

Law and 'the right to die': Filling a reservoir with an eye-dropper

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LAW AND 'THE RIGHT TO DIE': FILLING A RESERVOIR WITH AN EYE-DROPPER

ABSTRACT: If we considered the assortment of cases that, mainly in America and Europe, raised along the years "right to die" claims, the task would frankly not turn out as the easiest: the collection would go from a PVS patient lying for years in a hospital ward to a person diagnosed with a fatal disease requesting a prescription for barbiturates, passing through a quadriplegic affected by a neurodegenerative syndrome, a cronic depressed, an inmate sentenced for having horribly raped and murdered a few women asking for euthanasia to avoid repeating his crimes once out of prison (practically, a self-inflicted death penalty), elderly spouses scared of loneliness if one outlived the other to the point of preferring to die together when they are still reasonably healthy, deaf-born twins resolute to die together as they lived inseparably, minors dying of an incurable disease, a woman too bothered by the natural decay of body and mind to stand the old age. What would be the core, the intrinsic nature combining all these somehow extreme, though real, calls?

Our civilization is markedly determined to remove the idea of death, to obliterate it from every public forum. Death is erased – from our houses, from our discourses, from our life – and we do not have a common emotional and cultural vocabulary to cope with it. Eternity has moved back in the popular consciousness, while longevity has come to the fore. In "right to die" claims, then, law is asked to provide something for which it is fatally ill-equipped: to be a comfort to our mortality. Emptying the public, also the private impoverishes in lack of communal and political thinking. Law is asked to fill the void – which is a task as impracticable and inane as filling a reservoir with an eye-dropper.

KEYWORDS: Right to die; Death as a Taboo; Rights and Change of Ethos ; Individualism; Choice.

I hope you can indulge me while I escort you in a vivid vision of the future. Let us suppose that, in a hundred years, science finds a cure to our mortality. The average life span for a human being will be so long that it will practically equate to an endless existence, rid of the unpleasantness that ageing brings normally along. When death would eventually come from a gradual, unpainful lassitude, a post-mortem social network – something analogous to *Eter9*, the experiment of artifi-

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cial intelligence capable to learn from the posts an individual uploads during her life to keep on posting for the eternity – will extend life in a virtual reality, as if the individual were still alive.

In those science fictional times, ‘right to die’ claims will be viewed as inherently attached to the essence of our era – in which regrettably we still need to cope with our finitude – like exotic, alien petitions typical of an epoch with which it would be more and more difficult to empathize. How would it be possible to describe those claims to our fortunate (?) posterity?

If we considered the assortment of cases that, mainly in America and Europe, raised ‘right to die’ claims along the years, frankly the task would not turn out as the easiest: the collection would go from a PVS patient lying for years in a hospital ward to a person diagnosed with a fatal disease requesting a prescription for barbiturates, passing through a quadriplegic affected by a neurodegenerative syndrome, a chronic depressed,¹ an inmate sentenced for having horribly raped and murdered a few women asking for euthanasia to avoid repeating his crimes once out of prison (practically, a self-inflicted death penalty),² elderly spouses scared of loneliness if one outlived the other to the point of preferring to die together when they are still reasonably healthy,³ deaf-born twins resolved to die together as they lived inseparably,⁴ a woman too bothered by the natural decay of body and mind to stand the old age.⁵

What would be the core, the intrinsic nature combining all these somehow extreme, though real, calls? What is its foundation? If the question appears hair-splitting, try to tell what Ms. Gross’s petition has in common with the one advanced by a quadriplegic affected by a neurodegenerative syndrome.

Clearly, each request to die is irreducibly individual. As the Irish Supreme Court pointed perceptively out, appellants understandably rely on their very personal distressing situations, each giving rise to a right in that very particular situation. «That reasoning reverses, however, the process of identification of the extent of rights of general application and risks converting the question of the identifica-

¹ A 24-year-old Belgian woman who had suffered from depression and entertained death wish since childhood was assisted in dying through a lethal injection in June 2015.

² It is the case of Frank Van den Bleeken, serving a life sentence in a Belgian jail, who had asked to die by lethal injection to end his untreatable psychological suffering. In September 2014, the Belgian Ministry of Justice confirmed that he would be allowed to die. Fifteen other Belgian inmates requested after him the same treatment. He had to be euthanised in January 2015; it was revealed instead that the process was suspended and he moved in another prison to be treated for his psychological condition.

³ In September 2014, François, 89, and Anne, 86, a Belgian couple married for sixty years, declared their wish to be assisted in dying together, despite the still good life quality and health, for the fear of being separated by death.

⁴ Marc and Eddy Verbessem, 45, were assisted in dying in Belgium in 2013 after finding they were going also to be blind and to be institutionalised.

⁵ In 2010, Ms. Alda Gross took a complaint to the ECtHR impugning the Suisse law providing that the sodium pentobarbital necessary for her assisted suicide had to be prescribed by a physician after a medical examination. Since Ms. Gross had expressed her wish to die not because she suffered from a fatal disease, but because of her advanced age and her growing fragility, she could find no doctors willing to sign the prescription. Still, the Second Section decision, in which the Court had found the Swiss law in breach of the ECHR Article 8, never became final for abuse of the right of individual application, as Ms. Gross was already dead at the time of the appeal to the ECtHR.

tion of rights and correlative duties, *into an ad hoc decision on the individual case.*»⁶ If the collective imagination attributes to the advocates of neglected rights in every time of history, from Spartacus to Rosa Parks, the predisposition to claim loudly those rights on behalf of an anonymous multitude, 'right to die' cases are quite an appreciable exception.

No matter how unclassifiable the category of 'right to die' claims is, we must find a way to describe them systematically for the future generations evoked by my science fictional example. The only common feature I can possibly see among them is the claim to have a choice: the 'right to die' is the right to have a choice.

Choice is byword of identity: without the certainty (or the delusion of it) that we are empowered to impress our own very personal mark on every single decision the course of our life commands, we end up feeling dispossessed of the proper grip on our own existence, on the brink of confusing ourselves in the multitude of indistinguishable human beings, all destined to an unnoticed wordly transit. Actually, the 'right to die' does not seem a very exhilarating choice, if one goes through the individual requests of which I gave an account: since sooner than later death would be eventually the final destination for 'right to die' appellants, their claims, each urged by particular tragic circumstances, do not certainly amount to a diversion from death, as death is always the intention of their decisions (if an oblique or direct intention, it is not relevant here). In order to find a comprehensive definition of 'right to die' claims for our posterity, we need to avoid concentrating on single petitions, single personal stories, each with its distress, sadness and amount of physical and emotional pain. We need instead to draw our attention on the cultural meaning of these claims, on what they represent in our civilization, on how people from outside look at them and on the cultural undertones they may – unawarely or not – attach to them.

If 'right to die' claims share the foundational interest of having a choice, what 'right to die' appellants appear to have generally in common is their dependency on something or somebody, as their autonomy has been significantly curtailed by the clinical condition, the degeneration, the disease or the mental disorder they suffer from. Dependency is bad. It is certainly bad for those singular, specific people limited in their expression or movement or abilities, but it is also bad in our civilization.

Let us take the case of how the separation between elderly parents and adult children is envisaged as a form of freedom in our culture. When my sister and I put forward to my parents the idea to live closer to one of us, leaving their secluded house on the coastline at least for a period of the year, they stared at us like two ungrateful daughters treating them like burdensome old retirees instead of young-looking, active and autonomous adults in their early seventies. Like many others of their generation in the Western world, they like an intimacy with their children from a distance.

The veneration of elders has been today replaced by the veneration of the independent self. If independence is so revered among elders, how important must it be for younger people? Nonetheless, «(o)ur reverence for independence takes no account of the reality of what happens in life: sooner or later, independence will become impossible. ... And then a new question arises: If independence is what we live for, what do we do when it can no longer be sustained?»⁷

⁶ Fleming v. Ireland, [2013] IESC 19, § 115 (emphasis added).

⁷ A. GAWANDE, BEING MORTAL. MEDICINE AND WHAT MATTERS IN THE END, New York, 2014, 22-23.

That of becoming dependent embodies one of the most dramatic fears in our culture of individualism, and 'right to die' cases are a very meaningful perspective by which observing how we address that fear. If you cannot be autonomous anymore, have at least a choice. I am not saying at all that this is what generally crosses the minds of 'right to die' appellants; I am trying to look systematically and from the outside at the culture from which the variety of individual petitions stems in order to single out systemic traits to the benefit of the future generations, eager to understand our unfamiliar times. It may be objected that 'right to die' claims are invoked also to avoid unendurable pain. This is true of some of the cases, but not of all. And, in a certain sense, taking into account pain would not change much the scenario I have been trying to sketch: in some way, pain and dependency could be paired as futile, scaring experiences.

So far, then, the theoretical prototype of the individual involved in 'right to die' cases would be characterised by her claim for a right to choose as a response to a situation of dependency. I disembodied the 'right to die' appellants from their actual predicaments and delineated a tentatively terse prototype whose most cherished attribute is her autonomy, defended until the end through the exercise of her reason to make the last choice. This is the prototype of a hyper-rational individual that also courts in different legal orders rested on to handle the heart-breaking complexities of the appellants' petitions.

To a certain extent, this prototype applied by judges to the real cases in front of them has been nurtured by the *Zeitgeist* of the *Quinlan* years: the *cerebrality* related to the peculiarities of the transplant era, the *abstraction* symbolised with the standardized patient in the informed consent case-law, the *exaltation of the individual's uniqueness* that came along with privacy as a constitutional concept – all played a part to establish the idea that people tend to wish a very rational control over the circumstances they are involved in and, consequently, that it is possible to understand how people think and act relying mainly on their reasoning.

This hyper-rational prototype seems «the conceptualist's revenge for the world's complexities», regrettably contributing «to treat people as though they want essentially the same kind of things and go about getting them in essentially the same kind of ways, to a view that human behaviour is characterized by a predominantly logical approach to life's perplexities.»⁸

The idealized hyper-rational prototype of individual that has a rational choice even in front of death is the deluding liniment for our fear of dependency. Accordingly, we may hope only for a *cognitive* access to the others, as our understanding is based not on the reach of the fears we ultimately share, but of their alleged hyper-rationalism.

From here comes the only possible risk of slippery slope that I can visualize with 'right to die' claims: that the simplification brought to the fore by this ideal hyper-rational prototype may trigger a generalization of how the modern individual needs and must appear to be a well-suited member of our societies – independent, rational, master of her own destiny, able to choose, never a burden to anybody. I insist: this is not the description of how real 'right to die' appellants are. This is the abstract, idealized, hyper-rational prototype that circulates in our culture, the self-sufficient individual insert-

⁸ C.E. SCHNEIDER, *Boethics with a Human Face*, *Ind. L. J.* 69, 1994, 1076-77.

ed in a community of approximate equals. But what about unequal parties⁹ – the less rational, the less economically independent, the less mentally gifted, the less educated, the less sociable, the less integrated? Where the line is to be drawn between a salubrious distance from the others – indispensable to lead one's own existence in accordance with her personal values – and the incomprehension of the weakest? The line is drawn when the space healthily separating us from the others and the power, helpful to make us understand whom we are and what we want, becomes absolute and ideological.

I think of the distinction between *experiential interests* and *critical interests* outlined by Ronald Dworkin¹⁰ with regards to the ideas that each person entertains on what is important to conduct a good life. The *experiential interests* are those activities or pastimes that give us pleasure: playing softball, cooking, eating, drinking, watching football games, seeing *Casablanca* for the twelfth time, listening to *Le nozze di Figaro*, working hard on something. The pleasure we derive from these experiences is certainly essential to a good life, but the value attached to each of them depends on the fact that we find them exciting or delightful as *experiences*. On the other side, most of the people believe to have also *critical interests*, whose satisfaction makes life truly better: they are not mere preferences on which experiences give us pleasure, but critical judgments on what contributes to make our existence good. Not recognizing these critical interests would be a mistake because it would worsen our life. For Dworkin, even bed-time conversions that people may sometimes have before death reconsidering the priorities according to which they have conducted their existence depend on *critical interests*.

Dworkin's distinction of these two classes of interests accompanying people in leading their lives is a representation of the hyper-rationalism I am trying to describe: the subject reflecting on the aspirations making her life better that Dworkin presupposes is a self-confident individual, capable of identifying what should be important in life and of giving it pre-eminence, even though she is always susceptible to mistakes. I read once a story about somebody walking with Samuel Beckett in Paris on a perfect spring morning and asking him: «Doesn't a day like this make you glad to be alive?» to which Beckett answered, «I wouldn't go as far as that.»¹¹ There are people that might find Beckett's reaction in contrast with what they are (or need to be) content with. Dworkin's subject has always a rational choice to do and a minimally developed attitude to the self-analysis.¹² How can this critical prototype reveal the reality of less educated, less prosperous, less self-possessed, less Western culture-oriented individuals in flesh and bone?¹³

⁹ For an exploration of theories of social justice including unequal parties, see generally MARTHA C. NUSSBAUM, *Frontiers of Justice. Disability, Nationality, Species Membership*, Cambridge MA., 2006.

¹⁰ RONALD DWORKIN, *Life's Dominion. An Argument About Abortion, Euthanasia, and Individual Freedom*, New York, 1993, ch. VII.

¹¹ OLIVER SACKS, *The Joy of Old Age. (No Kidding.)*, in *The N.Y. Times*, July 7, 2013, at SR12.

¹² See, for example, the story of Sandy Bem, narrated in ROBIN MARANTZ HENIG, *The Last Day of Her Life*, in *The N.Y. Times Magazine*, May 14, 2015. See also DAVID MITCHELL, *The Importance of Being Important: Euthanasia and Critical Interests in Dworkin's Life's Dominion*, in *UTILITAS*, 7, 1995.

¹³ CHARLES FOSTER, *Choosing Life, Choosing Death. The Tyranny of Autonomy in Medical Ethics and Law*, Oxford, 2009, 155, 161 («Clinicians, courts and other decision-makers should bear in mind too the compelling evidence that when patients are in the situation envisaged by their advanced directives, they very commonly value their

For the reflections I exposed up to now, it is useful to refer to the Vincent Lambert affair, the recent case occurred in France involving a quadriplegic young man trapped in a minimally conscious state (MCS) whom the medical staff would have allowed to die, disconnecting the artificial nutrition and reducing the hydration, with the support of half of the family and the dissent of the other half. In less than two years, after the resolution of withdrawing life-sustaining treatment according to the terms and conditions of the so called '*loi Leonetti*',¹⁴ enacted in France in 2005 to avoid the «*obstination déraisonnable*» for dying patients undergone a treatment «*inutile*», «*désproportionné*» or that aims at «*le seul maintien artificiel de la vie*», the *Tribunal administratif* de Châlons-en-Champagne was resorted to twice, and twice also the *Conseil d'État*, while the final pronouncement of the ECtHR to which half of the family appealed has been released in June 2015.¹⁵

In both the *Conseil d'État* rulings of February and June 2014, the *Union nationale des associations de familles de traumatisés crâniens et de cérébro-lésés* (UNAFTC) presented a memory in court in which it was argued that «*seule la personne concernée est à même de se prononcer sur le caractère artificiel de son maintien en vie; que décider de l'arrêt de l'alimentation et de l'hydratation artificielles pour autrui revient à se prononcer sur l'utilité de cette vie.*» The UNAFTC stressed that this kind of procedure hinged on the evaluation of the physician in charge denies the paramount element of the patient's will and the salient and insuppressible role it should have in determining a certain course of action. In spite of what the *Conseil d'État* emphasized – that the physician cannot reckon only on predetermined evaluations of the patient's condition and that, on the contrary, should make the effort to understand the uniqueness of her state –, it is a fact that the *Code de la santé publique* as amended by the '*loi Leonetti*' puts the medical judgement at the core of the process at the end of which a choice will be made.

The UNAFTC gathers more than five thousand families in France. Its mission is to promote national and EU policies in favour of brain injured patients in order to improve the services of care and assistance for brain-damaged persons and to accompany, support and inform their families. On the website, people leave the account of their experience: the most recurrent complaints have to do with a state of abandonment and solitude they endure when it comes to deal with institutions, local authorities, public services. The idea of a collective procedure involving only physicians and implying a potential collateral effect of *standardizing the approach towards patients sharing a similar diagnosis* must look like a nightmare coming true to them: an old-fashioned approach – the paternalistic supremacy of doctors over patients –, according to which truth lies in the highbrow, mysterious rituals and knowledge of physicians. Vincent Lambert's case may help highlight how the *ethos* surrounding the acknowledgement in some form of the 'right to die' is related to the perception of those vulnerabilities that, in some circumstances, justify the recurrence to a physician-assisted suicide, either through the withdrawal of a life-supporting or saving treatment or through an active medical intervention.

cimpromised life far more highly than they thought they would when they were healthy. ... autonomy lacks perspective. ... It lives in a cowardly and blinkered way in the present».)

¹⁴ Loi n° 2005-370, 22 avril 2005, relative aux droits des malades et à la fin de vie. Through fifteen articles, this bill has modified several articles of the *Code de la santé publique* and the *Code de l'action sociale et des familles*.

¹⁵ Affaire Lambert et Autres c. France, application no. 46043/14, 5 June 2015.

Ignoring the elephant in the room, I have not alluded so far to the vision that our society as a whole has about death. If dependency is a fear, death is a taboo. When I think of how we deal with death in our civilization, my mind always goes to the zen story about two young fish that happen to meet an older fish swimming the other way and asking: «Boys, how is the water?» They swim on for a bit, then look at the other going: «What the hell is water?»¹⁶ Water for the fish, just like death for human beings, is far from being an alien matter. Still, our civilization is markedly determined to remove the idea of death, to obliterate it from every public forum. Death is erased – from our houses, from our discourses, from our life – and we do not have a common emotional and cultural vocabulary to cope with it. Eternity has moved back in the popular consciousness, while longevity has come to the fore. If, among medieval Christians, eternity was recognized as a social need, with «a church in every parish, regular services, catechism for the young, compulsory communion, and so on», it is longevity that has taken its place among modern citizens: «hence doctors and hospitals in every district, regular check-ups, health education for the young, compulsory vaccination, and so on.»¹⁷ We lost our confidence in the care of souls and are instead haunted by the maintenance of perfectly healthy bodies.

Without a common vocabulary, without a public discourse on our common fears and taboos, what remains is the individual right of choice. Life and death are thus both a lonely pursuit.

It is my self, I alone that lasts through life; it is only my self on which the sense of that life can be founded. ... Once life has been emancipated from all pre-arranged, inalienable responsibility ... everything will abruptly come to a stop the moment that only power behind life, 'the ego', my own self, ceases to be. Loneliness of life results in the loneliness of death (itself being its result). It is because life lost the only sense given to it 'of right' – that of *being for* – that death lost its meaning as well. Its terror cannot be shared. It is, after all, my thoroughly private, self-centred and (in its intention) self-sustained world that will disappear. ... My death will be a non-event.¹⁸

In this context, we are left «with nothing to affirm or behold outside our own will.»¹⁹

It is to be acknowledged, though, that

(t)he more publicly sanctioned our right to choose death, so it seems, the more buried, the more hidden, the meaning of that death in our lives, and the more excluded from any common, public discourse. The more public becomes the espousal of choice, the more private the content and substance of that choice.²⁰

Vincent Lambert's case has split his large family in two totally antithetical views on his clinical conditions and on the consistent decision to take. Reportedly, nobody questioned the content of the medical evaluation or its scientific reliability. Rather, what some opposed was a different *social and personal* assessment of his state: while his wife and some of his brothers and sisters claimed that with-

¹⁶ DAVID FOSTER WALLACE, *This Is Water: Some Thoughts, Delivered on a Significant Occasion, About Living a Compassionate Life*, Boston, 2009, 3, 4.

¹⁷ MICHAEL WALZER, *Spheres of Justice* (1983), reprinted in M. SANDEL, *Liberalism and Its Critics*. New York, 1984, note 58, 212-13.

¹⁸ ZYGMUNT BAUMAN, *Mortality, Immortality & Other Life Strategies*, Palo Alto, 1992, 49-50.

¹⁹ MICHAEL SANDEL, *The Case Against Perfection. Ethics in the Age of Genetic Engineering*, Cambridge MA., 2007, 100.

²⁰ DANIEL CALLAHAN, *The Troubled Dream of Life: In Search of a Peaceful Death*, Washington, 2000, 35.

drawing the life-supporting treatment corresponded to his genuine will, for his parents and other brothers and sisters (among which one is quadriplegic), Vincent Lambert was severely impaired, polyhandicapped, but not on the verge of death, so the *Code de la santé publique* as amended by the '*loi Leonetti*' could not apply.

Such a radical, irreconcilable rift between the two sides exacerbated especially because of the lack of advance directives on the part of the patient and of a guardian appointed to decide on his behalf. Despite the several informal occasions in which Vincent Lambert had exchanged his views on the matter with his wife, and despite the compatibility of these positions with his personality affirmed by some of his siblings, no incontrovertible proof was registered for such a circumstance. And the provisions of the *Code de la santé publique* applicable to the case could not help in this regard, since they refer generically to «*la famille*» and, only in lack of it, to «*un des proches*» – understandably omitting any hierarchical order among the relatives, even though some may take care of the patient more directly and follow more closely her clinical evolution.

The '*loi Leonetti*' is the only bill that has been unanimously voted by the representatives of the National Assembly during the history of the French Fifth Republic (1958). It certainly expressed a wide political support and the majoritarian sensitivity of the French people about these contested issues. Nonetheless, despite the effort the '*loi Leonetti*' attempted to make in order to amend and update the *Code de la santé publique*, it ended up overlooking some crucial implications: too frequently – and the Vincent Lambert's case is only the apex of an uncountable bulk that rests under the surface – no evidence is available to prove the genuine will of the patient. Generally speaking, only a miniscule percentage of individuals drafts and signs advance directives in those countries where it is admitted – and France does make no exception. In France and elsewhere, no public registry has been constituted to file the advance directives, and the policies to raise awareness on this topic are fortuitous and vague. So it is the judiciary that, more often than not, is called on to unravel the knot.

Maybe it would seem not entirely unreasonable to wish for policies fostering a *compulsory* system of advance directives at least for circumstances as extreme and reportedly uncontroversial as Vincent Lambert's, verified through cross-examinations on the part of at least a medical team different from the one in charge of the patient. Especially considering the high percentage of population currently dying in intensive care units in the Western world – or, for the elderly, in health care facilities –, the improvement of such a system would possibly be twofold: firstly, for those truly wishing for themselves the withdrawal of life-saving or life-supporting treatment in cases assimilable to Vincent Lambert's beyond any doubt, their will – conveniently kept updated accordingly to a predetermined and adequate regularity – would be incontrovertibly stated and removed from the somehow arbitrary and, in the best of circumstances, approximate evaluation of others. Secondly, a declaration properly signed, officially and formally, would spare the family, the medical staff in charge and the courts potentially referred to the dreadful distress and tragic inconvenience of disentangling and probing the mystery of the true, authentic will of the patient. In this way, in «right to die» matters, at least those involving PVS patients, the will would be unequivocally and responsibly declared.

In addition, the legal obligation to draft and sign advance directives should go hand in hand with the constitution of a public registry especially dedicated. Each personal file might include instructions on the acceptance or refusal of life-prolonging treatment in extreme cases of PVS, the name of the per-

son to appoint as a guardian to supervise the execution of the advance directives, the expression in favour of the organ donation.

Several would be the opportunities of improvement coming from a system more or less like this:

- 1) each individual should declare, formally and officially, her own orientation for circumstances as hopeless and uncontroversial as Vincent Lambert's. A formal declaration would generally require a more systematic and profound reflection on the matter and a serious assumption of responsibility for what the individual is going to state.
- 2) the process each individual would have to undertake in order to evaluate and opt for such extreme circumstances should be accompanied by an intelligible and comprehensive information regarding the scientific evolution in the matter of brain damage and the stages of consciousness after a brain injury and before the brain death. At that point, the dense confrontation among scientists and physicians should find a way to percolate in some form in the public debate.
- 3) the loss (partial or total) of consciousness, the role of technology in prolonging life, the different moral orientations in this regards and, most importantly, the prospect of death would enter at last the public fora – a process necessarily implicating a reflection on the inaccessibility of the idea of death in our culture and the deep reasons why it is removed from our everyday perception. In other terms, it would constitute the first act of the battle against death as a taboo.

This kind of system would certainly challenge some of the most entrenched rituals of our times – death and its ramifications are not at all part of the public agenda and only seldom of the interpersonal communication. A legal obligation to anticipate one's own determination would certainly arouse some thick skepticism and a plethora of counterarguments: yet, its provocative potential, more than its actual feasibility, represents its real strong suit.

With nothing to share, nothing to cope with together, «(t)he weakness of the self-determination ideal is magnified in confronting the inevitability of death,»²¹ and here is where Therpandrus's obsession begins: when choosing for the sake of choosing is the aim, when all the options have the same, identical value for the only reason that they are spontaneously chosen, and it is the choice itself which gives them value.²² But the *ideology* of choice may turn out as very misleading when it burdens the individual with the idea that he or she is the total master of their well-being and the direction of their life and how little this ideology contributes to possible change in the organization of society as a whole. ... Choice is a powerful mechanism in people's hands. It is the basis, after all, of any political engagement and of the political process as a whole. However, when choice is glorified as the ultimate tool by which people can shape their private lives, very little is left over for social critique. While we obsess about our individual choices, we may often fail to observe that they are hardly individual at all but are in fact highly influenced by the society in which we live.²³

²¹ ROBERT A. BURT, *Deat Is That Man Taking Names: Intersections of American Medicine, Law, and Culture*, Oakland CA., 2004, 86.

²² CHARLES TAYLOR, *The Malaise of Modernity*, Toronto, 1998, note 10.

²³ RENATA SALECL, *The Tyranny of Choice*, London, 2010, 13, 149.

In this context, the free man to whom Therpandrus ideally would have liked to resemble in order to decide for himself how many strings to add to his instrument may turn into a solitary being, incapable of sharing with the others his fears and taboos and gradually indifferent or even annoyed by the dependent, the unrational, the weak.

In 2011, the number of families in the United States living with two dollars or less per day has reached 1.5 million, twice as large as in 1996. One citizen out of seven depends on the government to satisfy basic food needs, and at least once a month many Americans go to bed on an empty stomach because they cannot afford a meal. An illness may push an entire family towards the abyss and, indeed, more than 60 percent of individual bankruptcies is accompanied by a member of the family's disease.²⁴ Are they in the least represented by the hyper-rational prototype I introduced? How about their experiential and critical interests?

I am not against the legalization of the 'right to die' because nobody can be forced to live in view of the presumption that the State knows better what is good for her. Still, I am not in favour of it either, because I tend to argue that the individual and collective problems related to 'right to die' claims are hardly responded to by acknowledging a vested right. It is good for the individual asking for it, but what about the others, what about common fears and taboos? In this regard, Daniel Callahan penetratingly presented his impression that

most people do not in any conscious way try to relate their claims on others, or on society – including their claim to euthanasia or their denial of it – to some coherent, rounded idea of themselves as persons. ... Only when I became uneasy about the conventional boundaries of the common debate did I start wondering if a different approach to the issues could be imagined: that of asking, not about our rights, but about the kind of people we should want to be.²⁵

I am terrified at the prospect of a *creeping totalitarianism* that, in the medium or long term, may produce the effect of imposing on individuals the ideal way of being, acting, choosing in this field to the point of changing how people look at disabilities or mental impairments or situations of helplessness. As it has been noted, «(t)he irony about assisted suicide is that concepts of personal autonomy, freedom, and dignity are used to empower persons with disabilities to kill themselves, rather than enabling them to live independent lives with dignity.»²⁶ Indeed, there are rights that, once legally recognized, develop an *ethos* that would most likely stand the test of time even if the right ceased to be enforced by public authorities: if the right to vote for African Americans were repealed, would the *ethos* behind that entitlement be enucleated from society? The 'right to die' is not only an individual entitlement: it brings along an *ethos* – a complex of moral attitudes, ways of being, expectations, social rules, empathy and condescension. «What are really contentious *vis-à-vis* PAS [physician-assisted suicide] are society's prejudgments and prejudices about the worthiness or worthlessness of a par-

²⁴ These data are gathered from JOSEPH E. STIGLITZ, *The Price of Inequality. How Today's Divided Society Endangers Our Future*, New York, 2012, *passim*.

²⁵ DANIEL CALLAHAN, *op. cit.*, note 156, 117.

²⁶ PAUL STEVEN MILLER, *The Impact of Assisted Suicide on Persons with Disabilities: Is It a Right without Freedom?*, in *Issues I. & Medicine*, 9, 1993, 47, 58. See also PENNEY LEWIS, *Rights Discourse and Assisted Suicide*, in *Am. J. L. & Medicine*, 27, 2001, 45, 66 (about the social stigma, potentially associated with vulnerabilities, that may influence or compel a disabled person to feel that she ought to exercise her autonomy in the sense of receiving assistance to commit suicide).

ticular life and the rationality of decisions of those who wish to decide for themselves how to live their lives up to and including their demise.»²⁷

It is always possible that men's neckties go from wide to narrow and then wide again; even their prolonged replacement with bow-ties or turtle-necks has no necessary long term implications.

This is not for moral attitudes. When the issue is important, when it reaches deep into the structure of our conceptions of ourselves, then a change in one aspect brings consequential change in other aspects and, in time, change becomes so pervasive and so interlocked that return to earlier moral visions is simply impossible, if not unconceivable.²⁸

The path of self-determination and individual autonomy is already traced like the bed of a river, and the water can hardly be redirected: if a positive obligation of the State to protect life can be pleaded for, on the other side it is hard to argue the existence of a duty to live imposed on individuals. Having said this, what can make a difference in the medium or long term is to frame 'right to die' claims not only as issues related to how broad self-determination and individual autonomy should be, but rather to the effort of preserving the endurance of our communal bonds without sacrificing individual freedom, to open up individual freedom without irreversibly damaging the existence of those already feeble communal bonds.

While writing these pages, the inspiration I tried to follow and hopefully to serve was not about militancy or activism. Every time I happen to tell somebody that I have been writing about the 'right to die', the immediate reaction is asking whether I am in favour or against it. Although this reduction of such a complex matter to the terms of a sporting match is understandable, it is also oversimplifying and slightly annoying – Pierre Bourdieu once said: «If you meet a dichotomy when thinking, be brave: try to escape.» It does seem to me that the necessity of contributions beyond any partisanship cannot but be confirmed: too much pain lies behind the claim of the 'right to die' to parade along the streets and celebrate its legalization or the denial of it. There is nothing mirthful or pacifying in it,²⁹ nor is the obscure mystery of death more approachable. Prudence and empathy should be in order: no one wins, many – in many ways – are defeated: those who die, those who stay. This Article, then, does not intend to offer an ultimate way to achieve this historical task, but more modestly to shed a light on the complexity of implications surrounding the 'right to die' cases in the centuries-old tension between the emancipation of the individual and the preservation of her ties with others.

Where does the feeble border between autonomy and solitude run? When do the communal bonds perilously come at risk? Will society lose its sensitivity towards the people affected by the vulnerabilities that make some claiming their 'right to die'? Will tax payers feel less obliged to contribute for assisting them in their needs? Will institutions decline over time their responsibilities towards the people impaired with those vulnerabilities? There is no answer, at least not a single one, and everybody is in charge of finding her own, if interested. What is certain is that it is everybody's responsibility to watch lest the dialogue is distorted in a jumble of opposing individual voices with no listening. This

²⁷ PHIL C.W. CHAN, *Exploring a Right to Physician-Assisted Suicide in Singapore*, in *Chinese J. Comp. L.*, 3, 2015, 119, 122.

²⁸ ROBERT A. BURT, *The Ideal of Community in the Work of the President's Commission*, in *Cardozo L. Rev.*, 6, 1985, 278, 278.

²⁹ PIER PAOLO PASOLINI, *Lettere Luterane. Il Progresso come Falso Progresso*, Turin, 1976, 25 (about the legalization of abortion).

article is intended to be a simple contribution to keep the dialogue public and open, to inquire the possible solutions to cope together with our common fears and taboos, to investigate how the relationship between the individual good and the communal good may stay balanced.

Let the questions public and open, and so be the possible answers, but it is everybody's responsibility that, in the end, the progression of freedom does not make equal to «a progressive liberation from the others.»³⁰ In 'right to die' claims, law is asked to provide something for which it is fatally ill-equipped: to be a comfort to our mortality. Emptying the public, also the private impoverishes in lack of communal and political thinking. Law is asked to fill the void – which is a task as impracticable and inane as filling a reservoir with an eye-dropper.

³⁰ GIULIANO AMATO, *Libertà: involucro del tornaconto o della responsabilità individuale?*, in *Nuove dimensioni nei diritti di libertà. Scritti in onore di Paolo Barile*, Milan, 1990, 29.