LIVING TO THE BITTER END? A PERSONALIST APPROACH TO EUTHANASIA IN PERSONS WITH SEVERE DEMENTIA

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ABSTRACT
The number of people suffering from dementia will rise considerably in the years to come. This will have important implications for society. People suffering from dementia have to rely on relatives and professional caregivers when their disorder progresses. Some people want to determine for themselves their moment of death, if they should become demented. They think that the decline in personality caused by severe dementia is shocking and unacceptable. In this context, some people consider euthanasia as a way to avoid total deterioration. In this article, we discuss some practical and ethical dilemmas regarding euthanasia in persons with severe dementia based on an advance euthanasia directive. We are using a personalist approach in dealing with these ethical dilemmas.

INTRODUCTION
Since 2002, euthanasia within a number of patient categories has been legal in Belgium and the Netherlands, provided that strict due care criteria are applied.1 In Belgian and Dutch legislation, euthanasia is defined as the intentional termination of life by someone other than the person concerned, at the latter’s request. Euthanasia of persons with severe dementia, as decreed in an advance euthanasia directive, is not allowed by the Belgian Act on Euthanasia.2 By contrast, in the Netherlands, euthanasia of persons with severe dementia, as decreed in an advance euthanasia directive, is allowed by law. The implementation of euthanasia in this patient population, however, is under discussion.3

This paper formulates clinical-ethical arguments regarding euthanasia in persons with advanced dementia, in which the persons’ wishes are decreed in an advance euthanasia directive, is allowed by law. The implementation of euthanasia in this patient population, however, is under discussion.3

2 Bills have been put forward in the Belgian Parliament to extend the current Act on Euthanasia towards persons suffering from dementia. See Belgian Chamber of Representatives, Wet voorstel tot wijziging van de wet van 28 mei 2002 betreffende euthanasie [Bill modifying act on euthanasia of 28th May 2002], 2007–2008, Doc 52 1050/001.

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life, and care. These values are based on the fundamental dimensions of the human person as they are formulated in the European personalist tradition of ethics. A central topic is the ethical evaluation of advance euthanasia directives. In conclusion, we conduct an ethical assessment and formulate a number of recommendations for clinical practice.

DEMENTIA: OUR CURRENT UNDERSTANDING

Clinical ethics aims to resolve the ethical problems that arise in clinical practice. Clinical practice constitutes both the departure point – in the form of ‘a problem’ – and the end point – in the form of ‘a solution’ – of reflection in clinical ethics. In what follows, we outline some relevant aspects of the latest clinical knowledge concerning dementia.

Prevalence

Of all individuals from various age groups, the elderly are especially prone to suffer from dementia. More than 20% of people suffering from dementia are over 85. Since the number of elderly people continues to increase worldwide, it is not surprising that the number of people suffering from dementia has increased dramatically. Research predicts that this number will double by 2050.4

Disorder-oriented diagnostics

In this paper, dementia is used as a generic term to refer to a spectrum of clinical syndromes. These syndromes are caused by various brain disorders and are all characterized by combinations of multiple problems in cognition, mood, or behaviour.5 Up to now, the diagnosis of dementia, irrespective of etiology, is based on a complex spectrum of clinical inclusion and exclusion criteria and on neuropsychological and radiologic results. This way, the reliability of dementia diagnoses ranges from 65% to 90% in specialized clinical settings.6

The exact duration of dementia is uncertain, due to the uncertainty about when dementia actually begins. Very often, decline is apparent for years before the diagnosis is made. About five years pass before a person needs constant care; and death comes, on average, in about three years after this. Prognostication in severe dementia is challenging and a barrier to providing end-of-life care. Hospice eligibility for dementia is largely based on the Functional Assessment Staging Scale.7 Stage 7 is defined as having profound memory deficits, total functional dependence, no knowledge of recent or past events, no verbal communication, no ability to ambulate. The duration of this stage ranges from months.

Care-oriented diagnostics

Besides diagnosing the disorder, determining the care needs of patients and assessing the burden on and the capacity of the informal care system is crucial. For persons suffering from dementia, long-lasting and intense care is an especially important consideration. Most people with dementia are cared for at home and are supported by informal caregivers and professional caregivers. Central informal caregivers often assume their duties in good spirits and because of their commitment to the person suffering from dementia; however, sometimes the task of caregiving can become overwhelming.8 Caregivers, on the one hand, face the physical burden of daily physical care, and on the other hand, they also face mental stress. The latter derives from several sources: grief over the loss of the person who was once their partner, father, or mother; guilt for sometimes failing in some aspect of caregiving, losing one’s temper, or relinquishing care to a nursing home; shame because of the behaviour of the person suffering from dementia; and social isolation. Even doubt about the course and the

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unpredictable nature of dementia symptoms can be a real burden.9

Pain control and palliative care

The current scientific state of affairs suggests that persons with dementia typically do not suffer severely from the dementia itself. Rather, any severe suffering they may experience is more likely to be related to symptoms (e.g. trouble breathing, agitation, confusion, pain, fear) caused by other disorders.10 It is difficult to diagnose pain in persons with dementia; therefore, pain often remains undertreated.11

Specific studies performed in hospices proved that applying a palliative care approach in the care of terminally ill patients with dementia contributes greatly to a dignified end of life, especially when caregivers apply adequate pain control and when they support the patient’s close relatives and loved ones.12 Even though hospice services benefit persons with severe dementia, most do not receive these services. Barriers to hospice enrollment include accurate prognostication, lack of recognition of dementia as a terminal condition, and accessibility of hospice services in nursing homes.13

Psychosocial experiences

Today’s generation of older people perceives the prospect of progressing dementia in their own way. The mental suffering that one experiences as one faces one’s progressing dementia is influenced by the fear of having to be dependent on others, the fear of losing one’s dignity, and the fear of being a burden.

Many healthy seniors take for granted their ability to arrange their lives according to their own desires and needs, with only minimal assistance from others. Autonomy as a social goal doesn’t only mean that elderly people who lose the capacities to lead an autonomous life are rather perceived as a ‘burden’ than as human beings. It also entails that these people consider themselves to be ‘less of a person,’ as people ‘who count as nothing.’14 Thus, older persons may view their situation as ‘problematic’ rather than ideal, if they involuntarily become dependent on others.15

The elderly often associate dignity with autonomy, independence, and preserving one’s intellectual powers.16 Some especially believe that the fear of losing one’s intellectual capacity and the risk of being handed over to the will of others when one becomes incompetent are notable reasons for wanting to be euthanized in a timely way.17

A growing number of seniors do not wish to become a burden to their relatives. They do not want to be reduced to people who are merely the object of other people’s responsibility. For many elderly ones, the fear of becoming a burden to their relatives is greater than their fear of death.18 Financial matters do not represent the only aspect of burden; rather older persons mainly fear that their relatives will have to pay a high emotional price when caring for them.19

EUTHANASIA IN PERSONS SUFFERING FROM DEMENTIA IN THE NETHERLANDS

Since the early 1990s, an intense social debate about euthanasia in persons with dementia has existed in the Netherlands. Recent research into the practice of euthanasia in persons with dementia reveals that 6% of Dutch elderly (61–92 years old) have an advance euthanasia

9 Despite the fact that it is known that multifaceted intervention can make a significant difference in the burden of care experienced, little has been done in a structural way in that area. See M. Mittelman et al. A Family Intervention to Delay Nursing Home Placement of Patients with Alzheimer Disease. JAMA 1996; 276: 1725–1731; M. Mittelman et al. Improving Caregiver Well-being Delays Nursing Home Placement of Patients with Alzheimer Disease. Neurology 2006; 67: 1592–1599.

10 For example, pneumonia is the immediate precipitating cause of death in more than 50% of cases. J.H. Chen et al. Occurrence and Treatment of Suspected Pneumonia in Long-Term Care Residents Dying with Advanced Dementia. J Am Geriatr Soc 2006; 54: 290–295.


13 The majority of persons with dementia die in nursing homes. Therefore, nursing homes are key providers of palliative care to these patients. Mitchell, op. cit. note 7.


The following types of elderly people were more likely to have an advance euthanasia directive: elderly who were single, elderly who did not adhere to a specific faith, elderly who did not trust their physician to carry out their end-of-life wishes, and elderly who suffered from a chronic disorder or who experienced functional restrictions.

No cases of euthanasia in persons with dementia based on an advance euthanasia directive have been reported in the Netherlands. However, this does not necessarily mean that euthanasia in persons with dementia does not occur in the Netherlands. Twenty-nine percent of Dutch physicians (general practitioners and nursing home physicians) stated that they have already treated a person with dementia who had an advance euthanasia directive. Three percent of these physicians stated that they have performed euthanasia in a person with dementia based on an advance directive. Forty-four percent stated that, although they have not performed euthanasia in these patients to date, they have not ruled out the possibility of performing euthanasia in the future. Fifty-four percent of the physicians ruled out the possibility of performing euthanasia on persons with dementia in the future. The latter considered euthanasia in persons with dementia to be unacceptable. Furthermore, they did not view an advance euthanasia directive as a valid request.

The study of Rurup et al. showed that the patients’ relatives often adopt a more tolerant attitude toward life-terminating behaviour in persons with dementia than nurses and physicians. Ninety percent of relatives, 57% of the nurses, and 16% of physicians agreed with the statement that euthanasia based on an advance directive in persons with dementia is acceptable.

FUNDAMENTAL VALUE OPTIONS

Clinical ethicists cannot restrict themselves to a description of the clinical state of affairs; they must interpret clinical reality in the light of ethical values. In what follows, we discuss four value options that are important for an ethical evaluation of euthanasia in persons with severe dementia based on an advance euthanasia request: dignity of the human person, relational autonomy, quality of life, and care. These value options are based on the fundamental dimensions of the human person as they are formulated in the European personalist tradition of ethics.

In personalism, the focal point is the human person. We consider the human person integrally, that is, as a whole being or self, as well as a part of and in relation to the whole reality. The conceptual view we have of the person will affect the care we give to people with severe dementia.

Dignity of the person with dementia

Every person with dementia should be treated as a person until his life ends. This value option refers to the inalienable dignity of human beings. The dignity of ‘being a person’ should not depend on whether one has or does not have certain capacities (e.g. intellectual capacities). The dignity of ‘being a person’ is actually based on the fact that all people belong to human society and that all people can relate to persons suffering from dementia; thus, people should acknowledge persons with dementia just as they are – human beings deserving respect. Nordenfelt uses the German word Menschenwürde to explain this notion of dignity. Menschenwürde refers to a kind of dignity that all humans have, just because they are humans. It is significant that Menschenwürde cannot be taken from the human being as long as he or she is alive.

This value option justifies the moral requirement of respecting the dignity of a person suffering from dementia, regardless of their social, mental, or physical capacities. Through care – e.g., expressed by care of the body – caregivers express their commitment to the ‘person being’ of the patient and by doing so they also show their respect for the patient. This brings us to the personalist criterion of ethics. Human choices and acts are ethically good if they respect and improve the dignity of

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the human person, which is considered to be an individual related to others. Consequently, the personalist view presents the value of the dignity of the human person as the foundation of all other values.

Relational autonomy

In the euthanasia debate, respecting a person’s autonomy as an important value is often stressed. People should be able to decide for themselves how they run their lives, without interference from others. The simple fact that it is the person’s own choice is considered the sole right-making characteristic of this choice. According to this view, autonomy is seen as a form of individual self-determination.

According to the personalist view on care, the focus is not on individual autonomy but rather on the relationship between care-providers, care-receivers, and relatives, in their world. This bond does not take away a person’s autonomy. On the contrary, it is one of its prerequisites. Persons lead their own lives to the extent that, by their choices and actions, they can identify themselves with their social environment and their life story, which manifests itself as a narrative of mutual bonds between people. According to the personalist approach, the human person is considered integrally, that means as a whole in their world. This bond does not take away a person’s autonomy, among other things, within a familial, cultural, and historical context. The growth of demented persons is to a large extent based on a balance between autonomy and solidarity, not just on individual self-determination.

Quality of life

There is a connection between the dominant influence of the ‘respect for autonomy’ principle and the ‘quality-of-life’ doctrine. People who uphold the quality-of-life approach assume that informed people, people who are able to give their consent, should be able to opt for euthanasia when the quality of their life has diminished to rock-bottom levels. According to this view, we really should not protect a person’s life, but we should protect the autonomy of a competent person.

In general, quality of life is difficult to determine in an objective way. After all, there is a risk that the subjective assessment of the quality of life becomes very important. Even if the circumstances are similar, different people will assess their quality of life in a totally different way. This assessment is influenced by the values, goals, and perceptions of the person. For persons with dementia, there is a real risk that their close relatives will project their personal fears and concerns onto the person suffering from dementia. If relatives impose the disvalue they attach, in terms of their own life plans, to the states they observe in the person with dementia, they may well be imposing on the person a meaning to quality of life that does not fit with the patient’s current lived experiences. Thus, it is in the best interest of the person with dementia that adequate attention is focused on the assessments of informal caregivers, nurses, and physicians who regularly come into contact with people suffering from dementia and who can testify to the quality of life (e.g. joie de vivre, successful control of pain and other distressing symptoms, possibility of exercising remaining autonomy) of people with dementia.

Care

Care is a basic facet of our everyday life. We all take part in care, especially in the type of care that puts caring of ourselves in first place. So care refers to numerous daily activities by which we maintain our position in life, and it includes everything that we do to maintain, continue, and repair our world, so that we can live as best as possible.

However, care does not just represent something that people do ‘by nature’ in order to endure in life – rather, care is an ethical task. Care represents some kind of responsibility, one that people sense and that is an important dimension of their relationships with others. In a

31 Meulenbergs & Schotsmans, op. cit. note 30.
way, care as an ethical task can never quite be seen as a burden imposed from the outside, but rather it is seen as a call coming from within; it implies an ethical demand.\textsuperscript{39} The ethical duty to care for one’s neighbour is our very essence. Intersubjectivity, as expressed in care, is rooted in the nature of humanity itself. I can only care actively and consciously for my fellow human beings and the world because I am structured according to my essence itself, as a ‘being-for-the-other-than-myself’.\textsuperscript{40}

The four value options make our view on the human person more explicit. This normative anthropological background helps us to make a well-informed ethical assessment of euthanasia in persons with severe dementia. However, before making that assessment, more reflection on the status of advance directives in dementia care is needed.

**ADVANCE DIRECTIVES IN DEMENTIA CARE**

A central topic in the debate of whether euthanasia in persons with severe dementia should be ethically legitimized is the ethical evaluation of advance directives. Two types of advance directives exist: advance directives concerning end-of-life care and advance directives concerning euthanasia.

**Advance directives concerning end-of-life care**

Decisions about medical treatments should be made together with the patient, as long as communication is possible. If the person with dementia can no longer reason on the matter, an advance directive can be the optimal instrument to ensure that the patient’s wishes are respected as much as possible. Advance directives concerning end-of-life care enable elderly people to communicate their views about their place of death, their psychological and spiritual care, and their medical care. Furthermore, this type of advance directive can offer older persons real mental comfort or reassurance, allowing them to retain control of their end-of-life healthcare, even after they have become incompetent. In this way, the wishes and interests of the formerly competent patient are maximally respected.\textsuperscript{41} The advance directive is an instrument that can help to let the author of the advance directive die in the most dignified way possible, without crossing a double boundary; that is, the boundary of therapeutic obstinacy and the boundary of life-terminating behaviour.\textsuperscript{42}

**Advance euthanasia directives**

In some cases, advance euthanasia directives can have similar positive functions as those mentioned above. An advance euthanasia directive can provide the author with some mental comfort as well as a sense of control by preventing an undignified death. However, several objections can be raised with regard to performing euthanasia in a person suffering from severe dementia, as directed by the person’s advance euthanasia directive.

First, the **dynamics of personal reasons** play a role. The guarantee that life can be ended when dementia reaches a certain phase can bring inner peace to an elderly person, if he has made a conscious decision based on sufficient information and if he can stick to his decision. However, perseverance is not something everyone has. Furthermore, some can draft an advance euthanasia directive in a state of panic or depression, or having little or unclear information about the course of dementia.\textsuperscript{43}

How much does social environment affect an elderly person’s decision to draft an advance euthanasia directive? Does their environment pressure them into believing that it is their moral duty to complete an advance euthanasia directive? This **pressure** can come from the family, who are no longer able to carry the burden of care. Pressure can also be exerted by society, which is unwilling to keep paying for the care.\textsuperscript{44} This can be real or imaginary pressure; even one’s imagination can be experienced as real.\textsuperscript{45}

Also, the risk of being discriminated against by society can motivate elderly people to draft an advance euthanasia directive. Caregivers contribute to the social representation of human dignity through their institutions and their actions vis-à-vis the people who have been made vulnerable by their disorder or disability. This responsibility is even more important when we talk about

\textsuperscript{40} Meulenberg & Schotsmans, op. cit. note 30.
\textsuperscript{45} McPherson et al., op. cit. note 19.
terminally ill patients. Every action and attitude that could be seen as discriminatory or stigmatizing toward the most vulnerable persons in our society should therefore be rejected. Caregivers can deliver an important social signal by confirming that persons with dementia are still full-fledged persons who are entitled to care and protection.

During our lives, we can change our minds. At a certain moment in time, a person can decide to terminate his life when a certain level of physical or mental suffering is attained. And later on, when this suffering actually occurs, he can wish to continue living. Apparently, people seem to adjust when they end up in a situation that they initially view as unwanted or negative. The problem with a person suffering from dementia, however, is the fact that it is impossible for that person to reconsider the decisions outlined in his advance euthanasia directive. The issue of irreversibility is much stronger in persons with dementia. Since we cannot know for certain what persons with dementia really experience, we will never know whether they will stick to their request. Doubts may for instance be raised when the patient seems to be unhappy with the course of action that has been suggested in the advance directive. It may be that he offers resistance when the action is performed. How is such resistance to be interpreted? Hence the dilemma faced by physicians and proxies: how to balance the actual preferences of the person with dementia against the patient’s earlier opinions laid down in a now forgotten advance directive?

When writing an advance euthanasia directive, the author has the almost impossible task of determining the moment of euthanasia. As a consequence, the physician has the difficult task of determining whether the current situation does indeed match the circumstances specified by the author in his advance directive calling for euthanasia to be performed. Even carefully formulated specifications about the chosen moment of death require interpretation. One should always check whether the conditions in which the elderly person had in mind while writing his advance directive, have been sufficiently met. The fact that it is impossible to determine the moment of death is especially due to the developmental phases of dementia itself and the related difficulties in diagnosing dementia.

Finally, a patient’s decision to write an advance euthanasia directive has important implications for all parties involved in the patient’s care. The decision to perform euthanasia at a certain moment in time has to be made by someone other than the patient himself. This can create dissensions between the parties involved (physicians, close relatives, etc.). This quite clearly demonstrates the contradiction that is inherent in the autonomy approach when applied to advance euthanasia directives in persons with dementia: To what extent can our fellow man be given the responsibility to ensure that our right to self-determination is respected?

AN ETHICAL ASSESSMENT

The ethical assessment is based on our framework of four values, on the one hand, and on the process of balancing these values on the other hand.

Framework of values

The above-mentioned value options and views on advance directives lead us to the following thoughts. First, as Western society places a high value on cognition as an integral aspect of an individual’s dignity, the loss of cognition that occurs in dementia may be equated with hopelessness and loss of dignity. For some people, this may in itself be a reason to opt for euthanasia. This perception leads to what Post referred to as ‘exclusionary ethics’: the value that society places on rationality and memory excludes individuals with dementia from the sphere of human dignity and respect, and leaves them socially marginalized. Furthermore, this argument reduces human dignity to what Nordenfelt describes as ‘dignity of identity’. However, the most fundamental notion of dignity – Menschenwürde – cannot be lost as long as persons exist, even in case of extreme bodily and cognitive deterioration. Those who have lost their cognitive abilities or have extreme pain, embarrassment, and anxiety have no less or no more dignity than the more fortunate. According to this interpretation, loss of dignity cannot be used as an argument for euthanasia in persons with severe dementia.

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48 Widdershoven & Berghmans, op. cit. note 41.
49 Ibid; Hertogh et al., op. cit. note 47.
50 Hertogh et al., op. cit. note 47.
52 Nordenfelt, op. cit. note 28.
Second, regarding the value of respect for autonomy, advance euthanasia directives do not sufficiently guarantee that the wishes of persons suffering from dementia and those of people involved in their care will be respected. In clinical settings, autonomy is rather an objective than an actual condition. Authors of advance directives often find themselves in a very weak position when their advance directives become applicable, because it is often unclear whether they had this particular situation in mind when writing it. One should always interpret the situation, but interpretation involves risks. Life-terminating behaviour is irreversible and thus prompts us to be very careful. The most basic fact, however, is the patient’s dignity; and endangered autonomy is just one of the many dimensions of this dignity. Therefore autonomy cannot be the only concern in medical/ethical decision-making. The ‘relative’ value of autonomy is also supported by our relational approach to autonomy: autonomy should always be seen within the network of a person’s relations and world.

Third, we would like to emphasize – based on our plea to preserve the quality of life of the person with dementia – the importance of adequately implementing palliative possibilities. The observation that currently most persons with severe dementia do not receive adequate hospice services refers to an important societal responsibility that is neglected.

Fourth, based on the acknowledgement that care constitutes the essence of human life, it seems that care for our demented fellow human beings can be considered as a moral duty that is sensed from within and which is performed in an individual and societal way. The five recommendations for clinical practice outlined in the paragraph below explain how we could contribute to accomplishing our care responsibility toward persons with dementia.

**Process of balancing**

In an ethical assessment, the above mentioned ethical values need to be balanced. Balancing is the process of finding reasons to support beliefs about which moral values should prevail. Balancing is concerned with the relative weights and strengths of different moral values. In the personalist approach to ethics, the value of the dignity of the human person is the ultimate criterion used to assess human behaviour. Human choices and acts are ethically good if they respect and improve the dignity of the human person, considered as a whole with a multitude of dimensions and as related to others and the whole of reality. The personalist view presents the value of the dignity of the human person as the foundation of all other values. With this position, we do not reject the worth and the achievements of the value of autonomy in the last decades. Quite the reverse, we are fully aware of the enormous impact the pledge for autonomy has had – and still should have – for our lives. Nevertheless, autonomy may have neither the first nor the last word, since it is linked with other fundamental values in human life. The human autonomy we are required to respect, therefore, cannot result in an absolute dominion over one’s own life but has to be understood in a broader framework of fundamental ethical values.

**RECOMMENDATIONS FOR CLINICAL PRACTICE**

Rejecting euthanasia in persons with severe dementia can urge our society to invest more in establishing high-quality care facilities for persons suffering from dementia and their relatives.

**A precise and timely diagnosis**

To preserve the quality of life, we must use all possible means of intervention that can contribute to a precise and timely diagnosis, that mitigates symptoms, and that ease adjusting to and dealing with the disorder. Sensitive communication of the diagnosis is beneficial as patients may be able to participate in decisions regarding their future healthcare before their condition deteriorates and they are rendered incapable of making such decisions themselves. Furthermore, a timely diagnosis enables informal caregivers to provide optimal support. Using diagnostic models that focus both on the disorder and the care process offers a wider range of intervention and motivation possibilities. Dementia care has medical, nursing, psychological, and social components and as such is thus preferably performed by multi-disciplinary teams. Physicians who are reluctant about euthanasia in persons with dementia should inform their patients with advance

54 Janssens, op. cit. note 26; Selling, op. cit. note 26.


euthanasia directives about their position in a timely manner. In this way, a transparent dialogue between the patients and their physicians is made possible and these patients are able to consider the consequences for their end-of-life care.

Attending to close relatives

What the close relatives and loved ones ‘offer’ should balance with their capacity to give – their abilities and circumstances. A loss of balance indicates that the boundaries of the care relationship should be reconsidered. On the basis of this reconsideration, one can consider alternatives. Therefore, it is best for the elderly to accompany their close relatives as they search for feasible care alternatives. The first step in assuming shared responsibility is for both parties mutually to acknowledge that care can be exhausting and to talk about this problem in a timely manner.  

Palliative care approach

Older people dying from end-stage dementia should have access to high quality specialist palliative care services. Presupposed is accuracy in prognostication and the acknowledgement that people dying from dementia have a terminal condition. This also includes the reconsideration of futile medical treatments. Although deciding whether a medical treatment is futile is often value-related, it is also important to test the decision against the medical-professional standard. Such testing does not alter the fact that communication between all parties involved is necessary and that the wishes of the person with dementia should be respected.

Healthcare institutions

Although the ethical debate about the end of life focuses on caregivers’ responsibilities, there is a growing awareness that healthcare institutions – especially nursing homes where the majority of persons with dementia die – also bear significant responsibility. The management of healthcare institutions is responsible for guaranteeing and maintaining the quality of end-of-life care. When caring for patients with severe dementia, caregivers also need adequate support from managers. Therefore, we advocate the development of ethics policies by healthcare institutions to guide all end-of-life medical decisions in persons suffering from dementia. Ethics policies can prevent illegal practices (e.g. life-terminating behaviour without request) and can shed light on the responsibilities of all parties involved (e.g. the responsibility of the informal caregivers and volunteers).

CONCLUSIONS

Ensuring a dignified end of life for persons suffering from severe dementia is a subject that requires more and more attention from caregivers and from society, in general. This paper showed that ensuring a dignified end of life for persons suffering from dementia is not an isolated fact. The decision on whether to perform euthanasia in persons with severe dementia is linked to how we view people, and to what role autonomy plays in people’s lives. Furthermore, the decision on whether to perform euthanasia also fits in with the global approach of other end-of-life medical decisions. Nevertheless, further ethical analysis is needed, not the least because dementia is becoming more prevalent.

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58 Goldsteen et al., op. cit. note 8; Papastavrou et al., op. cit. note 8.
59 Post, op. cit. note 44; C. Hertogh. Advance Care Planning and the Relevance of a Palliative Care Approach in Dementia. Age Ageing 2006; 35: 553–555; Mitchell, op. cit. note 7; Birch & Draper, op. cit. note 57.