

Euthanasia in Persons with Advanced Dementia: A Dignity-Enhancing Care Approach

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ABSTRACT

In current Western societies, increasing numbers of people express their desire to choose when to die. Allowing people to choose the moment of their death is an ethical issue that should be embedded in sound clinical and legal frameworks. In the case of persons with dementia, it raises further ethical questions such as: Does the person have the capacity to make the choice? Is the person being coerced? Who should be involved in the decision? Is the person's suffering untreatable? The use of Advance Euthanasia Directives (AED) is suggested as a way to deal with end-of-life wishes of persons with dementia. However, in the Netherlands—the only country in which this practice is legal—the experiences of patients, doctors, and relatives have been far from satisfactory.

Our paper analyses this complex ethical challenge from a Dignity-Enhancing Care approach, starting from the Dutch experiences with AED as a case. We first consider the lived experiences of the different stakeholders, seeking out a dialogical-interpretative understanding of care. We aim to promote human dignity as a normative standard for end-of-life care practices. Three concrete proposals are then presented in which this approach can be operationalized in order to deal respectfully with the end-of-life choices of persons with dementia.

Keywords: Euthanasia; Assisted suicide; Advance directives; Palliative Care; Ethics; Dementia.

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INTRODUCTION

Among the many ethical issues linked to dementia care, end-of-life choices of persons with dementia have become the object of intense debate.[1] Against the societal background of established and emerging euthanasia and assisted suicide (EAS) legislation, increasing numbers of persons with dementia express their desire to choose *when* to die.[2] They may not want to die early, when they are still competent and are enjoying life, but they also do not want to wait too long, when they have lost both the capacity for rational decision-making and the capacity to execute decisions.

In this paper, we address the ethical issue of euthanasia requests in persons with advanced dementia. We signal the limitations of the Dutch practice of Advance Euthanasia Directives (AEDs) as a particular tool to implement a person's decision of when to die. We propose the Dignity-Enhancing Care Model as a comprehensive framework to critically reflect on the end of life of persons with advanced dementia in general, and the role of AED therein, in particular. By doing so, we do not pretend to solve all of the ethical issues at stake, nor do we intend to prevent people from drafting AEDs. Rather, we aim to open the perspective to a more respectful approach to the complexity of end-of-life situations. Three main characteristics of the model will be unpacked. First, it considers the *lived experiences* of the different stakeholders involved to analyze issues around euthanasia requests; second, it holds at its core a search for a dialogical-interpretative understanding of adequate care for persons with advanced dementia; and third, it aims to promote human dignity as a normative standard for end-of-life care practices. Finally, we present three concrete proposals through which this approach can be operationalized in order to deal respectfully with the end-of-life choices of persons with dementia.

CURRENT PRACTICES AND PERSISTING QUESTIONS

During the past 20 years, an increasing number of Western countries have addressed the issue of competent patients choosing *when* to die by adopting EAS legislation.[3]

Mostly, EAS for competent patients is ethically legitimized using respect for autonomy as the core principle.[4] This autonomy-centred approach is strongly supported by empirical studies reporting on perceptions of patients, relatives, healthcare professionals, and the general public, who tend to consider respect for autonomy as a fundamental value for realizing a dignified death.[5, 6] The centrality of this principle is also reflected in the definition of euthanasia as used in the EAS jurisdictions of both Belgium and the Netherlands, the two countries where this practice was first legalized. Euthanasia there is defined as “intentionally terminating life by someone other than the person concerned *at the latter’s request*” [emphasis added].[7] Nevertheless, in the case of incompetent patients, such as individuals with advanced dementia, the application of respect for autonomy in its common interpretation seems to be inadequate and even problematic. How so?

Euthanasia in persons with advanced dementia under an AED is legal only in the Netherlands. The Dutch experience can therefore be used as a study case to critically reflect upon AED as a particular tool to implement the decision of when to die. Since 2002, Dutch citizens have been allowed to draft an AED while still competent and ask for the request to be granted when reaching late stages of the disorder after they are deemed incompetent. Nonetheless, instances are very scarce of euthanasia being carried out under an AED for persons with advanced dementia.[8] The reasons for the gap between the formal possibility offered by the legal system and its practical implementation into real euthanasia cases mainly result from legal and ethical inconsistencies.

From a legal point of view, critiques of the current Dutch legislation highlight the impossibility of meeting the same due care criteria in euthanasia involving persons with advanced dementia as in euthanasia involving competent patients.[9] According to Dutch law, six due-care criteria must be met for a euthanasia case to be considered legal (see Table 1). De Boer points out that “the whole structure of the due care criteria rests upon communication and shared-decision making”.[10] However, in the case of persons with advanced dementia, it becomes difficult to assess whether there is unbearable and hopeless suffering (2nd criterion) and whether the request was voluntary and well considered (1st criterion). Even more difficult is to comply with the 4th and 3rd criteria, which demand a joint decision by the doctor *together* with the patient about possible alternatives after the latter being informed about his/her diagnosis and prospects. These difficulties are reflected in the actual practices of euthanasia in persons with advanced dementia. This reality became evident in a content analysis of EAS reports published by the Dutch euthanasia review committees: 25% (4/16) of the studied euthanasia cases under AED did not meet the legal due-care criteria, in particular those that assessed unbearable suffering and the voluntary and well-considered character of the request.[2]

Table 1. Requirements of due care in the Dutch Euthanasia Legislation.[10]

1. The physician is convinced that the patient has made a voluntary and well considered request
2. The physician is convinced that the patient’s suffering is unbearable, and that there is no prospect of improvement
3. The physician has informed the patient about his or her situation and prospects
4. The physician has come to the conclusion, together with the patient, that there is no reasonable alternative in light of the patient’s situation

5. The physician has consulted at least one other physician, who must have seen the patient and given a written opinion on the due care criteria referred to above, and

6. The physician has terminated the patient's life or provided assistance with suicide with due medical care and attention.

From an ethical point of view, underlying moral framework that supports euthanasia in competent patients is based on *compassion* for suffering that is considered unbearable and hopeless; and on *respect for the patient's autonomy*. Neither of these two principles is easily applicable in the case of persons with advanced dementia. First, it is difficult to assess suffering as unbearable and hopeless in persons who have lost awareness of their situation and lack the capacity for in-depth communication.[10] Second, it is not clear what respect for the person's autonomy means in these situations. Clinical evidence shows that until very late stages of their condition, persons with dementia remain alert and are capable of interacting with their environment.[11] They still have subjective experiences and express preferences. This situation provokes a complicated and muddled debate about the relationship between *precedent* and *current* autonomy of the person with dementia. In other words, whose autonomy has to be preferentially respected: the one expressed by the still-competent person in the form of an AED, anticipating unknown situations; or the one expressed in non-cognitive ways—through utterances or behavioral expressions—by the present person with advanced dementia? This dilemma strikes at the heart of the philosophical question concerning the identity, or sense of self, of persons with dementia. In general, two main positions can be delineated: on the one hand, there is a stance that insists on the continuity of personal identity and on the priority of “critical interests,” which constitute a stable set of

identity-defining values and beliefs.[12] On the other hand, there is a stance that emphasizes the discontinuity that advanced dementia implies—a new personal situation completely different from anything experienced before—and priority is given to the actual person's “experiential interests”.[13] Expressed in this dichotomous, mutually exclusive way, the discussion may have serious flaws, since both positions are right, yet incomplete. Several authors argue for a middle path that does not blindly follow the AED, nor simply discards the AED when the patient becomes incompetent.[14-16] They propose to bring into dialogue the repeated and stable desires of the “*then self*” expressed through the AED, with the current preferences of the “*now self*,” ones communicated non-verbally and need contextual interpretation. A middle path considers a patient’s motivation for an advance request but also considers the impact that granting such a request would have on the persons granting it. This path requires a process-oriented and dialogical view of the relationship between doctors, patients, and the responsible family members. Such a view will be developed henceforth following the structure of the Dignity-Enhancing Care model, which is closely aligned with an experiential and relational approach to autonomy.[17, 18]

In summary, the current autonomy-based approach to euthanasia in persons with advanced dementia is highly problematic from a practical, legal, and ethical point of view. Further ethical scrutiny is needed in order to better address the complexities encountered in end-of-life practices involving persons with advanced dementia.

ANSWERING RESPECTFULLY TO COMPLEXITY: THE DIGNITY-ENHANCING CARE APPROACH

In order to deal with the complexity of euthanasia requests in persons with advanced dementia, we propose using as a framework the Dignity-Enhancing Care approach.[19]

This comprehensive approach is based on respect for persons as *relational* beings in their full lived reality. The model considers vulnerability, care interactions, and dignity as key elements of ethically sound care practices.

With this new framework, the ethical essence of end-of-life care practices for persons with dementia can be characterized as providing *care* in response to the *vulnerability* of a human being in order to maintain, protect, and promote his or her *dignity* as much as possible. Likewise, this ethical framework relies on three complementary organizational pillars. First, it stems from concrete *lived experiences* of all those involved in care practices. Second, it is committed to providing adequate care, reached through engaging in *interpretative dialogues* among the different stakeholders involved. Third, it aims at promoting human dignity, providing a *normative standard* based on a specific anthropological view. We now consider in turn each of these pillars, applied to euthanasia requests in persons with advanced dementia.

Lived Experiences of Vulnerability

Our reflection starts from the lived experiences of real human beings. We, therefore, focus on empirical studies that give voice to patients, healthcare professionals, responsible family members, and general public. How do these stakeholders experience end-of-life practices applied to persons with advanced dementia, and more particularly, their desire to choose when to die?

Persons with dementia. Persons with dementia report fearing the late stages of dementia, commonly described as a humiliating condition that affects sense of self and personality.[20] Thus, persons with dementia may express their willingness to choose when to die. Writing an AED, as legalized in the Netherlands, seems to provide persons with dementia with some mental comfort, as well as a sense of control, by preventing the

possibility of experiencing an undignified death.[14] Despite a possible emerging trend, euthanasia in persons with advanced dementia is still rarely implemented based on written advance euthanasia directives.[2] Several studies over the 20 years of Dutch experience have shown that the directive was frequently discussed too late in the process and mainly with relatives, with the final result being that the directive was almost never enforced.[10, 21] Similarly, a Belgian study showed that 20% (8/38) of patients at early stages of dementia considered making practical arrangements about having euthanasia carried out in the future, even if their expectations would go unmet, since euthanasia under AED is not currently permitted in Belgium.[22]

When exploring patients' reasons for considering euthanasia, persons with dementia expressed strong fear about being a burden to others and losing their autonomy.[22] Qualitative studies confirm that persons with dementia experience their disorder as increasing vulnerability and gradual dependency on others.[23] They frequently characterize their condition as a "sense of loss" in many domains: memory, communication, independence, dignity, relations, among others. Nevertheless, empirical studies also reveal that persons with dementia do not experience it passively. On the contrary, they go through an adaptive process and use coping strategies, including emotion- and problem-oriented strategies.[24]

Healthcare professionals. Although half of all elderly-care physicians in the Netherlands have treated a patient with dementia who has an AED—showing that such requests are relatively common—euthanasia under an AED was scarcely carried out by them.[10] Studies confirm that most Dutch physicians (82%) can easily imagine complying with EAS for patients suffering from "physical" diseases like multiple sclerosis, but they are much more reluctant (29-33% agree) to do so in persons with advanced dementia.[25, 26]. Imagining this possibility was even lower (8%) among

nursing home physicians, those who are most often involved in the care of these patients.[27] Reasons for denying AED-based requests from persons with advanced dementia range from legal arguments to moral objections. In the same vein, a 2019 survey of dementia specialists in Belgium reported a high rate of disapproval (65%) for changing the law to allow writing an AED for people with dementia.[1]

Studies focused on experiences of Dutch physicians dealing with AEDs in persons with dementia confirm that a heavy emotional and ethical burden is placed on physicians.[28] Most difficulties experienced by doctors related to communication issues with persons with dementia and their relatives. Doctors often felt pressured by family members, whose expectations seemed to be shaped by society's negative view of dementia along with the "right to die" view.[28] Several concerns were explicitly highlighted. First, the difficulty in accurately assessing unbearable suffering: *"Someone suffers unbearably when he says he is suffering unbearably... I lack the tools to ascertain it. I'm not saying it is not true, but I also can't say that it is"*.[29] Second, considering the patient's actual behavior: *"A dementia patient who has an advance directive for euthanasia and does not ask for it, termination of life, you know, or does not very explicitly utter all kinds of wishes to die and does so consistently, then I wouldn't even consider it, so to speak"*.[29] Similarly, the third concern was that it is difficult to determine the appropriate moment for granting the euthanasia request: *"[Imagine a person with dementia who says] 'If I become demented and do not recognize my family anymore, I want euthanasia'. And if such a person at a later moment in time happily engages in activities, and his daughter comes to visit him, and he doesn't recognize his daughter anymore, I could of course say; 'Good afternoon, I am the doctor and I am going to give you an injection'. This was written down at one point by this person, but is it what he wants now?"*[28]

Responsible family members. The perceptions of relatives with an AED-based euthanasia request seem to be ambivalent. On the one hand, 90% of relatives of persons with dementia in the Netherlands agreed that "euthanasia is permissible for incompetent patients if they signed an advance euthanasia directive when they were still competent".[30] A similar proportion was found for relatives surveyed in Canada, except that they agreed only if the person was in a terminal stage and showed signs of distress.[31] Another study, on the other hand, one that focused on the actual experiences of relatives, found that only 14% wanted the euthanasia request to be strictly enforced.[29] In the majority of cases (62.7%), relatives interpreted AEDs as a constraint placed on life-sustaining treatments. Their reluctance came from their feeling that the extent of suffering would be impossible to determine and that an actual wish of the person with dementia may be absent.[29]

Qualitative studies confirm that vulnerabilities experienced by relatives of persons with dementia are present when actual end-of-life decision-making arises, especially in the case of EAS.[32] Family members generally express their willingness to participate in end-of-life decision-making processes; nevertheless, they report feeling uncomfortable with their role, one charting 'unfamiliar territory'.[33] Family carers who engage in the end-of-life process of persons with dementia expressed feeling stress, guilt, fear, doubt, and anxiety.[33] To cope with these feelings, family members highly valued strong relationships with healthcare professionals, ones based in trust.[34]

General Public. Contrary to the reluctant attitude of most Dutch physicians toward AED in persons with advanced dementia, empirical research suggests that 60-77% of the general public had an accepting attitude.[26, 27] Qualitative studies show that members of the general public have a negative image of advanced dementia, especially when they have personally witnessed it in friends or relatives.[35] They tend to see dementia as a

degrading condition, characterized by humiliating suffering, lacking any prospect for relief. One of the participants stated: *“If you see elderly people who have gone downhill and behave like small children, you say, “I don’t want that”. So, then there has to be the option that if you become like that, you can say, “Just give me a pill or an injection or whatever””*. [35]

The negative image of dementia may bolster people’s interest in ending their life when they want. Some authors even suggest that the dominant social presentation of dementia is more damaging to one’s personhood than the underlying neurological impairment. [14] Public perceptions of dementia are shaped by fear and stigma, causing older people to worry about dementia more than any other health decline. [36] Older adults' fear of living with dementia is based on the perceived loss of independence, control, identity, and dignity. [37] One older adult stated: *“Well it’s people that can’t remember anything or anybody. They can’t go out on their own or do their shopping or anything like that, and they forget who their relations are...I dread it”*. [37]

In summary, societal narratives about the fear of dementia shape public perception of this disorder as well as the experiences of people living with dementia and their relatives. One shared aspect of these narratives is that people with dementia should have the opportunity to choose when to die, so they can mitigate the fear and inevitable suffering of advanced dementia.

Multi-perspective and multi-layered vulnerability. As demonstrated, substantial disagreement exists among the four stakeholders: physicians, persons with dementia, relatives, and the general public regarding euthanasia in persons with advanced dementia. Even in the Netherlands, where there is broad consensus in support of euthanasia based on major arguments of compassion and respect for patient’s

autonomy, physicians stand apart from all other stakeholders, particularly regarding persons with advanced dementia.[26, 27] What are the reasons behind this divide? More permissive attitudes among the general population might be attributed to superficial knowledge of the condition compared to what physicians know and, secondly, to appreciably different roles of non-specialists and physicians regarding decision-making.

The chasm between the expectations of non-specialists regarding freedom to choose the moment of death and what physicians think they can actually do, should be further clarified, as they provoke feelings of vulnerability and powerlessness on both sides. As summarized by a Dutch elderly care physician: *“I find this a very difficult and complex matter,if they [patients and relatives] ask for death, well..., in the early stages of dementia people will say; What a waste; you’ve still got some good years ahead of you”. But if they’re late, they will say: “Well, it’s too late now, he’s gone completely nuts.” And to plan this. “That’s just as difficult as everyone thinks it is, you see”*. [28]

The above-mentioned perceptions of all stakeholders reveal a multi-perspective *lived experience* of vulnerability, which can also be characterized as multi-layered with physical, psychological, relational, and moral aspects. Vulnerability is clearly present, although expressed differently, in all the persons involved in AED-based euthanasia practices. We take this vulnerability as the starting point for developing ethically sound answers to this complex issue.

Care through an Interpretative Dialogue

According to Margaret Walker,[38] care is the practice of responsibility in which all people involved react to vulnerability. Nevertheless, what the "adequate care response" is to this vulnerability is not self-evident, since care circumstances inevitably change and both care-receivers and givers are embedded in a dynamic flow that demands

constant evaluation, interpretation, and deliberation. Therefore, adequate care is necessarily reached through a dialogical process of communication and mutual understanding. What does this mean for end-of-life care of persons with advanced dementia in general, and for the practice of AEDs in particular?

Generally speaking, medical interventions in dementia care are more focused on “cure” aspects than on “care” needs. Thus, we are facing a contradictory situation. On the one hand, persons with advanced dementia receive too many futile interventions in an effort to prolong some kind of life. On the other hand, their specific end-of-life care needs seem to be insufficiently met.[39] A major reason for this deficient end-of-life care is patients’ diminished ability to communicate, resulting in a misinterpretation of their real needs.[40]

Advance directives may *a priori* be a useful instrument for persons with advanced dementia to inform others about their end-of-life preferences. However, their use remains highly problematic, mainly because of two particularities of dementia.[41]

First, unlike other incompetent patients, such as comatose patients, persons with dementia usually experience a slow and progressive decline in competence. Second, even if people with advanced dementia could eventually be deemed incompetent, they still interact to some degree with their surrounding environment. They are able to express preferences or disagreement via basic utterances and simple behaviors. These particularities of persons with dementia lead to a potential conflict between their documented wishes, as stated in an advance directive, and their current interests, as conscious and alert beings, although with diminished competency.

Further, advance directives do not spontaneously execute themselves; an independent agent is involved. Very often, advance directives place a huge burden on family members and healthcare professionals, who have to actively execute them.[42]

Relational analyses uncover difficulties for each of the stakeholders involved: first, the *patient's* perspective may be inadequately understood by caregivers. Supporting this notion, people with dementia tend to rate their quality of life significantly higher than outsiders.[35] Second, *family caregivers* feel that advance directives are often difficult to interpret. They report being uncomfortable in these situations.[33] Third, *healthcare professionals* usually have limited knowledge of the patient's life history and therefore face a difficult dilemma: either focus on the currently expressed preferences of the person who has dementia now, at the risk of overlooking the previously documented preferences; or accept the preferences as described in the advance directive, regardless of the current wishes expressed by the incompetent person with dementia.[43] All perspectives considered, this complexity points out the need to promote an interpretative dialogue between the different stakeholders involved in end-of-life care practices.

Similar challenges are found in AED use in persons with advanced dementia. Physicians confronted with an AED have to determine whether the previously expressed desires match the patient's current wishes, and they have to do this without actually discussing it with the patient.[28] De Boer and colleagues conclude that AEDs cannot replace actual communication occurring in the present, because mutual understanding is an essential part of ethical end-of-life decision making, and this communication is often absent at the time of AED enforcement.[29] An inherent paradox is present in the design of AEDs, namely that AEDs "were developed for situations in which the patient is no longer able to actively communicate a request for euthanasia, but exactly this lack of in-depth communication seems to be the crucial factor in the non-compliance with AEDs".[10]

Even from a legal standpoint, actual patient-physician communication and mutual understanding seems to be essential in order to assess due-care criteria. In this regard,

Hertogh and colleagues argue that the “unbearable and hopeless suffering” condition demanded by the law to carry out an euthanasia request, does not primarily refer to the intensity or severity of the suffering but to the shared conclusions of the doctor and patient in a particular situation that these are in fact present.[14, 42] They argue that it is not up to the patient or the doctor *alone* to decide if there is no way to alleviate the person’s suffering other than euthanasia.

In summary, “blind” adherence to AEDs is not a care practice that provides an adequate response to the vulnerabilities experienced by persons with dementia, their relatives, and healthcare professionals. An interpretative dialogue that respects the multi-layered vulnerability of the different stakeholders is necessary to achieve what can be considered as good care.

Dignity as Normative Standard

Any clinical and legal framework on end-of-life care is ultimately based on normative criteria that identify what is considered good care. In the previous section, we showed that a unilateral approach that respects only the *precedent* autonomy of the person with dementia is unsatisfactory in adequately responding to the different vulnerabilities of the stakeholders involved. Therefore, some authors advocate basing end-of-life decisions on the “best interest standard,” one that considers the *current* situation of the person with dementia.[14] We will argue that this approach is still lacking in one respect. We purpose to extend the scope of the framework beyond the person with dementia by re-orienting the normative standard of good end-of-life care. We argue that “enhancing the dignity of *all* stakeholders involved” should be at the core of this normative standard.

Achieving dignity is often invoked as a guiding principle for end-of-life care practices; nevertheless, it has been criticized for its vagueness and ambiguity. In a literature review of dignity and health, Jacobson,[44] outlined two major lines of thinking about dignity: the first considers it to be an inherent, irreducible and stable dimension of every human being. By contrast, the second line considers it to be a subjective and changeable dimension influenced by external factors. Analysis of this dichotomic view of dignity leads one to the point of identifying two complementary, yet distinct, forms of dignity that can be described as absolute and contingent; basic and personal; objective and subjective; *menschenwürde* and dignity of identity; dignity of stature and dignity of merit; human dignity and social dignity, among others. The general distinction between basic dignity—as something intrinsic and ontological, and dynamic dignity, as an extrinsic personal quality that is related to people’s perception of themselves in the context in which they live—can also be recognized in other authors’ writings that address the notion of dignity in end-of-life care.[5, 45]

Although different concepts, autonomy and dignity seem to be closely interrelated, especially at the end of life. Rodriguez-Prat et al.[5] have shown that in end-of-life contexts, perceived dignity is mediated by a person’s sense of autonomy and ability to control physical functions and their immediate surroundings. This stereotypically reflects a value in Western culture, which highly values independence and rationality, and therefore considers that autonomy must be recognized and respected in order for one to be thought of as a dignified person.[5, 44] How are these values maintained in persons who are incompetent? With dementia, a critical question arises about the relationship between dignity and autonomy, since it is a disorder that particularly affects the self. If dignity refers to an individual maintaining self-respect and being valued by others, and autonomy is the capacity for making decisions that reflect the self who

makes them, then maintaining both dignity and autonomy in persons with dementia becomes problematic.

In the debate about autonomy in persons with dementia, extrinsic conceptions of dignity seem to align better with the value of precedent autonomy and the priority given to the “*then self*,” i.e., when the patient was still competent. Intrinsic conceptions of dignity are better identified with the importance of preserving personal identity of the “*now self*” and respecting his/her preferences. Nonetheless, as suggested by Koppelman,[46] this “seemingly irresolvable” debate has stalled, since both viewpoints are attractive but incomplete. While the former highlights a commitment to a stable set of identity-defining values that gives the patient control, the latter appeals to compassion and empathy towards a current personal identity, one that expresses itself in a less-cognitive way. A comprehensive view needs to consider the “whole self,” putting both perspectives into dialogue without simply neglecting the other.[46]

Thus, “enhancing dignity” cannot be simply equated with “respecting autonomy,” and in this regard, several scholars argue that the concept of human dignity is unavoidably complex.[45, 47] Moreover, Kirchhoffer and Dierickx highlight that any concept of dignity is necessarily underpinned by a certain view of the person, and the latter cannot be reduced to one or other feature.[47] Along these lines, care for the human body is an important dimension of dignity-enhancing care, but it is not unique. The psychological, relational, social, and spiritual dimensions of the person deserve attention too, as they correspond to the multi-layered dimensions of human dignity. In other words, dignified end-of-life care for people with dementia is a kind of care that endeavors to promote the fullness of the person in *all* his or her dimensions.[19]

In summary, we do not support a narrow view of dignity that focuses exclusively on the

loss of autonomy of the person with dementia. Therefore, our stance does not consider AED to be an appropriate response to the ethical challenge of persons with dementia who express their desire to choose when to die (*then* self). Rather, we hold a broader view of dignity that additionally takes into account the perspective of the actual person with advanced dementia (*now* self). Our analysis of the various vulnerabilities experienced by all the stakeholders involved in AED practices prompts us to put at the center of the discussion not only the person with dementia but also their family members, and healthcare professionals responsible for their care. Since these parties also experience vulnerabilities, their perspectives deserve to be heard and added into the decision-making processes. Thus, a complex view of vulnerability, characterized as multi-layered and multi-perspective, calls for a complex view of dignity, equally multi-layered, and multi-perspective. How does one position these views into dialogue, balancing their legitimate interests and concerns, until ‘good end-of-life care’ is achieved for persons with dementia? We suggest three concrete operationalizations of the Dignity-Enhancing Care approach that may adequately respond to the complexities we have identified in end-of-life practices of persons with advanced dementia.

OPERATIONALIZATION OF THE DIGNITY-ENHANCING CARE MODEL

The Dignity-Enhancing Care approach demands that care be given in response to the vulnerabilities of human beings in order to maintain, protect, and promote their dignity as much as possible. Through the analysis of lived experiences, a call for interpretative dialogues and development of a normative standard, the Dignity-Enhancing Care approach is applied to persons with dementia who express their desire to choose when to die. We now focus on three ways this approach can be practically implemented: (1) Relational autonomy is proposed as an account of autonomy that considers the

experience of multi-layered *vulnerability* expressed by the four stakeholders in end-of-life situations; (2) advance care planning is a practical tool for decision-making in care for incompetent patients, which calls for an *interpretative dialogue* in order to be applied; (3) finally, attention is turned to the practice of palliative care in persons with advanced dementia as a way to *promote the dignity* of persons from a holistic point of view. These three concrete ways of applying dignity-enhancing care enable persons with dementia to choose how to die in a dignified way.

Relational Autonomy

Our analysis revealed that the current way of dealing with AEDs as exemplified in the Netherlands, may override the actual wishes of incompetent persons with advanced dementia. It puts an excessive burden on doctors who are treated as if they were mere instruments executing an AED and harms family members when they have to make difficult decisions concerning AED compliance. A relational account of autonomy is therefore proposed as an appropriate understanding for incompetent patients who remain active agents into advanced stages of their dementia.[48] From a relational perspective, family members and healthcare professionals are encouraged to promote the remaining autonomy of persons with dementia, along with promoting their quality of life and dignity.[14]

“Relational autonomy” is an emerging concept, increasingly used in the end-of-life ethics literature, although it still needs more fleshing out to be adequately operationalized in end-of-life care practices.[18] Along these lines, new attempts of conceptualization have proposed a multidimensional, relational, scalar, and temporally extended account of autonomy, one that can effectively guide end-of-life care practices.[17]

In the same vein, relational autonomy contributes to the normative foundation of the Dignity-Enhancing Care approach, one that promotes an engaging dialogue between the different stakeholders involved. In the case of *persons with advanced dementia*, a relational account of autonomy brings to the front the wishes of incompetent persons who are not able to express themselves in a verbal manner but remain in communication with their relational environment. *Family members* are also called to participate in the decision-making process, while offering them adequate support according to their particular needs and experiences of vulnerability. *Healthcare professionals* share the responsibility of making decisions, but they are not left alone in the difficult process of balancing the patient's current wishes and the long-standing preferences expressed in the form of advance directives. Finally, *society* is encouraged to nuance its views on aging and dependency, reducing stigma against and fear of dementia.

Literature on the ethics of dementia care harbors many examples of such a multi-perspective dialogic approach to end-of-life decision-making. Karlawish et al.[49], for instance, propose a “consensus-based approach” that aims to provide end-of-life care to patients who lack decision-making capacity and takes into account the physician's guidance and the relatives inputs. McCarron and colleagues[50] propose five concrete steps to facilitate discussions between the healthcare staff and family members, ones based on relationships of trust built up through time. These steps make a particular effort to understand the patient's attempts at communication, and with life-story strategies as a record of the person's preferences and wishes. These proposals can be considered to be attempts to operationalize relational autonomy in the case of persons with advanced dementia. They are not exclusively focused on cognitive aspects of communication but include body language, emotions, and feelings. Interpretation thus becomes an essential component of dementia-care practices. Furthermore, this

interpretative dialogue is not reduced to isolated, discrete moments of choice; it is rather exercised over time through relations of trust and mutual understanding. This is precisely what advance care planning comprises.

Advance Care Planning

Advance care planning (ACP) is a continual process of reflection and dialogue that assists persons in sharing their personal values, life-goals, and preferences regarding future medical decisions.[51] This ensures that future care during serious and chronic illnesses is consistent with articulated desires of the person with dementia.[52] ACP aims to facilitate timely discussions about the goals of care between persons with dementia, healthcare professionals, and family members. It has demonstrated the ability to prevent burdensome and futile interventions, and thereby to promote comfort for persons with dementia, allow better access to palliative care, relieve caregiver strain, and reduce healthcare costs overall.[53]

Despite these positive outcomes for all stakeholders, ACP still has little implementation in clinical reality.[54] Reasons invoked by the different stakeholders are varied: *Persons with dementia* often lack information about the practice and tend to avoid what is experienced as a complicated and sensitive matter[55]; *healthcare professionals doubt whether they could actually meet patients' wishes and what their individual role and responsibility is*[54]; *family members* criticize the treatment-oriented approach of these documents and would like to address broader aspects of care, such as maintaining daily function, promoting comfort, etc.[34] These difficulties confirm the necessity of an interpretative dialogue between the different persons involved, especially when the difficulty of advancing the many possible scenarios at the end of life is considered. Clinical experience shows that if the guidelines remain vague and open, they can easily

be misinterpreted by healthcare staff, but if the directives are too concrete and contextual, they are difficult to apply in changing circumstances. Thus, permanent dialogue and interpretation are essential components of ACP when it comes to respecting the complexity of end-of-life situations.

Finally, our understanding of ACP embraces a prudent stance that considers the wishes of the “*then self*,” drafted in the ACP by the still-competent person, and the actual preferences of the “*now self*,” expressed in non-verbal ways and interpreted by the family members and healthcare professionals. By adopting such an understanding of ACP, we reject a “blind adherence” to legal documents that solve the problem at the cost of oversimplifying it, giving sole priority to one stakeholder. An interpretative, dialogical approach to ACP aims to respect the multi-perspective character of end-of-life care for persons with dementia, both diachronically (*then self* and *now self*) and synchronically (the patient, family, healthcare professionals, and society).

Palliative Care

Palliative care philosophy has a holistic vision of care that includes not only the bodily dimensions of comfort and pain control but also the psychological, social, and spiritual dimensions of being human. Likewise, its caring-focus goes beyond just the person with dementia; it also considers family members and healthcare professionals. In this sense, palliative care articulates well with the multi-layered and multi-perspective vision that has been laid out in this paper. In particular, the Dignity-Enhancing Care approach describes the vulnerability and dignity of persons with dementia and their relational environment, which overlaps with the holistic philosophy of palliative care.

As stated before, we believe the starting point for end-of-life care for persons with dementia is the lived experiences of vulnerability of the different stakeholders involved.

In this regard, research reveals that more than 50% of *persons with advanced dementia* at the end of life live with chronic and persistent symptoms, including pain and agitation.[56] These complex and distressing symptoms are underdiagnosed and poorly treated, requiring further collaboration between multidisciplinary healthcare professionals. Besides, *family members* often suffer from “caregiving burden” which negatively affects their health and quality of life.[53] Finally, *healthcare professionals* who treat persons with dementia at the end of their life report feeling ill-prepared due to the lack of acute prognostic skills and prospective models that can assist their decision-making.[53, 56]

This multi-perspective view of multi-layered vulnerability can be adequately addressed by palliative care. This care approach has proved effective in different domains that enhances quality of life of persons with dementia.[57] Furthermore, it can lessen caregiver burden and help medical decision-making by ensuring that treatment decisions are consistent with patients’ wishes and articulated goals of care.[53] However, studies suggest that persons with dementia do not benefit from timely and optimal palliative care. This is largely due to dementia being under-recognized as a terminal condition, and patients are referred too late [40]. For this reason, the European Association for Palliative Care has established eleven domains aimed at improving palliative care for older adults with dementia (see Table 2).[58]

Table 2. The EAPC eleven domains of palliative care for dementia:

- | | |
|----|---|
| 1. | Applicability of palliative care |
| 2. | Person-centred care, communication and shared decision making |
| 3. | Setting care goals and advance planning |
| 4. | Continuity of care |

5.	Prognostication and timely recognition of dying
6.	Avoiding overly aggressive, burdensome or futile treatment
7.	Optimal treatment of symptoms and providing comfort
8.	Psychological and spiritual support
9.	Family care and involvement
10.	Education of the health care team
11.	Societal and ethical issues

These eleven domains fall under the umbrella of a holistic view of the person, considering the person from five dimensions: physical (domains 3,6, and 7); psychological (domains 1,5, and 8); relational (domains 2 and 9); social (domain 11) and spiritual (domain 8). Nevertheless, this proposal may not be complete, as Poole and colleagues point out some domains that need further development in order to afford optimal palliative care to persons with dementia.[59] Their qualitative study suggests that palliative care does not always meet patients' and families' preferences, and thus should strengthen the following aspects: first, integrate end-of-life views of *persons with dementia* in different stages of the condition; second, improve understanding of dementia as a palliative condition, especially encourage that view among *family carers*; third, explore how interventions promoted by *professionals*, such as ACP, can be more effectively implemented in dementia care. These three areas are remarkably relational, referring to the different stakeholders involved in end of life, and thus confirm once again that end-of-life care in persons with dementia is best characterized as multi-perspective.

In conclusion, persons with dementia at the end of their life become increasingly vulnerable, not only in a physical sense but also in psychological, relational, social, and spiritual senses. Nonetheless, they are not alone in this regard: family members and

healthcare professionals also experience this progression via different dimensions of vulnerability. Palliative care can provide an appropriate response to these lived experiences if its holistic approach is developed in two ways. First, it must pay adequate attention to all dimensions of the person. In this way, the multi-layered aspects of a person's dignity is actually enhanced. Second, it must consider the perspectives of the different stakeholders involved, each of whose is multidimensional. By doing so, palliative care responds to the complexity of end-of-life situations through dialogical strategies applied between persons with dementia and their relational environment.

CONCLUSION

Our analysis addressed the ethical challenges of dealing with persons with dementia who express their desire to choose *when* to die. After the examination of AED's practice in the Netherlands, we proposed the Dignity-Enhancing Care approach to critically reflect upon end-of-life issues in dementia care. As shown, this model is at its core multi-perspective and multidimensional. Thus, it acts as a lens that enables one to gain a comprehensive look at this difficult ethical issue. The model begins with the lived experiences of vulnerability and responds to them with a shared understanding of adequate care as the best way of promoting human dignity.

In order to operationalize the Dignity-Enhancing Care approach in real end-of-life care of persons with dementia, we described three concrete proposals. First, we consider it important to take a relational view of autonomy, which takes into account the different stakeholders' perspectives. Second, a dialogical-interpretative understanding of the practice of ACP should be engaged. Third, a comprehensive approach to palliative care should be applied to persons with dementia in order to promote a rich, multi-layered concept of dignity for all the persons involved. These three proposals are not intended to

be an alternative to AEDs, but rather a way to improve the context of end-of-life care. Together they try to offer concrete protection to vulnerability, thereby increasing the dignity of all parties involved.

When carefully pondering empirical data and respecting the complexity of end-of-life practices for persons with dementia, the issue is not adequately resolved by considering the vulnerability of just one stakeholder alone—the *then* self. A comprehensive view takes into account the different perspectives of *all* people involved, in line with a dialogical solution. Only in this way can dementia care adequately respond to vulnerability and also enhance the dignity of all persons affected by this complex ethical challenge.

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