

First Do No Harm: Euthanasia of Patients with Dementia in Belgium

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In Memory of Ed Pellegrino

Abstract

Euthanasia in Belgium is not limited to terminally ill patients. It may be applied to patients with chronic degenerative diseases. Currently, people in Belgium wish to make it possible to euthanize incompetent patients who suffer from dementia. This article explains the Belgian law and then explores arguments for and against euthanasia of patients with dementia. It probes the dementia paradox by elucidating Dworkin's distinction between critical and experiential interests, arguing that at the end-of-life this distinction is not clearcut. It argues against euthanasia for patients with dementia, for respecting patients' humanity and for providing them with more care, compassion, and good doctoring.

Keywords: autonomy, Belgium, beneficence, euthanasia, dementia paradox, critical and experiential interests

Life is real! Life is earnest!
And the grave is not its goal;
Dust thou art, to dust returnest,
Was not spoken of the soul.

■ Henry Wadsworth Longfellow, A Psalm of Life

I. INTRODUCTION

This is the third of a series of "First Do No Harm" articles that concern the policy and practice of euthanasia in Belgium.¹ Euthanasia is defined as a practice undertaken by a physician intentionally to end the life of a person at his explicit request. Since the enactment of the *Euthanasia Act* in 2002, biannual reports are being published by the Belgian Federal Control and Evaluation Commission, established by the government in September 2002, assigned to monitor the law's application. In 1998, 4 years before the legislation of the Belgian *Euthanasia Act*, a nationwide survey estimated that 1.3% of all deaths resulted from euthanasia and physician-assisted suicide ([Deliens et al., 2000](#), 1806). A constant increase in registered euthanasia cases has been observed, predominantly in the Flemish part of Belgium ([Deliens et al., 2000](#); [Bilsen et al., 2009](#), 1119–21; [Smets et al., 2010](#)).² Approximately one of seven terminally ill patients dying at home under the care of a General Practitioner (GP) expresses a euthanasia request in the last phase of life ([Meeussen et al., 2011](#), 1068). A Flanders (the Dutch-Flemish speaking part of Belgium) 2010 study shows that euthanasia and physician-assisted suicide occurred in 2% of all Flemish deaths ([Chambaere et al., 2010](#), 896). This rate was higher than that in 1998 (1.1%) and in 2001

• ¹ The first two are [Cohen-Almagor \(2013\)](#), 515-21) and [Cohen-Almagor \(2015\)](#), 625–29). Further papers will concern euthanizing patients who are tired of life, and euthanizing children.

² See also VoxEurop, 2011, August 23. Rise in assisted deaths. VoxEurop [On-line].

<http://www.voxeurop.eu/en/content/news-brief/878961-rise-assisted-deaths> (accessed October 15, 2015).

(0.3%) ([Bilsen et al., 2009](#), 1119). The annual figures are constantly rising at a rapid pace: 235 in 2003; 495 in 2007; 704 in 2008, and 1,133 in 2011 ([de Diesbach et al., 2012](#), 3). In 2012, there were 1,432 cases and in 2013, 1,816 euthanasia cases were reported (Caldwell, 2014).

This article concerns the practice of euthanasia of patients with dementia. At present, people in Belgium are contemplating enlarging the scope of the law to include such patients. The *Euthanasia Act* which stipulates euthanasia only for competent patients has paved the way to ending lives of incompetent patients ([Chambaere et al., 2010](#), 895–6). The article opens with background information on the Belgian law and then goes on to explore arguments for and against euthanasia of patients with dementia. Contra Ronald Dworkin, it is argued that patients who suffer from dementia should not be euthanized. We should respect their humanity and provide them with more care and treatment, not death. Four arguments are put forward against euthanizing patients with dementia; two concern the physicians—beneficence and medicine-as-a-profession—and two concern the patients—the fluidity of life and the unattractiveness of death.

II. THE BELGIAN LAW

On January 20, 2001, a commission of Belgium's upper house voted in favor of proposed euthanasia legislation, which would make euthanasia no longer punishable by law, provided certain requirements are met ([Weber, 2001](#), 372). According to the *Euthanasia Act*, physicians who perform euthanasia do not commit a crime if they comply with the statutory requirements. The *Act* stipulates in Art 3 No 1 ([Belgian Act on Euthanasia, 2002](#)):

The physician who performs euthanasia commits no criminal offence when he/she ensures that

- the patient has attained the age of majority or is an emancipated minor, and is legally competent and conscious at the moment of making the request;
- the request is voluntary, well considered and repeated, and not the result of any external pressure;
- the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident;
- and when he/she has respected the conditions and procedures as provided in this Act.

An earlier proposal of the *Euthanasia Act* contained a change of the Penal Code. It stated that the provisions concerning murder were not applicable if and when the conditions of the *Act* were observed. However, that proposal met fierce objections of some senators who argued that no exceptions can be made to the rule "Thou shalt not kill." The legislators thus decided not to change the Penal Code ([DeBondt, 2003](#), 301). DeBondt further explains that the focus of the *Act* is the free will of the patient asking for euthanasia. The *Act* states a number of requirements that should be met before the performance of euthanasia would be legal. The majority of these requirements as well as the concept of the will of the patients are seen as "civil law" concepts. Thus, this *Act* is, in the first place, a civil law act.³

On October 25, 2001, Belgium's Senate approved the law proposal by a significant majority: 44 for, 23 against, 2 abstentions, and 2 senators who failed to register a vote. In society at large, an opinion survey showed that three quarters of those asked were broadly in favor of legalizing euthanasia (Osborn, 2001; [Deliens and van der Wal, 2003](#), 1239–40). On May 16, 2002, after only 2 days of heated debate, the Belgian lower house of parliament endorsed the bill by 86 votes in favor, 51 against and with 10 abstentions ([Vermeersch, 2002](#), 394–7; [Griffiths, Weyers, and Adams, 2008](#), 304–29).⁴ The legalization of euthanasia was

³ Personal email communication (September 26, 2014).

⁴ One referee commented: The majority in the parliament is radically in favor of the right to self-disposal of life and body. After the crisis in the abortion debate (the refusal of the Belgian King to sign the law), Belgian politicians decided to leave ethical issues to the decision of members of parliament.

finalized without the broad involvement of and consensus among the medical professions ([Smets et al., 2011](#), 581).

The legislation lays out the terms for doctors to end the lives of patients. Potential candidates for euthanasia need to reside in Belgium to be granted this service. Patients must be at least 18 years old and have made specific, voluntary, and repeated requests that their lives be ended. At least 1 month must elapse between the written request and the mercy killing ([Belgian Act on Euthanasia, 2002](#); [Cohen-Almagor, 2009a](#), 436–9). The 1-month requirement is valid only when the patient is not considered as “terminally ill” (i.e., neurological affections like quadriplegia).

III. EUTHANIZING PATIENTS WITH DEMENTIA

One study showed that 21.1% of patients whose lives were terminated without explicit request suffered from dementia ([Chambaere et al., 2010](#), 895–6). In 2009, it was decided not to prosecute Dr. Marc Cosyns after he euthanized an 88-year-old woman who asked to die but was *not* terminally ill. She was not fully lucid and had not given written consent. The patient’s own physician had opposed the euthanasia request (Baklinski, 2009; [Cohen-Almagor, 2009b](#), 208–10).

In 2008, Belgian author Hugo Claus died by euthanasia while suffering from Alzheimer’s. Jacqueline Herremans, president of the Belgian association for the right to die in dignity, said that all the guarantees provided for in the law, including a visit to a psychiatrist, were “certainly respected” ([La Dépêche, 2008](#)). According to a member of the official committee evaluating euthanasia cases, it was likely that Claus “still in the early stages of Alzheimer’s, made the decision while he still had his faculties” ([La Dépêche, 2008](#)). Bert Anciaux, culture minister for Belgium’s Dutch-speaking Flanders region, explained the timing of Claus’ death by saying that he wanted to leave with pride and dignity ([La Dépêche, 2008](#)).

Death *with dignity* should always be sought. But euthanizing patients with dementia is morally problematic. Euthanizing patients who do not suffer from somatic illnesses is highly controversial due to the complexity of the situation. Such decisions require taking into account the psychological needs of the patients, the influence and psychological situation of their intimate caregivers, the susceptibility of patients to depression and demoralization, the patients’ ability to understand and to process information, as well as their emotional state.

The Belgian Federal Control and Evaluation Commission had on various occasions endorsed euthanasia cases of patients who suffered from depression and dementia ([de Diesbach et al., 2012](#), 6). In the Netherlands as well, there were cases in which patients with dementia were euthanized with the help of a physician ([Berghmans, 2012](#)). The Belgian and the Dutch are willing to condone euthanasia in the earlier stages of dementia because then patients are capable of making such a decision. The problem here is that patients are euthanized prematurely, when they can have months of quality life. Euthanasia in the later stages of dementia is considered wrong because then patients who do not know what is happening to them are euthanized, and this contravenes the competency and autonomy considerations. Terminating the life of a patient who is not aware of what is happening to her is problematic even in the eyes of Dutch experts who condone euthanasia for patients with dementia in particular circumstances.⁵

Therefore, the impact of the Christian democrats in bio-ethical debates has become limited. After a long period of dominating the ethical scene in Belgium, Christian democrats no longer have a real impact on medico-legal (in case of bioethics) discussions.

⁵ Exchanges with Dr. Bert Keizer (December 29–31, 2012, and July 16, 2013). Dr. Keizer is author of, among other works, *Dancing with Mr. D* (Keizer, 1997).

Indeed, the debate regarding the question whether it is legitimate to end lives of patients with dementia is not new. Those who support such a practice accentuate the autonomy and self-determination of the patient, the dignity of the patient, the patient's wishes, and considerations relating to quality of life. Those who oppose the practice challenge the above considerations and argue that end-of-life practices should be confined, if at all, to competent patients. Otherwise, there are valid grounds for fear of abuse. I ([Cohen-Almagor, 2001](#), 96–112) have debated this issue in the past with my teacher and Oxford scholar Ronald Dworkin. Let me elaborate on the pertinent arguments.

IV. WHAT ARE THE BEST INTERESTS OF PATIENTS WITH DEMENTIA?

Dworkin argues that human life as such is *not* sacred. Life that includes only animal-like experiences without any critical interests is not sacred. In *Life's Dominion*, [Dworkin \(1993, 236\)](#) emphasizes the notion of dignity as the central aspect of the intrinsic importance of human life. "Dignity" is utilized to put a high value on human cognition and one's intellectual capacities.⁶ [Dworkin \(1993, 201–13\)](#) draws a distinction between experiential and critical interests, explaining that we all want pleasure and enjoyment in virtue of desires and ambitions. We also want to live worthwhile lives. That is, we look at our lives as a kind of assignment, a mission. The first kind of interest is called *experiential*; the second, *critical* interests.

A patient's right to be treated with dignity is the right that others acknowledge his critical interests: that they recognize that he has a moral standing and that it is intrinsically, objectively important how his life goes. Many people do not want to be remembered as living in circumstances perceived by them as degrading. Patients' fears about dependence include the impact of caring on those responsible for their well-being and the impact on their own dignity. [Dworkin \(1993, 210–12\)](#) contends that some people are horrified that their death might express an idea that they detest as a perversion: that mere biological life—just hanging on—has independent value.

[Dworkin \(1993, 215\)](#) maintains that when we think of dignity, it is *not* just life in *any* form that is important. Anyone who believes in the sanctity of human life believes that once a human life has started, it is intrinsically important that that life goes well, that the investment it represents is realized rather than frustrated. Dworkin explains that when we think of a person's prudential values we think of his life as a whole—past, present, and future. People strive to give their lives a certain meaning, structure, and direction. They would not like their lives to be marred by a condition that is strikingly at odds with the rest. [Dworkin \(1993, 230\)](#) speaks of life as a thematic unity: "when we consider how the fate of a demented person can affect the character of his life, we consider the patient's whole life, not just its sad final stages, and we consider his future in terms of how it affects the character of the whole." Accordingly, past desires matter a great deal because they inform the patient's life project. They set the parameters for the project's continued success. They are so important to the extent of trumping the patient's present interests.

[Dworkin \(1993, 180, 230–2\)](#) has no qualms referring to some patients as vegetables. He assumes that harm is being done when a patient is living as a vegetable (1993, 232). Dworkin contemplates a case where a person named Margo had executed a formal document directing that if she should develop Alzheimer's disease or a life-threatening disease, she should be euthanized as soon and as painlessly as possible. Dworkin asks whether autonomy requires that her wishes be respected now when she is ill, even though she seems perfectly happy with her dog-eared mysteries, the single painting she repaints, and her peanut-butter-and-jelly sandwiches. In such a case, an apparent contradiction

⁶ Others are using the concept of dignity to accentuate the inner worth of personhood and the sanctity of life. See [Kass, 1991](#); [Pellegrino, Schulman, and Merrill, 2009](#).

seems to exist between past and present wishes, between past and present autonomy. [Dworkin \(1993, 226–33\)](#) endorses respecting Margo’s past wishes, arguing that a competent person making a living will to provide for her treatment if she becomes demented is making the kind of judgment that autonomy, in the integrity view, most respects, a judgment about the overall shape of the kind of life she wants to have led. In other words, Dworkin implies that a life lacking critical interests is a poor life in terms of its quality. What we seek is not just any form of life but rather *life in earnest*. This reasoning brings him to conclude that a life that merely includes peanut-butter-and-jelly sandwiches, and similar trivial things, is not worth living. Eating these sandwiches cannot bring a person to consider her life as a kind of assignment, as a mission.⁷

I must demur from Dworkin’s remiss use of the word “vegetable” when referring to human beings. People remain beings of the human species notwithstanding their physical or mental condition. They still deserve to be treated compassionately, professionally, and morally. They should not be treated as we treat an asparagus or kohlrabi. Vegetables are means to an end. We use them for survival and pleasure. Humans are *never* means to an end. Humans are always worthy of respect and concern. Furthermore, reducing the notion of personhood to the ability to reason does not do it justice. Humans are complex beings with many abilities: cognitive, mental, spiritual, emotional, and physical. We derive happiness and a sense of satisfaction from many things that are not necessarily related to our ability to reason. People can realize themselves, be autonomous, *and* behave irrationally. People may choose to act on emotions rather than logic and reason ([Cohen-Almagor, 1994, 9–19](#)). People may derive an immense sense of happiness and satisfaction from utter nonsense. Contrary to Dworkin’s arguments, my contention is that even the thin pleasure of peanut butter and jelly is worthwhile. Past autonomous decisions should not categorically and unequivocally trump present nonautonomous life. People may find pleasure in things that had no importance for them in the past. Their present order of priorities should not be ignored. Four arguments are presented in support of this claim: beneficence, medicine-as-a-profession, fluidity of life, and the unattractiveness of death.

A. Beneficence

Beneficence is the act of doing good. Dworkin emphasizes the patient’s autonomy which is, indeed, an important consideration in the treatment of patients. When it comes to treating patients with dementia, this important consideration comes into conflict with a no less important consideration that guides the work of physicians: being kind and merciful to your patients. Do your very best for them. Physicians are duty bound to care for their patients ([Pellegrino and Thomasma, 1988](#)). Beneficence would dictate continuing to treat Margo, not to terminate her life. Acting for Margo’s benefit would dictate making her life as comfortable as possible, not ending her life journey because this is something she wanted in the past, when she was healthy.

In Belgium, the physician is required to inform the patients who request euthanasia of the state of their health and of their life expectancy, discuss with the patients their euthanasia request and the therapeutic measures which can still be considered, as well as the availability and consequences of palliative care. Euthanasia should be the last resort, after exhausting all avenues of showing beneficence to patients. Whether euthanasia is a good thing for patients who suffer from dementia is questionable.

B. Medicine-as-a-profession Argument

⁷ Bert Keizer commented: You and me we DO have qualms here. I think you are entirely correct in your diagnosis of Dworkin’s problem. His dismissive attitude towards ‘merely’ experiential life is a personal quirk, stemming from his own biography as a university-professor who thinks that being intellectually active and stunning is THE life worth living.

Patients with dementia typically do not suffer from the dementia itself ([Gastmans and De Lepeleire, 2010](#), 80). As far as we know, the changes in the brain that occur in dementia do not cause pain (Alzheimer's Australia, 2011). In the last stage of dementia, the vast majority of patients are no longer aware of their condition and have no recollection of their autonomous self. Now, at what stage would you warrant euthanasia for such patients? I have asked some leading physicians who treat such patients in six countries: Israel, the United Kingdom, the United States, Canada, Belgium, and the Netherlands, whether they would euthanize patients with dementia. Nearly all of them answered unequivocally "No." Generally speaking, physicians are trained to fight to maintain life, not to terminate life. It would be inconceivable for the physicians I interviewed to euthanize patients because of their past wishes when at present they do not wish to die and when they find some, even very limited, meaning in their lives. One Dutch physician, Bert Keizer, said "only in the first stage. Later it is too late." He himself admits that the first stage is too early to depart life but thinks that if patients are willing to take the risk of foregoing some pleasant months or a year even, then they are in a position to take leave in the early stages.⁸

First Do No Harm is a guiding principle in medicine. For the majority of physicians, it is inconceivable and utterly unprofessional to euthanize patients with dementia in Margo's condition. She would seem to be happy in her small yet significant joys of life, and then someone might recall that years ago she filled out an advance directive in which she expressed a wish to be euthanized upon becoming demented, and referring to Dworkin, say that we should respect the old wish and ignore the present Margo. Many physicians would find this argument bizarre and distressing, in direct conflict with their set of beliefs and with their professional responsibilities. This, for instance, was Edmund Pellegrino's view.

C. The Fluidity of Life Argument

Dworkin thinks that one's directives are predetermined and unchangeable, but this is not necessarily the case. We are not able to know how our lives will look when we are about to die. We are not able to say that values and priorities that are important to us now will be as important to us until the very last day. The notion of an unchangeable, unified personality is doubtful. People *do* change and these changes may become meaningful to us in circumstances that we cannot envisage. Indeed, the very idea of autonomy reflects our ability and desire to construct and reshape realities, to re-evaluate values and ideas, to renounce old beliefs, and to accommodate ourselves to new situations. People may realize their autonomous wishes only to realize later that this was not what they wished for themselves and change the course of their lives.

Dworkin assumes that people, as rational agents, may have certain attitudes regarding dementia and decide beforehand that some forms of life are repugnant, meaningless, and not worth living. People try to assess how their situation might look in the future and decide on their destiny according to the data they currently have on the demented state. However, people are not only thinking creatures. Not all factors can be grasped by our rational faculties. Not all data can be digested by applying reason and judgment. Sometimes we do things we could not imagine doing. Sometimes people act in accordance with their sentiments rather than in accordance with their brains. Sometimes people are pushed to do something by their instincts, their impulses, factors that they find difficult to explain in rational terms. On some occasions people are overpowered, overwhelmed by the reality they confront, yet humans learn and adjust. They accommodate themselves to situations imposed on them. We witness this time and again with people who were involved in traumatic injuries as a result of road accidents, acts of terror and of war. The majority of the victims opt to continue living.

⁸ Discussion with Dr Bert Keizer, Amsterdam (July 16, 2013) and his comments on this paper. See also Rurup, Onwuteaka-Philipsen, Pasman *et al* (2006).

True, patients with dementia express themselves in the experiential way, not in the cognitive way; but we cannot say in advance that only a certain level of autonomy is worth living. Life is in flux, circumstances are in flux, and personality is in flux. People do change not only as a result of facing physical and/or mental deterioration but also as a result of social changes, learning, and experiencing new things in life. Patients in Margo's condition are weakly related to their past and similarly weakly related to their future. They thus have only a weak basis for prudential concerns about anything but their present and their near future. There is no such thing as timeless prudential value ([Hawkins, 2014](#), 523–40).

One can rightly question to what extent Margo can positively respond to previous autonomous desires and whether her old putative conception of the good is valid to her present condition. The situation we are thus confronting poses a paradox. We should insist that only competent, autonomous people may have the option to decide the moment of their death when, for them, life is no longer worth living, when it is no longer life in earnest. They do not wish to be euthanized prematurely but at some point in the future. Upon reaching that point, people are no longer competent and autonomous, and at that point often there is no clear indication that they wish to die. It is plausible to assume that—like the victims of physical traumas—patients with dementia accommodate to the new circumstances and may have changed their priorities and find meaning in other, even mere experiential interests. Thus, performing euthanasia prematurely is a shame because it cuts life in earnest. Performing euthanasia at a later stage of dementia upon advance directives might not be relevant to the present condition and, indeed, might negate the patient's present wishes. Either way, euthanasia of patients with dementia is thus morally wrong.

D. Unattractiveness of Death Argument

With death, the body returns to earth. For many people, then there is nothing. Death is the end of the journey with no further prospects, no promise or hope. From the scientific, physical, and empirical perspectives (to be distinguished from the metaphysical, spiritual, and religious perspectives), after death there is void. Due to this realization, the majority of people cling to life even in the most distressing conditions. When forced to live under physical constraints as a result of traumatic events, most people provide explicit and clear indication that they wish to continue living ([Cohen-Almagor, 2001](#)). These clear indications are lacking when patients with dementia are concerned. Only upon experiencing continuous suffering that makes life a painful struggle people may find death an attractive proposition. Only when life becomes a weighty burden the proposition of death gains attractiveness. The majority of patients with dementia are not in this category.

Roughly speaking, dementia is comprised of three stages. In the early stage, signs emerge that the patient suffers from dementia. The patient slowly realizes that there is a problem. The patient, who is still autonomous, may indicate that she does not wish to live as a demented being. Such a life is contrary to her critical interests. Then dementia progresses. The patient's mental faculties deteriorate. She loses her autonomy. Finally, comes the third and last stage when the patient leads animal-like or, in Dworkin's terms, vegetable-like life. In many cases, learning is possible, including the correcting of behavior that we deem problematic, until late in the process. There are no reciprocal meaningful relationships between the patient and the people around her.

Many of the cases are not Margo-like cases. There are patients with dementia whose condition has a significant negative impact on their lives. They do not find any satisfaction in life. Their condition is irreversible, irrecoverable, distressing, and frustrating. They are fully dependent on others for their most basic daily functions and activities. The severe cases involve lack of any autonomous functioning in the late stage, following a steady decline ([Sharp, 2012](#), 235). The process is very sad and painful, more so to the patient's loved ones (those around the patient's bed who are important to the patient, who truly care for the patient and want her best interests) who witness how the person they loved deteriorates and

slowly disappears.⁹ The patient's loved ones find it especially difficult to cope with the noncognitive symptoms of dementia which include the patient's agitation and her wandering around and getting lost. The majority of patients with dementia experience such symptoms especially in the second and third stages of the illness ([Robinson et al., 2006](#); [Burns and Iliffe, 2009a](#)). It is also difficult and quite frustrating for the medical team to treat patients who are nonautonomous, nonresponsive, and noncommunicative, who do not show appreciation and who require basic and intimate care.¹⁰

In the first stage of dementia, patients tend to suffer from fears of becoming a burden on loved ones and the medical care, losing independence, and losing one's dignity ([Gastmans and De Lepeleire, 2010](#); [Albers, Van den Block, and Vander Stichele, 2014](#)).¹¹ The suffering is mental. The suffering can be alleviated with due holistic palliative care that addresses the patients' mental, psychological, physical, and social needs, with assurances that the patients have an intrinsic value notwithstanding their deteriorating condition, with family solidarity ([Ter Meulen and Wright, 2012](#), 361–8), and with compassion and respect for the patients who are now at a juncture where they need attention more than ever before. As patients with dementia tend to be elder adults,¹² they should be reassured that it is payback time. All their lives they gave to others—their children, their friends, their society; now it is their turn to receive. The moral imperative is to provide compassion and care for people with dementia.

With the advance of dementia, its distressing symptoms become more frequent ([Aminoff and Adunsky, 2004](#); [Aminoff and Adunsky, 2006](#)). Dyspnea, pain, and agitation become more common as death comes nearer. But all are treatable symptoms. Studies have shown that cognitive behavioral therapy, palliative and hospice care could greatly improve the care of patients with advanced dementia. Patients with dementia who receive hospice care have fewer hospitalizations and milder psychiatric symptoms as compared with those who did not receive hospice care ([Bekelman et al., 2005](#); [Hughes et al., 2007](#); [Shega et al., 2008](#); [Sachs, 2009](#)). Furthermore, families of patients with dementia who receive hospice care report greater satisfaction with care ([Sachs et al., 2004](#), 19, 1057–63; [Sachs, 2009](#); [Shega et al., 2008](#)). Table 1 summarizes the considerations.

⁹ For further discussion, see [Pivodic and colleagues \(2014\)](#).

¹⁰ A nurse in the Antwerp research seminar who works in a nursing home asked whether there is any meaning in treating such patients; whether their lives can be termed "life". The nurse said he feels that he is treating vegetables. He is required to wash them each and every day. Sometimes he is required to feed them with a tube. There is no relation between these patients and the nursing home team. There is no sharing, no reciprocity. No form of consciousness. The nurse asked: Is there a sense of taking care of these people? Interestingly, following my explanation about the difference between vegetables and human life, the nurse denied that he used the term "vegetable" only a few minutes before. It is certainly challenging to treat human being in such a condition.

¹¹ For further discussion on the concept of dignity, see [Duwell et al \(2014\)](#).

¹² The majority of people with Alzheimer's are 65 and older. See Alzheimer's Association, What Is Alzheimer's?, accessed October 15, 2015, http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp. See also [Burns and Iliffe \(2009b\)](#), 158).

Table 1.
Euthanasia of patients with dementia

Stage	Autonomous consent	Suffering	Required care	Providing Euthanasia (Time)	Euthanasia – Ethical aspects
1	+	+	+	Premature	Problematic
2	-	++	++	Questionable	Problematic
3	-	+++	+++	Timely	Problematic

Thus, euthanasia of patients with dementia is always problematic. When individuals are aware of the complexities of dementia and factor in the contradiction at the end of life whereby with severe dementia they will not be able to remember their previous wish and may well be pursuing other interests, yet they are making a conscious decision that this is the time when their own lives should be terminated, that decision is bound to be fraught with doubts: at the onset of the illness death is premature; in the later stage it is questionable because the patients show that some aspects of life are still meaningful to them, and in the last stage the patients are no longer autonomous to make such a momentous decision and the physicians cannot be sure what the patients then want.

The dementia paradox cannot be solved by euthanasia. It needs to be addressed by more care, compassion, and good doctoring. The medical team has a crucial part to play in promoting quality of care from diagnosis until the last stages of dementia, through assessment of changes in cognitive functioning—memory, day-to-day functioning, depression, fears, communication difficulties, and behavior—alongside identification and treatment of symptoms ([Burns, O'Brien, and Ames, 2005](#); [Downs and Bowers, 2008](#); [Burns and Iliffe, 2009b](#)). As Edmund Pellegrino reiterated in many of our conversations about this matter, early requests to die are often the result of desperation that the medical staff and the patients' beloved people can forestall by providing the understanding, support, care, and sharing that will assure the patients that they are, and will remain, members of the human community. What we should do is humanize care for the living rather than dehumanize patients and promote their death.

V. CONCLUSIONS

Although the legalization of euthanasia was finalized without the broad involvement and consensus among the medical profession, the acceptance of euthanasia has increased among the medical profession from 78% in 2002 to more than 90% in 2009 ([Miccinesi et al., 2005](#); [Smets et al., 2011](#), 590; [Van Wesemael et al., 2012](#)). Social and peer pressure make it difficult for those who oppose euthanasia to uphold their position in the liberal culture that has been developing. A similar phenomenon has been recorded in the Netherlands following the legislation of the Dutch euthanasia law ([Cohen-Almagor, 2004](#), 154).

Johan [Bilsen and colleagues \(2009, 1120\)](#) found that following the *Euthanasia Act* there was an increase in all types of medical end-of-life practices with the exception of the use of life-ending drugs without explicit request.

The liberal state has an obligation to protect all people, especially the vulnerable.¹³ Given that ending patients' lives without request is more common than euthanasia ([van der Heide](#)

¹³ One referee commented that not only the "usual suspects" (minorities, poor) are the most vulnerable. It may be white men who are actually most vulnerable to the temptation to request euthanasia. They have been socialized to believe that life is not worth living if they are not dominant,

[et al., 2003](#), 345–50), and given the significant number of terminal sedation cases ([Claessens et al., 2008](#), 325; [Bilsen et al., 2009](#), 1119–21), a call for caution is warranted. The Belgians are researching the way their dying patients are being handled in a medical context. Their culture of self-searching is certainly necessary.

In Belgium, patients who have advance directives requesting to stop treatment upon becoming severely demented will have their request honored. Their treatment will be stopped together with their artificial feeding and they will die.¹⁴ I have argued that in the early stage when the patient is autonomous, death would come much too early. In the second and third stages, the patient is no longer competent and autonomous to decide. Those who surround the patient suffer as they witness the mental deterioration of their loved one. But their suffering should not dictate the medical treatment of the patient. The patient, like Margo in the Dworkin example, may find satisfaction in experiential interests. For these patients, present experiential interests might be more important than critical interests that were voiced in the past. One is in no position to discard them merely because they seem low in the minds of healthy people. Something that has a limited value in the present may gain enormous meaning in the future. One may argue that then experiential interests become for patients with dementia critical interests. These are the essential things in their lives.

Opinion polls indicate that the majority of the Belgian public, 85% to 93% of them, support euthanasia (a growing support after 2002) ([Cohen et al., 2006](#), 663–9; [Cohen-Almagor, 2009a](#)). This support is similar to the support of the medical profession. It would be coercive to deny them what they perceive as a fundamental right. But the history of euthanasia in Belgium is young. The *Euthanasia Act* was passed only in 2002, and the country is still in the early learning stages. What is disconcerting is the fast move to press forward further end-of-life practices without paying ample attention to caution. One cautionary barrier after the other is removed to allow greater scope for euthanasia ([Cohen-Almagor, 2013](#); [Siegel et al., 2014](#); [Vincent et al., 2014](#)). The scope of tolerance toward the practice is enlarged so that, as yesterday's red light becomes obsolete today and as one qualification is removed, practitioners and law makers are already debating a further step and other groups (patients who are tired of life, children, patients with dementia) to be included within the more liberal euthanasia policy as if the restrictive logic behind the *Euthanasia Act* were no longer valid. This is quite astonishing because human lives are at stake. What is required is a careful study, accumulation of knowledge and data, addressing the above concerns, learning from mistakes, and attempting to correct them before rushing in a frenzied fashion to introduce more liberal ways to euthanize patients. Haste makes waste.

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independent, and fully in control. In case of a severe illness, if they lose their "autonomy," some men will believe that their lives are completely useless. See [Krag \(2014\)](#).

¹⁴ Bert Keizer commented: In the Netherlands too. This is considered normal practice. We as a rule do NOT give patients with dementia a nasogastric tube for feeding if they no longer eat properly. It is a mild death and is regarded as the inevitable course of the disease.

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