

OPEN PEER COMMENTARY

Commentary: Can an effective end-of-life intervention for advanced dementia be viewed as moral?

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Abstract

We comment on Dr. Terman's considerations on the moral justification of ceasing assisted feeding and hydration for people with advanced dementia. The core idea of his paper is that an advance directive can solve future dilemmas regarding assisted feeding. We submit that this static instrument is unfit for the complex and dynamic nature of assessing how to deal with refusals to eat, in particular for people with dementia. It overvalues the past in relation to the present situation and leaves no room for the possibility of changing wishes. Moreover, the perspectives of professional caregivers and families are not addressed because the focus is entirely on individual autonomy in early dementia. Multiple perspectives should be considered in interpreting directives and the actual situation in light of the patient's view of life in order to realistically account for what is morally justifiable in care in advanced dementia.

KEYWORDS

advance care planning, advance directive, autonomy, dementia, end of life, ethics, family, feeding methods, morals

COMMENTARY

Dr. Terman aims to inspire debate on the issue of facilitating “timely dying” in advanced dementia.¹ He presents arguments for and against the view that advance directives, indicating when ceasing assisted feeding and hydration is allowed, can lead to morally justified interventions that prevent prolonged dying with suffering. We recognize and underline the importance of a constructive dialogue on this morally charged topic. We agree with Terman that a semantic discussion on whether assisted feeding is basic care or a medical treatment adds little or nothing to the debate (see his treatment of “Criticism II”).¹ We also agree that comfort-focused treatment, which is common in care for people with dementia, is important in preventing prolonged dying with suffering.

There is much to say about the way Terman presents each of the eight criticisms and the arguments against them.¹ But we question whether the concise renderings offered by Terman can do justice to the points of criticism. Also, the distinctions between “ethical,” “legal,” and “(im)moral” are insufficiently explored and it remains unclear what exactly is meant by the central question of whether “an effective end-of-life intervention for advanced dementia can be viewed as moral?” However, in this commentary, we focus on the content of the argument by asking: Is the central premise, from which Terman discusses whether ceasing assisted feeding can be moral, convincing? This is the premise that an advance directive could solve very particular and precise end-of-life dilemmas for people with dementia and ensure a peaceful and timely dying. In our view, this is a simplification of a very complex issue in which a number of arguments and perspectives are neglected.

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First, the premise implies that the directive itself should be very specific and precise, covering a wide range of conceivable end-of-life situations. Aiming for advance directives of this kind would require forcing people in an early stage of dementia to make explicit statements about a situation they may not know or foresee. Research shows it is very difficult for patients with dementia to imagine their future, including their care preferences.^{2,3} In advance care planning conversations, patients do not think in terms of specific medical interventions or decisions, but rather in broadly formulated care goals. This could be the reason why most advance directives are written in vague terms that need to be interpreted by family and health care providers to apply them to the situation at hand.^{4,5}

Second, in addition to competence issues and the possibility of discrepancy between their former and present will, people with dementia are also “there,” interacting with their environment in their own way. We acknowledge the suffering that dementia brings to patients and their families. But people living with dementia can also be happy, content, unaware of their situation, or experiencing a certain quality of life. The actual situation may thus be different from what was dreaded in advance. Especially with dementia, it is quite unpredictable how much observable suffering there will be in advanced stages of the disease. If, for example, the advance directive marks the point when one no longer recognizes one's own children as the moment of too much suffering which should trigger the cessation of feeding, the actual well-being of the person with dementia is no longer a factor of importance. In Terman's approach, the possibilities in the advanced stages of dementia of coping with the disease, having a diminishing death wish, or having a change of heart, are not addressed.^{6–8} By putting the advance directive in a guiding role, or assigning it a decisive status, the locus of authority is placed completely in the past. The (perhaps unintended) effect is viewing the person with dementia standing in front of you in the present completely through the lens of the advance directive, and as a result, ignoring his or her actual situation. This is contradictory to the concept of person-centered care, which is common policy in nursing homes and in caring for people with dementia in general.^{9,10}

Besides the lack of attention to these two arguments, there are two perspectives that deserve more reflection when it comes to the actors Terman calls “authorities with power”: the perspectives of health care professionals and family. Health care providers experience the tension and stress of the moral dilemma of whether to cease feeding at least three times a day when they are confronted with a patient's refusal to eat without clear cause. Research shows professionals struggle with this, and they differ in their interpretation and response.¹¹ In Terman's approach, this perspective is not accounted for. The primacy of the advance directive reduces professionals to mere executors, as they are not the ones who make the actual decision to cease assisted feeding. One may wonder whether the professionals are then “authorities with power” or in fact rather powerless.

As regards the perspective and role of family, research shows that considerations about family members appear to be very important for patients when they have a wish to die.^{12,13} End-of-life choices and wishes are influenced and shaped by relationships with family members.^{12–15} Research in the Netherlands shows that the family has

an important role in interpreting the wishes contained in the advance directives.¹⁶ They are often the experts on the patient's life story and what he or she considers important in life, which is crucial to interpreting the directive and making the right decisions. Of course, family can also be a very problematic factor in this process; they may have different opinions and interests among themselves and this creates difficulties in medical decision-making.^{17,18} But family members are also stakeholders rather than the bystanders or “well-meaning third parties” to which Terman reduces them. We want to underline that taking family members' perspectives seriously does not dismiss ceasing assisted feeding as an option or, as a rule, harm the patient's autonomy.

We agree with Terman that it should be possible to include ceasing assisted feeding in advance directives and that this could be a viable way to a peaceful end of life. It can indeed be moral under circumstances. It seems right to consider the preferences of people with dementia in some form. However, it may be immoral to leave this solely in the hands of a document based on precedent autonomy which is a very limited format for people with dementia due to their reduced self-determination. A cross-cultural study on the conceptualization of a good end of life with dementia found that even in Western countries patients benefit from, and value, relationships more than full autonomy.¹⁹

We are aware that our approach of involving health care providers and family in assessing the desirability of end-of-life interventions may be viewed as paternalistic by advocates of individual autonomy and self-determination. In our view, however, issues such as ceasing assisted feeding are too complex to consider through the narrow lens of autonomy that is statically defined in a directive. A wider and more dynamic scope is needed that fits the reality of the daily life of people with dementia, their family, and their health care providers.

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The authors have nothing to report.

CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest. Author disclosures are available in the [supporting information](#).

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SUPPORTING INFORMATION

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