers receive a comprehensive guide with over 300 pages of detailed information within 34 chapters grouped by the following five key sections: (1) Understanding Dementia, (2) General Caregiving Tips, (3) Dealing with Behavioral Issues, (4) Self-Care, and (5) Resources. The guide also includes fillable handouts on emergency information, hospital-to-home records, personal health records, self-care strategies, medication management, a handout for searchers, and problem-solving that caregivers are encouraged to fill out and keep handy. To help optimize use of the guide, caregivers participate in a workshop that details the key topics and helps them understand dementia, manage problem behaviors, and take better care of themselves. DWD is a data-driven program that has served more than 7,500 caregivers from 41 states and Washington, D.C. Participants in DWD have demonstrated an increase in dementia knowledge and confidence in their ability to provide care (8).

Context

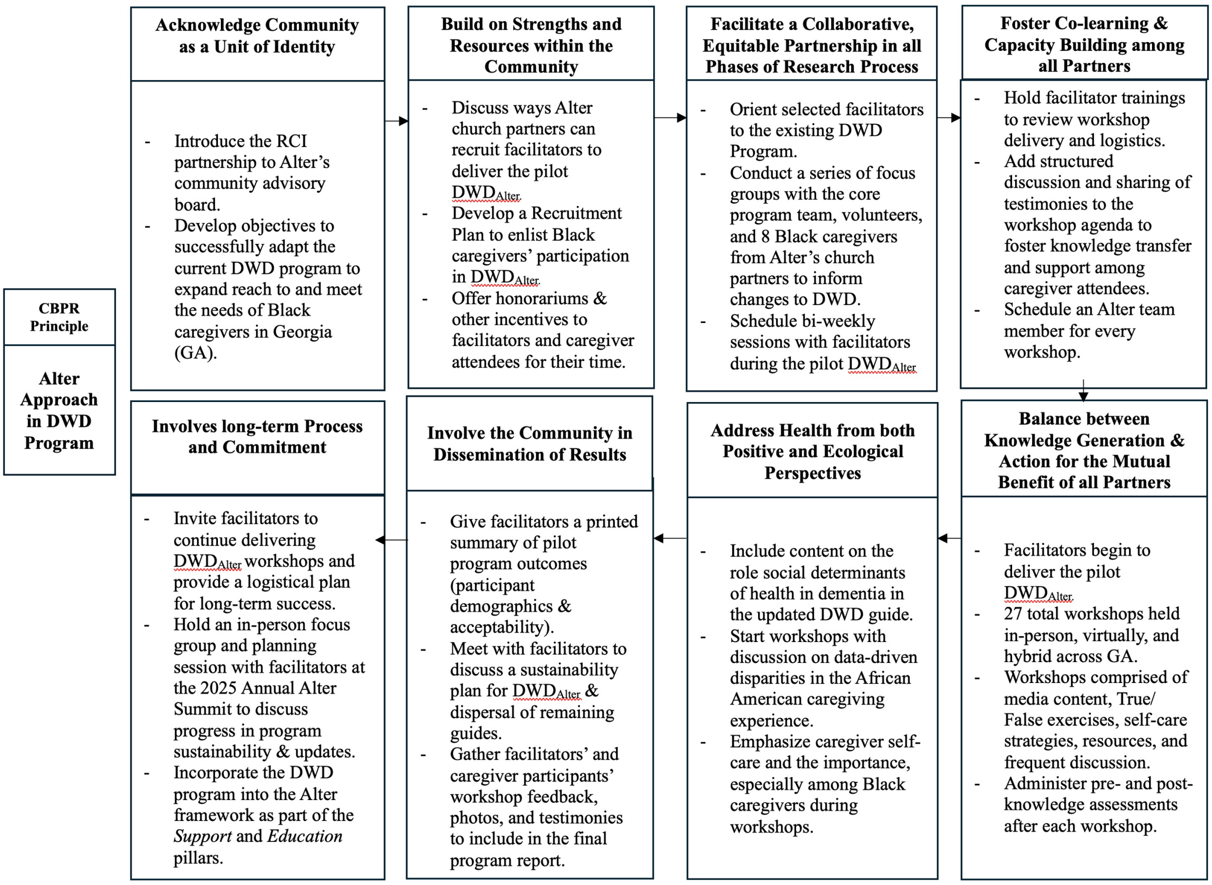
Providing free and accessible dementia education through Black faith communities is a promising strategy for addressing caregiving disparities. In 2024, the Rosalyn Carter Institute for Caregivers (RCI), partnered with Alter, a nurse-led, community-based program focused on building resources and awareness around dementia in Black and faith communities (9). This collaboration sought to address the challenges faced by Black caregivers by engaging community members to adapt the existing, evidence-based *Dealing with Dementia* (DWD) program [$\text{DWD}_{\text{Alter}}$] and extend its reach and relevance to Black caregivers in Georgia, with particular attention to reaching those in rural communities. The primary intent of the collaboration was to engage trusted community-based partners in delivering relevant resources and education directly into the hands of Black dementia caregivers who need them the most.

In this Community Case Study, the programmatic elements, outcomes, implications, and limitations of the pilot $\text{DWD}_{\text{Alter}}$ Program are described, along with a plan for its sustainability. Outcomes of this pilot program include an evaluation of participant demographics and program satisfaction (acceptability). Assessment of program effectiveness, specifically changes in caregiving self-efficacy and dementia knowledge before and after participation, is currently underway in collaboration with RCI's Data Manager and analysis team.

In general, Alter uses a Community-Based Participatory Research (CBPR) approach when conducting research and addressing dementia-related disparities and inequities in Black communities. CBPR is a partnership approach that equitably involves community members, researchers, organizations, and other stakeholders in research and practice processes, and recognizes the unique strengths that each brings (21). CBPR aims to combine knowledge and action to create positive and lasting social change. CBPR has become a common research approach in public health, medicine, and nursing (21). To successfully deliver the pilot $\text{DWD}_{\text{Alter}}$ to Black caregivers and evaluate its outcomes, RCI's existing DWD program and protocol were adapted to align with the 8 key principles of CBPR (10, 21). Figure 1 depicts how each CBPR principle was carried out during $\text{DWD}_{\text{Alter}}$. The following sections provide detailed descriptions of how these principles were intentionally implemented.

Programmatic elements of the adapted DWD program

To begin revising the DWD program, the core program team was first oriented to the existing DWD program through a 1.5-day



CBPR Principle

Alter Approach in DWD Program

Acknowledge Community as a Unit of Identity

- Introduce the RCI partnership to Alter's community advisory board.
- Develop objectives to successfully adapt the current DWD program to expand reach to and meet the needs of Black caregivers in Georgia (GA).

Build on Strengths and Resources within the Community

- Discuss ways Alter church partners can recruit facilitators to deliver the pilot DWD$_{\text{Alter}}$.
- Develop a Recruitment Plan to enlist Black caregivers' participation in DWD$_{\text{Alter}}$.
- Offer honorariums & other incentives to facilitators and caregiver attendees for their time.

Facilitate a Collaborative, Equitable Partnership in all Phases of Research Process

- Orient selected facilitators to the existing DWD Program.
- Conduct a series of focus groups with the core program team, volunteers, and 8 Black caregivers from Alter's church partners to inform changes to DWD.
- Schedule bi-weekly sessions with facilitators during the pilot DWD$_{\text{Alter}}$

Foster Co-learning & Capacity Building among all Partners

- Hold facilitator trainings to review workshop delivery and logistics.
- Add structured discussion and sharing of testimonies to the workshop agenda to foster knowledge transfer and support among caregiver attendees.
- Schedule an Alter team member for every workshop.

Balance between Knowledge Generation & Action for the Mutual Benefit of all Partners

- Facilitators begin to deliver the pilot DWD$_{\text{Alter}}$.
- 27 total workshops held in-person, virtually, and hybrid across GA.
- Workshops comprised of media content, True/ False exercises, self-care strategies, resources, and frequent discussion.
- Administer pre- and post-knowledge assessments after each workshop.

Address Health from both Positive and Ecological Perspectives

- Include content on the role social determinants of health in dementia in the updated DWD guide.
- Start workshops with discussion on data-driven disparities in the African American caregiving experience.
- Emphasize caregiver self-care and the importance, especially among Black caregivers during workshops.

Involve the Community in Dissemination of Results

- Give facilitators a printed summary of pilot program outcomes (participant demographics & acceptability).
- Meet with facilitators to discuss a sustainability plan for DWD$_{\text{Alter}}$ & dispersal of remaining guides.
- Gather facilitators' and caregiver participants' workshop feedback, photos, and testimonies to include in the final program report.

Involves long-term Process and Commitment

- Invite facilitators to continue delivering DWD$_{\text{Alter}}$ workshops and provide a logistical plan for long-term success.
- Hold an in-person focus group and planning session with facilitators at the 2025 Annual Alter Summit to discuss progress in program sustainability & updates.
- Incorporate the DWD program into the Alter framework as part of the *Support* and *Education* pillars.

FIGURE 1
A CBPR-driven approach to *Dealing with Dementia*: a guide for Black caregivers (DWD).

training with an RCI DWD Program Specialist. We then discussed the RCI partnership with the Alter community advisory board, composed of faith leaders, community members, caregivers of persons living with dementia, and individuals living with dementia. After addressing the concerns of the Alter community advisory board, plans were made to tailor each aspect of the program, including the DWD guide, workshop, facilitator training, as well as the logistics of delivering the program and recruiting Black program participants. The core program team consisted of 9 Alter members, including the Program Manager, Alter Founder, Co-Founder, Grant Manager, Community Outreach Director, and 4 Community Liaisons.

Curriculum revision

During the process of adapting the DWD comprehensive guide and workshop, we first conducted four 2-h focus group sessions with the core program team as well as volunteers and 8 Black dementia caregivers from several of Alter's church partners. Before participating in the focus group, participants received the original DWD guide and participated in the paired workshop led by the RCI DWD Program Specialist. During the focus groups, we assessed each section of the guide to address how best to adapt content and speak to the realities of the Black caregiving experience. After all focus groups, the recorded sessions were transcribed, and the core program team analyzed conversations to determine which suggestions were feasible to apply to the guide.

We worked with a graphic designer to apply the recommendations. The title of the guide was modified to *Dealing with Dementia: A Guide for Black Caregivers*, and all pictures were changed to depict Black individuals and families. We incorporated inspirational quotes from the focus group session throughout the guide to ensure Black caregivers and community members saw themselves in the education program. Some quotes included, *"Being a caregiver may seem very hard sometimes but always remember it is definitely worth it." "Caring for a loved one is a gift from God!" "There is help and resources available."* In the Introduction section, we included data-driven facts and overall information about Black families faced with dementia, such as the influence of social determinants of health on Alzheimer's disease-related ethnic and racial disparities. In the Resource Section, we included additional resources recommended by Black caregivers, such as United Way Programs and Black elder law attorneys. Outside of the Resource section in the guide, we assembled a resource packet to distribute to program participants. The packet included flyers for different dementia- and caregiver-related research studies, dementia-related and brain health pamphlets and reading material, and a breakdown of treatments to slow the progress of/address dementia-related symptoms produced by the Alzheimer's Association (5).

Changes to the structure of the guide were also recommended and applied. For example, caregivers preferred the chapters under the section ‘General Caregiving Tips’ to be rearranged, starting with ‘The Care Team’ as chapter 1 versus chapter 3. We kept the existing fill-in handouts as they are useful tools for caregivers.

We also worked with the graphic designer to update the paired workshop slide deck to reflect culturally relevant pictures, updated information on dementia and dementia-related diseases, and visually appealing graphics and media content. Specific changes included an updated video—*A Black Family's Battle with Alzheimer's Disease*, page references from the guide for all 30 true and false exercises, and detailed information on caregiver burnout. The workshop maintained its original duration of 4 h.

To help reach a greater number of caregivers, we offered printed versions of the revised guide and an electronic version sent through email.

Procedure manual

To effectively deliver the revised DWD Program, we altered RCI's existing procedure manual (protocol) to align with the abilities of facilitators, Alter resources, and input of Alter's advisory board that would help reach primarily Black caregivers. The protocol outlined procedures for holding virtual and in-person workshops and tips for advertising. We developed an ‘RCI-DWD’ sub-resource tab on the Alter website and advertised all upcoming workshops. The tab linked to a public-facing calendar, and as facilitators scheduled their workshop, we developed custom links to the respective registration forms for interested participants. The registration forms collected participants' names, addresses, email addresses, and caregiving status. To accommodate participants with limited comfort with or access to technology, they could call Alter and provide the information, or facilitators could give a handwritten list of interested participants, and a core program team member would register them.

As part of the protocol, we offered $40 honoraria to caregivers who completed pre–/post-program surveys and evaluations (all had to be completed to receive the honorarium), and a $250 honorarium to facilitators for each workshop they held. We encouraged facilitators to provide food/snacks at in-person workshops, and we provided reimbursements for any costs. Mileage reimbursement was also offered to facilitators and core program team members who attended in-person workshops. At least one core program team member was present for every workshop to assist and support the facilitators, administer the DWD guides (in-person), surveys, evaluations, printed copies of the workshop slide deck so participants could take notes, and provide office supplies (pens, easel paper, markers for group discussions, and highlighters). Additionally, the core program team members set up a table to distribute the aforementioned resource packets and answer additional questions (resource packets were emailed to virtual workshop attendees).

Zoom links were set up by the core program team manager and sent to everyone who registered and the assigned facilitator. Virtual attendees received an electronic copy of the guide for the workshop and were mailed a physical copy after attending. If caregivers urgently needed the guide but could not attend a workshop, we arranged a 5–10-min individual meeting to discuss the purpose of the DWD Program and highlight the key parts of the guide. Caregivers completed RCI's existing Individual Receipt Form and were then given a guide (either a mailed copy or an electronic version emailed, depending on preference). The Individual Receipt Form is a shortened form with the following information collected: Name, mailing address, email address, phone number, age (under 60/60 + years), Veteran status, active caregiving status, and person(s) caring for.

Alongside regular meetings with the Alter advisory board during the implementation process of the $\text{DWD}_{\text{Alter}}$ Program, we held 1-h meetings with facilitators every 2–3 weeks. The purpose of the meetings was to bring everyone together and discuss updates/feedback about the workshops, any concerns, and to provide a space to share honest feedback on the adapted program.

Program assessments

RCI's existing DWD pre- and post-program surveys were used to assess the effectiveness of the updated workshops. All questionnaires included the facilitator's name and workshop date. The pre-surveys (baseline) included demographic and caregiving background items, the Revised Scale for Caregiving Self-Efficacy (11), and the Dementia Knowledge Assessment Tool Version 2 (DKAT2) (12). We suggested minor edits to the workshop evaluation, which assessed participant acceptability using Likert-Scale responses (strongly disagree – strongly agree), that were IRB-approved and applied. For example, since the program was adapted and geared toward the needs of Black caregivers, we included the question *This workshop addressed the cultural realities of caregiving*. Other items included: *The Dealing with Dementia Guide will help me in my caregiving journey*; *The information shared in the workshop was new information to me that may improve my caregiving experience*, and an evaluation of the facilitator. The evaluation survey also included open-ended questions for participants to provide their honest feedback on the program. During in-person workshops, core program team members administered traditional printed surveys, and virtual workshop attendees completed the survey via Microsoft Forms.

Selection of DWD program community facilitators

RCI uses a Train-the-Trainer (TTT) framework to deliver the widespread DWD program. TTT involves individuals receiving training in a given subject and instruction on how to effectively monitor and supervise others in the approach while delivering the program as intended (13). The core program team first brainstormed who should be trained as program facilitators to deliver the DWD workshops and established the following eligibility criteria: (a) 18 years of age or older, (b) self-identify as Black or African American, (c) comfortable with public speaking, (d) reside in Georgia (e) able to attend one DWD facilitator training session, and (f) able to deliver 2 at least DWD workshops (in-person or virtual). We then created an electronic screening form that included the eligibility criteria questions and asked why they wanted to become a DWD facilitator and how far they were willing to travel within Georgia. The screening form was distributed to a pre-existing pool of Alter's advisory board members and faith community partner sites. We also promoted participation as a DWD facilitator in Alter's monthly partner updates through MailChimp and visited several faith community partner sites in Georgia to promote this opportunity and set up numerous phone calls with Alter church ambassadors to encourage participation. Twenty Black community members were initially screened, of whom eighteen were eligible. All were affiliated with Alter's faith-based community partners. An additional 4 eligible facilitators – friends and community members of the selected facilitators – were recruited during the pilot to support program delivery. Ten facilitators resided in rural Georgia counties (Troup, Talbot, and Dawson Counties) and 12 resided in urban settings (Fulton, Gwinnett, Newton, Dekalb, and Fayette Counties). For this project, facilitators' and program participants' reported zip codes were classified as either 'urban' or 'rural' using zip codes cross-referenced with the USDA's Rural–Urban Commuting Area (RUCA) codes (14) and neighborhood classifications from the Georgia Rural Health Innovation Center (15).

Selected facilitators were oriented to the existing DWD program, receiving the original guide and participating in the paired workshop led by RCI's DWD Program Specialist. We hosted the selected facilitators in person at the annual Alter Dementia Summit (an annual community conference focused on eradicating dementia-related disparities in the Black community through spiritual connectedness, brain health awareness, research, and community resources). The purpose of the facilitator meeting was to begin planning together how the DWD workshops would be delivered. Facilitators then participated in the DWD facilitator training, which was tailored to align with their needs. To account for facilitators' existing work schedules, we streamlined the facilitator training by removing redundant exercises, consolidating discussion topics, and shortening its duration from 1.5 days to 4 h, while still meeting training objectives and securing approval from the RCI DWD Program Specialist. Prospective facilitators were given 3 options to attend the training (weekday evening/morning, weekend). We collaborated with the graphic designer to update the training slide deck, which included the revised family caregiver workshop slide deck and new slides on facilitator expectations and logistics. After facilitators were trained, they were incorporated into the program team and assisted with recruitment, delivery, and sustainability of $\text{DWD}_{\text{Alter.}}$ Throughout the remainder of this paper, "we" refers to both the core program team and the community facilitators.

A Facilitator "Toolkit" was developed in collaboration with the graphic designer. It included a mixture of physical and virtual materials needed to deliver the workshops. As part of the toolkit, all facilitators received: (a) printed Alter/RCI partnership press release; (b) mailed and electronic version of the adapted guide; (c) printed and emailed procedure manual; (d) printed and electronic facilitator training slide deck; (e) electronic workshop advertisement flyer templates (plug-in ready): 1 print ready & 1 social media template; (f) new family caregiver workshop slide deck: emailed, printed, and via thumb drive. During the pilot program, we held biweekly, two-hour informal Zoom meetings with facilitators to address questions, concerns, and general comments about workshop delivery.

Participant recruitment

An extensive recruitment plan was developed in collaboration with the community facilitators to gain participation in DWD. We first collaborated with Alter's videographer to create recruitment videos and announcements for facilitators and Georgia church partners to include in their digital bulletins.

We also shared the recruitment videos on Alter's social media accounts regularly. We recruited participants through facilitators' community networks, Alter's community advisory board, and by word-of-mouth through caregivers involved in the focus groups. We shared the program in Alter's quarterly emailed newsletters (listserv that reaches over 100 Black families affected by dementia). We coordinated with Alter's director of community engagement to attend health fairs and community outreach events that had an influx of Black attendees, with a special focus in rural Georgia. We targeted specific Area Agencies on Aging (AAAs) in the Southern Georgia Regional Commission, Sowega Council on Aging Southwest Georgia vicinities to build partnerships and disseminate information on the revised DWD program to predominantly Black churches. Alter signed up as a vendor at Georgia festivals and community events typically frequented by Black community members, such as the wellness zone of the Annual Ice Cream Festival and the Marcus Garvey Commemoration Celebration. The pilot program was promoted at senior centers, predominantly Black faith-based communities, and agencies that serve older adults. We conducted outreach within Alter's pre-existing pool of care partners engaged in the 'Black Dementia Minds' collaborative and held speaking engagements at the James M. Dixon Foundation for Alzheimer's Research and Support Caregiver Seminar and Dementia 101 Presentation sponsored by Call for Caring Inc. and Calvin Court Senior Living Residence.

Outcomes

Twenty-two total non-Hispanic Black community members were trained as $\text{DWD}_{\text{Alter}}$ facilitators, comprising twenty-one females and one male. Workshops were held between June 20th, 2024, and August 31st, 2024. Fifteen facilitators held at least 1 workshop during the time frame, 13 of whom held 2 workshops, and one facilitator held 5. Twenty-seven total workshops were delivered, comprising 12 virtual, 3 hybrid, and 12 in-person sessions. Three hundred and sixty-five people registered for workshops, and 264 attended.

Four workshops were held in rural settings that took place virtually and at local Technical Colleges and libraries in Randolph and Talbot counties. The remaining workshops were held at churches and virtually in metropolitan Atlanta cities and communities. The 7 facilitators who did not hold a workshop by the end of the pilot cited unexpected medical problems, limited time, and personal schedule constraints. Of these 7, 5 were from rural communities and 2 were from urban settings. One hundred and twenty-three individuals completed the Individual Receipt Form and received a guide, but did not attend a workshop, 22 of whom received an electronic PDF version of the guide.

One hundred and eighty-four attendees completed pre-workshop surveys, and 158 completed post-workshop surveys. An assessment of participant demographics and acceptability were completed as a result of the pilot $\text{DWD}_{\text{Alter}}$. The average age among those who reported it was 56.4 years (n = 177), and 79% (n = 177) identified as a family caregiver. The youngest attendee was 20 years of age, and the oldest was 89 years. Ninety-five percent (n = 178) of respondents identified as Black or African American, and 96% (n = 180) identified as non-Hispanic. Most attendees who reported their gender were female (n = 162, 87%) and employed/self-employed full-time (n = 81, 43%).

Among those who reported their highest level of education, 4% (n = 37) attended some school, 20% (n = 37) completed high school/ GED, and 49.5% (n = 91) received a bachelor's degree or above (master's, professional degree, doctorate). Among respondents who reported their zip codes in their personal information, 36% (n = 66) lived in classified rural communities. Responses to all demographic items are in Table 1.

TABLE 1 *Dealing with Dementia* pre-survey respondent demographics.

Characteristic	M [range]/*N* (%)
Age (years)	56.4 [20–89]
Gender	
(Female)	162 (87%)
(Male)	21 (11%)
(Not listed)	1 (0.5%)
Race	
(Black or African American)	178 (95%)
(White)	2 (1%)
(Asian or American)	1 (0.5%)
(Other)	3 (2%)
Ethnicity	
(Non-Hispanic/non-Latino)	180 (96%)
(Hispanic/Latino)	4 (2%)
Educational attainment	
(Some school)	6 (3%)
(High school/GED)	37 (20%)
(Some college)	35 (19%)
(Associate' s degree)	15 (8%)
(Bachelor's degree)	42 (23%)
(Master's degree)	42 (23%)
(Professional/doctorate degree)	7 (4%)
Employment status	
(Employed/self-employed full-time)	81(43%)
(Employed/self-employed part-time)	12 (6%)
(Homemaker)	3 (2%)
(Retired)	66 (36%)
(Unemployed)	10 (5%)
(Other)	12 (6%)
Are you a current family caregiver?	
(Yes)	147 (79%)
(No)	37 (20%)
Are you a professional caregiver (CNA, LPN, etc.)?	
(Yes)	33 (18%)
(No)	151 (81%)
Residential zip code classification	
(Urban)	118 (64%)
(Rural)	66 (36%)

87 participants did not report age. All other demographic characteristics were missing 80 responses.

Program evaluations were completed by 201 attendees. The majority of respondents strongly agreed with the following items: *The Dealing with Dementia Guide will help me in my caregiving journey* (n = 159, 82%); *This workshop helped me understand how to use the guide to find the answers to my caregiving questions* (n = 159, 82%); *The information shared in the workshop was new information to me that may improve my caregiving experience* (n = 134, 69%); *I will recommend this workshop to others* and *This workshop addressed the cultural realities of caregiving* (n = 161, 83%). Responses to all evaluation items are shown in Table 2.

Discussion

Program implications and constraints

Approximately 375,000 family caregivers in the U.S. support someone living with dementia or dementia (Alzheimer's Association, 2024). As the late Rosalynn Carter aptly stated, "*There are only four kinds of people in the world—those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers* (8)." In this context, the adapted DWD program reached 387 individuals, whether through receiving the guide with a brief overview of the information or by participating in the paired workshop. While many participants were active caregivers, the inclusion of former caregivers and individuals anticipating future caregiving roles meant that vital information reached beyond immediate needs, offering preparation and support for those on caregiving journeys or assisting someone in their circle.

Applying CBPR principles—centering the community through shared decision-making, utilizing local resources, and iteratively gathering feedback—enhanced the cultural relevance and acceptability of the program. Partnering with the community strengthened the development and implementation process and fostered trust and ownership. The high volume of "strongly agree" responses and overwhelming positive open-ended feedback in participant evaluations validated the value of culturally responsive approaches. Research has shown that culturally tailored education fosters greater engagement and helps learners retain information more effectively (16, 17).

Despite its successes, the pilot $\text{DWD}_{\text{Alter}}$ faced key limitations. Because the limited grant period allowed only 2.5 months for facilitators to deliver the workshops, pre- and post-data collection was limited, preventing meaningful comparisons with findings from earlier evaluations of the DWD program.

Additionally, the short timeline prevented 7 facilitators from hosting a DWD workshop before the end of the grant period due to scheduling and availability constraints. Additionally, a program participant noted that using "Black" in the title seemed unnecessary if the emphasis on Black caregivers was not sustained through content. While the workshop, guide, and accompanying imagery referenced Black families, the core content remained broadly applicable, and some felt it insufficiently centered the Black caregiving experience, despite its name, *Dealing with Dementia: A Guide for Black Caregivers.* Although components of the program were adapted based on input from Black faith and community members, incorporating specific frameworks and caregiver narratives to explicitly and intricately guide

TABLE 2 *Dealing with Dementia* evaluation responses.

Question	Strongly agree	Agree	Neither agree nor disagree	Strongly disagree
1. The *Dealing with Dementia* Guide will help me in my caregiving journey.	159 (82%)	28 (14%)	2 (1%)	6 (3%)
2. This workshop helped me understand how to use the guide to find the answers to my caregiving questions.	159 (82%)	28(14%)	2 (1%)	6 (3%)
3. The information shared in the workshop was new information to me that may improve my caregiving experience.	134 (69%)	42 (22%)	11 (6%)	6 (3%)
4. Overall, the workshop was helpful to me.	163 (84%)	25 (13%)	1 (0.5%)	6 (3%)
5. I will recommend this workshop to other caregivers.	175 (90%)	12 (6%)	2 (1%)	6 (3%)
6. This workshop addressed the cultural realities of caregiving.	161 (83%)	26 (13%)	7 (4%)	1 (0.5%)

Responses	About right	Too long	Too short	
Did you feel the length of the workshop was…	179 (92%)	12 (6%)	4 (2%)	

the development of culturally tailored content could have further enhanced the relevance and impact of the information. With additional time and resources, the tailoring process could have been more comprehensive and better aligned with culturally specific caregiving models.

Another limitation was the program's limited reach in rural communities, a priority we had hoped to address more fully. Of the 7 program facilitators who did not deliver workshops by the deadline, 5 were based in rural communities (half of the total rural-based program facilitators), representing a significant shortfall. Consequently, many rural Black caregivers may not have had the opportunity to participate. This shortfall highlights a broader issue: the need to equitable access to resources in Black rural communities, which remained a shortcoming of our $\text{DWD}_{\text{Alter}}$. If we had supported these facilitators in organizing participation and spaces for the program, we could have substituted other facilitators to ensure the education was still provided. In addition, among the 184 workshop attendees who completed pre-program surveys, only 66 resided in rural communities—a lower proportion than expected based on outreach efforts. This shortfall is especially concerning given the well-documented lack of access to formal caregiving support and dementia education in rural communities (18). Structural barriers such as transportation challenges, healthcare workforce shortages, and lower general awareness of Alzheimer's disease and related dementias often leave rural caregivers underserved (19). Black caregivers in rural communities are particularly vulnerable to "falling through the cracks" of existing support systems, despite facing disproportionate caregiving burdens and limited culturally competent care options (1). Meeting caregivers "where they are" remains one of the most pressing challenges (18). This includes ensuring awareness of available resources and offering services in trusted community spaces. Encouragingly, two program facilitators responded to the limited rural participation in the DWD program by independently continuing workshop delivery in LaGrange and Box Springs, Georgia, well beyond the grant period. In recognition of these ongoing needs, the core program team has begun further developing/strengthening partnerships with rural Black churches to enhance outreach and deepen connections with local caregivers. Strengthening these place-based partnerships is a critical next step in expanding the reach and long-term sustainability of culturally tailored caregiver support.

Program sustainability

The development and delivery of the adapted DWD Program came with its fair share of challenges. To ensure the lessons learned were sustained, a formal Sustainability plan was co-developed with the program facilitators to ensure that resources spent on the DWD Program were not lost. As a result, $\text{DWD}_{\text{Alter}}$ was integrated into the Alter framework as an ongoing support and education resource. Today, Alter's resources reach more than 90 faith-based partnerships nationwide, expanding the program's reach and positioning $\text{DWD}_{\text{Alter}}$ to have a lasting impact on Black communities across the country. Program sustainability is an important component of public health practice, ensuring that effective interventions continue to benefit communities beyond initial funding periods (20). Sustainable programs are more likely to maintain positive health outcomes, build long-term community trust, and adapt to evolving needs over time. Without sustainability planning, even well-designed initiatives risk losing momentum or failing to address health disparities in a lasting way. Embedding sustainability strategies—such as community partnerships, capacity building, and policy integration—can help institutionalize public health gains and promote health equity (20).

In efforts to encourage shared responsibilities, a sustainability planning meeting was held in September 2024, with 10 community facilitators and 3 core program team members to discuss actions to support this project for a long-term period. During this planning meeting, attendees discussed their experience as facilitators and holding DWD workshops in their communities. Considering the discussion and feedback received throughout the project, the following steps will be implemented to sustain Alter's and the community's effort to deliver the adapted DWD workshop and guide to Black caregivers in Georgia.

Alter will establish a partnership with 8 libraries in South Fulton for the community facilitators to host workshops. Under the guidance of the program core team, current community facilitators will continue to organize and deliver workshops in their respective communities using the tools they were provided during the project period. Facilitators will continue to be responsible for securing workshop locations and videoconferencing platforms to hold the workshop. Facilitators will also continue to be responsible for the advertisement of workshops and submitting requests to Alter's Director of Community Engagement to advertise the workshops on Alter's event page.

While initial outcomes focused on participant demographics and satisfaction (acceptability), more robust analysis is needed to evaluate effectiveness, including changes in caregiving self-efficacy and dementia knowledge before and after program participation. Collaboration with the Rosalynn Carter Institute's Data Manager to conduct statistical analysis and assess these outcomes is underway.

Data availability statement

The datasets presented in this article are not readily available because the data outlined in the outcomes were preliminary evaluative data. Although collected, pre-post data has not yet undergone in-depth analysis with a biostatistician. Requests to access the datasets should be directed to Karah Alexander, karah.lynea.alexander@emory.edu.

Ethics statement

The studies involving humans were approved by IRB Committee of Georgia Southwestern State University. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

KA: Writing – original draft, Supervision, Methodology, Writing – review & editing, Data curation, Conceptualization, Investigation. FE: Conceptualization, Writing – original draft, Resources, Investigation, Funding acquisition, Methodology, Writing – review & editing, Supervision. JT: Writing – review & editing, Funding acquisition, Resources, Project administration, Writing – original draft, Conceptualization, Validation. MC: Resources, Conceptualization, Writing – review & editing, Supervision, Project administration, Writing – original draft, Data curation. TM: Writing – review & editing, Writing – original draft.

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Conflict of interest

JT was employed by Sage Navigator Inc.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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Exploring peer education for migrant informal caregivers of mentally ill loved ones: a realist evaluation protocol

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Introduction: Informal caregivers with a migration background who care for someone with a mental illness often experience elevated caregiver burdens due to factors such as discrimination, language barriers, and stigma. In The Netherlands, a peer education intervention called 'They Are not Mental?!' (TANM) addresses these challenges by reducing stigma, increasing help-seeking behaviors, and improving access to healthcare. This transdisciplinary study evaluates how contextual factors and mechanisms influence its outcomes.

Description: This research protocol outlines a realist evaluation of the intervention using a mixed-methods design, including interviews, post-questionnaires, and observations. The study will develop and refine the program theory to determine for whom, in what contexts, why, and how the intervention works.

Discussion: This protocol shows how we plan to investigate how, why, for whom and under what circumstances TANM produces its intended outcomes, using a realist evaluation approach. This approach is well-suited for evaluating complex interventions because it accommodates for dynamic and iterative interventions. Its focus is on understanding patterns and mechanisms within specific contexts, using program theories.

Conclusion: The evaluation of TANM will inform future intervention adaptations and guide future efforts to support vulnerable populations, particularly migrants navigating caregiving challenges.

KEYWORDS

informal caregivers, migration background, mental illness, mental health, peer education, integrated care, realist evaluation

1 Introduction

Informal caregivers – often family members or friends who provide unpaid care to loved ones – play an important role in supporting individuals with a diagnosis of a mental health condition (1, 2). For caregivers with a migration background, meaning those who have moved to a new country and are in a situation in which they might be less familiar with local customs, norms, or care system, this responsibility often comes with additional challenges and increased stress, due to stigmatizing beliefs regarding mental illness, language and cultural barriers and limited access to support services (3–5). These caregivers face a "double adaptation burden," with stress intensified by their caregiving role and experiences as migrants. To alleviate this burden, providing appropriate support is important (5, 6). In response, the culturally sensitive intervention "Ze Zijn Toch Niet Gek?!" (translation: "They Are not Mental"; hereafter TANM) was developed to support informal caregivers with a migration background who care for a loved one with a mental illness. This paper presents the protocol for a planned realist evaluation of TANM, aiming to develop a theoretical framework which explains the mechanisms through which support programs like TANM produce their desired outcomes and gain insights for its improvement.

Members of migrant communities are often at increased psychological health risks, due to challenges such as adapting to a new culture and encountering discrimination. As such, informal caregivers play an important role in supporting those affected (4, 7, 8). Caregiving for someone with a mental illness can be stressful and difficult for all informal caregivers, irrespective of migration status, but caregivers with a migration background face additional challenges that can intensify this caregiver burden (1, 3, 9, 10). These challenges include stigma, which is a general phenomenon across societies and can be influenced by culture-specific explanatory models – such as viewing it as a result of black magic, spirits, punishment of a divine entity or higher power, or the evil eye. Stigma can foster feelings of shame within families and discourage both patients and caregivers from seeking help (3, 4, 11–15). Additionally, cultural expectations around family caregiving, including gendered norms and ideas about family obligations, can further increase caregiver burden (3, 16, 17).

These cultural taboos, combined with systemic barriers like language differences and cultural misunderstandings, can make it difficult for informal caregivers and their loved ones to acknowledge the need for support, limiting the access to formal care (5). These intersecting challenges make caregiving for individuals with mental illness particularly difficult within migrant communities.

One way to address barriers in accessibility is through integrated care, which focuses on breaking down organizational boundaries and aligning services to better meet the needs of individuals, rather than being shaped by what each organization provides separately (18). Integrated care requires collaboration between healthcare, social and community services (18, 19), and ideally, the involvement of the target group. By making care systems more navigable and tailored to the target group's needs, integrated care is a promising way to empower vulnerable individuals (20). This is particularly relevant for informal caregivers with a migration background, who often face additional challenges in navigating healthcare systems and accessing support (5). For caregivers of individuals with mental illnesses, tailored interventions are important for addressing their physical, psychological, and social needs. Through collaboration with relevant services, integrated care can better meet these needs and enhance the overall quality of psychosocial care by supporting these informal caregivers, who may experience additional barriers due to language, cultural differences, or unfamiliarity with available services (5, 21–23).

To address the challenges faced by informal caregivers with a migration background who care for a loved one with a suspected mental illness, TANM was developed as a peer education program. A key aim of TANM is to enhances caregivers' resilience – the dynamic process of adapting to adversity, which helps buffer against caregiver burden (24–26) - through improved access to information, reduced stigma surrounding mental health, and stronger connections between migrant families and the healthcare system. Additionally, TANM enhances coordination between community-based support and healthcare organizations, by incorporating elements of integrated care. A detailed description of the TANM, including its structure and implementation, is provided in Section 2.

Since its development in 2014, TANM has undergone slight adjustments, including changes in funding and target groups. Its evolving nature requires an evaluation method that can adapt to these changes. A realist evaluation (RE) design was chosen because it provides a framework not only to assess whether the intervention works, but also to explore why, for whom, and under what circumstances it works. This approach is well-suited for an exploration to understand how underlying contexts and mechanisms – such as stigma and taboos – impact the intended outcomes of TANM (27). Given the complexity of these factors, this research takes a transdisciplinary approach, involving collaboration with the intervention's coordinating organizations to ensure that different perspectives are integrated into the evaluation process circumstances (27–29). This research aims to evaluate TANM using a RE approach, in order to develop a program theory that explores how contexts and mechanisms, such as stigma and taboos, impact its intended outcomes. The research will answer the following questions:

> *'Did intervention participants, ambassadors and coordinators perceive changes in its short-term outcomes related to discussing mental health taboos, understanding mental illnesses and caregiver support, and their perception of the healthcare sector? How did the intervention components and contextual factors contribute to this change?'*

Considering the goals of TANM, we expect these changes to have a positive direction; that is, we anticipate that participants will discuss mental health taboos with their friends and families, develop a better understanding of mental illnesses and caregiver support, and hold a more positive perception of the healthcare sector.

In the following sections, we describe key components of our realist evaluation design, including the program theory, data collection methods, and planned analyses.

2 Intervention description

TANM is a peer-facilitated intervention aimed at strengthening the resilience of informal caregivers with a migration background who support a loved one with a suspected mental illness in the second largest city of the Netherlands, Rotterdam. Developed collaboratively by a community empowerment organization, a mental health prevention agency and a support association for families affected by mental health issues, TANM is a 3-session program that aims to increase resilience in the long-term, by (1) addressing mental health taboos (2); improving access to information and care and (3) fostering trust between migrant communities and the healthcare sector. Since the long-term goal of increasing caregivers' resilience extends beyond the scope of the current research, we will focus on evaluating its short-term objectives, which include: encouraging open discussions about mental health within migrant communities, improving understanding of mental illnesses and available support for caregivers, and fostering trust between migrant families and the healthcare sector to reduce barriers to professional support.

TANM relies on peer educators, referred to as *ambassadors*, who share similar lived experiences with the participants, particularly through their migration background and, for some ambassadors, their caregiving role. Peer education is an approach to engage 'hard-to-reach' populations, such as those with limited resources, language barriers or distrust in the healthcare system. Peers serve as intermediaries who can leverage cultural understandings and trust to identify participants and adapt the intervention's messages to meet the group's needs (30–32).

Within TANM, ambassadors are volunteers who are active community members, often demonstrated through a strong social network or prior volunteer experience in their neighborhoods, and they recognize the importance of discussing mental health. Ambassadors are invited through outreach by the community empowerment organization, as well as through referrals from ambassadors of previous years. They are selected based on the following criteria:

- Affinity with and access to target groups;
- Willingness to share personal experiences;
- Ability to lead discussions and educate others;
- Ability to establish contact with healthcare professionals and translate the needs and concerns of the target group to these professionals.

Once selected, ambassadors receive specialized training, covering three main areas: (1) basic knowledge of mental health conditions, such as depression, psychosis and schizophrenia, which includes symptoms, causes, treatment options and the effects of medication and substance use; (2) informal caregiving, including definitions, perceptions, signs of caregiver burden, and available support services; and (3) practical skills in peer education, such as presentation techniques and an introduction of the content of the peer education sessions. The training is delivered in the Dutch language by a prevention specialist with a background in psychology, a Family Experience Expert (FEE; explained in Section 2.1 about Phase 3) and a caregiver support coach affiliated with the local caregiver support service, which has been part of TANMs coordinating organizations since 2023. The training is highly interactive and fosters a culturally sensitive approach by encouraging ambassadors to share personal experiences and explanatory models they are familiar with. A key message throughout the training is that differing perspectives on mental health conditions can coexist, and that creating space for these perspectives during the peer education sessions is essential.

After completing the training, ambassadors recruit participants for their groups and lead the intervention's peer education sessions in the dominant language spoken within their group. This could be Dutch, but also, for example, Arabic or Turkish. Ongoing support is provided to the ambassadors in two ways, through regular feedback meetings with members of the coordinating organizations and fellow ambassadors, and through direct access to a designated contact person within the coordinating organizations who is available for individual questions, support or guidance through phone, messaging or in-person contact.

Our evaluation will focus on the current round of TANM (September 2024 – March 2025), which is co-organized by four partners, following the addition of a helpline and support service for caregivers in Rotterdam in 2023.

2.1 Intervention structure and content

The intervention is structured into three main phases (see Figure 1 for an overview): the preparation phase, the peer education sessions, and the follow-up training and home visits phase.

2.1.1 Phase 1 – preparation

The organization of TANM recruits ambassadors – i.e. key figures from various communities in Rotterdam. Ambassadors undergo training to become peer educators. This training equips them with the knowledge and skills needed to identify symptoms of mental illness, facilitate peer education sessions, and recruit participants for Phase 2.

2.1.2 Phase 2 - peer education sessions

Peer educators facilitate three structured sessions, focusing on topics such as understanding mental health issues, the role and challenges of informal caregiving, and available support options. Detailed session topics and objectives are outlined in Appendix I. Ambassadors identify participating informal caregivers who may need additional professional support and refer them Phase 3.

2.1.3 Phase 3 - follow-up training and home visits

This optional phase provides tailored support to meet the needs of the identified informal caregivers. For each group, a member of one of TANM's coordinating organizations, together with the ambassador, conducts a needs assessment to determine the most appropriate follow-up support for the identified caregivers. This may include five to six training sessions with a psychologist for a group of identified informal caregivers, which are based on the training 'Psychological vulnerability in your immediate environment' (33) but adapted to fit the unique needs of migrant caregivers. Alternatively, one-on-one consultations by a Family Experience Expert (FEE) for an individual caregiver may be offered. The FEE is someone who has personal experience supporting a relative with mental health issues and has received specialized training, enabling them to reflect on their own experiences, develop communication skills, and establish professional boundaries. Phase 3 is flexible and not attended by all Phase 2 participants.

3 Methods

Realist evaluation (RE) is a theory-driven approach that provides a framework for evaluating interventions, policies, measures, and other complex social programs or systems. It examines what works, how, for whom, why and under which circumstances, considering the influence of factors like culture and socioeconomic status on outcomes (27, 28, 34, 35). The underlying idea behind REs is that outcomes are the product of multiple causes and depend on mechanisms and contextual elements (36, 37). Together, these form context-mechanism-outcome (CMO) configurations, which form the basis of the so-called program theory (37). There is no standard methodology for REs, but it is encouraged to use a mixed-methods approach, combining both quantitative and qualitative methods (35, 38). This flexibility makes RE particularly suited for evaluating complex interventions, like TANM (27, 28, 35). Our RE of TANM consists of both qualitative and quantitative methods and will follow the RE reporting standards as made clear by the RAMESES-II project (37).

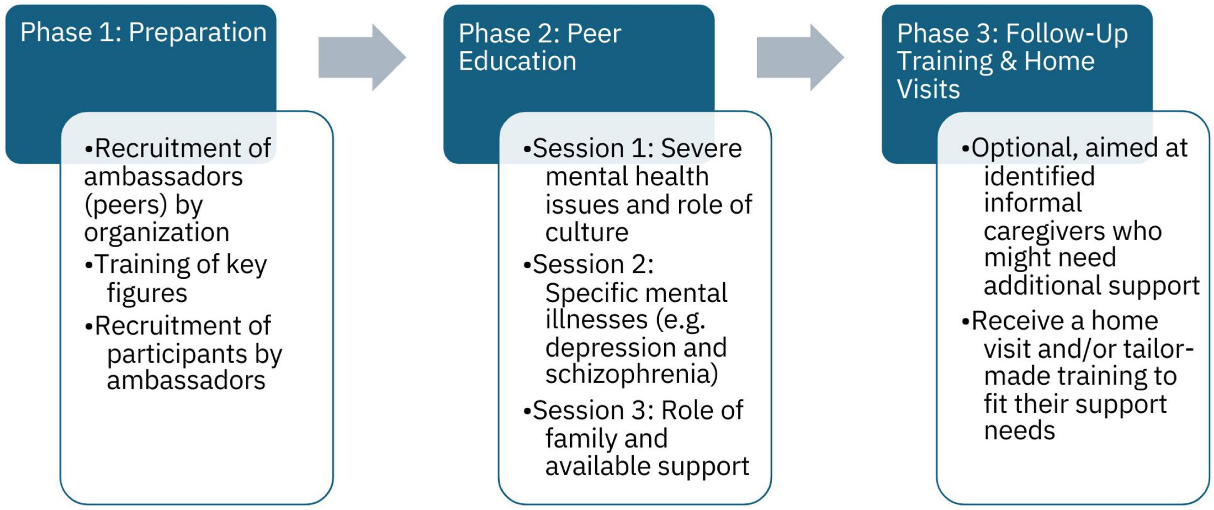

FIGURE 1
Phases of the intervention TANM.

The RE of TANM, combines these methods in four phases. The first phase, which has already been completed (see Figures 2, 3), focused on developing an initial program theory. This theory, presented in section 3.1, serves as the foundation for the remaining phases of our RE. This protocol outlines the steps for phases 2–4, involving: (1) interviews with participants, peer educators, and other stakeholders; (2) post-intervention questionnaires; and (3) observations of the peer education cycle sessions. This study is conducted by a research team with experience in intercultural research, including two researchers who have a migration background themselves. The following sections provide detailed descriptions of each phase and method (see Figure 2).

The study protocol was approved by the Ethics Review Committee of the Department of Psychology, Education and Child Studies, Erasmus University Rotterdam (application number ETH2425-0079).

3.1 Phase 1: development of the initial program theory

The first phase of our RE involved developing an initial program theory, which explains which mechanisms caused what outcomes in what contexts (36). Our theory was based on a logic model, derived from available intervention documentation (e.g., ambassador training manual), six interviews with ambassadors and six interviews with caregivers who were part of the 2023 intervention round, and a focus group with the members of the coordinating organizations. Data were collected and analyzed in April–June 2024, and the initial program theory was drafted by one researcher (MH) and refined through iterative discussions with co-authors (PK, SD). The last draft was discussed with the project lead of TANM and then finalized. The initial program theory forms the basis of the further evaluation, for which the methodology is presented in this protocol. The theory is outlined in the next paragraph and in Figure 3.

In our analysis, we found nine CMO-configurations that fitted in four clustered themes, as can be seen in Figure 3. The first theme we found is related to the taboo on mental illness among migrant communities (pictured in blue). The second theme related to increasing accessibility to information, care, and support (pictured in green). The third theme related to bridging the gap between migrant families and the healthcare sector (pictured in yellow). Lastly, the fourth theme related to community empowerment and social capital (pictured in red). The nine CMO-configurations within these four themes serve as a starting point for the data collection and analysis in the following phases of the RE. For more details about our initial theory, see Supplementary material I where we shortly discuss the cluster themes and details of each CMO-configuration.

3.2 Phase 2: data collection for theory refinement

Phase 1 resulted in a conceptual model which will guide further empirical data collection aimed at testing and refining it – that is, adapting the program theory based on this new evidence (36). During the most recent intervention cycle, which started in September 2024, researchers will collect qualitative data (i.e., interviews, observations), quantitative data (i.e., post-intervention questionnaire) and logbook data (e.g., notes of meetings with TANM's coordinating organizations and feedback meetings with peer educators). Recurring consultations with the coordinating organizations were held throughout the development of the research protocol. Data will be collected by a team of co-researchers with diverse cultural backgrounds, including Moroccan, Turkish, Indonesian, and Dutch. This equips the team with insights and skills to connect with participants in a culturally sensitive manner. Supplementary material I elaborates on the initial program theory, while Tables 1, 2 provide an overview of how each CMO-configuration is linked to at least one of the above-mentioned data sources. This ensures that all CMO-configurations are addressed through planned data collection and data analysis. With our approach, we will assess short-term and intermediate

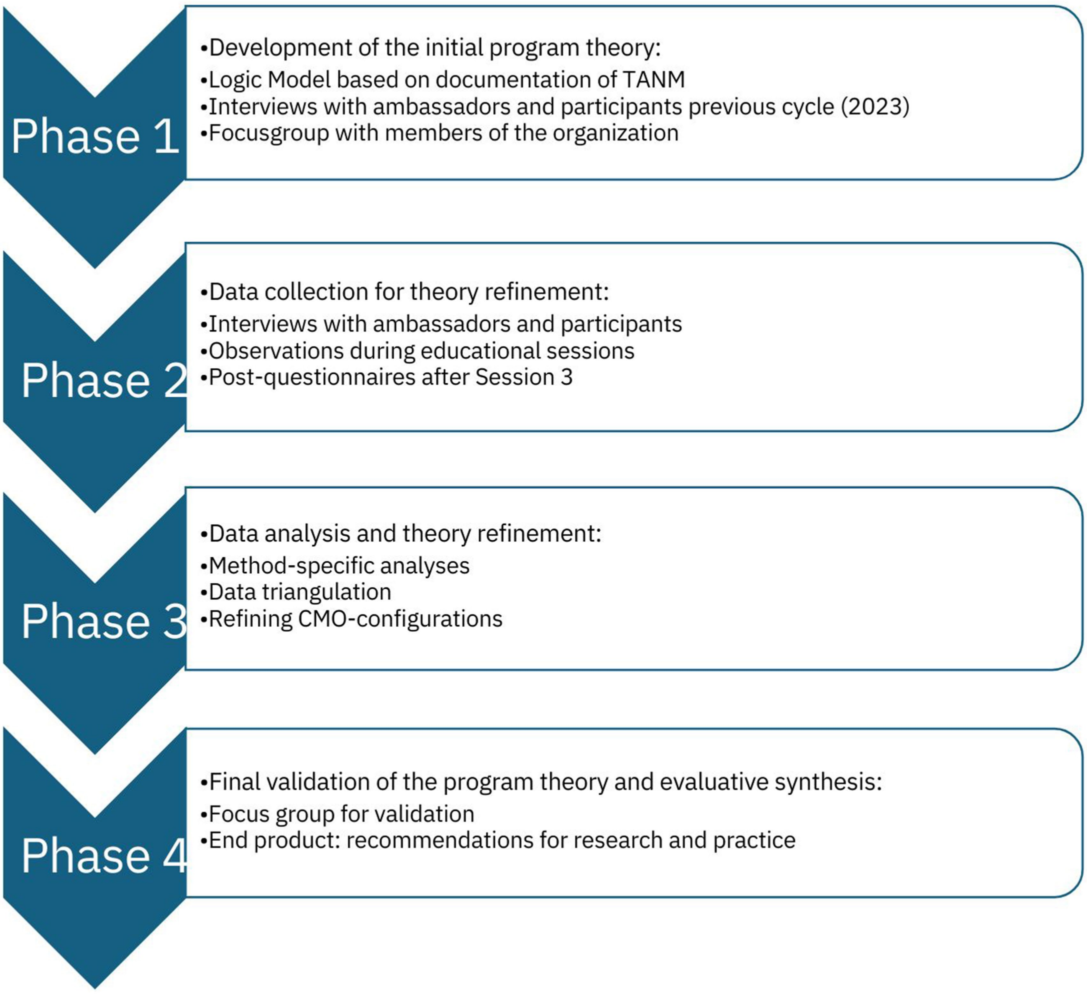

FIGURE 2
Four phases and corresponding methodologies of our RE approach.

outcomes of the TANM intervention components and contextual factors.

3.2.1 Interviews with ambassadors

The interviews with ambassadors aim to explore their experiences with TANM and will be guided by topics from our initial program theory. This enables exploration of contextual elements and mechanisms driving the intervention's intended short-term outcomes. The outcomes are related to discussing taboos with friends and family, a better understanding of mental illnesses and caregiver support, a more positive perception of the healthcare system, and the ripple effect where knowledge is shared outside of the intervention group (39).

Table 1 provides an overview of all CMO-configurations, whereas Table 2 provides an overview of which CMO-configurations will be covered in the interviews with the ambassadors.

3.2.2 Interviews with participants

Like the interviews with the ambassadors, those with TANM's participants aim to explore their experiences with TANM, focusing on how and which intervention components and contextual factors influence TANM's observed and experienced short-term outcomes. These interviews will address the same CMO-configurations explored in the interviews with the ambassadors (see Tables 1, 2).

We will interview two types of participants; (1) Those identified as informal caregivers and who attended Phase 2, the peer educational cycle, and Phase 3, the tailored follow-up support; and (2) participants who only took part in Phase 2.

3.2.3 Observations

The observations aim to document how the peer educational sessions are delivered, with a focus on contextual factors and mechanisms. We will look at mechanisms, such as providing informational support and discussing individual experiences, and contexts, such as group dynamics and alternative explanatory models of mental illnesses. See Tables 1, 2 for a full overview of the related CMO-configurations.

Observations were conducted using a semi-structured observation guide, designed to capture context and mechanisms from the initial program theory (e.g., social support based on Cohen & Wills (40),

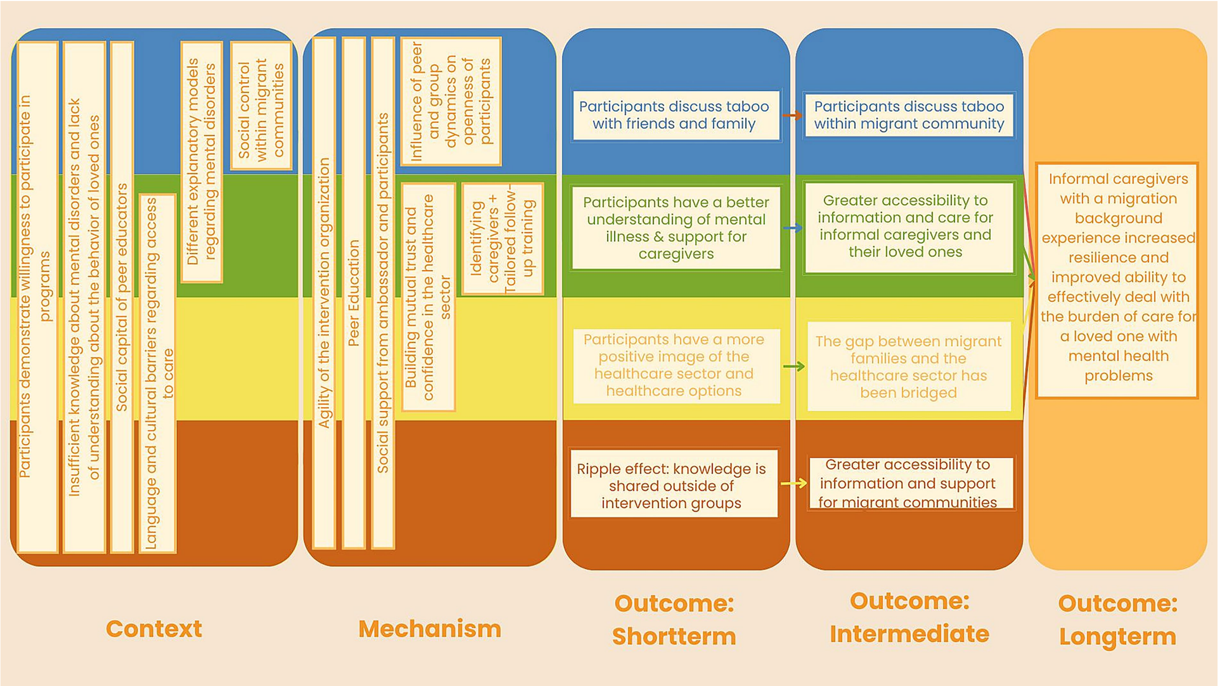

FIGURE 3
Initial program theory of TANM.

TABLE 1 Link between CMO-configurations and data sources.

CMO ID	Context-mechanism-outcome configuration: summary	Data collection method
1a	Ambassadors model openness through sharing personal caregiving and mental illness stories. This reduces stigma and encourages participants to discuss mental health topics and to seek help within and beyond their group.	Interviews, questionnaire, observations
1b	Participants, motivated to understand their loved one's mental illness, gain emotional and informational support from fellow participants and ambassadors. This fosters discussions reducing stigma and enhancing understanding within and beyond their group.	Interviews, questionnaire, observations
2a	Ambassadors share information and experiences to bridge language and cultural gaps. This helps informal caregivers and migrant families build trust in the Dutch healthcare system and develop more positive perceptions.	Interviews, observations
2b	Interactions with representatives from care organizations during peer education sessions help migrant families overcome distrust and unfamiliarity. These foster increased trust and willingness to seek help from the Dutch healthcare system.	Interviews, observations
3a	Peer education and informational support enhance migrant families' awareness of available healthcare options. This improves accessibility and fostering better utilization of support services.	Interviews, observations
3b	Ambassadors identify informal caregivers and refer them for tailored follow-up support. This follow-up equips them with the skills and support needed to manage caregiving responsibilities and burdens effectively.	Interviews
4a	Trusted peers (i.e., ambassadors) with strong community ties recruit participants and create a safe, reassuring environment. This increases participation in mental health support programs, despite stigma or mistrust.	Interviews, questionnaire
4b	Participants share knowledge and personal stories with their intervention groups and with their communities. This reduces stigma and spreading understanding about mental health and caregiving.	Interviews, questionnaire, observations
4c	From an organizational perspective, flexibility in adapting training content, communication, and support to cultural and practical needs is needed. This enables inclusive participation and enhances access to information and care for migrant families.	Interviews, observations

TABLE 2 Overview of data collection methods, CMO-configurations, sample size, frequency, and purpose in realist evaluation.

Method	CMO-configuration	Sample size/frequency	Purpose in realist evaluation
Interviews with ambassadors, semi-structured	1a, 1b, 2a, 2b, 3a, 3b, 4a, 4b, 4c	$n = 10$	Understanding ambassador's perspectives on CMO-relationships
Interviews with participants, semi-structured	1a, 1b, 2a, 2b, 3a, 3b, 4a, 4b, 4c	2 per ambassador, total $n = 20$	Exploring firsthand experiences of short-term outcomes and factors that influenced these changes
Observations	1a, 1b, 2a, 2b, 3a, 4b, 4c	1–2 per group	Capturing real-time behaviors of ambassadors and participants and context
Post-intervention questionnaire	1a, 1b, 4a, 4b	Approx. $n = 100$ (10 ambassadors, ~10 participants each, varying)	Identifying patterns and insights from participants to support interpretation of qualitative findings
Logbook	1a, 1b, 2a, 2b, 3a, 3b, 4a, 4b, 4c	All attended meetings with TANM's coordinating organizations and all feedback meetings	Providing context for interpreting the findings and aligning them with the program theory

aspects of peer education based on Voorham (32)). Specifically, we will focus on:

1 *Social influences*: References to cultural norms, values, and alternative explanations for mental illnesses; individual experiences shared by participants or ambassadors.
2 *Social support*: Types of social support observed and the ways in which they are expressed.
3 *Role of the ambassador*: Adaptations of content by the ambassador (e.g., translation or cultural tailoring); peer education aspects such as similarity and professionalism.
4 *Group dynamics*: Interactions, trust, inclusivity, dominance of specific members, and both verbal and nonverbal communication.

The guide includes space for additional notes and researcher reflections after observations (full guide is added in Supplementary material II).

The observations will take place during Phase 2 of TANM, with at least one session per intervention group observed by researchers who are fluent in the language spoken in each group. This ensures an accurate understanding of what is observed. Given the expected sensitivity of the topic and the potential caution of participants toward outsiders like researchers, we made efforts to minimize interference with the natural flow of the educational sessions. Accordingly, we schedule our observations to coincide with planned visits from TANM's coordinating organizations' representatives. As such, we observe all final sessions, as we are present to administer the questionnaire (see 3.2.4). Additionally, if an organizational visit is planned during the first or second peer education session, we join these visits, observing these sessions as well. This will total to at least 10 observations from the final peer education session, added by one to 10 observations from the first or second sessions. This will result in at least 10 observations of the final peer education sessions, with an additional one to 10 observations from the first or second sessions.

3.2.4 Questionnaire

The quantitative component of this study is of exploratory nature and involves the use of a post-intervention questionnaire conducted among participants of the peer education sessions. It aims to capture differences between participant groups, and it will collect insights into the context and mechanisms related to social support, perceived stigma, group composition, and group dynamics (see Tables 1, 2).

All Phase 2 participants are asked to complete the questionnaire at the end of the final third session. Based on advice of the coordinating organizations, we address practical challenges associated with the target group, such as expected language barriers, diverse backgrounds, and varying literacy levels, the questionnaire was simplified to a maximum B2-level in Dutch. We minimized the number of questions and made answer options straightforward (e.g., yes/sometimes/no) to avoid confusion.

At the end of the third session, the attending researcher distributes paper questionnaires and explains the study's goal, questionnaire, and informed consent, and instructs participants to complete them individually. In groups where participants do not understand Dutch, a research assistant fluent in the group's language translates each question aloud, one at a time, for the entire group. This approach allows participants to listen to the translation and fill in their responses individually.

Rather than relying on pre-validated questionnaires, the items were constructed based on theoretical concepts from our CMO-configurations. The questionnaire starts with demographic questions (i.e., age, gender, country of birth of the participant and their parents), and questions related to caregiving responsibilities (i.e., frequency and care recipient). It is followed by section on group composition (specifying familiarity and relationships with group members and ambassador prior to the intervention), social support mechanisms (inspired by Cohen and Wills (40)), and mental health taboos and group dynamics. Lastly, an open-ended section allows participants to share lessons or insights gained during the intervention. Table 3 provides an overview of the themes and items, with the full questionnaire available in Supplementary material III.

3.2.5 Logbook

To document the study process and decisions made throughout, researcher MH makes notes in a logbook. This logbook contains notes of all attended meetings with TANM's coordinating organizations as well as feedback meetings held with the ambassadors and representatives from the coordinating organizations. The notes capture key decisions during the study and intervention process, feedback received by the coordinating organizations and ambassadors,

TABLE 3 Overview of questionnaire themes, items and example questions.

Questionnaire themes	Number of items	Examples of items and answer options
Group composition	5	Did you know the other participants before the start of the sessions? Answer categories: yes/no. If yes, where from? Answer categories: previous training, church, (volunteer) work, common friends or acquaintances, neighborhood or district.
Social support mechanisms	5	Can you talk to the other group members when you do not feel well or need support? Answer categories: yes/sometimes/no
Mental health taboos and group dynamics	4	Did your group members talk about their experiences with caring for a loved one? Answer categories: yes/sometimes/no

and personal reflections of the researcher. As such, these notes will provide context for interpreting the findings and aligning them with the program theory, contributing to a nuanced interpretation of the results and supporting the data triangulation process in Phase 3. The template of the logbook has been added to Supplementary material IV.

3.3 Phase 3: data analysis and theory refinement

The analysis process comprises method-specific analyses for each type of data collected, followed by an integrative synthesis to triangulate our findings and refine the initial program theory. Below, we describe each type of analyses, followed by a description of how we will triangulate the data and refine the program theory.

3.3.1 Qualitative data: interviews and observations

Audio recordings of interviews will be transcribed verbatim, and observation schemes, completed during fieldwork, will be digitalized. Additionally, the open-ended question from the post-intervention questionnaire will be transcribed and analyzed as part of the qualitative data.

Thematic analysis will be conducted using both deductive and inductive approaches. Deductive analysis is guided by the initial program theory, with a coding framework structured around the concepts within our CMO-configurations (see Figure 3). At the same time, inductive analysis allows new themes and mechanisms to emerge within the predefined categories of context, mechanisms, and outcomes (41).

The analysis will follow Braun and Clarke's (42) six-step framework: starting with familiarization with the data through repeated reading, followed by systemic coding, theme development and refinement. Coding will be conducted in Atlas.ti [Version 24; (43)].

3.3.2 Quantitative data: questionnaire

Quantitative data from the post-intervention questionnaire will be analyzed using SPSS [Version 29.0.0.0; (44)] to examine differences across intervention groups and assess the potential influence of contextual factors on perceived mechanisms and outcomes. Based on the initial program theory, we expect differences between groups (i.e., whether participants knew each other or their ambassador beforehand and the cultural homogeneity of the group), which may influence social support and group dynamics (such as sharing personal experiences with caregiving and/or mental illness and perceptions of taboo). To explore these potential mechanisms within our program theory, we will conduct crosstabulations of these independent and dependent variables, supplemented by chi-square tests to assess the statistical significance of observed differences.

Based on previous studies on peer education with migrants [e.g., (45, 46)], we estimate an effect size of 0.4. Using a power analysis in R (47) with the pwr package (48) we expect to need around 60 completed surveys to achieve sufficient power. Given that we anticipate collecting around 8–12 questionnaires per intervention group, totalling approximately 80–100 questionnaires, we expect to have adequate power for our questionnaire analysis.

Missing data will be included in the analyses as is, unless responses to other questions suggest that the omission can be reasonably filled in based on available information. In such cases, missing responses may be assessed using other relevant data from the same participant. All decisions regarding missing data will be reported transparently in the final analysis.

3.3.3 Data triangulation

The data triangulation process will integrate findings from the interviews, observations, and post-intervention questionnaires. Firstly, we will identify patterns where different findings from different data sources align, confirming the validity of specific CMO-configurations from our initial program theory. Discrepancies will be explored, by analyzing the inconsistencies between data sources to understand the variations in context, mechanisms, or outcomes.

The logbook that was kept by researcher MH will serve as a tool to help identify explanations of discrepancies between sources, by offering rationale behind actions and decisions, as well as personal reflections of the study process.

Inspired by Rees (49), a synthesis matrix will be developed to systematically map findings from all sources to the initial CMO-configurations. This matrix will be organized around the four overarching themes from our initial program theory (See Figure 3). Under each theme, the relevant CMO-configurations will be listed, along with associated concepts from the program theory. Data from the interviews, observations and post-intervention questionnaires will be aligned with these themes, allowing for identification of new or modified CMO-configurations, where applicable. This will ensure a structured approach to integrate qualitative and quantitative findings and provide an overview of how data supports or challenges the initial program theory.

3.3.4 Refinement of the program theory

Insights gained from the integrated data will guide the iterative refinement of the program theory. This process starts with evaluating the existing CMO-configurations of the initial program theory based on the triangulated evidence. If the findings indicate that certain configurations are only partially supported or not confirmed, they will be adjusted accordingly. Additionally, if the data reveals previously unconsidered mechanisms or contextual factors, new CMO-configurations will be developed and integrated into the program theory.

The first author (MH) leads the refinement process, while the co-authors provide feedback and discuss discrepancies. We will mitigate potential bias caused by our positionalities – i.e., our backgrounds and perspectives - through regular discussions within the research team. Additionally, throughout the project, regular meetings are held with the TANM's coordinating organizations to discuss the progress and research design, review the preliminary results, and adjust accordingly.

3.4 Phase 4: final validation of the program theory and evaluative synthesis

The adjusted program theory (Phase 3) will be subjected to a validation process to ensure its relevance and credibility. The theory will be validated in a focus group with the members of t TANM's coordinating organizations. Feedback and information received during the focus group could lead to one last round of refinement, before reaching the final program theory of TANM. Once the program theory is finalized, we can answer our research questions concerning the perceptions of a successful change in TANM's short-term outcomes. The process is concluded with an evaluative synthesis of TANM, that assesses whether it achieves it outcomes and which factors influence its success.

4 Discussion

While previous studies have explored experiences of informal caregivers with a migration background [e.g., (50, 51)] and the stigma surrounding mental illness within migrant communities [e.g., (52–54)], this study will build on that foundation by evaluating an intervention that is aimed at supporting informal caregivers with a migration background who care for a loved one with a mental illness. This protocol shows how we plan to investigate how, why, for whom and under what circumstances TANM produces its intended outcomes.

This protocol employs a RE approach, which is suitable for evaluating interventions that are dynamic, culturally sensitive and context-dependent – like TANM. Unlike traditional randomized experiments, which may not capture the complexity or nuances of real-world settings, RE allows for the consideration of variations in context and experiences as integral to understanding outcomes (27, 55). Its flexibility helps to overcome challenges such as language barriers (35). This makes it a fitting approach for evaluating culturally sensitive interventions like TANM. RE extend qualitative insights to broader patterns by linking context, mechanisms and outcomes, making it more useful for informing policy and practice (27, 55) – which is ultimately the goal of our evaluation of TANM.

However, the flexibility of RE also presents challenges, such as the lack of clear methodological guidance (56). To address this, we employed a mixed-methods approach (35) and multiple data sources for triangulation. Additionally, while RE often uses arrows within program theories, they do not always establish universal causality. Depending on the selection of methods applied in a RE, causality is not necessarily implied. Instead of aiming for universally applicable explanations, REs develop so-called "middle-range" theory – explanations that are specific enough to be useful in practice but broad enough to apply beyond a single case. These theories link empirical findings to hypotheses about how an intervention works, helping to guide future research and program implementation, rather than providing definitive conclusions (56). This study's program theory will serve as a foundation for future research on culturally sensitive caregiver interventions, such as longitudinal studies assessing long-term impacts or comparative research across different cultural contexts to explore their influence on outcomes.

Our RE approach aligns with its growing use in health system research, particularly in transdisciplinary collaborations. Similar to previous studies [e.g., (57, 58)] we primarily employ qualitative and exploratory methods to evaluate TANM. By sharing the lessons learned from implementing this protocol, we aim to inform the design and evaluation of culturally tailored interventions in integrated healthcare, particularly in reaching underserved and hard-to-reach populations (5, 20).

4.1 Strengths and limitations

A key strength of this study is its use of multiple data sources for triangulation, adapted to participants' cultural, linguistic and health literacy needs. Additionally, through collaboration with TANM's coordinating organizations and ambassadors, the relevance and approach of our study is enhanced by including people with lived experiences of integrated care. We expect to have a suitable approach in our research. However, as an exploratory study, it cannot establish causality but rather provide insights for future research and practice (56).

Conducting research alongside intervention implementation also required pragmatic decisions. For instance, the post-intervention questionnaire was only available in Dutch, though spoken translations were provided in Turkish, Arabic, and Tamazight, when possible, either by a researcher or a bilingual participant willing to help. Additionally, recall bias may affect interviews conducted after the intervention. We mitigated this through real-time observations, which provided immediate insights to cross-verify participant accounts.

Cultural and language differences may also introduce biases, such as translation bias, where meaning is lost or altered when translating questions or responses (59); and interpretation bias, where differences in cultural norms or expression lead to the wrong interpretation of participants' response (59, 60). While efforts were made to minimize these biases through matching researchers with participants (e.g., Turkish-speaking researchers for Turkish-speaking groups), this could either facilitate openness or lead participants to withhold information due to feelings of shame or stigma when the researcher was perceived as an insider of their community (61). To navigate these complexities, we incorporated team reflections to account for cultural nuances and researcher positionality.

5 Conclusion

This protocol outlines our approach for evaluating and refining TANM's program theory. By integrating multiple data collection methods and applying both inductive and deductive analyses, we aim to understand the intervention's mechanisms and whether participants, ambassadors, and coordinators perceive improvements in discussing mental health taboos, understanding mental illnesses and caregiver support, and fostering trust in the healthcare system. Beyond TANM, this study contributes to broader research, policy, and practice in integrated care, particularly in reaching vulnerable populations, including those with a migration background.

Ethics statement

The studies involving humans were approved by Ethics Review Committee of the Department of Psychology, Education and Child Studies of the Erasmus University Rotterdam (application number ETH2425-0079). The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by each participant.

Author contributions

MH: Investigation, Writing – original draft, Visualization, Project administration, Methodology, Conceptualization. PK: Methodology, Supervision, Conceptualization, Writing – review & editing. ÖU-B: Methodology, Writing – review & editing. MS: Conceptualization, Writing – review & editing. SD: Methodology, Conceptualization, Supervision, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Generative AI statement

The authors declare that no Gen AI was used in the creation of this manuscript.

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Exploring the burden and support needs of informal caregivers for the older adults in Kazakhstan: a mixed-methods study protocol

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Background: The growing population of older adults, often affected by chronic illnesses, disabilities, or frailty has led to a substantial increase in the need for informal caregivers.

Objective: This paper is a protocol for a study that aims to investigate the effects of caregiving on informal caregivers of older adults in Kazakhstan with special emphasis on the cultural context.

Methods: The protocol outlines a mixed-methods study that will be conducted in four cities in Kazakhstan. A total of 400 informal caregivers of older adults with two or more limitations in Activities of Daily Living (ADL) will be recruited to participate in a survey, aiming to evaluate care-related burdens and quality of life and health-related quality of life. The Institute for Medical Technology Assessment (iMTA) Valuation of Informal Care Questionnaire (iVICQ) was selected to be the main research instrument. Additionally, a subset of participants who express their willingness to participate will be selected from the pool of survey respondents to engage in semi-structured interviews, allowing for a deeper understanding of their experiences and providing insights into their social and medical support needs.

Conclusion: This study will be the first investigation of the impact of caregiving on informal caregivers of older adults in Central Asia. The results will contribute to the literature by providing insights into older adults care within the specific national and cultural context of Kazakhstan with potential generalization to other Central Asian republics of the former USSR.

KEYWORDS

Kazakhstan, caregivers, aged, caregiver burdens, quality of life

1 Introduction

The latter half of the twentieth century witnessed a significant increase in the global population of older adults (1). According to the projections by the United Nations, it is anticipated that by 2050, the number of older individuals will be twice that of children under five, and will even surpass the working-age population (2). Moreover, it is projected that the average life expectancy will increase to 77.1 years by the year 2050 (2).

Kazakhstan, like many other countries, is also experiencing these demographic trends. The United Nations Population Fund (UNFPA) projects an increase in the number of individuals aged 65 and above from 1.4 million in 2019 to 3.4 million by 2050 (3). Culturally, approximately 64% of older adults in Kazakhstan reside in the household of their family members or relatives, thereby relying on their children or relatives for support (4). The growing number of older adults with chronic diseases, disabilities, or frailty highlights the pressing need for physical support and both formal and informal care.

Engaging in a wide range of caregiving responsibilities can have adverse effects on the health and social well-being of informal caregivers. Moreover, it can result in an increased burden and a reduced quality of life among these individuals. Research findings indicate that caregiver's own health (5, 6), behavioral disorders of the care recipients, dementia (7), functional dependency of the older adults (8), female gender (9, 10), low education (11), depression, social isolation (12, 13), financial stress (14), lack of care choices (15), co-residence with the recipient of care, and the number of hours dedicated to caregiving (12) are all risk factors that can contribute to the burden experienced by informal caregivers. It is important to consider these factors in order to gain a better understanding of the challenges faced by caregivers who provide informal care with the further going aim to address these challenges and provide appropriate support to caregivers.

Numerous questionnaires have been developed to assess the burden experienced by caregivers. Some of these questionnaires focus on exploring negative effects of caregiving on informal caregivers, while others include items that investigate the positive influence of caregiving. Moreover, the Caregiver Strain Index + (CSI+) questionnaires incorporate both positive and negative inquiring related to caregiving. Table 1 provides examples of the questionnaires most commonly used in the literature.

In cultures where there is a strong emphasis on reverence and care for parents or older family members, along with a belief in filial responsibility to provide for their needs, caregiving may not be perceived as highly stressful for caregivers (16, 17). However, it is important to acknowledge that these cultural norms, when combined with family expectations and an increased sense of responsibility, can also be stressful for caregivers and even contribute to an elevated risk of experiencing symptoms of depression (18). Therefore, it is important to assess both the positive and negative effects of caregiving within the context of cultural traditions. In adherence to Kazakhstani traditions, the approach to caring for older adults family members is significantly influenced by cultural values and familial structures. Within this paradigm, it is customary for older adults individuals to cohabit with their children, emphasizing a substantial focus on respecting and fulfilling a sense of duty towards older family members. Considering the cultural idiosyncrasies of Kazakhstan, we posit that individuals engaged in caregiving will demonstrate a heightened occurrence of positive dimensions and derive increased gratification from their caregiving role. Consequently, we anticipate an amelioration in their quality of life, accompanied by a concurrent alleviation of the caregiving burden.

The inclusion of the "Life Course Perspective" and "Stress Process Framework" is essential for understanding and analyzing the caregiving experience. The former considers long-term influences, while the latter examines short-term stressors on caregivers' well-being. Combining these frameworks in our article helps conceptualize caregiving as a complex process, encompassing both long-term and short-term effects, enduring trends, and crisis moments. This deepens our understanding of how factors shape the caregiving experience, informing the development of effective approaches to support caregivers and enhance their quality of life (19).

Despite the global focus on promoting active longevity among older adults, there is a growing recognition of the urgent need to provide comprehensive support and care for the caregivers involved in their well-being. Kazakhstan has not yet adequately addressed the needs faced by caregivers. The burden they carry remains largely unassessed, with healthcare and social services lacking the necessary tools to evaluate their needs. Moreover, the absence of caregiver registration mechanisms has led to a scarcity of data on the exact number of family caregivers. Therefore, research is warranted to gain a deeper understanding of the impact of caregiving on the burden and quality of life of caregivers in Kazakhstan and other former Soviet republics of Central Asia.

TABLE 1 Characteristics of questionnaires for measuring caregiver burden.

Questionnaire	Number of items	Scoring scale	Character of questions	Interpretation
Caregiver Burden Inventory (CBI)	24	0–5 Likert Scale	Negative	Score ≤ 36 indicate a risk of a burnout Score ≥ 24 indicate the need to seek some form of respite care
Zarit Burden Interview (ZBI)	22	0–4 Likert Scale	Negative	Score range of 61–88 indicate a risk of burden
Caregiver Strain Index (CSI)	13	Yes/No responses	Negative	Score ≤ 7 indicate a risk of extremely burden
Caregiver Strain Index plus (CSI+)	18	Yes/No responses	Negative & Positive	Score ≤ 7 indicate a risk of extremely burden
Positive Aspects of Caregiving (PAC)	9	0–5 Likert Scale	Positive	Higher scores mean a more positive perception of the caregiving experience

We have developed a research protocol for a study aimed at investigating the impact of caregiving on informal caregivers of older adults in Kazakhstan with special emphasis on the cultural context. Moreover, the study will examine the factors that influence the burden of care, care-related quality of life, and overall health and well-being of caregivers to provide the basis for development of models for medical and social care for caregivers in Kazakhstan.

2 Materials and methods

2.1 Study design

A sequential explanatory mixed-method design will be employed (20). The study will be carried out in two phases across four major cities in Kazakhstan: Astana (the capital), Almaty (the former capital), Semey in the East and Aktobe in the West of the country. The population sizes of these cities are 1.2 million, 2.0 million, 0.8 million and 0.9 million, respectively. The complete study plan is illustrated in Figure 1.

The study will be conducted in two phases. Phase one will consist of a quantitative study, followed by phase two qualitative interviews to provide a more comprehensive understanding of the study results. To collect quantitative data, we will utilize the Institute for Medical Technology Assessment (iMTA) Valuation of Informal Care Questionnaire (iVICQ) (21) as the research instrument. This questionnaire will primarily focus on assessing the levels of burden associated with caregiving, as well as the quality of life and health-related quality of life of the participants.

In phase two, the focus will be on collecting qualitative data to explore the contextual aspects of caregiving including experiences, needs, and requirements of caregivers in relation to providing care, as well as the availability of healthcare-and social support. To gather this information, we will conduct semi-structured interviews with participants selected from the pool of respondents until we reach saturation. The interviews will be analyzed using an inductive content analysis approach to get insights into the caregivers' experiences (22).

2.2 Sample size

For the quantitative phase, we will invite 400 informal caregivers from four cities in Kazakhstan, with 100 informal caregivers selected from each city, to participate in the study. The sample size was calculated to assess the prevalence of binary outcomes with a precision of 5% for an infinite population. The calculated minimal sample size was 396, which we rounded up to 400. As for informal caregivers, we were more interested in associations between numeric outcomes and potential predictions, therefore we calculated sample size required for applying linear regression models with 5 predictors to explain at least 15% of the total variance with levels of alpha-and beta errors of 5 and 20%, respectively. All calculations were made with G-Power software. Only primary caregivers will be invited. However, in cases where two caregivers caring for the same older adult identify themselves as primary caregivers, we will include both of them.

During the qualitative phase, participants who completed the questionnaire will be invited to participate in interviews. Subsequently, the recordings of each interview will be encoded. The data collection

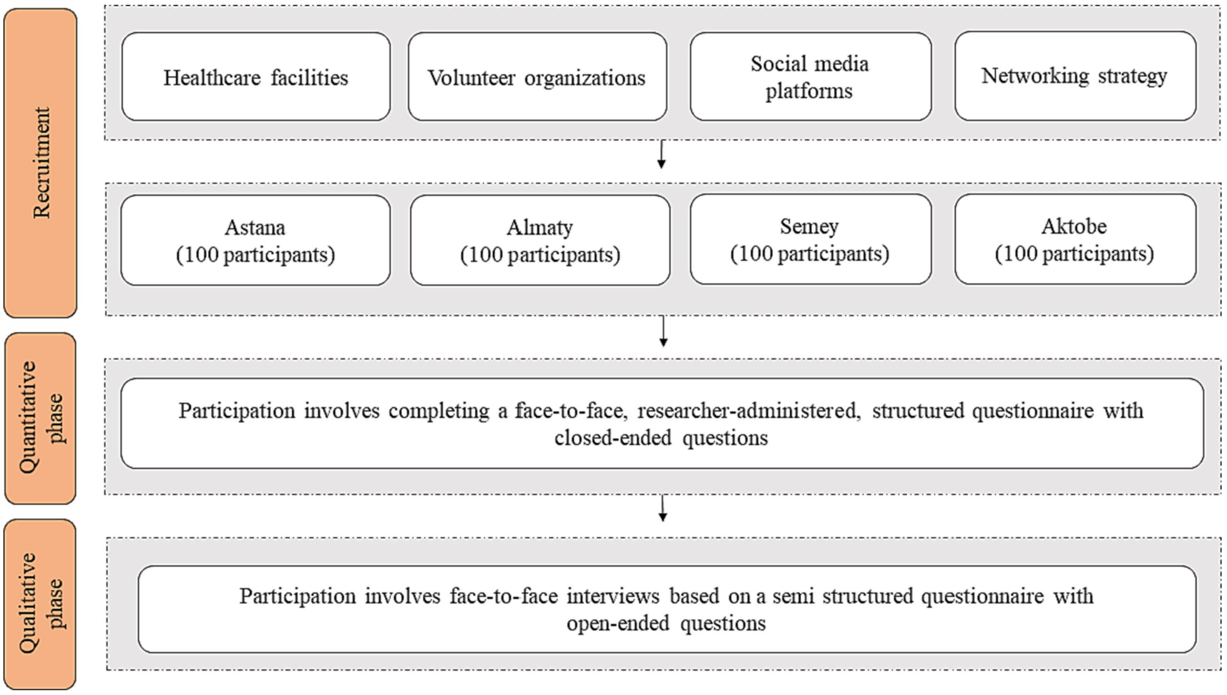

FIGURE 1
Study plan.

process will continue until the saturation point is reached (22). After reaching this point, additional 2-3 interviews will be conducted to ensure that no further data collection provides new information or leads.

2.3 Eligibility criteria

All individuals who will give their consent to participate and meet the eligibility criteria will be included in the study. The inclusion and exclusion criteria for family caregivers are presented in Table 2.

2.4 Recruitment of participants

As there is no national registry of informal caregivers in Kazakhstan, a diverse range of recruitment strategies will be employed to ensure representativeness of the sample. The following approaches will be utilized:

- Recruitment via healthcare facilities: we will identify older adults aged 65 and above who face limitations in their daily activities through healthcare facilities in the four study sites. Subsequently, we will reach out to family caregivers either through phone calls or home visits to extend an invitation for their participation in the survey.
- Recruitment via volunteer organizations: we will partner with volunteer organizations that offer support to individuals facing challenging circumstances. These organizations will serve as platforms to reach out to potential caregivers.
- Advertising on social media platforms: we will advertise the study across multiple social media platforms, targeting individuals who may be fulfilling caregiving roles for older adults. By using the power of social media, we aim to maximize the visibility of the study and attract potential participants.
- To enhance the efficiency of recruitment, we will implement a networking strategy will be employed. We will actively encourage participants who have already agreed to take part in the study will be encouraged to refer other eligible individuals from their social networks who might be interested in participating in the study.

Upon agreeing to participate, caregivers will be requested to provide informed consent by signing a consent form. Confidentiality and anonymity of all participants will be ensured.

TABLE 2 Eligibility criteria.

Inclusion	Exclusion
≥18 years of age	Cognitive impairment or mental illness
Experience of providing informal care for older adults aged ≥ 65 years	No informed consent
Older adults should have at least two limitations in activities of daily living.	
Provision of informal care for ≥ 2 weeks	
Proficiency in either Kazakh or Russian	
Permanent residence in Kazakhstan	

2.5 Data collection

2.5.1 Phase one

In the quantitative phase, we will be using the iVICQ questionnaire (21) as a comprehensive, consistent, validated, and non-disease-specific toolkit for investigating informal care. This questionnaire is not limited to a specific disease. It allows for the collection of information about both caregivers and care recipients. Additionally, it includes tools for assessing the caregiving burden, quality of life, and health-related quality of life. It can be used the entire questionnaire or specific sections, making it suitable for quick screening using brief scales. To ensure linguistic accuracy and cultural appropriateness, we have conducted a rigorous process of independent forward and backward translations for the Kazakh and Russian versions of the iVICQ questionnaire. Native language researchers proficient in English, Kazakh, and Russian reviewed the translations for accuracy. The survey questionnaire will be pilot tested in the study sites prior to the main study.

The questionnaire will be administered in paper format by members of the research team. It is expected that participants will need approximately 20–25 min to complete the questionnaire. The opinions of informal caregivers will be used to collect the characteristics of care recipients.

The primary section of the questionnaire focuses on gathering demographic characteristics about informal caregivers and care recipients. This includes date of birth, gender, education level, family income, and marital status. Furthermore, we will assess the health-related quality of life using the EQ-5 L-5D questionnaire (23). To assess the functioning of care recipients, we will use the Barthel index (24). Additionally, it includes characteristics of the informal care situation, such as the number of hours per week dedicated to caregiving, the intensity of informal care, and the need for professional assistance.

The second section focuses on assessing the subjective burden and evaluating the well-being of caregivers using the Caregiver Strain Index Plus (CSI+) (25), the Care-related Quality of Life Instrument (CarerQol-7D) (26), the Self-Rated Burden scale (SRB) (27), the Assessment of Informal Care Situation (ASIS) (28), Process Utility (PU) (27), and Perseverance time (Pt) (29). Furthermore, the monetary valuation of informal care will be determined using the opportunity cost method (30). A summary of these variables and the recoding process is presented in Table S1 in the Supplementary material.

In accordance with the classification of education levels, we will utilize the nine-level classification system employed in the Kazakhstan National Census of 2020 (31). The education levels will be categorized into three main categories: low, medium, and high, following the International Standard Classification of Education. The low category represents education levels below secondary or equivalent, while the high category denotes university or higher education level (32).

To classify income data, we will adopt the classification methodology used in the Kazakhstan National Census of 2020 (31). This methodology takes into account small gaps between income levels to ensure accurate representation of the caregiver's income (33). The income data will be divided into three categories: low, medium, and high. The low category represents income levels below the average wage, while high signifies an income higher than the average wage in Kazakhstan.

To assess the health-related quality of life, we will apply the EQ-5D-5L questionnaire. To ensure linguistic accuracy, we will utilize the available interviewer administration version of the EQ-5D-5L questionnaire in both Kazakh and Russian languages. These versions have been translated and certified by the Legal EuroQol team, ensuring the accuracy and reliability of the translation.

2.5.2 Phase two

Upon completing of the survey, participants will be invited to participate in a qualitative study. Face-to-face interviews based on a semi-structured questionnaire comprising open-ended questions will be conducted at a time and location convenient for the participants. The interview guide will cover specific topics while allowing for adaptability and flexibility to accommodate the unique experiences and concerns of participants.

Prior to the interview, participants will receive a comprehensive overview of the study objectives and framework. The interviews will be recorded. Each interview is expected to last approximately 30-45 min. The guide for conducting semi-structured interviews is presented in Table S2 in the Supplementary material.

2.6 Data analysis

2.6.1 Phase one

The quantitative data analysis will be performed using R-Studio Version R4.1.3 (2009–2023 Posit Software, PBC). Distributions of continuous variables and frequencies of categorical variables will be assessed followed by calculations of descriptive statistics. Normally distributed numeric data will be presented using means and standard deviations. Medians and quartiles will be used for skewed data. Chi-squared tests will be utilized for bivariate analysis of categorical data. Categorical data will be presented as proportions with 95% confidence intervals (CI). To identify independent predictors of care-related burden we will use multivariable logistic regression while for quality of life, we will apply multivariable linear regression.

2.6.2 Phase two

In the analysis of qualitative data, descriptive statistics will be utilized to summarize demographic information. The interviews will be transcribed verbatim, capturing all spoken words. For text analysis, we will utilize MAXQDA 2022 software. Semi-structured interviews will be conducted, applying an inductive content analysis approach to analyze the participants' experiences. The transcribed texts will be divided into meaningful units, known as semantic units, which will be assigned codes while preserving the contextual information. These codes will then be analyzed and organized into relevant categories based on their similarities and connections. Throughout this process, similar categories will be integrated to form subthemes, ultimately leading to the emergence of main themes.

3 Discussion

The proposed study represents a pioneering effort to investigate the impact of caregiving on informal caregivers for older adults in Kazakhstan. The study employs a mix-method approach to facilitate a comprehensive examination of informal caregiving in this Central Asian republic. The quantitative component will assess the care related burden and quality of life among caregivers. The qualitative component will gather valuable insights into caregivers' experiences, needs, and requirements. The advantages of mixed design research include providing a new understanding of the complexity and multifaceted nature of healthcare research. By integrating both quantitative and qualitative methods, we can optimize the breadth and depth of the research. This approach will allow us not only to consider the socio-cultural context but also the intricacies of caregiving that closely resemble real-life situations. By collecting comprehensive data through mixed studies, we can gain a deeper understanding of the problem at hand and explore potential solutions (20, 34).

This research protocol is designed to examine the quality of life and caregiving burden associated with informal care, as well as to identify the most significant predictors and needs within the understudied population of informal caregivers in Kazakhstan with potential implications for other countries of Central Asia. The study focuses on a broad range of informal caregivers providing care in the context of disability, illness, aging, or frailty.

The burden of caregiving can vary depending on the specific condition (35–40). However, solely focusing on particular illnesses restricts the identification of common determinants of caregiver burden for older individuals (41, 42). Understanding the overarching determinants can help in the development of effective policies and interventions that promote health and well-being. Therefore, it is essential to develop specific interventions that aim to enhance the physical and mental independence of patients, while also addressing the social support needs of caregivers (42). These interventions should be targeted towards individuals who are at the highest risk and actively engaged in caregiving.

Despite the commonality of caregiver needs, research indicates that there are variations in the well-being of caregivers across different countries (43). This implies that caregiver needs differ depending on the country of residence and specific cultural and socio-economic conditions. Therefore, there is a need for studies that investigate the needs of informal caregivers in specific countries, considering demographic, cultural, and economic factors (45–47).

In many Asian countries, deeply ingrained and sometimes explicit legislative norms dictate that the responsibility of caring for older adults family members falls on children and relatives. An exceptional aspect of Asian and particularly Central Asian culture is the practice of multigenerational households, where several generations including grandparents, parents, children, and grandchildren live together (17, 48, 49). This arrangement often leads to the delegation of caregiving duties to family members, resulting in an underdeveloped system of social and specialized medical support for caregivers (50). The research on caregiving burden in Asian countries yields conflicting findings. Some studies suggest that the concept of filial responsibility can mitigate the burden experienced by individuals (18). Conversely, other studies propose that such responsibilities may lead to increased stress and burden (51). Given these disparities, there is a need for a study focused on the caregiving burden in Central Asian countries. The findings from such a study would significantly contribute to shaping and enhancing social support systems for caregivers in the Central Asian region.

Caring responsibilities significantly have a substantial impact on the quality of life for caregivers. Specifically, caregivers often experience a higher frequency of physical and health-related issues, resulting in a decline in their perceived quality of life (52–54). However, there is evidence to suggest that psychosocial interventions can alleviate the burden on caregivers and improve their quality of life (55).

The utilization of tools to assess the impact on caregivers is important, as these instruments can be employed in primary healthcare settings as frontline operational tools (56). This allows for the identification and timely referral of caregivers to healthcare and social service specialists, reducing the burden on caregivers and enabling them to provide care for older individuals at home for an extended period.

As the demand for informal caregiving continues to rise, our study will document the experiences and needs of home-based caregivers. Conducting an in-depth analysis of this field will be valuable in fostering the improvement of care for older individuals taking into account the needs of both caregivers and care recipients.

The caregiving situation for informal caregivers can vary depending on the relationships they have with care recipients, such as being a spouse or adult child. It is possible that these different informal caregivers also have distinct needs. In a systematic review of mixed studies (57) aimed at examining and comparing the needs of different groups of informal caregivers based on their relationships with care recipients, the results showed that, alongside common needs, the studied groups also had unique needs. The synthesis of the 22 included articles led to the identification of seven themes of needs among spouses, adult children, and adult siblings as informal caregivers: the need for information, support, personal time, addressing personal issues such as managing their own health, maintaining their relationship with their care recipient, being recognized and considered as a caregiver. In our study, we will explore and compare the identified needs of different groups of informal caregivers based on their relationships with care recipients. Understanding the needs of different groups of informal caregivers in Kazakhstan can contribute to the development of individualized solutions to enhance their quality of life and that of their care recipients.

3.1 Potential limitations of the study

Firstly, since there is no national registry of caregivers in Kazakhstan, it is challenging to obtain a representative sample. However, we used four strategies to improve representativeness of the sample for better generalization of the results.

Secondly, as this is a cross-sectional in nature, it does not allow drawing conclusions on cause-effect relationships. Further longitudinal studies will be required to explore causal effects of the identified associations.

Thirdly, it is possible that we may not be able to capture all perspectives in the qualitative research component due to limitations in the sample size. However, we will strive to delve deeply into the topic during interviews to conduct a detailed analysis of the experiences and needs of caregivers.

In spite of these limitations, this study represents the first attempt in Central Asia in general and in Kazakhstan in particular to utilize CSI+ and CarerQol-7D tools to measure care-related burden and quality of life among informal caregivers.

Data availability statement

The original contributions presented in the study are included in the article/Supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The study presented in this research protocol will be performed in accordance with Declaration of Helsinki. The study protocol was approved by the Research Ethics Committee of West Kazakhstan Marat Ospanov Medical University, Aktobe, Kazakhstan on November 19, 2021. The anonymity of participants will be guaranteed. No personal data will be utilized in the project.

Author contributions

AZ, GK, and NG contributed to conception and design of the study. AZ wrote the first draft of the manuscript. AZ, AG, and GK wrote sections of the manuscript. AZ, AG, and NG edited the final version. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1248104/full#supplementary-material

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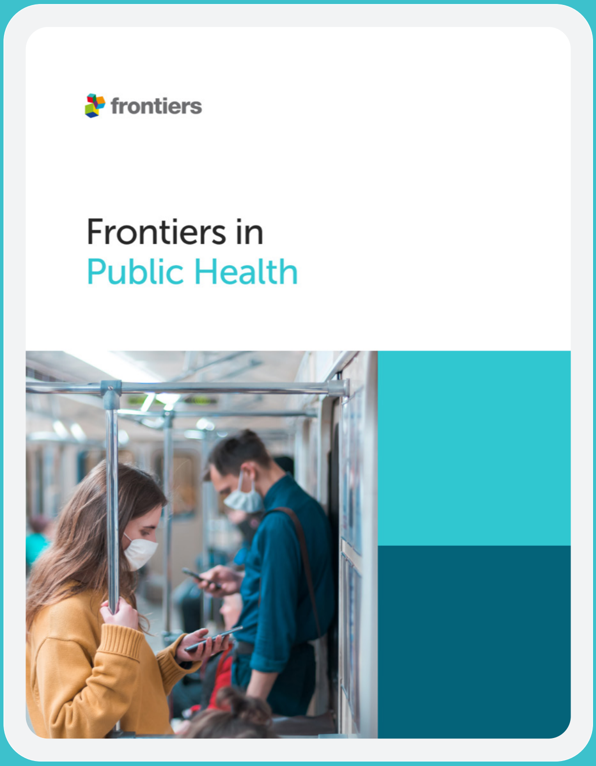

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