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SCIENTIFIC CONTRIBUTION

# Assumptions and moral understanding of the wish to hasten death: a philosophical review of qualitative studies

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**Abstract** It is not uncommon for patients with advanced disease to express a wish to hasten death (WTHD). Qualitative studies of the WTHD have found that such a wish may have different meanings, none of which can be understood outside of the patient's personal and sociocultural background, or which necessarily imply taking concrete steps to ending one's life. The starting point for the present study was a previous systematic review of qualitative studies of the WTHD in advanced patients. Here we analyse in greater detail the statements made by patients included in that review in order to examine their moral understandings and representations of illness, the dying process and death. We identify and discuss four classes of assumptions: (1) assumptions related to patients' moral understandings in terms of dignity, autonomy and authenticity; (2) assumptions related to social interactions; (3) assumptions related to the value of life; and (4) assumptions related to medicalisation as an overarching context within which the WTHD is expressed. Our analysis shows how a philosophical perspective can add to an understanding of the WTHD by taking into account cultural and anthropological aspects of the phenomenon. We conclude that the knowledge gained through exploring patients' experience and moral understandings in the end-of-life context may serve as the basis for care plans and interventions that can help them experience their final days as a meaningful period of life, restoring some sense of personal dignity in those patients who feel this has been lost.

**Keywords** Wish to hasten death · Dignity · Autonomy · Values · Qualitative studies · Medicalization

## Introduction

It is not uncommon for patients with advanced disease to express a wish to hasten death (WTHD) (Monforte-Royo et al. 2011). Although the WTHD is regarded by some authors as being synonymous with notions such as allowing a life-ending process to take its course, letting go, acceptance of dying, moving on to another reality, being tired of living or rational suicide, this is not necessarily the case. Indeed, we would argue that a distinction needs to be made between the WTHD expressed in the specific context of a disease process and a general wish to die that may have different degrees of intentionality, ranging from a generic desire that does not necessarily imply taking steps towards ending one's life to a formal request for euthanasia (Ohnsorge et al. 2014a). Furthermore, the WTHD may vary in intensity over time, indicating the ambivalence that many patients feel about their situation. Some authors also point out that the WTHD can signify for patients something other than an actual wish to die: for instance, it may be the expression of a wish to live but not in this way (Monforte-Royo et al. 2012).

Rehmann-Sutter (2015), quoting Chochinov, ask whether the WTHD should be considered part of a normal adaptation to a life-threatening disease, and if so, where is the line between normal and pathological. As these authors point out, the answers to these questions transcend the medical sphere and "depend on philosophical assumptions

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about the normative significance of end-of-life care and of dying" (Rehmann-Sutter 2015, p 5). They go on to say that in arriving at what we wish for "we evaluate and re-evaluate our moral understandings, self-images, convictions, and deepest commitments" concerning life and death (Rehmann-Sutter 2015, p 8).

As noted above, the expression of a WTHD may sometimes be confused with a request for euthanasia or assisted suicide. In Western societies there has been intense debate among clinicians, ethicists and the general public regarding whether or not such practices should be decriminalised. One feature of this debate has been the emergence of notions such as self-appointed death, self-chosen death or self-determined death, indicative of a certain change in mentality and attitudes, of an attempt to normalise death as a voluntary act. This highlights how the way in which we talk about death and dying is both a cause and a consequence of our ideas about suffering and death, ideas that presuppose and generate moral understandings that are circumscribed to particular situations.

All this suggests that the WTHD cannot be understood without taking into account the socio-cultural context and the moral understandings of those patients who express such as wish. Walker (2007) defines moral understanding as the background against which people define themselves, act in relation to others and understand the world. Our behaviour as individuals will also be influenced by the judgements, ideas and expectations that others have of us (Ohnsorge et al. 2012). Thus, as Walker puts it, our identity, our sense of who we are, is a narrative that "is threaded through by another story, one about 'what this means'. The last involves a history of moral concepts acquired, redefined, revised, displaced and replaced, both by individuals and within some communities of shared moral understanding" (Walker 2007, p 119–120).

In light of the above, the aim of the present study was to analyse the moral understandings of patients who express a WTHD (as well as those of their relatives and healthcare professionals, where such data were reported). The starting point for this analysis was a recent systematic review and meta-ethnography conducted by our group of 14 qualitative studies on the WTHD in advanced patients (Rodríguez-Prat et al. 2017). The results of that review indicated that a WTHD can only be understood by considering the meanings that patients ascribe to it, in other words, what it is that they really desire or wish to communicate when they express such a wish. The present study returns to the studies included in our previous review in order to analyse in greater detail the verbatim statements made by participants. Our goal in doing so was to show "how meaning is personally attributed and to examine the moral reasoning that people make use of when expressing certain preferences" (Ohnsorge et al. 2012, p 631).

## Method

The starting point for this study was the aforementioned systematic review and meta-ethnography on the WTHD in patients with life-threatening illness (Rodríguez-Prat et al. 2017). The search strategy used in that review applied a combination of MeSH and free-text terms to the Pubmed, Web of Science, CINAHL and PsycINFO databases. Fourteen qualitative studies were finally included, involving a total sample of 280 participants (patients, families and healthcare professionals). These studies had been carried out in Australia (Kelly et al. 2002), Canada (Lavery et al. 2001; Nissim et al. 2009), China (Mak and Elwyn 2005), Germany (Pestinger et al. 2015; Stiel et al. 2010), The Netherlands (Dees et al. 2011), Switzerland (Ohnsorge et al. 2014a, b, 2012), Thailand (Nilmanat et al. 2015) and the USA (Coyle and Sculco 2004; Pearlman et al. 2005; Schroepfer 2006). For more detailed information about the method used in the systematic review, see Rodríguez-Prat et al. (2017).

Meta-ethnography (Noblit and Hare 1988) is an inductive process in which systematic and constant comparisons are made between the concepts found in different studies, the goal being to obtain an interpretive synthesis or critical understanding of a given phenomenon based on multiple facts, cases and narratives. In the case of our previous review of qualitative studies on the WTHD the meta-ethnographic method enabled us to propose an explanatory model of the phenomenon from a clinical point of view. In addition, we observed that the majority of the verbatim statements made by patients who expressed a WTHD reflected assumptions that could be organized within a common frame of reference. More specifically, examination of these statements led us to identify four types of assumptions that generally feature in both clinical and ethical-philosophical discourses in the end-of-life context, and which, from an ethical-philosophical point of view, can help to understand in greater depth the personal background of these patients:

1. Assumptions related to patients' moral understandings in terms of dignity, autonomy and authenticity.
2. Assumptions related to social interactions in terms of how others assign value to the individual and to the individual's life in the context of an illness (related to the notion of social dignity).
3. Assumptions related to the value of life, in terms of what makes it worthy or unworthy (assigning value and meaning to life).
4. Assumptions related to medicalisation as an overarching context within which the WTHD is expressed.

In the sections that follow, we operationalise each of the first three classes of assumptions, offering a conceptual framework for understanding them in the end-of-life context and for linking them to the statements made by patients in the reviewed primary studies of the WTHD. In addition, and given that a person cannot be understood in isolation from his or her embodied and contextual reality, we also examine those statements which make reference to medicalisation as an overarching framework within which many patients experience and attribute meaning to their illness. Consequently, the fourth class of assumptions, those related to medicalisation, are considered not separately but as a thread running throughout each of the other classes. With the aim of illustrating each of the concepts that we develop, Table 1 lists some of the most representative quotes taken from primary qualitative studies of the WTHD.

## Assumptions about moral understandings

The specific meaning ascribed to suffering, pain, illness and death varies across cultures (Illich 1976; Le Breton 1999; Morris 1991). In Western societies the social representation of these phenomena (i.e., how society conceives of or experiences them) is closely linked to the birth of modern medicine and to what is known as medicalisation (Clark 2002; Illich 1976; van Wijngaarden et al. 2016), the process whereby "'non-medical' problems become understood and treated as 'medical' problems" (Conrad 2008, p 5). Through this social process, natural phenomena such as illness, death and mourning become redefined and articulated within the framework of a medical paradigm. With respect to the WTHD there are four points to consider in relation to medicalisation. First, if the latter means that the normal challenges of life become treated as medical problems, then natural stages of our experience, such as illness and the end of life, may be regarded as problems to be solved by medical science. In this regard, some authors have linked the medicalisation of death and dying to a growing faith in the ability of science, rationality and progress to offer solutions to what were previously regarded as normal features of human life (Conrad 2008). One example of this would be the prescription of drugs to someone experiencing sadness at the loss of a loved one, even though the person in question does not have a medical problem (Parens 2013). The second point is that the medicalisation process may lead us to lose sight of the subjective dimension of the person; the 'patient' thus becomes treated as an 'object' whose problem can be solved (Parens 2013), rather than as someone located in a particular context, a person with beliefs, values and the ability to act in accordance with them. Third, a medicalised view may lead to physician-assisted suicide and euthanasia being seen as the "technological solution to the problem of death and (feared) suffering in the shape of a very effective lethal injection" (van Wijngaarden et al. 2016, p 266). The results of our aforementioned systematic review suggest that death may be seen by patients as a way of escaping suffering, and thus medical intervention, backed by the law, would become the means through which this wish is realised. Finally, and as pointed out by Wijngaarden et al. (2016), the fact that clinicians have to make decisions about how a person's life may be prolonged or shortened can influence patients' own view of their illness. For example, some patients may reject their dependence on life-support machines, due to the loss of quality of life that is implied. Consequently, a loss of control or autonomy may, for some patients, be a reason why they wish to die.

Within a context of medicalisation, therefore, the identity of the ill person may be redefined through, for example, the use of drugs that affect cognitive functioning or dependency on life-support machines or systems. With regard to the latter, Ariès (1975) offers an illustrative quote from the Jesuit historian François de Dainville, whose response to being intubated in an intensive care unit was to state: "I am being deprived of my death".

Among patients who expressed a WTHD in the studies included in our review, the fear of becoming dependent on life support machines was sometimes the result of personal experience or of having witnessed such a situation in a loved one: "My first husband, he suffered a long time. He had on those machines, and I used to say, 'God,' I said, 'don't let me go under those machines" (Schroepfer 2006, p S135). Other patients saw it as inevitable that someone in their condition would not wish to be dependent on technology. For example, one man said that his need for artificial ventilation prevented him from enjoying everyday activities, which for him were what brought a sense of dignity to his life (Lavery et al. 2001). Another patient felt that dependency on medical interventions of this kind raised questions about the meaning of life: "Someone with a tube sticking up the bottom, a tube sticking into the nostrils, another somewhere else. I mean, what for? Can you save them?" (Mak and Elwyn 2005). These statements illustrate how medical and technological interventions may influence a person's experience of illness and potentially contribute to the WTHD. However, this is not necessarily the case for all patients who express a WTHD, many of whom will be fully competent when they discuss such a wish, even though there may have been other times when they were not, due to the treatment they required.

Some of the statements made by participants in the studies reviewed enabled us to identify social representations of death and suffering, linked in part to the overarching context of medicalisation. For instance, some patients referred to their body as a broken machine, and death as the proof that this machine could not be repaired. In another recurrent image the end of life was seen as a process of intense

**Table 1** A selection of quotes from primary studies of the WTHD

| Themes and subthemes | Moral self-understandings | Images of medicalisation |
|---|---|---|
| "Um, the ability to perform simple things like, you know, going to the bathroom on your own and not through a bag, um, breathing with your own lungs, not dependent upon a machine to keep the body parts functioning, um being able to do anything, I mean as long as you can think then you can live, but if you can't [sic] no longer even formulate a thought due to dementia or you know the ravages of the disease. You know, if you were to stand there in your former self, would you want to see yourself in that position? I know I wouldn't. You get to the point where there's no return, you know, I can understand somebody saying, well geez, you know, like I used to be somebody, but now, like I mean, you know, I'm no better than like a doll, somebody has to dress me and feed me and I guess it's uh, I don't know how to explain it, really" (Lavery et al. 2001) | Dignity understood as being autonomous, independent. Former self: assumption of a previous self (authentic self vs. ill self) | Loss of self in illness. Being dependent on life-support machines |
| "I say: I have made my decision. I don't want you to treat me any longer. Someone says, now you are probably too weak for chemo. I say: if I'm not too weak and they want to give me chemo, I will refuse it, because in the little time that is left to me I want quality of life, not quantity of life. I decided that a year ago: if this were to overcome me, then that's what I would choose" (Dees et al. 2011) | Self-agency. Authenticity achieved through decision-making capacity. Worthy life: quality of life | Quality of life *vs.* quantity of life. "Medical invasion": power of medicine |
| "Not wanting to be seen by those that love me as this skin-and-bone frail, demented person. In other words, I don't want that image of me for me, and I don't want that image to be kind of a last image that my daughters and loved ones have of me. And that's just a dignity issue" (Pearlman et al. 2005) | Idea of the preservation of the self (split identity: image of the person before and during the illness). There is some kind of inner authenticity that needs to be preserved when facing others. Social dignity: how the person is seen by others and a sense of maintaining the self in the eyes of others | Social identity: illness limits your life |
| "Finally the illness that dominates everything will wipe out all life has to offer me, what I feared most is exactly what will happen to me. I won't belong anymore, the emptiness of existence, the lack of independence, being unable to do things myself, being at the mercy of others whom I will have to beg to do the things I need in a way that's suitable for me" (Dees et al. 2011) | Loss of value of life (emptiness of existence) due to the lack of independence. Value of oneself (dignity): being able to do things on your own | Representation or anticipation of future suffering. Life is unenjoyable in illness. Illness that dominates everything |
| "And I don't feel this is a life for me [pause], carrying on living like this. That's why [pause] um, I am [pause] very – how should I put it, so you understand me – I'm on the move a lot and [pause] then I thought, if I can't live like before, life has no value, does it? And [pause] I drove my car a lot, and I can't do that anymore either. [...] Yes, did a lot of travelling. [...] I feel my life isn't worth anything at all any more, if I just lie here and wait" (Ohnsorge et al. 2014a) | Split identity (before and during the illness). Life as not worth it (no dignity): life has no value, it is not worth it if the possibility of carrying out meaningful activity is lost | |

**Table 1** (continued)

| Themes and subthemes | Moral self-understandings | Images of medicalisation |
|---|---|---|
| "Oh, it's the dignity and wholeness of my body, as well as spirit. And, it is, it's cruel too for others to have to do this when there's no end in sight, other than death. To just, to clean me up. I just don't want that... Dignity is that I have control over my body, when, when, not, not a virus that is going to take my life. I'm the one who's going to decide when my life will end, not a virus, and not with great pain. Not anything else other than in, in my control. It is my control, my choice to do" (Lavery et al. 2001) | Dignity as having control over life. Dignity as self-determination | Possibility of deciding when life is over: ("it is not a virus that is going to take my life") |
| "Pain is my biggest fear. It puts me in a darkness and a lack of will to go forward and a desire to die... The pain wants me to have a vehicle to just, just stop my life" (Coyle and Sculco 2004) | Life with pain is not worth it (in some circumstances it would be preferable to die) | Possibility of deciding when life is over Death is preferable to suffering: "pain as the biggest fear" |
| "... It should be up to me to decide... when I've had enough suffering... One of my landmarks, if I'm at the point where all I can do is lie on a bed all day long, then to me that's probably not living anymore" (Pearlman et al. 2005) | Values: own decision-making: not worth living if losing functionality and independence | - Suffering as something worse than death |
| "I immediately turned to the option of Exit [pause], because I said I'd like to have this option whatever happens. If things become unbearable for me for some reason, but I'm still not dying, then I'd like to be able to grant myself my own death [...] This is really only about ending a situation that has become unbearable, and not having to rely on either being hit by another stroke or some doctor being understanding after all. I want to be able to keep this in my own hands for when the moment comes. I was a very self-determined person all my life, and that's very important to me" (Ohnsorge et al. 2014a) | Life is not worth it if in pain. Dignity as self-determination: "grant myself my own death"; "keep this in my own hands" | Possibility of having some control over the dying process: "I want to be able to keep this in my own hands" |
| "He didn't want to kill himself: he didn't want to die. It was about finding any method to be vital and the list was narrowed down to the most- the simplest things, and when they were gone, he didn't have a reason... so it wasn't just the diarrhea or the lack of driving; it was just losing, like his definition -what his sense of vitally was. And when that was gone, then he was ready" (Pearlman et al. 2005) | No way of maintaining an authentic self (losing the self). Dignity as being able to do ordinary activities related to being oneself (preservation of the self). | Illness seen as a process of loss |
| "[When metastasis was diagnosed] I immediately set about the option of Exit ... because I said, I would like to have this possibility in any case. If for any reason it becomes unbearable for me, but I'm still not dying, then I would like to bring about my own death. And I saw to it all, that it was ready, that I had the prescription, and I talked to these people. That's sort of there on demand now" (Ohnsorge et al. 2014b) | Autonomy and self-determination as core values | Having some control over death: "bring about my own death" (if things get worse) |

and prolonged suffering, due to the technological possibility of keeping a person alive: "I am only afraid of an agonizing death. Taking too much time" (Pestinger et al. 2015, p 715). In a medicalised context this, according to Callahan (1989), has to do with exchanging a short life and a fast death for a long life and a slow death.

Having introduced the contextual framework of medicalisation we will now seek to illustrate how the statements made by patients reflect assumptions about their own value as individuals and their moral understandings. Specifically, we will examine assumptions about dignity, autonomy and authenticity. It will be seen how each of these three classes of assumptions can help to understand the premises on which an individual attributes value to his or her life.

### Assumptions about dignity (the value of oneself)

In the 1950s the term 'dignity' began to be used in the palliative care context to refer to a new attitude towards the care and condition of patients (Clark 2002). The idea of dignity has since grown in importance, and safeguarding this aspect of a patient's life has become a key objective in clinical practice (Chochinov et al. 2002; Guo and Jacelon 2014; Östlund et al. 2012; Street and Kissane 2001). Many studies of dignity in the end-of-life context refer to it in ontological terms, such that dignity is understood as an intrinsic and inalienable value of human life, as something common to all persons which is not altered by circumstances (Leung 2007; Pullman 1996; Steinhauser et al. 2000; Sulmasy 2005).

On another level, however, dignity may be conceived of as an empirical and dynamic quality, as part of the person's sense of identity in relation to physical, psychological, spiritual and social factors, all of which will be mediated by the experience of illness (Chochinov et al. 2002; Street and Kissane 2001). Although these two levels are sometimes discussed separately, they are not mutually exclusive and dignity may be conceived of as an ontological foundation on which the empirical aspect is constructed. Dignity can also be understood in terms of value, in the sense of the value that people attribute to their life at a given moment, together with the factors that make life something worth valuing. Chochinov et al. (2002) note that dignity overlaps with concepts such as pride, self-respect, quality of life, well-being, hope and self-esteem, as well as with the extent to which a person perceives him or herself to be worthy of honour and esteem from others. Here we have assumed that dignity is a dynamic quality that is nonetheless founded on an intrinsic and inalienable feature of human life, and as such it is similar to the value that a person attributes to him or herself (i.e., the sense of self-worth). Thus, for the present analysis we identified statements in which patients made some reference to the notion of self-worth and then analysed them in light of our operationalised definition of dignity.

Illness, which for many of the participants in our review was perceived as the first steps towards death, was the defining context of lived experience for those who expressed a WTHD (Kelly et al. 2002). Thus, their perception of personal dignity was mediated by the fact of being ill. In a context of medicalisation, and in terms of what Kellehear (2007) refers to as social death, one might say that the person begins to die in illness. This would certainly be consistent with an observation made by Pearlman et al. (2005, p 236), who noted that "patients and their families viewed functional losses as markers of the patient's transition from life to death". The notion of social death is also interesting because it offers a framework for understanding the tendency for some societies to exclude people once they are no longer productive or autonomous, or have become a burden on others. This individualistic attitude towards the value of human life, which is characteristic of Western society, for example, can also be seen in new attitudes towards death (Taylor 1992): death as the loss of self (of one's individuality). And if, as was suggested above, death begins with illness, then a loss of self will also occur when the patient receives a diagnosis. It is then that the patient will begin to stop living, despite his or her wishes: "[I] wish to live but can't live" (Mak and Elwyn 2005, p 345).

Many of the statements made by patients who had expressed a WTHD reveal ideas, value judgments and assumptions about their identity (who am I?) and self-worth (what they believe gives value to their life). When talking about their reasons for wishing to die, many of them, both explicitly and implicitly, referred to the notion of dignity as we defined it above (i.e., as a dynamic concept). For the majority of participants the value they attributed to life (their sense of dignity) was seen as something they could lose in the state of vulnerability brought about by their illness (Dees et al. 2011; Lavery et al. 2001; Pearlman et al. 2005). As the disease progressed they began to lose control over bodily functions and became dependent on others to perform certain everyday tasks (going to the toilet, taking a shower, getting dressed, eating, etc.). In some cases the loss of dignity was also linked to their anticipating a future in which they would lose their intellectual capacity or even conscious awareness (Dees et al. 2011; Pearlman et al. 2005; Pestinger et al. 2015). Their advancing illness was thus experienced as all-consuming, as a process in which aspects of the self would be progressively lost until nothing was left (Dees et al. 2011; Kelly et al. 2002; Lavery et al. 2001; Nissim et al. 2009; Ohnsorge et al. 2014a; Pearlman et al. 2005).

In this context, a hastened death was seen as a way of ending the loss of self, which was often synonymous with a perceived loss of dignity. For these patients, illness had

stripped them of all that had been meaningful in their life, and some of them expressed their fear of being reduced to the status of a vegetable (Lavery et al. 2001; Pearlman et al. 2005). Others sometimes felt that their illness was something to be hidden (Dees et al. 2011), or spoke of the dying process as messy and undignifying (Schroepfer 2006). Seen as the end of all possibility, the loss of self was described by participants as a destructive enemy to be feared (Dees et al. 2011; Kelly et al. 2002; Nissim et al. 2009; Pearlman et al. 2005).

An increasingly mechanistic view of the body has also had an impact on representations of illness. The body is seen as something that can be repaired, and pain as an external factor capable of dehumanising the person: "All of a sudden, it dawned on me that there was no solution, and if there was no solution to my cancer, then why was I hanging around? I got thinking about death as a practical matter. Why hang around and cause a lot of people a lot of grief?" (Coyle and Sculco 2004, p 704). In this context, Walter (1994) argues that the metaphor of death as the Grim Reaper has been replaced with a factual representation of death as a killer disease. This paves the way for the myth of the physician who fights death (Illich 1976), and if the latter occurs it is because medicine has been unable to solve the technical problem of illness.

*Assumptions about autonomy*

The debate in some countries over whether euthanasia or assisted suicide should be decriminalised has raised the possibility of people being killed on request. This kind of medicalised control over the dying process implies a shift from the idea of death as something natural and inevitable that all must suffer to death as something to be mastered or brought under technological control (Ariès 1975). The transition from life to death thus becomes a matter of choice due to the authority of the self, the latter having replaced older sources of authority such as the will of God or doctor's orders (Walter 1994). This is also reflected in the tension between 'loss of control' and the 'desire for self-determination' that emerges in a context of medicalisation (Quill and Battin 2004; Walter 1994; White and Callahan 2000). Whereas loss of control would be a consequence of having to follow doctor's orders, the desire for self-determination would be an expression of what Walter (1994, p 54) refers to as the authority of the self: "I did it my way".

The statements made by patients who expressed a WTHD show how the apparent power of medicine to control death and dying has given rise to two opposing and related scenarios. On the one hand, many people fear that their life will be prolonged under poor and artificial circumstances, a situation which they imagine will be accompanied by pain and a loss of both control and, perhaps, dignity (Brody 1989; Callahan 1989; White and Callahan 2000). Medical intervention may thus be seen as something that exerts a high price, draining the patient of energy and impeding the natural process of dying: "In a sense it's artificial that I'm still alive. Even a few years ago that would not have been the case for me to survive that long, but there are limits to what any organism will take or can do, and I have reached my limit" (Nissim et al. 2009, p 169).

In response to the perceived loss of control, many patients expressed a desire for self-determination, the right to decide when and how their life should end, which paradoxically would most likely require medical intervention: "I don't want to deal with it so I think I would speed up things myself. I don't want to be lingering here in palliative care, lying day and day, slowly dying. Oh no, I don't want to do that. So, suicide is a way of exiting. I don't want to talk about that because I like life and I have lots to live for, but if I come to the point when I am too weak to do anything, then I don't want to stay" (Nissim et al. 2009, p 168).

Whereas suffering and pain were seen as placing limits on the possibility of an enjoyable life, personal agency was invoked as a way of having some control over the dying process, in this case, by removing suffering through death: "how long am I supposed to put up with this? And then it occurs to you: well, you don't have to, you can get out of it at any time" (Ohnsorge et al. 2014a, p 10). In other cases, autonomy was regarded as the value or quality that underpinned and defined the sense of personal dignity, and for these patients 'keeping it in their own hands' was what defined them as persons.

*Assumptions about authenticity*

Authenticity has traditionally been understood in different ways. In the broad sense it has to do with being "faithful to an original [or a] reliable, accurate representation […] To say that something is authentic is to say that it is what it professes to be, or what it is reputed to be, in origin or authorship" (Varga and Guignon 2016, p 1). This definition is consistent with a view widely expressed in the end-of-life context, whereby those who find themselves in this situation can—and should—be able to make decisions that reflect the person they profess to be. Although, from a normative point of view, it is difficult to determine the basis of authenticity, one of the arguments that is often made in support of a voluntary death is that patients' thoughts, desires and actions should be respected as authentic expressions of who they are (Quill and Battin 2004).

The statements made by patients who expressed a WTHD reveal that the idea of authenticity often appears in the form of what one might call a 'split identity', in other words, the self before and after the onset of illness. In fact, some patients specifically described themselves in

terms of a 'former self' and an 'ill self' (Coyle and Sculco 2004; Dees et al. 2011; Mak and Elwyn 2005; Nilmanat et al. 2015; Nissim et al. 2009; Ohnsorge et al. 2014a, b). The former self was viewed as the authentic (and dignified) self that wished to live, as the true person and as how the patient wished to be remembered. By contrast, the ill self was described by the same patients as useless, as having lost the will to live due, for example, to a diminished quality of life. Allusions to the ill self were thus often made when patients spoke about not wanting to be remembered as someone depleted and dependent on others. Conversely, certain actions, such as deciding to refuse further medical treatment, were seen as ways of maintaining the authentic self in spite of the illness.

Autonomy was at times seen as an aspect of authenticity, since some patients experienced illness as being in opposition to their autonomous (authentic) self and as exerting control over their circumstances. The wish to have some control over the dying process was thus described in terms of preserving the authentic self ["I am in control of this body. This is mine, I will do whatever I want to do with it" (Schroepfer 2006, p S136)], or in terms of dignity ["dignity is that I have control over my body [it is] not a virus that is going to take my life. I'm the one who's going to decide when my life will end, not a virus, and not with great pain" (Lavery et al. 2001, p 365). In this context, some patients spoke of 'granting myself my own death (if things get worse)' as being the last act that a human being can perform in the name of authenticity.

**Assumptions about social interactions**

In relation to what we referred to earlier as 'social death', the way an individual is seen by others plays a crucial role in the construction of his or her identity. In the context of medicalisation there are two issues that are especially relevant in terms of social interactions: the transfer of care and the idea of being a burden on others. When care of the dying was transferred to the hospital setting (such that this is where death occurred) the role of accompanying the dying person passed from relatives or priests to doctors (Ariès 1975; Walter 1994). The end-of-life was thus confined to a medical context, a private, hygienic and technological environment (Walter 1994). For the family, the removal of death from the home meant that they could no longer perform the rites and rituals associated with care of their dying relative. As a result, death not only ceased to be a part of people's domestic experience but also became an object of taboo, an unpleasant thing to be avoided (Gorer 1955). The doctor became the new master of ceremonies of this scenario, controlling the process of dying and administering drugs in order to deprive patients of the experience (Illich 1976; Walter 1994).

The equating of being ill with being a burden on others has become widespread within this context. One of the consequences of medicine being seen as a way of combating death (Callahan 1989) was that the dying process gradually ceased to be seen as part of normal human experience, as a final stage of life through which the person would be accompanied and cared for. The loss of this kind of care narrative, in which accompanying the dying person was seen as a meaningful act, is one of the factors that has led to ill people in the modern age being regarded as a burden.

The impact of interpersonal relations—the importance the individual gives to how others see and value him or her—was evident in many of the statements made by patients who expressed a WTHD, as well as by relatives and healthcare professionals. It is interesting to note that in many cases the WTHD was linked to patients' beliefs about the value judgments of others (i.e., you think that others believe you are a burden to yourself and others, that you're no longer worthy and suffering unbearably) (Coyle and Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Lavery et al. 2001; Mak and Elwyn 2005; Nissim et al. 2009; Ohnsorge et al. 2014a, b, 2012; Pearlman et al. 2005; Schroepfer 2006; Stiel et al. 2010). In fact, of the 122 quotes reported in the studies reviewed, 43 referred to the patient's social context. Of these, 15 made reference to the role of relatives and healthcare professionals in the patient's experience. The remaining 28 quotes, however, referred to patients' assumptions about how others would view them in terms of dignity (personal value) and the value of their life (Coyle and Sculco 2004; Dees et al. 2011; Kelly et al. 2002; Lavery et al. 2001; Mak and Elwyn 2005; Nissim et al. 2009; Ohnsorge et al. 2014a, b, 2012; Pearlman et al. 2005; Schroepfer 2006; Stiel et al. 2010). In other words, the majority of quotes in which the social context was referred to as a factor in the WTHD concerned how patients believed they were seen by others.

Many of these statements had to do with what one might call social dignity. Thus, not wanting to be seen by others as ill and frail, and the wish to preserve or maintain the self in the eyes of others was a common concern among these patients. In addition, the idea that their illness would also affect those around them was linked for some patients to a wish to avoid making others suffer. In such situations the WTHD arose as a way of sparing others from burden, as a form of altruism. This notion of social dignity was also related to the sense of belonging (Lavery et al. 2001). When patients felt excluded from their community or social groups as a result of their illness, this was often experienced as a rupture in their life story. A lost sense of belonging also occurred when patients could no longer fulfil a previous social role that had given meaning to their life. For one patient, the value she assigned to herself had to do with the experience of knowing that she was loved and needed

by those around her (Lavery et al. 2001). She declared that life without love was what was causing her to lose any wish to keep on living.

## Assumptions about the value of life

Many of the statements made by patients alluded to reasons why life was no longer worth living. This attributing of value to life can be considered in terms of the Aristotelian distinction between *zoê* and *bios* (Aristotle 1995). *Zoê* denotes our biological existence, the 'bare life' that is common to us all. In this respect, the loss of control over bodily functions and diminished functional capacity leading to the loss of independence (aspects of *zoê*) was one of the main reasons cited by patients, relatives and even healthcare professionals for why life had lost its value (Coyle and Sculco 2004; Dees et al. 2011; Lavery et al. 2001; Mak and Elwyn 2005; Nilmanat et al. 2015; Nissim et al. 2009; Pearlman et al. 2005; Pestinger et al. 2015).

At times, however, the two views of life, *zoê* and *bios*, were intertwined within a single reality. This was the case, for example, when the suffering (which can be both *zoê* and *bíos*) caused by illness was given as one of the reasons why a patient had lost the will to live. Some patients stated that they would rather die than live with pain and suffering, because for them a life of pain was not worth living. It should be noted that the idea that life is no longer worth living cannot be understood within a purely biologistic framework (*zoê*). On the contrary, such an attribution requires a rational judgment (*bios*).

In Western society, ideas of transcendence or spirituality no longer provide a frame of reference for many people's lives (Taylor 1992), and thus the belief that death is the door to the afterlife and that suffering is God's retribution on this earth has waned. This contrasts with the centuries-old Christian view that man is a creature of God, and therefore is not master of his own life; one only has to think of the social condemnation of suicide or of the sick in medieval times, their final battle being to accept that their fate was in God's hands (Ariès 1975). According to Ariès (1975), the ideal death in the Middle Ages was one that allowed the dying person and those around him to prepare themselves, to become aware of the situation; one should die knowing that death was approaching, and thus a sudden death was viewed as the worst of punishments. This contrasts with what one observes in the statements made by patients in the qualitative studies we reviewed, for whom death was seen as a kind of salvation, as that which would release them from their present suffering (Coyle and Sculco 2004; Lavery et al. 2001; Nilmanat et al. 2015; Nissim et al. 2009; Ohnsorge et al. 2014a; Pearlman et al. 2005). Having lost quality of life they felt that the very value of life had been undermined, which some of them expressed

in terms of a tension between quality of life and quantity of life (Dees et al. 2011). Other patients posed specific questions about the meaning of their suffering, asking, for instance, "why me?", "why [am I] suffering so?", "why [am I] hanging around?" (Coyle and Sculco 2004; Nilmanat et al. 2015; Nissim et al. 2009). For many of them, the WTHD emerged in response to a loss of meaning in life and of the will to live. Only a few patients held a somewhat more positive view of their illness, either as a result of their religious beliefs or because their attitude was one of acceptance (Ohnsorge et al. 2012).

## Discussion

Thus far we have analysed the statements made by patients who expressed a WTHD in relation to different classes of assumptions. In this section we take a more critical look at the different areas of our analytical framework, namely: medicalisation; assumptions related to moral understandings: dignity (including social dignity), autonomy and authenticity; and the value of life.

### Medicalisation

Parens (2013) argues that there are good and bad forms of medicalisation. The present philosophical analysis has mainly considered negative aspects, such as dependence on life support machines, the depersonalisation of death in the hospital context, or the use of drugs that prevent a person from being aware of the end of life. However, the statements made by patients also reveal the positive side of medical intervention, in that it can help to control pain or other symptoms of the illness. Thus, medical technology and integrative care can be combined to improve diagnosis or to develop the best interventions, and this can be done while respecting a person's dignity or authenticity. A related issue here is that some patients related their WTHD to the experience of pain. Therefore, giving them medication to relieve pain or to treat symptoms of depression or other kinds of psychological distress may be one way of addressing the anguish and fear that they regard as triggering their WTHD.

It is also worth noting that many of the quotes (41 of 122) referred to the kind of future that patients imagined awaited them. While in some cases these ideas were influenced by their own past experience or that of a close friend or relative who had gone through something similar, for other patients they were the result of images of death and dying that were present in the cultural context (Pestinger et al. 2015). This highlights how important it is for healthcare professionals to understand the emotional distress (fear, anxiety, uncertainty, hopelessness) experienced by

patients at the end of life, and to provide them with adequate information about their situation. In this respect, medicalisation can play a useful role in challenging some of patients' worst fears about the dying process, and may potentially help them to accept suffering and the final days of life as meaningful. Indeed, rather than being seen as a prelude to death in which the person is stripped of value, the end of life may also be an opportunity to establish deep bonds with loved ones, or to re-evaluate one's own identity in accordance with what the person considers to be important and meaningful.

## Dignity

As we have seen, dignity was commonly experienced as a dynamic and subjective quality that could be undermined by the loss of functional capacity or the perceived loss of self. Interestingly, none of the statements made by patients referred to dignity as an intrinsic aspect of human life, despite the fact that such a definition often features in theoretical discussions of the concept. One might argue, however, that the labelling of certain experiences as undignified rests upon an a priori idea of an intrinsic dignity that has not been respected.

In this context, Taylor (1989), among others, has highlighted the importance of mutual recognition—based on an idea of universal and egalitarian dignity—as a cornerstone of personal identity. In the clinical context, this kind of recognition would entail that a person's dignity is preserved through the care that he or she receives at a time of great vulnerability (i.e., I offer you the care you need because I respect you and recognise you as a person with dignity). This recognition of the patient as a human being (and thus, by definition, as a person with dignity) may go further towards protecting his or her dignity that would a conception of dignity based on those aspects of ourselves which we believe make us worthy (or not) of respect from others (Taylor 1989).

From the clinical perspective, the equating of dignity with autonomy can be linked to the ethical system of principlism, as developed in the Anglo-American context, which argues that autonomy is the pillar on which bioethical guidelines are founded. However, a slightly different view is present within European bioethics, which highlights the centrality of dignity and argues that it cannot be reduced to the concept of autonomy (Rendtorff 2002). For instance, the final project report on *Basic Ethical Principles in European Bioethics and Biolaw* identified dignity—alongside autonomy, integrity and vulnerability—as a framework for protecting the person from dehumanising technological developments. After examining and discussing the meaning of the concept, the report defined dignity as "a quality of the person as such. It now refers to both

the intrinsic value of the individual and the intersubjective value of every human being in its encounter with the other. […] Dignity concerns both oneself and the other: I must behave with dignity, and I must consider the dignity of the other" (Kemp and Rendtorff 2008, p 240). This definition could be used to guide both practice and policy in the end-of-life context, where the aim would be to ensure that advanced patients continue to be treated as human beings with inherent value. From a legal perspective it may be difficult to agree on what the implications of the notion of intrinsic dignity are [one has only to think of the vague definition of this concept that appears in the Universal Declaration of Human Rights (United Nations General Assembly 1948)], but recognising the other as a dignified human being is nonetheless a prerequisite for respecting the person in his or her entirety, especially when that person is rendered vulnerable by advanced disease.

The privatisation of death in modern society can mean that it becomes an anonymous event happening to an uninformed individual (the patient) who has no control over his or her final days. Dying in hospital may thus deprive the person of the respect and dignity that he or she deserves. The title of a recent research paper is revealing in this respect: 'Do the circumstances allow for a dignified death?' (Jors et al. 2014). As we have seen in some of the patient quotes, the immediate environment of persons facing the end of life does not always leave them feeling valued or cared for, and thus we could say that the circumstances do influence a person's sense of dignity. This suggests that considering the impact which aspects of the environment (treatment by doctors and nurses, respect for privacy, etc.) can have on a person's sense of dignity is important not only for developing personalised care plans, but also for ensuring that the training received by health professionals equips them to recognise the dignity inherent to each individual. However, the ability of patients themselves to recognise that dignity is a quality they possess simply by being human can also help them to maintain a sense of personal dignity despite their illness (Rodríguez-Prat et al. 2016). Ultimately, it is not the circumstances that determine a 'dignified death', but rather the person who, through his or her values and beliefs, attributes value and meaning to life and to the self.

An alternative to hospitalised death can, of course, be found in the hospice movement, whose philosophy is to offer compassionate and holistic care (from pain management to emotional and spiritual support) to people facing a life-limiting illness. In our systematic review of qualitative studies on the WTHD the samples of patients were drawn from a variety of settings (in- and outpatient palliative care units, hospices, large cancer centres and nursing homes). However, we were unable in that review to determine the possible influence of the setting on patients' experience,

as this would require a more detailed analysis of primary study data.

## Autonomy

A narrative of self-determination could often be observed among those patients who, faced with the end of life, expressed a strong desire to take control of their circumstances and the process of their illness. For these individuals, losing control over their life and seeing the illness affect their functional and cognitive ability, undermining their ability to make decisions and to live as they would wish, was itself experienced as a form of suffering, as ceasing to be themselves. In situations such as these it can be important for health professionals to draw attention to the idea of intrinsic dignity, as this may help patients to hold on to something that goes beyond their identification with the ill self, with the person who has lost the most profound and authentic aspects of his or her identity.

A further point has to do with what might be called a culture of emancipation focused on individual experience and the rights of patients, as from this perspective the WTHD might perhaps be understood as an expression of individual liberty that occurs against a background of medicalisation. Based on our analysis, and in agreement with van Wijngaarden et al. (2016), we would argue that this culture of the individual with a strong desire for self-determination could also be seen as a reaction against medicalisation. In other words, the fact that medicalisation places advanced patients in a situation that they may experience as dehumanising, due to their dependence on life-support machines, drugs and medical professionals, etc., may provoke in these patients a strong desire for autonomy, for the ability to decide how they will see out their final days.

## Authenticity

Our analysis of patient statements indicated that being authentic was equated with being independent and capable of making decisions in keeping with one's life to date. Through what we referred to earlier as a 'split identity', patients seek to hold on to the healthy and autonomous self, the person they were before illness struck. However, reducing authenticity to autonomy may evoke an illusory image of the human being as invulnerable, as someone who should not be ill. Whatever the case, the roots of this romantic idea of authenticity can be found in contemporary narratives about constructing the self, where self-exploration, individual choice and control are seen as the basis for a valid identity (Ferrara 1998; Taylor 1992, 1989). From this perspective, the criterion for moral behaviour becomes decision making by a self-possessed and bounded individual who is capable of constructing his or her own character

(Taylor 1989). Bearing in mind the progressive deterioration that characterises the end of life for advanced patients, a return to the idea of death as part of life, to the image of a vulnerable human being, may help patients achieve some form of acceptance during their final days.

Although, on a theoretical level, this view of authenticity may appear to be important and to have its echo in the medical decision-making process, it is not clear to what extent the concept is useful from the perspective of liberal philosophy. One of the reasons for this is that decision making is often governed by economic criteria that reduce the scope of choice to the social and economic value that is attributed to the person (notably less for the ill and older people), thus setting the bounds within which he or she may choose. From an ethical point of view, and linking the issue of authenticity to the idea of burden or 'social death', it is, as Rehmann-Sutter (2015) point out, "problematic if society (or a family) is structured in such a way that those who are no longer useful start feeling they are nothing but a burden. This is ethically problematic because it does not treat these people as beings with inherent moral worth" (Rehmann-Sutter 2015, p 169). Social death in the context of illness has to do with this (dis)attribution of the value of life and of the person. For some of the patients interviewed, being ill was synonymous with being useless (Mak and Elwyn 2005; Schroepfer 2006), and here again, one sees how what we take to be the basis of personal dignity can have numerous implications. If who you are, what you're worth or the foundation of your dignity are decided by society, then it is easy, for example, to be reduced to your economic value. In fact, being an economic burden on the family was mentioned by some patients as a reason for their WTHD (Mak and Elwyn 2005). At all events, this kind of financial pressure will be most strongly felt in those countries where health care is not adequately funded or insured.

A further point to note is that medical discourse has been associated with bureaucratic procedures whose impact on the patient can be to heighten the sense of loss (Walter 1994). Viewing authenticity in terms of decision making (i.e., deciding within the limits of what is possible) rather than choice making (i.e., the desire for unlimited self-determination) might help patients to focus on who they are still able to be and what they are still able to do. There is clearly a tension here between the imposition of economic criteria, the expropriation of health and the idea of authenticity as something not subject to extrinsic rules, which ultimately renders it an empty concept.

## Value of life

A topic of recent debate in the clinical context has been whether 'meaning in life' may serve a protective role (psychologically) in patients with advanced disease, and

there is evidence to suggest that those individuals who express a WTHD experience a loss of meaning in life (Monforte-Royo et al. 2011). In our analysis of patient statements we observed that a loss of life's value or meaning was the result of suffering for which there was no hope of a cure. It was also linked to a sense of diminished autonomy and control.

A recent systematic review of meaning-in-life interventions in the palliative care context concluded that patients can benefit from being given a space in which to reflect on areas or aspects that bring meaning to their life (Guerrero-Torrelles et al. 2017). We have seen in the present analysis that the value or meaning of life can be undermined when symptoms are not adequately managed (e.g., when a patient is in pain). This suggests that once the physical and psychological/emotional factors associated with a WTHD have been identified, interventions that can help patients rediscover a sense of dignity, of their own worth as a person, including in the eyes of others, may help them to live out their illness as a process of personal growth and a part of life.

## Conclusions

Medicalisation appears to impact on the experience of patients who express a WTHD and to influence the way in which they conceive of their suffering, the end-of-life process and death. In a context characterised by suffering of this kind it is important that health professionals are able to understand patients' assumptions and moral understandings about their situation so as to respond adequately to their needs and help them, as far as possible, to recover some of the social and intrinsic dignity they feel they have lost. An idea of authenticity based on decision making or self-agency may help to define a space in which advanced patients retain some room for manoeuvre, enabling them to experience their final days as a meaningful period of life.

**Compliance with ethical standards**

**Competing interests** The authors declare no competing interests.

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