

Review Article

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Autonomy and control in the wish to die in terminally ill patients: A systematic integrative review

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Abstract

Background/Objective. Personal autonomy and control are major concepts for people with life-limiting conditions. Patients who express a wish to die (WTD) are often thought of wanting it because of loss of autonomy or control. The research conducted so far has not focused on personal beliefs and perspectives; and little is known about patients' understanding of autonomy and control in this context. The aim of this review was to analyze what role autonomy and control may play in relation to the WTD expressed by people with life-limiting conditions.

Methods. A systematic integrative review was conducted. The search strategy used MeSH terms in combination with free-text searching of the EBSCO Discovery Service (which provides access to multiple academic library literature databases, including PubMed and CINAHL), as well as the large PsycINFO, Scopus, and Web of Science library literature databases from their inception until February 2019. The search was updated to January 2021.

Results. After the screening process, 85 full texts were included for the final analysis. Twenty-seven studies, recording the experiences of 1,824 participants, were identified. The studies were conducted in Australia ($n = 5$), Canada ($n = 5$), USA ($n = 5$), The Netherlands ($n = 3$), Spain ($n = 2$), Sweden ($n = 2$), Switzerland ($n = 2$), Finland ($n = 1$), Germany ($n = 1$), and the UK ($n = 1$). Three themes were identified: (1) the presence of autonomy for the WTD, (2) the different ways in which autonomy is conceptualized, and (3) the socio-cultural context of research participants.

Significance of results. Despite the importance given to the concept of autonomy in the WTD discourse, only a few empirical studies have focused on personal interests. Comprehending the context is crucial because personal understandings of autonomy are shaped by socio-cultural-ethical backgrounds and these impact personal WTD attitudes.

Introduction

Autonomy and control are key arguments put forward by people who favor the legalization of euthanasia and assisted suicide (EAS) (Quill and Battin, 2004; Van Brussel, 2014) and one of the greatest causes of multidimensional end-of-life suffering (Monforte-Royo et al., 2012; Ohnsorge et al., 2014a). Although the notions of autonomy and control undoubtedly feature in clinical, (bio)ethical, and sociological research on the issue of the right to die (McCormick and Conley, 1995; Bakitas, 2005; Rodríguez-Prat et al., 2016), there are two concerns that hinder a more detailed understanding of these notions.

The first is the lack of clear distinction between similar terms. On the one hand, terms such as control, autonomy, or self-determination are often treated as synonyms, even though they are not equivalent concepts (Lavoie et al., 2011; Monforte-Royo et al., 2018). The first has to do with dependency from care, with loss of body functions, and a loss of control of the situation, whereas the second meaning of autonomy and self-determination is on the level of philosophical anthropology.

On the other hand, many studies do not distinguish between a wish to die (WTD), a wish to have death hastened, and requests for EAS (Tolle et al., 2004; Ganzini et al., 2006). This lack of precision in the terms used to refer to distinct concepts can lead to simplifications. A person who expresses a desire to die (DD) (without undertaking actions that lead to it) because of a loss of physical functioning or loss of bodily control does not necessarily share the same motivations as someone who requests EAS because he/she wishes to die on his/her own terms or because they have a desire for self-determination.

The second concern is that it is often unclear whether the conclusions drawn from studies about autonomy are derived from the experiences of dying people (Monforte-Royo et al., 2011; Ohnsorge et al., 2014a). At times, the conclusions are based on the views of healthcare

professionals (Kelner, 1993; Peretti-Watel et al., 2003; Seale, 2009; Goel et al., 2014), or the perspectives of family members or the general public (Chambaere. et al., 2012; Inthorn et al., 2015). It is difficult to know to what extent the autonomy argument emerges from dying people themselves, as opposed to healthcare professionals and the members of the general public.

Published data from places where EAS has been legalized, such as Belgium, The Netherlands, and Oregon, confirm that some individuals who have obtained EAS permission, subsequently, revoke their decision or die instead of causes other than EAS (Public Health Division, 2020). The aim of this review was to analyze what role autonomy and control play in relation to the WTD expressed by people with life-limiting conditions.

Methods

This systematic review was conducted in February 2019 through January 2021 in accordance with PRISMA guidelines (Moher et al., 2009). The search strategy combined MeSH terms with free-text searching (see Table 1). This strategy was applied to the EBSCO Discovery Service, as well as the large PsycINFO, Scopus, and Web of Science databases. No limits were placed on publication years.

All articles for review were selected by applying these inclusion criteria: (1) primary studies examining the perspective of terminally ill people in the context of a request or WTD, (2) primary studies looking at personal autonomy, empowerment, self-efficacy, or locus of control (acknowledging that different terms are used to refer to the concept of autonomy or control), (3) written in English, and (4) published in peer-review journals. Studies only involving healthcare professionals, relatives, caregivers, or pediatric terminally ill persons were excluded. After these criteria were applied, the reference list of each retained research article was reviewed in order to identify any additional articles that were potentially relevant to the review. Disagreements regarding the inclusion or exclusion of articles were discussed among the authors. Figure 1 shows a flowchart of the article selection process.

We extracted and synthesized the data using the integrative method (Whittemore and Knafl, 2005), a method that permits the synthesis of diverse data methodologies. We designed a matrix to extract the main characteristics of each article following the data analysis process proposed by Whittemore and Knafl (2005): data reduction, display and comparison, and conclusion drawing. Because the analysis involved the integration of quantitative and qualitative findings, we used a data-based convergent synthesis design, so that in presenting the results, we highlight the complementarity of the data and findings that these designs yield (Hong et al., 2017).

The studies included were evaluated using the CASP guidelines for qualitative research (1999) (Supplementary Table S1) and the STROBE guidelines for quantitative research (von Elm et al., 2014) (Supplementary Table S2). None of the reports were excluded for any reasons of quality (Dixon-Woods et al., 2007).

Results

Twenty-seven studies were included in this review. After analyzing the extracted data, three themes emerged: (1) the type of research and aims of the studies undertaken, (2) the presence of the concept of autonomy or control in studies about the DD, and (3) the different ways in which autonomy or control are

Table 1. Search strategy

1	exp personal autonomy/
2	((((autonomy or self determination or empower* or self-efficacy or locus of control or prefer*) adj3 patient*) or patient* control*).mp.
3	(patient* adj3 decision*).mp.
4	1 or 2 or 3
5	exp assisted suicide/
6	(euthanasia or assisted suicide or ((death or die) adj2 (wish* or desire* or hasten*))).mp.
7	5 or 6
8	4 and 7
9	exp terminal disease/
10	exp terminally ill patient/
11	(terminal* ill* or terminal* disease* or end of life or dying).mp.
12	9 or 10 or 11
13	8 and 12
14	limit 13 to conference abstract
15	13 not 14
16	8 and 13 and 15

Significance of bold values represents final strategy.

conceptualized (taxonomy). The following is a discussion of these three aspects.

Descriptive analysis

We identified research articles that to some extent focused on patient autonomy or control in relation to EAS requests or expressed DD among terminally ill persons. Supplementary Table S3 lists the studies included and indicates the authors, year of publication, country in which the study was conducted, research design, study population and objectives, and findings regarding personal autonomy, empowerment, self-efficacy, or locus of control.

The studies were focused on (1) identifying the reasons for the DD and analyzing the factors (sociodemographic and clinical) related to this desire, (2) identifying the reasons for requesting EAS and/or demedicalized assistance in dying or suicide and analyzing the factors (sociodemographic and clinical) related to this request, (3) exploring the nature and impact of suffering, (4) exploring the decision-making process among persons who requested demedicalized assistance in suicide, (5) exploring what people with advanced cancer want in relation to personal control, and (6) exploring the reactions of terminally ill persons in relation to existential issues.

The studies were conducted in Australia ($n = 5$), Canada ($n = 5$), USA ($n = 5$), The Netherlands ($n = 3$), Spain ($n = 2$), Sweden ($n = 2$), Switzerland ($n = 2$), Finland ($n = 1$), Germany ($n = 1$), and the UK ($n = 1$). Twelve studies used qualitative research methods, while 4 involved mixed methods and 10 were quantitative in design.

When the subjects/participants were considered, 16 studies were focused on specific populations, primarily people dying of cancer ($n = 14$), HIV ($n = 1$), or ALS ($n = 1$). The remaining studies included people with a number of diagnoses such as cancer, AIDS, neurological disease, psychiatric disorders, cardiorespiratory disease, and renal failure.

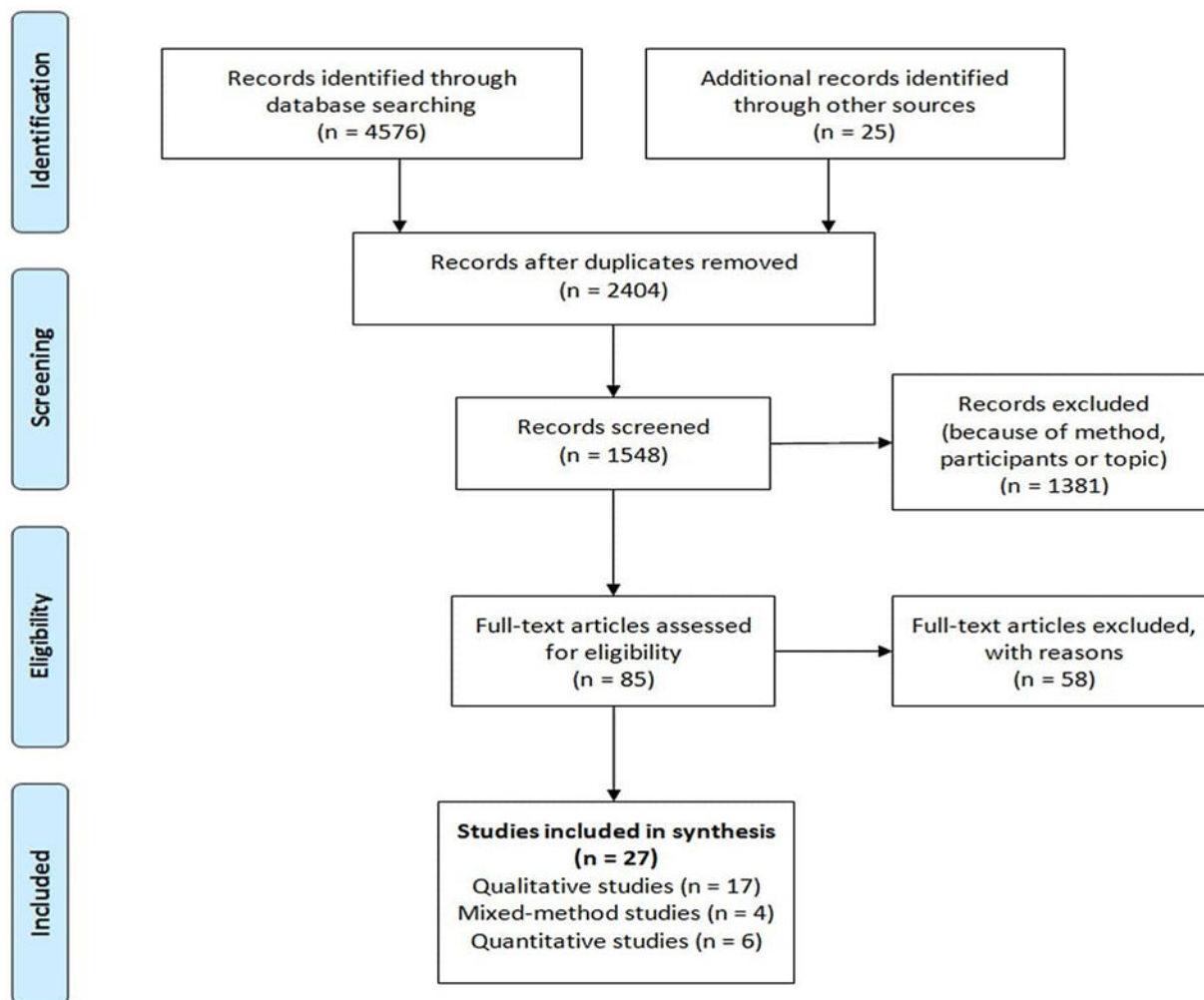


Fig. 1. PRISMA flow diagram for study selection.

Presence of the concept of autonomy or control in studies about the DD

The analysis reveals that the data regarding the DD came from only a small number of participants in each study. In the study by Chochinov et al. (1995), two participants (out of 200) reported a strong DD (but without the intention to pursue a hastened death). Among the reasons stated by them for desiring to die, one of these two persons alluded to a loss of control due to the loss of physical function. Another illustration is the study by Albert et al. (2005), who compared ALS patients who expressed a DD but did not act on it with ones who did hasten their death. Their analysis showed that perceived control over the management of ALS increased in only three patients (out of 80) who pursued a hastened death.

Among the participants in the study by Wilson et al. (2007) who were in favor of legalizing EAS ($n = 238$), the main reason stated was the right to choose ($n = 93$). However, only 22 people alluded to control as a factor in support of EAS legalization. When the authors analyzed the DD, they identified 357 individuals without a current interest in a hastened death, of whom 21 stated that loss of control was a concern to them. Of the 22 people with a current interest in a hastened death, only 5 were concerned about loss of control. Similarly, Güell et al. (2015) found, when

comparing participants who had expressed a DD with those who had requested euthanasia, that the only item on which the two groups differed significantly was “retaining autonomy to choose how and when to die/I will die,” a finding endorsed by a higher percentage of those who had requested euthanasia [33% (3 patients) vs. 4% of those who had merely expressed a DD].

Also relevant here are studies that gathered personal opinions about EAS (Wilson et al., 2007). In some cases, research participants were in favor of legalizing EAS, even though they themselves were not personally interested in such an option at the present time. In the study conducted by Wilson et al. (2007), 36 participants (9.5%) reported that they would request for EAS at some point of their course of their disease, and 151 (39.8%) affirmed that it could be an option for the future but not at the moment of the interview. In the same vein, in the study conducted by Volker et al. (2004), only one participant made reference to assisted suicide in relation to control over the dying process. In this case, the patient was against the idea of taking his own life.

Other terminally ill persons employed the notion of autonomy in arguing against EAS (from 9% to 34% of participants in the studies included in this review). The possibility of healthcare professionals assisting someone to die was seen by these participants

as a loss of autonomy, in contrast to the alternate view that EAS increased patient autonomy (Karlsson et al., 2012). Accordingly, the eventual legalization of euthanasia was seen by one research team as increasing the power of the healthcare system rather than the autonomy of patients (Karlsson et al., 2012). Although the majority of participants who argued against EAS did so on religious grounds [“in the end it is in the hand of God” (Ohnsorge et al., 2014a, p. 7)], some made reference to secular or moral values (humanism and philanthropy) or to the need of considering the impact of this decision among the family members: “I don’t think it’s something we have a right over. . . life is given and life is taken away but it’s not ours to decide” (Kelly et al., 2002). On euthanasia, “It’s not a unilateral decision, because it’s also got to do with the people around you” (Karlsson et al., 2012). Another common argument put forward against the legalization of EAS was that humans have no right to decide the time of their death (Wilson et al., 2007; Karlsson et al., 2012).

Taxonomy

The 27 studies reviewed used a variety of terms to refer to similar but distinct concepts: loss of functionality, loss of control, locus of control, self-efficacy, agency, self-determination, and right to choose. Based on the definitions used by study authors and participants, it is possible to propose a taxonomy of the notion of autonomy in the context of a DD (see Supplementary Table S4).

Loss of functionality

In nine of the studies, the DD or interest in EAS was related to a loss of functioning (present or in a hypothetical future). This loss of physical mobility or the impossibility of performing activities of daily living was often alluded to as a consequence of advanced disease (Pearlman et al., 2005; Ohnsorge et al., 2014a). Loss of functionality was described as a factor that leads to loss of control over the body and the living or life situation, and as a trigger then for perceived loss of dignity and loss of the self (Lavery et al., 2001; Pearlman et al., 2005). It was also linked to dependency and a lost ability to participate in meaningful activities (Ohnsorge et al., 2014a).

Loss of internal control

The loss of internal or psychological control was the most common theme in the studies reviewed. This internal control, as emphasized in the primary studies, referred to the different functions of the WTD. The WTD has an internal emotional effect that helps patients to deal with their situation (Albert et al., 2005; Ohnsorge et al., 2014a). As long as the participants expressed this WTD, they felt that they had some control over the course of their illness and their life. In this sense, expressing a wish to hasten death and stating that one wants to take control of the situation was a coping strategy because it enabled them to feel “in control” of their destiny (Albert et al., 2005; Ohnsorge et al., 2014a).

The loss of internal control can be understood from the idea of meanings of the WTD: what the person wishes to express through this communicative act (Kuuppelomäki, 2000; Wilson et al., 2007; Karlsson et al., 2012). The different meanings of a wish to hasten death emerged from the original studies in relation to autonomy were: “wish for control over the situation,” “desire for control over when and how to die,” “last control,” and “the if-then scenario.”

These themes were considered inseparable from maintaining this internal emotional effect (psychological control).

The wish for control over the situation (when they might die or over the illness or disease itself) was a common explanation for the expression of a WTD (Coyle and Sculco, 2004; Dees et al., 2013). For some persons, the fact that they could exert some control relieved their suffering or anxiety about dying (Coyle and Sculco, 2004; Albert et al., 2005).

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 [...]. 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, p. 8)

However, for people in countries where pursuing a hastened death had been legalized, the idea of choosing where and when to die was not merely a coping strategy but also a potential reality, as shown by one participant from The Netherlands:

When I became ill, I was afraid that I would get brain metastases. I guess I just want to have everything arranged properly for the GP, the family, and myself. I became a member of the euthanasia society and gave my GP an euthanasia directive. (Dees et al., 2013)

Another frequent meaning of the WTD is what is referred to as the “if-then scenario.” In this case, the patient does not currently express an interest in hastening death but contemplates a hypothetical future in which his/her situation becomes unbearable. This notion of “if-then” is described by some authors as having a “safety net” and this brought relief to them (Coyle and Sculco, 2004; Nissim et al., 2009; Ohnsorge et al., 2014a, 2014b): “If I had to go through [an episode of acute shortness of breath] again, I would throw myself in front of a subway train. I am not going through that again” (Coyle and Sculco, 2004).

In some studies, the DD was conceived as a form of self-determination (control over one’s own life) (Lavery et al., 2001; Coyle and Sculco, 2004; Pearlman et al., 2005; Ohnsorge et al., 2014a, 2019). The results of 12 studies that included persons who expressed a current WTD show that the main justification they gave for this wish was the right to have control over how they died. A common argument was that they wanted to choose how and when they died, and in this respect, the possibility of requesting EAS was seen as the final control they could exert: “You must be allowed to decide for yourself whether you want to live or not” (Karlsson et al., 2012).

In the study by Pestinger et al. (2015), illness was described using the metaphor of chaos, the antithesis of absolute control. The possibility of taking action and of exerting control over the illness process was identified as a form of freedom and self-determination.

Discussion

This review of 27 research articles provides information about the role that autonomy may play in relation to the DD and the wish for EAS. Our analysis focused on three aspects: (1) a detailed exploration of the sociodemographic data emerged from the descriptive analysis, (2) the analysis of the presence of the concept of autonomy and control in studies about the DD, and (3) the lexical exploration of the terms used in the literature to refer to the

concepts regarding autonomy, control, and self-determination (taxonomy). In what follows, we discuss the context in which studies were conducted, and the characteristics of participants and the taxonomy used in the studies. We also discuss the ethical implications arisen from the studies included.

Context in which studies were conducted and the characteristics of participants

First of all, we analyzed the descriptive aspects of the included studies. Analyzing the background of the settings of these studies is advised as a way to better understand what the importance of the value of autonomy in this context is, and how autonomy can articulate the expression of the DD.

From a sociocultural point of view, the fact that all 27 studies were carried out in developed countries (although only English language articles were assessed) is consistent with the importance that these advanced high-income societies ascribe, at least theoretically, to autonomy (Rodríguez-Prat and van Leeuwen, 2017). A meta-ethnography on the wish to hasten death identified 14 qualitative studies examining this phenomenon from the perspective of patients (Rodríguez-Prat et al., 2017). Only 2 of these 14 studies were conducted in non-Western countries [China (Mak and Elwyn, 2005) and Thailand (Nilmanat et al., 2015)], and in neither of them did the theme of autonomy emerge as an explanation for this wish. Other studies in which participants from other cultural traditions were asked for their opinion on the right to die likewise confirmed not only the absence of arguments in favor of death and dying self-determination but also a rejection of the possibility of choosing how and when one dies (Johansen et al., 2005). However, in the Western context, other early studies have explored views, opinions, perceptions, attitudes, and experiences in relation to EAS or the DD, and apparently without finding a relationship to the desire for autonomy or personal control (Johansen et al., 2005).

Studies conducted in countries characterized by different cultural paradigms reveal a view of autonomy that differs from the traditional liberal model (Rodríguez-Prat et al., 2017). In the study by Ho et al. (2013), carried out in China, reference is made to a more relational autonomy, in which the wider social context such as the family is important for healthcare decision-making. As is evident from the studies included in this review, moral understanding plays a key role in the expression and execution of a DD. The notion of moral understandings has been defined as the network of judgments, beliefs, expectations, and values that articulate our identity, the way we interrelate to other people, and the basis from which we understand the world (Walker, 2007). In this sense, what patients understand about dignity, meaning of life, or autonomy shape their attitude towards their end-of-life situation. Among participants with a current interest in pursuing a hastened death, the main reason cited was the right to choose and the right to exercise control over how they would die (Wilson et al., 2007). Thus, it would not be surprising that the argument in favor of choosing how and when one dies is more present in countries where EAS has been legalized than in countries where it has not been legalized.

The description of the individuals who are interested in EAS might be understood to reflect a Western discourse, with this being less religious or spiritual, less likely to tolerate suffering, hold assumptions regarding the circumstances under which life is no longer dignified, have little/less support from others in the immediate environment, and have a tendency to regard autonomy as a supreme value defined in terms of individual decision-making and rights (Hagens et al., 2016; Rodríguez-Prat et al., 2017).

Taxonomy

The analysis of the terms used in relation to autonomy and the DD deepen into the different dimensions that autonomy can have from the participants' expressions and experiences.

From our analysis, we can distinguish three levels in relation to the loss of autonomy (Monforte-Royo et al., 2018): loss of physical functioning (normally understood as loss of control), loss of internal control (locus of control or self-efficacy), and loss of control over one's own life (autonomy, self-determination, or self-agency), all of which are linked to the idea of the right to decide how and when to die.

Although the loss of physical functioning is not in itself a predictor of the DD, it is important to consider its potential impact in terms of depression (Monforte-Royo et al., 2018), demoralization (Breitbart et al., 2000), or a perceived loss of dignity (Kissane et al., 2001), all of which may be key variables in the emergence of such a desire to end one's life.

In the cross-sectional studies we reviewed, the idea of internal or psychological control was also illustrated in the instruments used, notably the Locus of Control Scale and General Self-Efficacy Scale. These scales were the only validated instruments used as a proxy for control. Although there are differences between the two concepts (locus of control and self-efficacy), both have been used to explain the extent to which an individual — through beliefs, expectations, and behaviors — feels and takes responsibility for what happens in life and for the goals that he/she achieves (Schwarzer, 1992). Thus, although these two instruments do not assess the different levels of autonomy, they may help to identify those patients who are more likely to want to exert control over the end-of-life process. It should be noted, however, that while some studies have shown a relationship between locus of control and the WTD (Robinson et al., 2017), the two reviewed studies authored by Owen et al. (1992, 1994) found no significant correlations in this respect.

The reviewed study by Robinson et al. (2017) also refers to the notion of control (specifically, the extent to which the individual feels in control of his or her life), although the authors only used one item for data gained from a general scale measuring the quality of life in their study. While it is difficult to draw an exact parallel between these notions of control (especially referring to the ideas of self-efficacy and internal/external locus of control) and the possible meanings and functions of the WTD, some of the quotations from interviewed research participants that were featured in the qualitative studies we included (specifically those referring to the use of internal strategies by patients) suggest that there are similarities: "I will do things my way [...]. Nobody is going to talk me in or out of a damn thing [...] I will always be in control" (Pearlman et al., 2005). From this quotation, even if it is not explicitly mentioned by the participant neither by the authors, we can identify an individual with high self-efficacy due to his self-confidence in mastering the situation.

Ethical implications

From the ethical perspective, many different considerations arise from this review's findings on autonomy. Autonomy is differently approached from principlist bioethics or from relational autonomy positions. Principlist bioethics, consistent with its philosophical liberal roots, which consider freedom and autonomy the main value, places respect for individual autonomy as the main of all

four principles of bioethics. Autonomy then becomes the criteria of interpretation of the remaining three — non-maleficence, beneficence, and justice. Therefore, requests from people capable of rational — autonomous — decisions are to be granted. The good of the patient, the patient's empowerment, or respect for the patient is interpreted from this perspective (Cavalieri, 2001; Dees *et al.*, 2013; Weinberger *et al.*, 2014).

Relational autonomy-based ethics criticizes the atomistic consideration of the individual that underlies the former approach as unrealistic (Gómez-Virseda *et al.*, 2019). This introduces the discussion on to what extent totally autonomous decisions are possible (Branigan, 2015; Allan and Allan, 2020). Relational autonomy points at the fact that human life is socially embedded (van Wijngaarden *et al.*, 2016, 2018), and that decisions of life and death are not indifferent for society, starting for the immediate circle of interpersonal relationships that is the family (Gudat *et al.*, 2019). At the core of the discussion is the dialogue autonomy–heteronomy that is proposed in this stream. Keeping this in mind, varied research avenues are open regarding the relevance of autonomy in the WTD: some of them belonging to the fundamentals of ethics (the notions of vulnerability, dignity, autonomy, and right), the characteristics of the WTD, the practice of care (the contents and scope of the duty of the health professional, different types of intervention, and their ethical analysis), and society and politics (laws regarding the end of life or the social consideration of sickness, death, and dependence).

The studies reviewed in this paper reveal the need to address any WTD and even the possibility of an expressed WTD as a requirement to design strategies to prevent this wish from being an option or necessity. This first indicates a major need for appropriate pain management to reduce occurrences of WTD. Improved management of emotional or psychological distress (depression and anxiety) is another major necessity (Johansen *et al.*, 2005; Nissim *et al.*, 2009). In keeping with this requirement, the idea that proper palliative care, which would address physical and psychological symptoms and eliminate the WTD, is widespread. Putting aside those who find EAS the best solution given that not all can access good palliative care (Huxtable and Mullock, 2015; Allan and Allan, 2020), the palliative care argument has been challenged by a particular type of patients who are not in pain or psychologically disturbed and nevertheless DD (Chapple *et al.*, 2006; Allan and Allan, 2020).

Finally, autonomy (along with compassion) has been historically the main reason for the legalization of EAS. However, the lack of a clear distinction between WTD and requests for EAS can have serious consequences (Johansen *et al.*, 2005). In fact, cases of the application of euthanasia without consent are documented in countries, where euthanasia is not legal (Asch, 1996; Pennec *et al.*, 2012; Trankle, 2014). Where EAS is legal, the struggle to prevent hastened or involuntary euthanasia and noncompliance with other protocols, such as reporting all cases, is an ongoing issue. Defective compliance with such guidelines has been proved in some cases in The Netherlands (Muller *et al.*, 1994; Jochemsen and Keown, 1999; Wolf, 2005). Abuse of deep sedation is another concern at times in this country (Hasselaar *et al.*, 2007) and also in Belgium (Robijn *et al.*, 2016). These concerns are evidence of a widespread perception of autonomy that stigmatizes vulnerability and dependence as less dignified, and so physicians feel responsible and bound to act accordingly. We agree with van Wijngaarden *et al.* (2016, 2018) that reflection and subsequent adoption of measures to reduce EAS and WTD at different levels that result in a more accepting, caring, hopeful, and inclusive society is required.

Limitations

One of the limitations of this review is that the studies included had different objectives and used samples with different characteristics. Another issue is that the majority of qualitative studies do not refer to or discuss the frequency with which the identified themes emerged (Sandelowski *et al.*, 2007). For example, the study by Bolmsjö (2000) reports a relationship between autonomy and suicidal ideation, but it is not made clear how many participants shared this experience (only one quotation supports this statement).

Finally, none of the primary studies included discuss notions such as relational autonomy or similar concepts. The insistence on autonomy as the core value behind EAS may generate a series of pejorative narratives around dependency, and this is not likely to reflect the inherently vulnerability of human beings.

Implications for clinical practice and future research

Regardless of the finding that autonomy or personal control may not be the main explanatory or only factor behind EAS or the WTD, perceived loss of control has been strongly correlated with anxiety, stress, and depression (Monforte-Royo *et al.*, 2018). This suggests that identifying areas over which terminally ill persons may wish to exert control (what they eat and where they live or die) is important.

Conclusion

This review reveals the variegated nature of the concept of autonomy and control and the requirement for careful conceptual distinctions of these terms. To date, the concept of “terminal illness” seems to be associated with cancer and only a few other conditions. Regardless, this review shows that autonomy is not the only reason behind the WTD or EAS, as it interacts with other considerations for each individual. Although autonomy is clearly a predominant value in Western societies, sociocultural differences were detected in the research conducted to date. In closing, the work presented here includes an analysis of the main ethical implications that appear — often implicitly — in the articles reviewed and we propose avenues of intervention and further research on a topic that is far from being exhausted.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S1478951521000985>.

Conflict of interest. There are no conflicts of interest.

References

- Albert SM, Rabkin JG, Del Bene ML, *et al.* (2005) Wish to die in end-stage ALS. *Neurology* 65(1), 68–74.
- Allan A and Allan MM (2020) Ethical issues when working with terminally ill people who desire to hasten the ends of their lives: A western perspective. *Ethics and Behavior* 30(1). doi:10.1080/10508422.2019.1592683
- Asch DA (1996) Issues at the end of life... The role of critical care nurses in euthanasia and assisted suicide. *New England Journal of Medicine Orthopaedic Nursing* 15(4), 37–41.
- Bakitas MA (2005) Self-determination: Analysis of the concept and implications for research in palliative care. *Canadian Journal of Nursing Research* 37(2), 22–49.
- Bolmsjö I (2000) Existential issues in palliative care-interviews with cancer patients. *Journal of Palliative Care* 16(2), 20.

- Branigan M** (2015) Desire for hastened death: Exploring the emotions and the ethics. *Current Opinion in Supportive and Palliative Care* **9**(1), 64–71. doi:10.1097/SPC.000000000000109
- Breitbart W, Rosenfeld B, Pessin H, et al.** (2000) Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *Journal of the American Medical Association* **284**(22), 2907–2911. doi:10.1001/jama.284.22.2907
- CASP** (1999) *Critical Appraisal Skills Programme. Ten Questions to Help You make Sense of Qualitative Research*. Oxford. Available at: http://media.wix.com/ugd/dded87_951541699e9edc71ce66c9bac4734c69.pdf
- Cavaliere TA** (2001) Ethical issues at the end of life. *Journal of the American Osteopathic Association* **101**(10), 616–622. doi:10.5840/asce19981825
- Chambaere K, Rietjens JA, Smets T, et al.** (2012) Age-based disparities in end-of-life decisions in Belgium: A population-based death certificate survey. *BMC Public Health* **12**, 447.
- Chapple A, Ziebland S and McPherson A** (2006) What people close to death say about euthanasia and assisted suicide: A qualitative study. *Journal of Medical Ethics* **32**(12), 706–710. doi:10.1136/jme.2006.015883
- Chochinov HM, Wilson KG, Enns M, et al.** (1995) Desire for death in the terminally ill. *American Journal of Psychiatry* **152**, 1185–1191.
- Coyle N and Sculco L** (2004) Expressed desire for hastened death in seven patients living with advanced cancer: A phenomenologic inquiry. *Oncology Nursing Forum* **31**(4), 699–709.
- Dees MK, Vernooij-Dassen MJ, Dekkers WJ, et al.** (2013) Perspectives of decision-making in requests for euthanasia: A qualitative research among patients, relatives and treating physicians in the Netherlands. *Palliative Medicine* **27**(1), 27–37. doi:10.1177/0269216312463259
- Dixon-Woods M, Sutton A, Shaw R, et al.** (2007) Appraising qualitative research for inclusion in systematic reviews: A quantitative and qualitative comparison of three methods. *Journal of Health Service Research & Policy* **12**(1), 42–47.
- Ganzini L, Beer TM and Brouns MC** (2006) Views on physician-assisted suicide among family members of Oregon cancer patients. *Journal of Pain and Symptom Management* **32**(3), 230–236. doi:10.1016/j.jpainsymman.2006.04.004
- Goel A, Chhabra G, Weijma R, et al.** (2014) End-of-life care attitudes, values, and practices among health care workers. *American Journal of Hospice & Palliative Medicine* **31**(2), 139–147. doi:10.1177/1049909113479440
- Gómez-Virseda C, De Maeseneer Y and Gastmans C** (2019) Relational autonomy: What does it mean and how is it used in end-of-life care? A systematic review of argument-based ethics literature. *BMC Medical Ethics* **20**(76). doi:10.1186/s12910-019-0417-3
- Gudat H, Ohnsorge K, Streeck N, et al.** (2019) How palliative care patients' feelings of being a burden to others can motivate a wish to die. Moral challenges in clinics and families. *Bioethics* **33**(4), 421–430. doi:10.1111/bioe.12590
- Güell E, Ramos A, Zertuche T, et al.** (2015) Verbalized desire for death or euthanasia in advanced cancer patients receiving palliative care. *Palliative and Supportive Care* **13**(2), 295–303. doi:10.1017/S1478951514000121
- Hagens M, Onwuteaka-Philipsen BD and Pasman HRW** (2016) Trajectories to seeking demedicalised assistance in suicide: A qualitative in-depth interview study. *Journal of Medical Ethics* **43**(8), 543–548. doi:10.1136/medethics-2016-103660
- Hasselaar JGJ, Reuzel RPB, Verhagen SCAHHVM, et al.** (2007) Improving prescription in palliative sedation: Compliance with Dutch guidelines. *Archives of Internal Medicine* **167**(11), 1166–1171. doi:10.1001/archinte.167.11.1166
- Ho AHY, Chan CLW, Leung PPY, et al.** (2013) Living and dying with dignity in Chinese society: Perspectives of older palliative care patients in Hong Kong. *Death Studies* **42**(4), 455–461. doi:10.1093/ageing/aft003
- Hong QN, Pluye P, Bujold M, et al.** (2017) Convergent and sequential synthesis designs: Implications for conducting and reporting systematic reviews of qualitative and quantitative evidence. *Systematic Reviews* **6**(1), 61. doi:10.1186/s13643-017-0454-2
- Huxtable R and Moullock A** (2015) Voices of discontent? Conscience, compromise, and assisted dying. *Medical Law Review* **23**(2), 242–262. doi:10.1093/medlaw/fvv008
- Inthorn J, Schicktanz S, Rimón-Zarfaty N, et al.** (2015) “What the patient wants...”: Lay attitudes towards end-of-life decisions in Germany and Israel. *Medicine, Health Care & Philosophy* **18**(3), 329–340. doi:10.1007/s11019-014-9606-5
- Jochemsen H and Keown J** (1999) Voluntary euthanasia under control? Further empirical evidence from the Netherlands. *Journal of Medical Ethics* **25**, 16–21. doi:10.1136/jme.25.1.16
- Johansen S, Hølen JC, Kaasa S, et al.** (2005) Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. *Palliative Medicine* **19**(6), 454–460. doi:10.1191/0269216305pm1048oa
- Karlsson M, Milberg A and Strang P** (2012) Dying cancer patients' own opinions on euthanasia: An expression of autonomy? A qualitative study. *Palliative Medicine* **26**(1), 34–42. doi:10.1177/02692163111404275
- Kelly B, Burnett P, Pelusi D, et al.** (2002) Terminally ill cancer patients' wish to hasten death. *Palliative Medicine* **16**, 339–345. doi:10.1191/0269216302pm538oa
- Kelner MJ** (1993) Patient control over dying: Responses of health care professionals. *Social Science and Medicine* **36**(6), 757–765. doi:10.1016/0277-9536(2893)2990036-4
- Kissane DW, Clarke DM and Street AF** (2001) Demoralization syndrome: A relevant psychiatric diagnosis for palliative care. *Journal of Palliative Care* **17**(1), 12–21.
- Kuuppelomäki M** (2000) Attitudes of cancer patients, their family members and health professionals toward active euthanasia. *European Journal of Cancer Care* **9**(1), 16–21. doi:10.1046/j.1365-2354.2000.00184.x
- Lavery JV, Boyle J, Dickens BM, et al.** (2001) Origins of the desire for euthanasia and assisted suicide in people with HIV-1 or AIDS: A qualitative study. *Lancet* **358**(9279), 362–367.
- Lavoie M, Blondeau D and Picard-Morin J** (2011) The autonomy experience of patients in palliative care. *Journal of Hospice and Palliative Nursing* **13**(1), 47–53. doi:10.1097/NJH.0b013e318202425c
- Mak YYW and Elwyn G** (2005) Voices of the terminally ill: Uncovering the meaning of desire for euthanasia. *Palliative Medicine* **19**(1), 343–350.
- McCormick TR and Conley BJ** (1995) Patients' perspectives on dying and on the care of dying patients. *The Western Journal of Medicine* **163**(3), 236–243.
- Moher D, Liberati A, Tetzlaff J, et al.** (2009) Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine* **6**(7), e1000097. doi:10.1371/journal.pmed.1000097
- Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, et al.** (2011) The wish to hasten death: A review of clinical studies. *Psycho-Oncology* **20**(8), 795–804. doi:10.1002/pon.1839
- Monforte-Royo C, Villavicencio-Chávez C, Tomás-Sábado J, et al.** (2012) What lies behind the wish to hasten death? A systematic review and meta-ethnography from the perspective of patients. *PLoS One* **7**(5), e37117. doi:10.1371/journal.pone.0037117
- Monforte-Royo C, Crespo I, Rodríguez-Prat A, et al.** (2018) The role of perceived dignity and control in the wish to hasten death among advanced cancer patients: A mediation model. *Psycho-Oncology* **27**(12), 2840–2846. doi:10.1002/pon.4900
- Muller MT, Van der Wal G, Van Eijk JTM, et al.** (1994) Voluntary active euthanasia and physician-assisted suicide in Dutch nursing homes: Are the requirements for prudent practice properly met? *Journal of the American Geriatrics Society* **42**(6), 624–629. doi:10.1111/j.1532-5415.1994.tb06861.x
- Nilmanat K, Promnoi C, Phunggrassami T, et al.** (2015) Moving beyond suffering: The experiences of Thai persons with advanced cancer. *Cancer Nursing* **38**(3), 224–231. doi:10.1097/NCC.0000000000000169
- Nissim R, Gagliese L and Rodin G** (2009) The desire for hastened death in individuals with advanced cancer: A longitudinal qualitative study. *Social Science and Medicine* **69**(2), 165–171. doi:10.1016/j.socscimed.2009.04.021
- Ohnsorge K, Gudat H and Rehmman-Sutter C** (2014a) What a wish to die can mean: Reasons, meanings and functions of wishes to die, reported from 30 qualitative case studies of terminally ill cancer patients in palliative care. *BMC Palliative Care* **13**(38). doi:10.1186/1472-684X-13-38
- Ohnsorge K, Gudat H and Rehmman-Sutter C** (2014b) Intentions in wishes to die: Analysis and a typology — A report of 30 qualitative case studies of terminally ill cancer patients in palliative care. *Psycho-Oncology* **23**(9), 1021–1026. doi:10.1002/pon
- Ohnsorge K, Rehmman-Sutter C, Streeck N, et al.** (2019) Wishes to die at the end of life and subjective experience of four different typical dying

- trajectories. A qualitative interview study. *PLoS One* **14**(1), e0210784. doi:10.1371/journal.pone.0210784
- Owen C, Tennant C, Levi J, et al.** (1992) Suicide and euthanasia: Patient attitudes in the context of cancer. *Psycho-Oncology* **1**(2), 79–88. doi:10.1002/pon.2960010205
- Owen C, Tennant C, Levi J, et al.** (1994) Cancer patients' attitudes to final events in life: Wish for death, attitudes to cessation of treatment, suicide and euthanasia. *Psycho-Oncology* **3**(1), 1–9. doi:10.1002/pon.2960030103
- Pearlman RA, Hsu C, Starks H, et al.** (2005) Motivations for physician-assisted suicide. *Journal of General Internal Medicine* **20**(3), 234–239. doi:10.1111/j.1525-1497.2005.40225.x
- Pennec S, Monnier A, Pontone S, et al.** (2012) End-of-life medical decisions in France: A death certificate follow-up survey 5 years after the 2005 act of parliament on patients' rights and end of life. *BMC Palliative Care* **11**, 25. doi:10.1186/1472-684x-11-25
- Peretti-Watel P, Bendiane MK, Pegliasco H, et al.** (2003) Doctor's opinions on euthanasia, end of life care, and doctor-patient communication: Telephone survey in France. *BMJ* **327**(7415), 595–596. doi:10.1136/bmj.327.7415.595
- Pestinger M, Stiel S, Elsner F, et al.** (2015) The desire to hasten death: Using grounded theory for a better understanding "When perception of time tends to be a slippery slope." *Palliative Medicine* **29**(8), 711–719. doi:10.1177/0269216315577748
- Public Health Division** (2020). Oregon's Death with Dignity Act. Retrieved April 26, 2021 from <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year23.pdf>.
- Quill TE and Battin MP** (2004) *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice*. Baltimore: The Johns Hopkins University Press.
- Robijn L, Cohen J, Rietjens J, et al.** (2016) Trends in continuous deep sedation until death between 2007 and 2013: A repeated nationwide survey. *PLoS One* **11**(6), e0158188. doi:10.1371/journal.pone.0158188
- Robinson S, Kissane DW, Brooker J, et al.** (2017) The relationship between poor quality of life and desire to hasten death: A multiple mediation model examining the contributions of depression, demoralization, loss of control, and low self-worth. *Journal of Pain and Symptom Management* **53**(2), 243–249.
- Rodríguez-Prat A and van Leeuwen E** (2017) Assumptions and moral understanding of the wish to hasten death: A philosophical review of qualitative studies. *Medicine, Health Care and Philosophy* **21**(1), 63–75. doi:10.1007/s11019-017-9785-y
- Rodríguez-Prat A, Monforte-Royo C, Porta-Sales J, et al.** (2016) Patient perspectives of dignity, autonomy and control at the end of life: Systematic review and meta-ethnography. *PLoS One* **11**(3), e0151435. doi:10.1371/journal.pone.0151435
- Rodríguez-Prat A, Balaguer A, Booth A, et al.** (2017) Understanding patients' experiences of the wish to hasten death: An updated and expanded systematic review and meta-ethnography. *BMJ Open* **7**(9), 16659. doi:10.1136/bmjopen-2017-016659
- Sandelowski M, Barroso J and Voils CI** (2007) Using qualitative metasummary to synthesize qualitative and quantitative descriptive findings. *Research in Nursing & Health* **30**(1), 99–111.
- Schwarzer R** (1992) *Self-Efficacy: Thought Control of Action*. Washington, DC: Hemisphere.
- Seale C** (2009) Hastening death in end-of-life care: A survey of doctors. *Social Science and Medicine* **69**(11), 1659–1666. doi:10.1016/j.socscimed.2009.09.025
- Tolle SW, Tilden VR, Drach LL, et al.** (2004) Characteristics and proportion of dying oregonians who personally consider physician-assisted suicide. *The Journal of Clinical Ethics* **15**(2), 111–118.
- Trankle SA** (2014) Decisions that hasten death: Double effect and the experiences of physicians in Australia. *BMC Medical Ethics* **15**(26). doi:10.1186/1472-6939-15-26
- Van Brussel L** (2014) Autonomy and dignity: A discussion on contingency and dominance. *Health Care Analysis* **22**(2), 174–191. doi:10.1007/s10728-012-0217-0
- van Wijngaarden E, Leget C and Goossensen A** (2016) Disconnectedness from the here-and-now: A phenomenological perspective as a counteract on the medicalisation of death wishes in elderly people. *Medicine, Health Care and Philosophy* **19**(2), 265–273. doi:10.1007/s11019-016-9687-4
- van Wijngaarden E, Goossensen A and Leget C** (2018) The social-political challenges behind the wish to die in older people who consider their lives to be completed and no longer worth living. *Journal of European Social Policy* **28**(4), 419–429. doi:10.1177/0958928717735064
- Volker DL, Kahn D and Penticuff JH** (2004) Patient control and end-of-life care part II: The patient perspective. *Oncology Nursing Forum* **31**(5), 954–960.
- von Elm E, Altman DG, Egger M, et al.** (2014) The strengthening the reporting of observational studies in epidemiology (STROBE) statement: Guidelines for reporting observational studies. *International Journal of Surgery*. doi:10.1016/j.ijssu.2014.07.013
- Walker MU** (2007) *Moral Understandings: A Feminist Study in Ethics*, 2nd ed. New York: Oxford University Press.
- Weinberger LE, Sreenivasan S and Garrick T** (2014) End-of-life mental health assessments for older aged, medically ill persons with expressed desire to die. *The Journal of the American Academy of Psychiatry and the Law* **42**(3), 350–361.
- Whittemore R and Knaf K** (2005) The integrative review: Updated methodology. *Journal of Advanced Nursing* **52**(5), 546–543. doi:10.1111/j.1365-2648.2005.03621.x
- Wilson KG, Chochinov HM, McPherson CJ, et al.** (2007) Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychology* **26**(3), 314–323. doi:10.1037/0278-6133.26.3.314
- Wolf SM** (2005) Assessing physician compliance with the rules for euthanasia and assisted suicide. *Archives of Internal Medicine* **165**(15), 1677–1679. doi:10.1001/archinte.165.15.1677