"In such a dark period, the only light": Patients' motivations and strategies to seek care from an online health community during the COVID-19 pandemic

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ARTICLE INFO	ABSTRACT
	This paper presents the findings of a qualitative study conducted in Italy about a peculiar online health community named #TERAPIADOMICILIARECOVID19 (#TDC19), which, since April 2020, has assisted people with COVID-19 with early-at-home therapy delivered by volunteer doctors, free of charge for patients. The aim of the paper was to analyse patients' motivations and strategies when negotiating risk in the context of this choice. Findings showed that patients' choices were the outcome of a process that forms an entangled ecology of care involving several dimensions, crossing micro, meso and macro levels: a) the process of knowledge-building by assessing mass-media, ascertaining the best protocol and recalling previous experiences with similar diseases; b) the experience of feeling abandoned by general practitioners (GPs) and healthcare institutions; c) the positive encounter with #TDC19's posts of gratitude written by people who were cured by #TDC19 doctors. In the end, patients' choice was not a leap of faith; they negotiated and balanced out the perceived risks associated with COVID-19 and with the possible available choices (GPs, do-it-yourself, #TDC19-doctors) based on a strategy that chiefly encompassed a blend of rational and in-between logics.

1. Introduction

The COVID-19 pandemic has unequivocally shaped recent years, leaving a notable impact on both individual lives and society at large. Although rivers of ink have been spilled so far, one issue, such as therapies, seems to have been explored far less in the sociological literature, with only few studies published so far (e.g. Campo, De Toffoli, Gobo and Strata, 2022). By presenting the findings of a qualitative study conducted in Italy in 2022, I argue that therapies promise to be a very interesting topic: as a matter of fact, they allow the exploration of the risk assessment involved in patients' process of seeking care.

I will proceed as follows: first, I will delineate the Italian context, presenting its peculiarity regarding available therapies; second, I will expose the background and the methods; then findings will be analysed and discussed; last, conclusions will be drawn.

2. The Italian online health community #TERAPIADOMICILIARECOVID19

The first Italian official document regarding home therapy against COVID-19 was published by the Ministry of Health on 30 November

2020. This guideline provided information about the disease, its phases and possible clinical progress; it highlighted the preeminent role of general practitioners (GPs) and paediatricians; it recommended some actions and drugs to be taken according to specific phases (Ministry of Health, 2020). Given that its two main suggestions concerned a) the action of watchful waiting and b) the use of paracetamol to contrast symptoms, soon after, this ministerial guideline became known in the whole public opinion and debate as the "paracetamol and watchful waiting" protocol.

As early as February, some networks of doctors formed with the aim of promoting early therapies (Campo, De Toffoli, Gobo and Strata, 2022). This paper specifically focuses on one of these experiences, started in April 2020 and based on the initiative of an Italian lawyer, Erich Grimaldi. Grimaldi gathered together some doctors in a private online health community hosted on Facebook called "#TERAPIADOMICILIARECOVID19-in-ogni-regione" (at-home-therapy-Covid-19-in-every-region: henceforth #TDC19). Its mission was to receive demands for assistance from people with COVID-19 and to deliver early-at-home therapy by means of volunteer doctors, free of charge for patients. The two main principles were the following: intervening early, at the first onset of symptoms; and "using non-steroidal

anti-inflammatory drugs (NSAIDs) in the hope of preventing the development of uncontrolled inflammation in the lungs and vessels" (Fazio & Bellavite, 2023, p. 178). A comprehensive debate about therapies goes beyond the scope of this article, the purpose of which is not to demonstrate the most suitable rationale. I leave this task to medical research. Here I simply report that some articles recognized NSAIDs as safe and effective for the treatment of outpatients with early symptoms of COVID-19 (e.g., Perico, Cortinovis, Suter, & Remuzzi, 2022; Ravichandran et al., 2021; see also Gremese & Ferraccioli, 2021) and that the Italian Ministry of Health (2020, 2022) included NSAIDs for the treatment of symptoms, even though paracetamol ended up being used more by Italian physicians. #TDC19 doctors contested the ministerial guidelines' rationale, did not comply with it and treated people with the early-at-home therapy, the backbone of which was NSAIDs. #TDC19 gathered more than 600 thousand members in a few months, and administrators claimed to have treated between 80 and 100 thousand people over the course of the pandemic.[1] People started to access and submit their own requests for help in April–May 2020. Accepted members who sought care from #TDC19 doctors, wrote a post in which they declared having COVID-19 and added other information for the anamnesis (age, sex, chronic diseases/conditions, weight, symptoms onset, kinds of symptoms, allergies, etc.); posts were approved; after an initial triage and according to a priority list, both undertaken by health professionals, they were assigned to an available doctor of the group who accepted the case; the doctor's name was communicated by replying to the first patient's post; following this point all further interactions were held privately and directly between patient and doctor through personal channels (e.g., telephone, Messenger, WhatsApp). Basically, #TDC19 worked as a service of telemedicine by matching patients with doctors. At the end of 2021, this procedure was replaced by a WebApp (www.terapiadomiciliarecovid19.org/). No money was due because the whole service was provided free of charge by volunteer physicians.

The composition of #TDC19 volunteering doctors was heterogeneous regarding both the specialty and the working provenience. Considering the latter, they were mainly GPs or employed by the National Health Service, but also some retired doctors and private practitioners were involved. Considering the former, specialties included GPs, general doctors, A&E physicians, anaesthetists, dermatologists, gynaecologists, urologists, paediatricians, physiatrists, and residents. Each volunteer doctor could consult other volunteering colleagues of the group via a private WhatsApp channel in case of need or doubts concerning a specific patient. Last, it may be useful to add that #TDC19 as a group maintained a neutral position regarding vaccination, promoting a free and informed choice from citizens, disapproving of obligations or policies such as the vaccine green pass, however never ever assuming an anti-vax position (in line with the array of attitudes reported by Gobo & Sena, 2022).

Consequently, Italians could seek care for COVID-19 in various ways. Of course, the main one is represented by the official channels, GPs and Local Health Authorities (LHAs); moreover, at least theoretically, we can mention self-care and complementary and alternative medicine (CAM). However, the Italian peculiarity seems to be the alternative informal/non-institutional group, represented by #TDC19 physicians.

It should be acknowledged that during the pandemic period several tensions arose in Italian society and the national health system (NHS). At the very least, we ought to mention the following. First, the high level of politicization of the entire public debate surrounding Covid-19 (Sacco et al., 2021). Then, the intergovernmental conflict over the balance of authority between central and regional governments, due to the Italian system of multilevel policy-making: this in turn produced a fragmented response to the crisis and an increase of uncertainty (Salvati, 2022; see

also Malandrino & Demichelis, 2020) that was replicated in the NHS (Bifulco & Neri, 2022). Furthermore, the conflict among experts and different medical perspectives regarding home therapies (e.g., Campo, De Toffoli, Gobo and Strata, 2022; Gobo, Campo, & Serafini, 2023). Last, the financial, personnel and structural resources shortage in the Italian NHS (Bifulco & Neri, 2022): it soon became overwhelmed in the first months of the pandemic outbreak bringing the "system near to collapse" (WHO, 2020, p. V); WHO (2020) described the initial reaction of hospitals as improvised, chaotic and creative (p. 20), and highlighted the lack of a proper planning (p. 2). Such widespread conflicts and tensions affected early-at-home therapies to the extent that the latter were widely seen with a great deal of suspicion, were accused of not having randomized controlled trials to support them, and physicians who practiced them were considered to be borderline black sheep, deviating from the national official guidelines (e.g., Facta, 2021; Giambelluca, 2022; Rodriguez, 2021).

Given the unique situation and the conflictual context sketched above, this paper focuses on patients' strategies and motivations in undertaking such informal #TDC19 channels. More specifically, this study intends to shed light on why people preferred to seek care for such a life-threatening disease from unknown doctors (who were considered by most of their colleagues and media as "black sheep", as reported) rather than their own GPs. To the best of my knowledge, this is the first study of this phenomenon. As put by Chauhan and Campbell (2021, p. 82), "healthcare decisions require patients to make choices", starting with whom to contact and when. This does not imply considering health as merely a question of personal responsibility and situations of choice; a well-established literature reveals more nuanced and complex scenarios (e.g., Henwood, Harris, & Spoel, 2011; Mol, 2008). However, the recognition of the personal health risk associated with having COVID-19 led many patients to make choices about what channel to undertake. Consequently, to understand these patterns I examined how they negotiated the risks associated with their choice, along with Chauhan and Campbell (2021).

3. Risk-perception and trust in the doctor-patient relationship

Risk-perception has long been dominated by the psychometric paradigm, which mainly focuses on "how individual perceptions of actual or objective levels of risk are distorted" (Tierney, 1999, p. 218), and consequently on how to mitigate the disjunction between lay perceptions and expert assessment of risk (Wilkinson, 2001). This entails the expert/lay-people controversy, otherwise identifiable as the rational/irrational dichotomy. Realist approaches assume the superiority of experts' science-based knowledge, viewing lay people's understanding as lacking objective information and being contaminated with irrational beliefs and emotions. In contrast, sociological perspectives helped move the debate beyond these oversimplified dichotomies. For example, Zinn (2008a, 2016) showed that lay-people do not act irrationally and suggested that when people face/perceive risks and uncertainties, they may rely on different reasonable strategies (Zinn, 2016), as delineated in a three-fold framework: rational, in-between and irrational. We have irrational (or non-rational) strategies when people base their own action on belief, ideology, faith and/or hope, and they may be useful for people to cope with situations that are deemed to be beyond their own control (Zinn, 2016). Rational strategies are enacted when people seek and obtain information about a particular risk (e.g., COVID-19) and make informed decisions accordingly (Fersch, Schneider-Kamp, & Breidahl, 2022). In-between strategies include trust, emotion and intuition, and are helpful when knowledge or time is limited and complexity is overwhelming, or when expert knowledge is contested (Zinn, 2016). Despite emotions being considered as problematic because of their variety (e.g., anger, fear, happiness, etc.) (Zinn, 2016), they are somehow involved in all activities and decision-making: "risk representations, cultures and concepts are invested with emotion" (Lupton, 2013, p. 634). In other words, any risk-perception is influenced by socio-cultural contexts and

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[1] Interviewed administrators and physicians stated that, given their role of volunteers and the huge amount of requests that they have to face daily, they were unable to store all patients' data in a precise way.

by personal experiences, including emotions (Lupton, 2013). An established literature highlights how risk-perception and trust are closely related concepts (Viklund, 2003). Trust is a highly complex and multi-dimensional phenomenon (Lewis & Weigert, 1985) that includes cognitive, emotional and behavioural dimensions, which merge together into a unitary social experience (Lewis & Weigert, 1985, pp. 970-971).

- the cognitive property regards choosing whom to trust, in which respect and under which circumstances;
- emotions complement the cognitive base and contribute to create emotional bonds among the actors involved in a relationship that requires trust;
- the behavioural enactment implies the undertaking of a risk under the individuals' expectation that the other party will act in their best interest (see also Arakelyan et al., 2021).

Chauhan and Campbell (2020) highlight that if any engagement with uncertainty involves trust, this gets amplified in the case of the patient-doctor relationship. Applied to the latter, we can synthetically conceptualise trust as "the manifestation of patients' belief that a practitioner can guide them towards desired health outcomes without deliberately harming them" (Chauhan and Campbell, 2020, p. 84). We can mention two kinds of trust (Chauhan and Campbell, 2020), which are tightly intertwined (Arakelyan et al., 2021): interpersonal trust, which emerges from personal relationship between trustees and trustors and develops through social interactions; and institutional trust, that refers to people's trust in abstract systems and strangers, which enables modern complex society to work smoothly.

Parsing out patients' sense- and decision-making in a situation of (perceived) risk and uncertainty, such as with COVID-19, therefore, must consider that they might combine all the above mentioned different strategies, depending on their preferences and on the decision-making context (Fersch et al., 2022; Zinn, 2016). Besides, it means addressing trust, both on interpersonal and institutional grounds, and then considering different levels, from macro to micro (see Fersch et al., 2022).

4. Methods

The findings hereby presented and discussed are part of a wider quali-quantitative study, conducted in Italy in 2022, which proceeded simultaneously and involved different types of actors: overall, the qualitative part included 18 patients, 12 #TDC19 doctors and 4 #TDC19 administrators-moderators; the quantitative part consisted in a survey that was filled out by almost 900 patients. In this paper, however, I focus on the qualitative part concerning patients' experience, in line with the purpose of investigating the nuanced issues of patients' strategies and motivations when seeking care from #TDC19 doctors.

The eligibility criteria were a) having had COVID-19 and b) having contacted #TDC19 to seek care-support. Consequently, our sample wittingly represents a niche of people who dealt with #TDC19 and it is not representative of the whole universe of Italian patients. In total I interviewed eighteen patients. Interviewees were recruited through #TDC19 in two ways: administrators gave me a list of past patients from which I chose my respondents; then, I published a post in the group receiving direct replies from members interested in participating in the study. The final sample (see Table 1) is unbalanced regarding gender (13 women, 5 men); previous studies have already shown that men are less prone to participating in studies than women (see Prati et al., 2021). The average age of our respondents is 50.2 (39–68). Respondents contracted Covid-19 over a period that went from February 2021 to April 2022,

Table 1
Socio-demographic characteristics of the interviewees.

Patient	age	gender	marital status	educational level	occupation	Covid-19 sickened period	previous morbidity	Region of residence
Patient-1	50	woman	unmarried	upper secondary education	employee (private company)	08/2021 + 02/2022	none	Marche
Patient-2	51	woman	widow	upper secondary education	school teacher	01/2022	high blood pressure	Lombardy
Patient-3	59	woman	married	Master	psychologist	08/2021	overweight (risk factor)	Emilia-Romagna
Patient-4	44	woman	married	upper secondary education	housewife	07/2021	none	Sardinia
Patient-5	49	man	married	Master	IT engineer	01/2022	overweight + high cholesterol (risk factor)	Abruzzi
Patient-6	53	man	divorced	upper secondary education	insurance broker	01/2022	none	Lombardy
Patient-7	39	woman	unmarried	Bachelor	nurse	04/2022	previous cancer	Umbria
Patient-8	51	woman	unmarried	upper secondary education	computer programmer	04/2021	none	Tuscany
Patient-9	56	woman	unmarried	upper secondary education	not working	12/2021	none	Lombardy
Patient-10	41	woman	unmarried	upper secondary education	shop assistant	08/2021	none	Emilia-Romagna
Patient-11	45	woman	married	upper secondary education	employee (private company)	12/2021	psoriasis + retinopathy	Liguria
Patient-12	49	man	married	upper secondary education	employee (public sector)	12/2021	heart murmur + asthma (from allergies)	Liguria
Patient-13	52	man	married	Master	socio-pedagogical educator	08/2021	none	Lombardy
Patient-14	49	man	married	upper secondary education	employee (public sector)	01/2022	high cholesterol	Veneto
Patient-15	49	woman	married	upper secondary education	freelancer	02/2021	none	Lazio
Patient-16	68	woman	divorced	Master	freelancer	03/2022	none	Emilia-Romagna
Patient-17	56	woman	common-law wife	Master	school teacher	04/2022	immunocompromised	Marche
Patient-18	43	woman	married	upper secondary education	employee (public sector)	03/2021 + 04/2022	none	Marche

namely from the third and fourth wave approximately (see Bonetti & Melani, 2022).

Semi-structured interviews were used because they allow all information deemed as relevant to be gathered, while also allowing some freedom as to whether to skip or develop more in depth certain issues according to respondents' own experience. Consequently, interviews followed (though not slavishly) a few main topics: COVID-19 personal experience (timing of onset, duration of disease, symptoms); the doctors who treated the patient (GPs, #TDC19 doctors) and the therapy; description of the relationship that patients had both with their GPs and with #TDC19 doctors, and specifically the interactions that occurred during their own period of COVID-19 disease; how they met #TDC19 and reasons for asking help from them; feeling about the media's and healthcare institutions' conduct in the field of COVID-19.

Interviews were conducted between June and September 2022 by telephone. Average interviews duration was about 50 min. All the interviews were audio recorded with the consent of the participants and subsequently transcribed verbatim. All data were rendered anonymous. All participants were previously provided with an information leaflet and a consent form in order to guarantee confidentiality and anonymity (Edwards & Holland, 2013; King, 2004). The study was approved by the Ethical Committee of the University of Macerata.

Data examination was performed using a manual approach (paper & pencil) following the six-phases process of reflexive thematic analysis (Braun & Clarke, 2022). A critical-constructionist approach was applied, using a blend of inductive and deductive modes. The purpose was to assume patients' perspective in order to unveil their nuanced motivations and strategies. Although Zinn's idealtypes of strategies (2008b, 2016) and the established literature about interpersonal and institutional trust informed the process and (above all) the following explanation. I started with familiarisation: a first reading allowed to achieve both an immersion in the data and critical engagement, as well as writing down some first notes and thoughts. Next, I started coding by writing sometimes pithy labels and sometimes longer ones, and by shifting from semantic to latent meanings. Many hundreds of codes were produced, but clustering decreased the number remarkably so that I could shift to phase three, namely, developing initial "candidate" themes. Then, I revised these candidate themes by re-engaging with codes, the entire dataset and the first notes produced during familiarisation, and also by checking recordings so as to avoid misinterpretations. Subsequently, I started the fifth phase, in which themes were defined and named. At the end of this process, I detected two families of motivations: negative and positive ones. On the negative side, I found an overarching theme ("the great distrust"), that included two themes. The first one, "a matter of knowledge", entailed three subthemes: "mainstream media misinform and terrorize"; "even stones know it: the ministerial protocol does not work"; "once upon a time – previous experiences". The second theme, "the abandonment", included two subthemes: "my GP was aloof, cursory, judgemental … and never called me back"; "'Hello! Hello! Anybody there?' The missing healthcare institutions". On the positive side, I found only one theme: "a breath of fresh air: the experience of other patients on #TDC19 assuaged me". This network of overarching themes, themes and subthemes gives a compelling explanation of patients' strategies and motivation in seeking healthcare support in informal/non-institutional patterns. This led to the last theme, which helps parse out patients' meaning, perceptions and experiences of being treated by #TDC19 doctors, so as to conclude the analysis: "in such a dark period, the only light".

5. Findings

Findings are presented and discussed following the abovementioned themes. I start with the negative overarching theme, which was named "the great distrust" because it aimed to stress the overall negative experience that our respondents had when interacting with the formal-institutional healthcare channel and during their personal process of

knowledge-building.

5.1. The "great distrust": 1) A matter of knowledge

The first focus is on the way in which our participants have acquired knowledge and information about COVID-19 and its treatment. More specifically, I detected three subthemes, which seem to be particularly important in this process and which tend to overlap in a non-linear way. The first one concerns mass media and their (active) role in framing risks and is named "mainstream media misinform and terrorize". Let's introduce the following excerpts to explain the reason for this perception:

They all said the same things (…) … all single-minded; would you find someone who was fighting his way upstream? (patient-5).

I think [mainstream mass media] treated information really badly. I think the purpose was to terrorise people as much as possible and not doing good information … beginning with the available at-home-therapies, that were never promoted (patient-7).

(…) pounding steadily always the same news, with bulletins upon bulletins about deaths and infections, that instilled an impressive feeling of fear (patient-12).

Prati and colleagues (2021, p. 315) found that people blamed "the media for spreading false information, sensationalising, or rather not providing enough information". While these authors did not distinguish among different media, we found such blame addressed to the mainstream channels. Probably, the high level of politicization that characterised the Italian public debate about COVID-19 (Sacco et al., 2021) affected these feelings. The main respondents' complaints were: one-sidedness; lack of proper debate among experts who sustained opposing views; not giving room to early-at-home therapies; confusion; sensationalising-dramatizing; stigmatising non-compliant people as uneducated, covidiots, selfish, and dangerous to others (as also observed by Monaghan, 2020). All this fuelled a perception of unreliability of the main mass media (national TV programmes and newspapers). Furthermore, they were accused of terrorising citizens by insistently delivering daily numbers of deaths and infected people, while omitting more nuanced information (e.g., average age of deaths, different mortality risk among population, co-morbidities, differences between infected and ill people, etc.). Consequently, our respondents judged mainstream media to lack critical spirit with regard to government policies and messaging. Concurrently, they felt spurred to seek information elsewhere. Social media, such as Facebook and Telegram, were among the main channels used in this attempt to find different information, often presented by doctors who did not partake in mainstream points of view. However, many respondents described also engaging with other actors: among them friends, doctors and nurses who they knew personally and judged to be reliable. Anti-intellectualism, described as the generalised distrust of experts and intellectuals (Merkley & Loewen, 2021), does not seem to fit; indeed, our respondents followed various non-mainstream experts (e.g., scientists and doctors) and intellectuals (e.g., journalists). Rather, we can interpret this activity with the concept of "choice omophily" (Centola & van de Rijt, 2015), by which we can assume that interviewees selected sources based on similar points of views and interests. Nevertheless, the purpose of this article is not to balance the alleged quality of different sources, nor is it to argue about fake news and misinformation via social media, as already done in many works. Instead, I highlight that because our respondents perceived that the mainstream media were not reliable, they did not trust them anymore, basically rejecting any information delivered by them, and definitively relied on other channels to stay informed. This recalls Zinn (2008a), who stated that lay people's trust is not uncritical and that when official institutions (we may apply it to the media, in our case) are perceived to engage in misinformation, trust in them rapidly decreases. Many respondents stated that they discovered some Telegram groups and/or

#TDC19 before feeling uncomfortable with mainstream media. In this way, such channels were initially used to compare countervailing information and over time they wholly replaced mainstream media. In other cases, these channels were found as a way of seeking other sources, as a reaction to such discomfort. In this sense, these various channels became a Mertonian functional alternative to mainstream media. Even more interestingly, they display the image of an ecology of care (Danesi et al., 2020) in which different information sources are used and activated in everyday life, depending on the issue (and its perceived importance) and on the context in which one lives.

One specific issue related to information and therapy arose in this study. We, then, turn to the second subtheme of this group: "Even stones know it: the ministerial protocol does not work!". The sharp sense of this statement was shared by all our respondents as a public common sense:

that protocol was the first to be adopted and it was a disaster … so, on my own I considered that it wasn't the right way to treat this virus. Besides, I followed the therapies [= #TDC19] since they were created … and they corroborated my idea (patient-7).

(…) she immediately gave me the right therapy: she prescribed me anti-inflammatories, not paracetamol! (patient-18).

Once again, clearly there is no intention to evaluate the different protocols in this study. However, interviewees did that, and simply hearing or being prescribed with "paracetamol and watchful waiting" was judged negatively, or even abandonment (next theme), as the right therapy for them was based at least on NSAIDs. Therefore, one of the main consequences of following alternative channels for information, which were increasingly relied on, was to achieve a different perspective and awareness on existing early-at-home-treatment for COVID-19. Even though in this research it is difficult to detect precise cause-effect mechanisms, it is clear that distrust regarding the ministerial protocol is related to the distrust felt towards those public institutions that wrote and promoted it. In other words, these people had no confidence in the government and the Ministry of Health's competency (e.g., performing tasks normally associated with them) and fiduciary responsibility (e.g., working for the best interests of the population; Storopoli et al., 2020). However, unlike Stropoli and colleagues (2020), we did not find a mediating role of perceived vulnerability: by and large, all respondents showed varying degrees of fear about having COVID-19, but this did not produce varying levels of confidence in political and healthcare institutions, remaining low in all cases.

The last subtheme detected in the field of knowledge is related to previous experience with other diseases like COVID-19, and it is named "once upon a time: previous experiences". I report the following quotations:

I'm 50 and I remember that when we had a flu or a cold, I mean viruses, well, doctors (…) came home to visit us … but above all, they treated us! When my GP told me "five days with paracetamol and watchful waiting" … for a cardiopathic and an asthmatic … well, I realized that I needed real doctors, who gave me something more than nothing … because paracetamol wasn't the solution (patient-8).

As a child I had bronchopneumonia and if I (…) had addressed it with just paracetamol, probably I wouldn't be here to tell it today … Well, I believe that the same is for COVID (patient-10).

Prati and colleagues (2021, p. 305) argued that public response to a pandemic such as COVID-19 may "be linked in the public consciousness to ideas and emotional responses of past epidemics". From our analysis, it looks like the public response to COVID-19 treatment is also affected, at least to some extent, by past experiences of illness and those related emotions that have become common ground over time. Indeed, many interviewees recalled they experienced (similar) diseases (flu-like viruses and/or bronchopneumonia) earlier in their own lifetimes, to have had home-visits from their doctors and, most importantly, to have been satisfactorily treated by their doctors. This latter remark links the kind of

therapy proposed by GPs to contrast COVID-19 symptoms with the kind of therapy that they remember having received in those past experiences. Notably, these singular experiences did not seem to stand within the perimeter of a private memory, but formed a public consciousness (see Prati et al., 2021), which was shared among our respondents. The issue of this subtheme is important in shaping trust in healthcare professionals and institutions: as Zinn (2008b, p. 443) highlighted, "lay people refer to their experiences when they judge whether they can trust".

By and large, this knowledge-process may be interpreted in terms of "post-trust environment", whereby trust cannot be taken for granted and citizens demand more critical information (Shapiro, Arora, & Bouder, 2023; see also Chan, 2021). In such a context, our respondents expressed reflexive trust (Zinn, 2008b) by selecting, negotiating and scrutinizing various sources and channels of information rather than uncritically accepting institutional ones (mass media and Ministry of Health). They acted as challenger (Glasdam & Stjernswärd, 2022) by threatening and challenging the dominant medical-political strategy regarding COVID-19 therapy. Moreover, it is possible to stress the adoption of a combination of strategies (Zinn, 2016), ranging particularly from rational (seeking information and acting accordingly) to in-between, with reference to a) (dis)trusting media, ministerial protocol, #TDC19, etc., and b) the emotions crossing all themes. Finally, the knowledge-making process acted from micro (previous personal diseases), meso (#TDC19 interaction, public consciousness formed by memories about diseases), to macro (Ministry of Health, healthcare institutions, mainstream media) levels, in which interpersonal and institutional trust overlapped.

5.2. The "great distrust": 2) the abandonment

The overall negative experience of distrust expressed by respondents includes the feeling of being abandoned by the formal channel. This was perceived both at meso (e.g. with LHAs) and micro (GPs) levels. At a micro level, we can synthesize what people felt and experienced as follows: "My GP was aloof, cursory, judgmental … and never called me back".

[I turned to #TDC19] because my doctor told me: "get paracetamol". Let's say, no treatment. When I got sick, my doctor knew I was not vaccinated, and for this reason he thought I was reckless, crazy … and all this stuff … anyway, when he knew I got COVID, of course, he conformed himself to the famous protocols and, no malice, he abandoned me. Period! Not even a single call. (…) since the day in which I told him I got COVID, he has never ever called me back. (patient-5).

I called my GP, who however (…) didn't take care of investigating that much. (…) well, the first thing he asked me was "but you are vaccinated? [I replied] "no", [and he] "but why didn't you?". Actually, in that moment I wasn't in the mood to start this kind of argument … (…)[he said] "Ahh! It's late to talk about it anyway. Well, let's do the swab; if you have fever, take paracetamol". Stop … eheh … The call lasted just few minutes, in this way. (…) I mean, you should consider that my doctor is always cursory, eheh … when you talk to him you always feel that he's in a hurry, (…) it almost seems that you are bothering him. Anyway, when I realised that his prescription was that, paracetamol and waiting, I turned to #TDC19 WebApp (patient-11).

The extant literature stresses that interpersonal trust in patient-doctor relationship springs from a set of patient perceptions: competence, caring, empathy, clear communication and honesty (Chauhan and Campbell, 2020). Particularly, Chauhan and Campbell (2020) found relevant medical competence and deep continuing relationships with practitioners to strengthen interpersonal trust. In the quotes hereby reported, we can see how basically all these issues are put into question. In

this study, the ministerial protocol prescribed by GPs was judged by our respondents at the very least as a matter of clinical incompetence, based on the patterns of information seeking and selection seen in the previous section. This GPs' choice was appraised to jeopardise our interviewees' desired outcomes (recovering, avoiding hospitalization), and consequently it caused a decline in their level of interpersonal trust in GPs, the relevance of which was explored by previous studies (e.g., Chauhan and Campbell, 2020). However, indisputably, it is the "human" side of this relationship to garner the most serious criticisms and our attention. All excerpts, in line with most respondents' experience, described a situation in which GPs were evasive during the first call, and in some cases were perceived as annoyed by the umpteenth phone call received on the same argument. Besides, patients got irritated by being judged for a health decision (not to get vaccinated), which they considered to be a personal and legitimate choice. It is possible to see from our respondent's narrations that GPs addressed this issue not on rational and scientific grounds (e.g., giving patients information, sharing and debating on scientific articles and trials, etc.), but, on the contrary, on an emotional basis. This seems to be in line with Lupton (2013), who criticized the assumption by which "expert judgement is free of emotional involvement" (p.641), while on the contrary maintaining that emotional "dimensions are a central feature of how the practices and discourses of public health operate to identify, measure and contain risk" (p. 643).

Even more importantly, GPs were blamed by our participants for having been absent during their patients' period of COVID-19 disease. After the first patient's call, in which (s)he reported having COVID-19, patients themselves recounted that their GPs never called them back to know their progress. Not once. This seems to frustrate patients more than the perceived clinical incompetence mentioned above.

However, the discordant relationship with GPs did not seem to pop up unexpectedly during COVID-19. Rather, it draws on an onward weakened relationship that has taken place over time, in line with Chauhan and Campbell's findings (2020). Interviewees talked about sporadic encounters with GPs for pragmatic reasons, e.g. the need for medical certificates and prescriptions for exams and/or drugs. Far from being the healthcare cornerstone, the primary point of reference, the professional who knows everything about her/his patient and who guides her/him towards the best medical solutions for each specific case, GPs were synthetically described in this study as bureaucrat paper-pushers. Significantly, many respondents stated that for specific health problems they would have gone to specialist physicians rather than to their own GP.

> With my GP I have a frugal relationship: certificates, prescriptions for drugs or exams. Stop. If I have any particular problem (…) I rather prefer to ask the consultant. (…) I saw [my GP] as the man who does prescriptions and that is still the case (patient-1).

> [The GP] is becoming almost useless (patient-3).

Consequently, we can state, along with Shapiro et al. (2023, p. 192), that trust is not a ready-made quality that is 'switched on' in times of crisis, but a dynamic property of everyday relationships. In our case, such relationships seem not to have been pursued over time and this, along with GPs' insistence on the ministerial protocol, affected negatively patients' trust in GPs when COVID-19 arrived.

Ardissone (2021), by adopting a relational approach in a study on a chronic disease (type 1 diabetes), found that doctor-patient figurations where not based on uncritical asymmetries and that among the most important variables for the relationship to work satisfactorily, physicians' clinical-therapeutic competence and interpersonal skills were required by knowledgeable patients. The findings of the present study are in line with this, both in not considering patient-doctor relationships in uncritical asymmetric ways and in highlighting the relevance of clinical competence and interpersonal skills. It is useful to stress that these variables also apply to a different kind of disease (a pandemic rather than chronic disease), in this case COVID-19, whose severe and sudden life-threatening implications (possibly taking place within a few days from the onset of symptoms) are well-documented in the literature and generally acknowledged by our respondents.

Complaints were also addressed at the meso level. The following quote exemplifies this issue and shows how a disappointing interaction with institutions provoked feelings of abandonment and bewilderment and led to distrust. In this case, institutions are represented by LHA and USCA (Special Continuity Care Units), multi-disciplinary health teams that were established in March 2020 for managing COVID-19 in the community (if activated by GPs), so as to prevent hospitalization.

> I mean, I also called the USCA, the LHA, but no one replied to me, so I felt a bit bewildered … [I called] also the doctor-on-call, but … Well, I felt I was alone, because nobody came home to visit me, to assist me. Nobody! Besides, nobody asked me "Madam, what therapy are you doing?". Nothing! (…) Consider this: on 31 December my son did the swab and he was positive; I called USCA many times with no answer, so I sent an email … do you know when they replied to me? After one and a half months!! (patient-2).

This theme allows an emphasis on the entanglement between interpersonal and institutional trust. Recalling Arakelyan and colleagues (2021), the healthcare relationships between patients and health providers (GPs and USCA's physicians) and the experiences of care affected negatively interpersonal trust, which in turn weakened the institutional one. But it also applies the other way round: the institutional distrust (regarding mass media, healthcare institutions, ministerial protocol) affected negatively the interpersonal one (e.g., those GPs prescribing the ministerial protocol).

5.3. At the end of the day, something positive. A breath of fresh air: the experience of other patients on #TDC19 group assuaged me

The negative experiences analysed in the previous sections were counterweighted by a very important positive one. Indeed, in the process of information seeking, by which our respondents shifted from national mainstream mass media to other channels, they met the experience of other patients on #TDC19. These experiences assuaged people and increased their trust in the group itself.

> [#TDC19] gave me a different truth: there were people who (…) with the therapies recovered in one day, or two days, etc. (…) [from 08/2021 to 02/2022] I recorded data of healed people. Therefore, I saw what was going on, I mean, I had each person's disease timeline … ehh, then, I realised that [the therapies] worked: I mean, 99.5% of people recovers, (…) it was a sort of counter-information for me (patient-5).

> I also read other people's experience, they all say "luckily, with the therapy that they prescribed me, I recovered quickly" … I mean, a lot of positive experiences! Then, this thing assuaged me, that's it! And reading them pleased me, because I thought "well, you see, it's not like they say; not all people who get COVID end up in hospital. There're some therapies". (patient-10).

> I trusted those posts … I read (…) that on the group on Facebook [#TDC19] they published all news of people who got sick, could not speak with their GPs for a therapy, and instead were helped out by at-home-therapies [#TDC19]. (…) well, when I got sick (…) I immediately got on it and I was recontacted immediately afterwards (patient-13).

The positive experiences coming from this information-seeking pattern garnered trust in people, so that when they got ill and experienced a sense of abandonment, as mentioned above, they felt like they had an ace up their sleeves. Patient 5's quote highlights another aspect: this case exemplifies something that was reported also by other respondents. Namely, the fact that many engaged as volunteers in

#TDC19, usually recording data concerning the patient-doctor interaction (e.g., symptoms, therapy, progress, recovery). So, this was presented by those interviewees as a particular and privileged form of getting alternative and first-hand information that helped to enhance positive feelings, emotions and retainment. However, it would be a mistake to overlook the rational dimension implied by this activity of seeking, scrutinizing and assessing the information coming from #TDC19's posts and work (e.g., see patient-13).

5.4. The choice to contact #TDC19. In such a dark period, the only light

Given the context depicted so far, our respondents chose to contact #TDC19 to seek healthcare support. It must be stressed that this decision was neither taken in a vacuum, nor was it irrational. On the contrary, it was enacted in a specific and situated context and, recalling Zinn (2008b, 2016), the choice to seek care from informal/non-institutional patterns (#TDC19 doctors), rather than following the formal/institutional one (embodied by GPs and LHA), was the reasonable and reflexive result of a combination of in-between (trust and emotion above all) and rational (seeking information and acting on it) strategies. Focusing on in-between strategies, such choice was based on the quality of the entangled interpersonal and institutional trust that was experienced at micro, meso and macro levels.

> I turned to this group online (…) because I had no other chance, eheh. I mean, chances were: going to your GP and then following "paracetamol and watchful waiting" protocol; or, resort to do-it-yourself (patient-11).

> To be assisted, because anyway I'm not a doctor; (…) to have support from a doctor, who tells you what to do (patient-9).

The following experience reflects the intricate relationship among different strategies employable by people in healthcare matters like Covid-19, and offers room for further reflection:

> (…) during the first three-four days (…)[I] followed (…)[my] GP and the doctor on call; then, my temperature was getting higher and higher, I reached 40.5 °C and then I thought "well, rather than going to hospital … I mean, if I really have to go I'll go … but at I wanna do an attempt with the therapies". (…) I discovered [#TDC19] (…) by chance (…), sometimes I saw that someone was speaking about these therapies so well. Plus, only positive witnesses. [So, I turned to this group] because I was desperate, and in my despair I tried to think "will someone help me seriously in such a situation?". And I tried (…). In my despair, before calling the ambulance, before taking other steps, I tried to send an email … (patient-6).

More than other previous extracts, the latter rolls out a feeling of hope experienced by this patient in relation to his action of emailing #TDC19. Attempting and despair are recalled to describe a situation that was deemed to go beyond his control and would frame this (part of a) choice as non-rational (Zinn, 2016). Emailing #TDC19 sounds like it is his last chance before being hospitalised, a way to avoid this extreme and unwanted outcome. However, I stress that this hope and "last chance" intertwined with, and relied on, at least two antecedents. First, it was based on previous activity of information building; in line with many other experiences hereby reported, this patient refused the mainstream media and replaced them with alternative channels, among them #TDC19, but also other doctors active on social media; all this allowed him to gain pieces of information about early-at-home therapies and other personal ("only positive") experiences before he got sick, and then to act upon them. Second, as most interviewees complained, patient-6 felt abandoned by formal healthcare channels and was disappointed with them for not having been treated adequately: while he was getting worse, he blamed his own GP for having applied the "paracetamol and watchful waiting" protocol, without tailoring it on his own case, and inviting him to call an ambulance if the saturation had

worsened; the doctor on call did the same. Besides, he asserted not having received calls back from them. Hence, focusing only, or even chiefly, on the irrational element of this action (e.g., hope) would underestimate the complex intricate network of reasons, experiences and strategies that actually came together. In any case, in such a complex process hope does not sound like the leading strategy, but, if anything, it came after the overarching experience of the "great distrust".

Even though deeply disappointed by formal medicine (e.g., healthcare institutions and practitioners), our respondents wanted to be treated by a Western allopathic doctor, without opting for CAM. As highlighted by many scholars (e.g., Chauhan and Campbell, 2020), in healthcare matters, risk can never be eliminated completely but only managed. Accordingly, our respondents negotiated with the risk of having COVID-19 and balanced out the different kinds of risk they were facing: either standing with GPs' "paracetamol and watchful waiting" protocol prescription, or do-it-yourself strategy, or, again, seeking #TDC19 doctors' support. In such a situation our respondents opted for the latter strategy, like (allegedly) tens of thousands of other Italians. So, in line with Chauhan and Campbell (2020), our findings show that patients' choice of practitioners was not just a leap of faith; instead, it involved deliberate, strategic risk-taking, based above all on a combination of rational and in-between logics, with conceivably a dash of non-rational hope as well.

The last piece of this mosaic is provided by the direct personal experiences that our respondents had with #TDC19 doctors, which in turn produced at least two consequences. First, it allowed patients to make comparison between #TDC19 doctors and their own GPs in terms of (perceived) clinical competence and interpersonal skills. While the former was present and kept in contact daily by phone or WhatsApp messages, until complete recovery, the latter disappeared; while the former showed empathy, interest in the patient, listened to the patient and explained both how the disease worked and how the specific tailored therapy provided was aimed to defeat it, the latter was perceived as aloof, cursory, judgemental and annoyed. Second, the personal experience fuelled and increased public consciousness because it became a cultural heritage, a public legacy, through being shared in two possible ways that are not mutually exclusive: either with posts of gratitude on #TDC19 for the treatment received, and/or with word-of-mouth dissemination during personal interactions with acquaintances.

> The doctor calls you in the morning and evening asking you whether your cough is getting better or worse, or how your cough is specifically; then adapts the therapy accordingly (…) on the basis of careful evaluations of your symptoms … well, I think it's outstanding! Whereas, your GP, ehh … at that time, he only would have told you paracetamol and watchful waiting. And so many times, they wouldn't even answer (…). I mean, the attention to detail, assessing the tiny changes and then adapting drugs each time, adding something … (…) The [#TDC19] doctor called me back also two weeks after recovery, to know if my problem [due to the use of an antibiotic] was still going on, or was over. Therefore, oh yes, they treated me a lot. (…) Yes, there's a bottomless difference in accuracy and in perseverance in asking details [between #TDC19 doctor and my GP] (patient-1).

> Both the psychological and clinical support from the [#TDC19] at-home-therapies' nurse and the doctor, who assisted me constantly until I became negative. (…) it helped me a lot, above all at psychological level, because when you are in a situation in which you don't know whom to ask, as nobody gave you information, nobody answered, nobody explained you anything, and, instead, there's someone who does it … well, this thing relieves, it makes feel you better. (…) the [#TDC19] doctor called me one, two times per day. When I got scared, because in some moments my saturation got lower, he called me even more times. Sometimes, he called me at the end of the day, and we stood talking also a quarter and asked me everything: anytime I measured my saturation, the fever, how my

breathing was. (…) even though I was alone at home, I felt safe, because I knew that, if I needed it, he was on the other side. (…) I will never ever cease to thank them, because for me they were, in such a dark period, the only light (patient-10).

Finally, quotes allow to stress that the cognitive-informational and emotional support are overlapping experiences, in line with previous studies (Rubenstein, 2014): being treated by a doctor in daily contact with patients and who tracks one's progress meticulously, and receiving information and answers to questions and doubts enhances the feeling of serenity, and consequently the emotional and psychological support. All this in turn seems to positively affect patients' trust in doctors by tightening it up.

6. Conclusions

This paper was the first to investigate how patients negotiated risk related to their choice of practitioner in the context of COVID-19. Italy is peculiar in this case because it presented a possible informal/non-institutional channel, represented by #TDC19 and its doctors. Of course, this paper has limitations, the most relevant of which concerns the sample. On one hand, its composition was unbalanced regarding gender, with prevalence of women, as also observed in previous studies (e.g., Prati et al., 2021), and age, with all adults (39–59) but only one elderly woman (68). On the other hand, its size was limited, even though it was focused only on a precise niche of people who sought care on #TDC19, in line with the aim of the study. Another drawback could be related to the period in which respondents contracted Covid-19, namely between the third and fourth wave: it could be argued that each wave had different levels of severity and mortality, which in turn could have affected people's attitudes and behaviours, even though it should be remembered that in 2021 Italy still registered high levels of deaths ascribed to Covid-19 (about 59,000, against about 78,000 in 2020; ISTAT and ISS, 2022). However, despite such shortcomings and the fact that the findings hereby discussed are not subject to generalisation, I believe that they may be helpful to describe in depth a specific social phenomenon effectively, by showing its nuances, and to spur further research on this issue.

It was showed that the pandemic did not render people powerless (Glasdam & Stjernswärd, 2022): they made choices in a very delicate and life-threatening context. Specifically, our interviewees' choice were situated in a complex, multidimensional network of reasons, experiences, interactions, emotions, strategies, etc., which formed an entwined ecology of care (Danesi et al., 2020). This was shown in the analysis that included: a) the process of knowledge-building by assessing the media, the best protocol and recall of previous experiences with similar diseases; b) the experience of feeling abandoned by GPs and healthcare institutions; c) the positive encounter with #TDC19 posts of gratitude written by people who were treated by #TDC19 doctors. This particular tangled ecology spurred respondents to seek care from #TDC19. Next, from the experience people had with these doctors, they could compare the latter to their GP and report their own experience to other people who were potentially in the same condition, in similar patterns and interested in being treated by #TDC19 doctors, therefore contributing to a feedback loop.

Some considerations are warranted.

First, this study excludes a possible conflict between patients and Western medicine as a whole, and/or a replacement of the latter with CAM. Indeed, people who turned to #TDC19 chose and wanted to be treated by allopathic doctors who used well-established allopathic medicines to treat them (e.g. NSAIDs). In the case of COVID-19, a potentially life-threatening pandemic, criticisms addressed single doctors (who were blamed for not treating them effectively, namely with the early-at-home therapies mentioned above) and the healthcare institution. Indeed, patients distinguished between pro-active physicians (who used early-at-home therapies and who even experimented

new ways, such as employing antimalarial and antirheumatic drugs, such as hydroxychloroquine) and those compliant with the Ministerial protocol, respectively supporting the former while blaming the latter. Somehow, this may reflect the existing conflict among these types of doctors that has been documented (Gobo et al., 2023) and that was in plain sight of the general public at the time. Arguably, rather than refusing Western medicine, people showed a non-asymmetric relationship with their doctors and made their choices considering the perceived clinical competence and interpersonal skills, as shown in previous studies (Ardissone, 2021). Besides, the fact that people sought care from allopathic doctors volunteering in an informal/non-institutional channel seems to suggest that it was the healthcare institution itself that was the object of most distrust, criticism and disappointment; probably this is because healthcare institutions published, upheld and were seen to force onto doctors (in primis GPs) the approach of "paracetamol and watchful waiting" protocol. Ultimately, this shows the intricate interplay between interpersonal and institutional trust, as posited by Arakelyan and colleagues (2021).

Second, the choice to seek care from #TDC19 was not a leap of faith or a thoroughly irrational move. On the contrary, and in line with Chauhan and Campbell (2020), people negotiated and balanced out the perceived risks associated with COVID-19 and with the possible available choices (GPs, do-it-yourself, #TDC19-doctors). This was based on a strategy that encompassed, first of all, a blend of rational and in-between logics; plus, a non-rational feeling of "hope" was demonstrated (Zinn, 2008b, 2016). As I have shown, people acted rationally when they sought information on different (perceived to be reliable) channels (some of them including non-mainstream doctors, scientists, and journalists), and then acted upon it regarding protocol, media and doctors to entrust with. Then, I showed the importance of (dis)trust in both interpersonal and institutional dimensions, impinging on people's interaction with GPs and with media and healthcare institutions (Ministry of Health and its protocol, LHA), as well as with #TDC19. These forms of trust are overlapping experiences, stemming from interactions and relationships, which form a network that crosses micro, meso and macro levels of social life. This is in line with Fersch et al. (2022), who suggested considering different levels of trust. Emotions crossed each theme and were always present. Even though theoretically it may be appropriate to keep each issue conceptually separated (Zinn, 2016), it becomes very cumbersome to disentangle emotions from activities, perceptions, experiences and trust (e.g., Lupton, 2013). Incidentally, Lewis and Weigert (1985) described trust itself as a multidimensional phenomenon that includes cognitive, emotional and behavioural dimensions. So, following these authors, trust is at the same time a rational and in-between strategy, to use Zinn's term, therefore highlighting the tight connection and the difficulty of disentangling these issues. In the same way, it was difficult to keep strategies rigidly separated, if not for analytical purposes. Based on these findings, it is possible to argue that together rational and in-between strategies were particularly and constantly evoked in our respondents' decision-making process. However, the non-rational hope was also somehow recalled by some of them in addressing the uncertainty that was experienced during the acute phase of their disease (e.g., high fever not decreasing, or getting worse during the first days). Indeed, this study showed that in real life, actions somehow involved all three logics, even though it would be possible to stress that in our case rational and in-between strategies tended to be more relevant and shaped people's action to a greater extent.

In conclusion, these findings help to avoid trivialising people's choice to seek care outside the institutional channels by presenting a more nuanced analysis in which above all patients' rational and in-between strategies and motivations emerged. Choice cannot be connected to a single mechanism, but rather to a complex set of variables in which trust plays a crucial role. Previous works highlighted the need to build trust before a pandemic occurs (e.g., Chan, 2021). My findings are in line with this, and accordingly this should invite public healthcare institutions and GPs to pursue a better relationship with citizens because

trust is a property that needs to be nurtured over time and cannot be summoned on demand. However, the trust-building process needs healthcare providers to consider that people do not interact in a supine asymmetric way and that they critically demand and scrutinize information. This should exclude top-down approaches while privileging forms of co-production of sense-making and action.

CRediT authorship contribution statement

Alberto Ardissone: Investigation, Methodology, Conceptualization, Data curation, Formal analysis, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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