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ETHICAL ISSUES RELATED TO END OF LIFE TREATMENT IN PATIENTS WITH ADVANCED DEMENTIA –THE CASE OF ARTIFICIAL NUTRITION AND HYDRATION

– Esther-Lee Marcus, Ofra Golan, David Goodman –

Abstract. Patients with advanced dementia suffer from severe cognitive and functional impairment, including eating disorders. The focus of our research is on the issue of life-sustaining treatment, specifically on the social and ethical implications of tube feeding. The treatment decision, based on values of life and dignity, involves sustaining lives that many people consider not worth living.

We explore the moral approach to caring for these patients and review the history of the debate on artificial nutrition and hydration showing the impact of the varying perceptions of the value of these patients' lives on changing norms. We argue that in light of the value of solidarity, decisions about life-sustaining treatment for patients with advanced dementia should be made on a case-by-case basis, as with any other patient, in consideration of the medical implications of the intervention which might best serve the goals of care (i.e., care and respect for dignity) for the individual patient.

Keywords: artificial nutrition and hydration, comfort feeding, dementia, dignity, end of life, ethics, solidarity, tube feeding, right to life.

INTRODUCTION

Dementia is a progressive, incurable illness which can last for many years. In patients with advanced dementia, the last year of life is characterized by severe disability which includes extreme memory deficits (e.g., the inability to recognize family members), minimal verbal abilities, the inability to ambulate independently – being bed- or chair-bound, the inability to perform any basic activities of daily living, and urinary and fecal incontinence.¹ Consequently, patients are dependent on others – family members and hired caregivers – 24 hours a day. In many cases they reside in nursing homes. The most common clinical complications are eating problems and infections, both of which require management decisions.²

¹ Mitchell [2015].

² Berry, Marcus [2000]; Mitchell, Teno, Kiely, et al. [2009].

Dementia is among the most common age-related conditions. The prevalence of dementia worldwide has been estimated as 4.7% of the population over 60, which equaled 35.6 million people in 2010. As society ages, more and more people reach the 'old' and 'old-old' ages (74–84 years and 85+, respectively). It is estimated that the number of people with dementia will almost double every 20 years from 2010 to 2050.³

The growing population of patients with dementia, and specifically with advanced dementia, presents society at large, and healthcare providers in particular, with the troubling issue of life-sustaining treatment for these patients. In addition to their full dependency on nursing care, these patients may require artificial feeding because of dysphagia and/or refusal to eat; most will occasionally suffer from infections or other conditions that require routine medical treatment, e.g., with antibiotics. Some patients with dementia may also require oxygen or may need to be mechanically ventilated to treat respiratory insufficiency due to aspiration pneumonia. This phenomenon has vast social and ethical implications, raising the question as to what the morally right treatment for these patients is. The current paper discusses these issues from the point of view of the caregivers' moral obligations towards these patients. The related question of resource distribution, which deals with the obligations of the healthcare system at the macro level, is beyond the scope of this paper.

THE SOURCE OF THE DILEMMA

We have no objective indication as to how patients actually feel when they are severely demented, and we have no idea what their best interests are. However, the roots of the comprehensive deliberation on this issue are much deeper since, as Stephen Post observes,⁴ in treating people with dementia we are "confronted with a human condition that we wish to avoid above all others." Dementia is perceived by the elderly as the most frightening condition. Surveys suggest that older people are more concerned about the possibility of developing dementia than they are about cancer, heart disease, or stroke.⁵ For family members who watch their loved ones deteriorate and see them lose their intellectual capabilities, change their behavior, and become unrecognizable from their former selves, the experience is extremely difficult. Even those who are not related to patients in this condition often feel that "being in their presence makes us very uneasy," as very

³ Doron [2014].

⁴ Post [2000] p. 6.

⁵ Nuffield Council on Bioethics [2009] p. 58, and the references in their footnote number 179.

courageously admitted by Meilaender: “there's a part of us, there's a part of me that inevitably wishes they'd go away not because it's such a problem, but because they're one of us. They show us our future, and they make us very uneasy.”⁶ Thus, the very core values of life and dignity on which the treatment decision is based, make it controversial: It involves sustaining life that many, if not most of us, consider not worth living or even worse than death, and considering the dignity of patients in such a state which is regarded as severely compromised.

The acknowledgement of these background perceptions is necessary for ethical decision-making. In Meilaender's words, these perceptions “suggest a tendency that we need to guard against. One needs to be conscious of it all the time and take it into account.”⁷ Furthermore, another ‘red flag’ that should be consciously borne in mind is the matter of cost and the temptation to save the huge cost of sustaining the lives of this growing patient population. As Callahan noted: “Given the increasingly large pool of superannuated, chronically ill, physically marginal elderly, it (‘denial of nutrition’) could well become the non-treatment of choice.”⁸

These considerations demand that treatment for such patients be thoughtfully decided for the well-being of the patient, rising above any perceptions the decision makers might have about the quality of his or her life. Two leading councils on bioethics that have dealt with the ethics of medical treatment for patients with advanced dementia – The President's Council on Bioethics in the United States in 2005, and the Nuffield Council on Bioethics in the United Kingdom in 2009 – concluded that “the goal of caregiving [...] should always be to serve the well-being of the person now here, always trying to benefit the life an individual still has, even when that life has been diminished by disease, debility, or dementia.”⁹ And that

[...] a decision to cease active treatment (for example withholding antibiotics that may possibly cure a chest infection) should not be made on the premise that a life with dementia is not worth living. Rather, in such cases, the benefits and burdens of treatment for this particular person must be considered.¹⁰

⁶ The President's Council on Bioethics [2004].

⁷ Ibidem.

⁸ Callahan [1983] p. 22.

⁹ The President's Council on Bioethics [2005].

¹⁰ Nuffield Council on Bioethics [2009] p. 56.

This clear guideline stems from the recognition of the personhood and equal value of individuals with dementia. This recognition is an essential component of the Nuffield Council on Bioethics' ethical framework.¹¹ The equivalent statement of the American President's Council on Bioethics is that:

Human beings who are dwindling, enfeebled, or disabled in body or in mind remain equal members of the human community. As such, we are obligated to treat them with respect and to seek their well-being, here and now. We should always seek to benefit the life incapacitated persons still have, and never treat even the most diminished individuals as unworthy of our company and care.¹²

However, the view that persons with advanced dementia are equal human beings has been subject to much philosophical controversy. That, together with the conscious or unconscious preference of death over life for these patients, seems to have influenced the bioethical discourse regarding decisions about life-sustaining interventions.

IS THERE A MORAL OBLIGATION TO PROVIDE LIFE-SUSTAINING TREATMENT TO PATIENTS WITH ADVANCED DEMENTIA?

Generally, the application of life-sustaining treatments may pose a dilemma when there are grounds to assume that the burden of the treatment for the patient might outweigh the benefits. This can happen either when the intervention itself is burdensome, or when patients consider their lives to be so miserable that death is preferable. If the patient is competent, the decision should be made by respecting that patient's autonomy. However, severely demented patients, by definition, are not autonomous agents. "When the patient lacks decision-making capacity, moral authority is transferred to a valid surrogate, a living will, or a durable power of attorney."¹³ Under such circumstances, decisions can be made according to the patients' presumed will as far as this can be determined, based on their prospectively stated preferences, if there were any. When a patient's subjective views are unknown, some jurisdictions apply the 'best interests' standard, which adopts "the perspective of a 'reasonable person', choosing as most people would choose for themselves."¹⁴ Other jurisdictions apply the presumption that a person wishes to continue living, unless proven otherwise (e.g. in Israel, the Dying Patient

¹¹ Ibidem, p. 30-32.

¹² The President's Council on Bioethics [2005].

¹³ Pellegrino [2000] p. 1066.

¹⁴ The New York State Task Force on Life and the Law [1992] p. 55.

Law¹⁵), or the ethical rule “*in dubio pro vita*” – “when in doubt, favor life”.¹⁶ We claim that none of these practical solutions is satisfactory for caregivers who are seeking moral guidance regarding life-sustaining treatment for patients with advanced dementia. This specific case involves extreme views about the value of the patient's life and the misery of being in such a state. Therefore, a more solid basis for decision making should be explored when facing such a sensitive situation.

ANALYZING THE DILEMMA

It is common in applied ethics to use the practical pluralistic approach of principlism when aiming for widely acceptable decisions in the area of healthcare. This approach is consistent with, or at the very least is not in conflict with, a multitude of ethical, theological, and social approaches towards moral decision-making, and focuses on the intersubjective agreements between them.¹⁷ It focuses on the common ground of the four *prima facie* moral principles of autonomy, beneficence, non-maleficence, and justice. The practical activity includes specifying how the principles are to be applied in specific situations and balancing them with the other competing moral principles. We apply the more specific “Four Principles Plus Scope”¹⁸ approach to medical ethics developed in the U.S. by Beauchamp and Childress, which is based on those four principles, and also considers the scope of application, “to what and to whom we owe these moral obligations”.¹⁹

GOOD ETHICS STARTS WITH GOOD FACTS

The preliminary guiding principle of any ethical deliberation is that good ethics starts with good facts. In this discussion, however, there are more uncertainties than facts.

We know that patients with advanced dementia are human beings (though according to certain views they are not ‘persons’), that they are sentient, and that their life depends on ongoing medical care. We also know that most people would not wish to live in such a state, and there are even cases in which we have the patient’s advanced directives not to be kept alive under such circumstances.

However, we do not know what is going on in such patients’ minds. It has been argued that we should think of people with dementia as capable of valuing,

¹⁵ The Dying Patient Law [2005]; Jotkowitz, Glick [2009].

¹⁶ Pavlovic, Lehmann, Wendt [2009] p. 1.

¹⁷ Bulger [2007] p. 85.

¹⁸ Gillon [1994].

¹⁹ *Ibidem*, p. 187.

even during the advanced stages of the disease.²⁰ People with severe dementia might show powerful responses to music. There are also examples of people in this state demonstrating strong emotional attachment to pets,²¹ or who are able to use artistic and creative skills.²²

We do not know, however, what such patients are actually experiencing. Do they have any feelings? Are they aware of their situation? Are they miserable or content? Do they feel deprived of their lost abilities or humiliated by such losses? Do they have any wishes? Do they wish to be kept alive, or to die? What are their spiritual experiences? Is their soul free or locked in? What if the loss of self-awareness spares these people from the fear of mortality towards the end of their life? What if it is a release from the present, from anxiety over the past and future, as Japanese writer Ariyoshi described advanced dementia?²³ What if this situation releases them to a higher spiritual level? Maybe as high as one of the definitions of Zen: “being free of the distractions and illusory conflicts of the material world”?²⁴

These uncertainties create an epistemic gap. Thus, any decision to let a severely demented patient die must be taken very cautiously.

We should also be very careful not to interpret the experience of such patients according to our own values and ideals. As Post warns us,

To maintain care, we must not interpret the experience of people with dementia against a background ideal of pure reason and self-control... If the pictures are sketched with achievement-oriented, socioeconomic, and cognitive values in mind, harm will result, since “people who become old and frail and unable to do all they could in the past tend to find unanticipated value in small gratifications.”²⁵

Therefore, any decision to forgo life-sustaining treatment for a severely demented person needs to be examined with great humility, acknowledging our ignorance and inability to appreciate the subjective experience of such patients, so that it may be inappropriate to apply our perceptions of their situation (for better or worse) to their situation. Some claim that the same considerations should be applied even in regard to the very patient's former perceptions.²⁶

²⁰ Jaworska [1999].

²¹ Nuffield Council on Bioethics [2009] p. 32.

²² Crutch, Rossor [2006].

²³ Post [2000] p. 6.

²⁴ Lin [n.d.] p. 1.

²⁵ Post [2000] p. 26.

²⁶ For a review of the precedent autonomy problem see McGee [2014].

THE RELEVANT ETHICAL CRITERIA

This lack of a factual basis leads to the conclusion that the four principles are not helpful in the case of advanced dementia. Persons in this stage of the disease are cognitively incapacitated in a way that makes them ‘unautonomous.’ As such, the principle of autonomy is not applicable, at least for the majority of the patients who had not given advanced directives as to how they would have wished to be cared for once they reach such a state. Moreover, lack of knowledge about the burdens and benefits of the treatment for the patient, or in other words, whether sustaining the life of a person with advanced dementia is beneficial or harmful, creates a situation in which the principles of beneficence or non-maleficence are inapplicable. The only principle which may be relevant to the issue at stake is the principle of justice as it pertains to the question of respect for the rights of patients with advanced dementia. In such cases, assuming that the obligation of healthcare professionals to sustain the lives of their patients is based on the latter’s complementary right to life, the question would be: is the right to life of persons with advanced dementia equal to that of other people? We will address this question later in the paper. Another possible interpretation of the principle of justice is that the obligation of the caregiver would mean, in this case, serving the well-being of all patients, which is the aim of treatment, and not necessarily to sustain life by all means.

However, under these circumstances we should examine more thoroughly the moral values to which we may resort in dealing with this dilemma. Certain values, like care and human dignity (the dignity of the human person), have been suggested in the analysis of similar dilemmas.²⁷ Elsewhere, we suggested²⁸ that the principle of solidarity, which is one of the values of European bioethics, could be used to promote the discussion and may offer some guidance.²⁹ Głos refers to solidarity as a basis and guideline for discussion of the roles and responsibilities of the healthcare system and the informal family caregivers towards people who suffer from dementia.³⁰

In the current context, solidarity involves recognition of the ways in which people with advanced dementia are similar to ‘us.’ In Jewish thought this idea is represented by the interpretation, held by many commentators, of the command-

²⁷ Gastmans, De Lepeleire [2010].

²⁸ Golan, Marcus [2012].

²⁹ Hayry [2003]; ter Meulen [2015].

³⁰ Głos [2016].

ment “you shall love your neighbor as yourself”³¹ – “love thy neighbor (for) he is like yourself.”³² In American bioethics it may be referred to as the principle of equality, as stated by The President's Council on Bioethics:

In part, our equality arises out of our shared vulnerability. We are all vulnerable to the deprivations of illness or injury and to the limitation of mortality, and thus we all have a personal interest in ensuring that needy persons are treated equally and adequately [...] (T)he commitment to equal human worth stands as the basis of a welcoming community – one that assures all living human beings, even those in a disabled or diminished state, that their lives still have meaning, worth, and value for all of us. It assures them that we would not prefer them dead even if we would like to see an end to the suffering that marks their present condition.³³

The conclusion based on the above analysis is that solidarity entails a moral obligation to give severely demented patients optimal medical and nursing care, using the same medical judgment and considerations that any other dependent patient would receive. This involves two perplexing issues: the suffering of the patient and the dignity of the patient, both of which must be addressed in order to determine whether life-sustaining treatment is indeed the ‘best care’ for a given patient. (According to Cohen, ‘best care’ encompasses both solidarity and the obligations of the caregiver to the patients, and the ‘best interests’ of the patient).³⁴ As with any other therapeutic decision, it should be based on the patient’s condition and prognosis, applying relevant evidence-based medicine to consider the benefits and burdens of the intervention.

Certainly, if the patient endures pain and suffering that cannot be alleviated, it may be permitted, and in certain circumstances even obligatory to refrain from prolonging life. In a study which followed the clinical course of 323 nursing home residents with advanced dementia over a period of 18 months, a large percentage of them encountered distressing symptoms such as dyspnea (46%), pain (39%), recurrent infections such as pneumonia (47%), and underwent burdensome interventions, e.g. hospitalization and parenteral therapy.³⁵ Therefore, any suffering entailed in the treatment and its outcomes should be given due weight. However, in the case of patients with advanced dementia, there is no indication that

³¹ Leviticus 19:18.

³² Leibovitz [2005].

³³ The President’s Council on Bioethics [2005].

³⁴ *Ibidem*; Cohen [2004].

³⁵ Mitchell, Teno, Kiely, et al. [2009].

being in this state as such involves suffering, although their suffering may be undiagnosed and underestimated (or overestimated) because of communication barriers. Furthermore, any claim that such individuals should not be tortured by being kept alive with no hope of recovery, should be examined very carefully “to think whether we're quite certain it's the patient who's being tortured or us.”³⁶

Indeed, dementia is a mystery; it is like a twilight zone between life and death. It is a phenomenon that makes everybody ask: Why? How come? And what is the reason behind it? People with dementia gradually lose their cognitive capacities, do not care any longer about issues to which they once attributed extreme importance prior to the disease, up to the stage in which they lose their recognition of self and others, accompanied by almost everything that formerly constituted their personal identity. However, the relations of the family and caregivers with the patient are preserved, at least officially, as strongly stated in the Academy Award winning Iranian film “A Separation” (2011) by Asghar Farhadi. In reply to his wife's claim regarding his father, who suffers from the Alzheimer's disease, “Does he even realize that you are his son?”, the husband answers “I know he is my father!!!”³⁷ Kompridis, when referring to patients in a vegetative state, suggests that personhood might be relational: “But what if personal identity is not in the head, not in the brain [...] What if personal identity is constituted in, and sustained through, our relations with others.”³⁸ In a recent article in this journal Głos claims

The [...] trait of human personhood emphasized by dementia is its embeddedness. The notion of embeddedness expresses the fact that a person is not an isolated individual but a zoon politikon deeply rooted in social relations.³⁹

Głos terms this ‘relational personhood.’

We suggest that when referring to the care of patients with advanced dementia at the end of their life, one should sometimes leave scientific advances behind and get back to the basics of human relationships, love, and unity. Avedis Donabedian, a physician, scholar, poet, and a founder of quality assessment in medicine, was interviewed shortly before his death from cancer. In the interview he claimed: “Systems awareness and systems design are important for health pro-

³⁶ The President's Council on Bioethics [2004].

³⁷ Official trailer available at https://www.youtube.com/watch?v=B2Sswx_vrWk.

³⁸ Kompridis [2009] p. 27.

³⁹ Głos [2016] p. 5.

professionals but are not enough [...] Ultimately the secret of quality is love. You have to love your patient.”⁴⁰

What the patients with dementia need – like every human being – is tender loving care, and the knowledge/feeling that they belong to their family and to whichever social network that defines their identity: X’s spouse/parent/sibling, Y’s friend/neighbor, or a member of any society. In actual terms, it might call on us to care for these people with love for as long as they live, to give them basic treatment necessary for their survival and comfort, but not to strive to keep them alive with sophisticated technology the purpose of which they are unable to comprehend, and the benefits of which are sometimes uncertain.

THE RIGHT TO LIFE

The scope of healthcare workers’ moral obligations towards their patients concerns, among other issues, the ‘right to life’. Who or what has this right to life? Clearly all people fall within the scope of the right not to be killed unjustly, but the scope of the right to be kept alive is less clear. However, in response to the question what we mean by people, “much debate, often extremely acrimonious, occurs in health care ethics over the right to life of human embryos, fetuses, newborn babies, and patients who are permanently unconscious or even brain dead.”⁴¹ The echo of this debate exists also in the voices of those who doubt the personhood of severely demented patients.

According to Pellegrino, the value of human life “may be interpreted as absolute, relative, or instrumental.”⁴² If taken as an absolute value, life must be sustained at all costs, because human life has an intrinsic value. At the other extreme, i.e. the instrumental approach, the lives of severely demented patients can be perceived as lacking utilitarian value, and, therefore, they may be left to die. The ‘relative’ interpretation mediates the two extremes and offers a more complex view: “human life has enormous intrinsic value; therefore, we cannot dispose of it at our will when it loses instrumental value. But in view of our inevitable human finitude, under certain specific conditions” there may be no moral obligation to provide life-sustaining treatment.⁴³ Usually such specific conditions are recognizable when there is a disproportionate relationship between the burdens and the effectiveness or benefits of treatment. However, the case of severely demented pa-

⁴⁰ Mullan [2001] p. 140.

⁴¹ Gillon [1994] p. 187.

⁴² Pellegrino [2000] p. 1065.

⁴³ *Ibidem*.

tients might be different, since the views about sustaining their lives stem, to a great extent, from how people see them.⁴⁴ For those who consider such patients non-persons, the loss of cognitive capacities *per se* might be regarded as specific circumstances in which life has a lesser value. This is the case with the unacceptable view of life unworthy of living (*lebensunwertes Leben*), as well as with other, less offensive philosophical views for which “what does have intrinsic value [...] is not biological life in itself, but the life of a human being in possession of at least a modicum of self-awareness and intellectual and other mental functioning.”⁴⁵ Such a life may be rejected, in line with, for example, John Harris's argument that a person is a being capable of valuing his or her own existence. Therefore, taking the life of someone considered a non-person is not wrong, since it does not deprive them of anything they value.⁴⁶ Yet, for those who see an intrinsic, though not absolute, value in the life of every human being – further investigation is necessary in order to determine if there are any conditions under which we should not or may not sustain the life of people with advanced dementia.

The effect of the consideration of the value of life of patients with advanced dementia on decisions about life-sustaining treatment is best illustrated by the issue of artificial nutrition and hydration. Nearly 90% of persons with advanced dementia develop eating problems, which may cause malnutrition. Whether or not to initiate artificial nutrition and hydration by a feeding tube is one of the sentinel decisions facing families and health care providers of these patients.⁴⁷

THE HISTORY OF THE DEBATE ON WITHHOLDING ARTIFICIAL NUTRITION AND HYDRATION

Until the mid-1980s, the idea that fluids and nutritional support might be withheld from dying patients was regarded as clearly immoral. This view is best reflected in the rule proposed in 1983 by the U.S. Department of Health and Human Services for the treatment of disabled newborns: “The basic provision of nourishment, fluids, and routine nursing care is a fundamental matter of human dignity, not an option for medical judgment.”⁴⁸ Nevertheless, a short while afterwards, the practice of the withdrawal of artificial nutrition and hydration from dying patients began to receive increased support from both physicians and bio-

⁴⁴ Lotto, Manfrinati, Rigoni, et al. [2012]; Skog, Grafstrom, Negussie, Winblad [1999].

⁴⁵ The President's Council on Bioethics [2004].

⁴⁶ Harris [1985].

⁴⁷ Mitchell, Teno, Kiely, et al. [2009]; Teno, Gozalo, Mitchell, et al. [2012].

⁴⁸ *Federal Register* [1983].

ethicists. In 1986 the Council on Ethical and Judicial Affairs announced that, under certain limited circumstances, life-prolonging medical treatment including medication and artificially or technologically supplied respiration, nutrition or hydration might be stopped or withheld,⁴⁹ and since the 1990s there has been almost universal support for this view.

The debate branched out to the question of which medical conditions justify withholding nutrition and hydration. After the terminally ill, the practice was applied to patients in a persistent vegetative state and to patients who are not necessarily dying, but whose quality of life is compromised, such as handicapped newborns.⁵⁰ This was followed by advocating withholding of parenteral fluids and nutritional support from severely demented non-comatose patients, and even from mildly demented patients.⁵¹

The following excerpt is an interesting observation of this phenomenon in its early years:

This new stream of emerging opinion is typically couched in the language of caution and compassion. But the underlying analysis, once laid bare, suggests what is truly at stake: That for an increasing number of patients, the benefits of continued life are perceived as insufficient to justify the burden and cost of care; that death is the desired outcome, and – critically – that the role of the physician is to participate in bringing this about.⁵²

The ethical arguments for and against cessation of tube feedings in people with advanced dementia relate basically to three controversial issues: (1) perception of the underlying cause of death in such cases,⁵³ (2) the nature of tube feeding;⁵⁴ (3) the benefit of sustaining the lives of such patients.⁵⁵ Those who believe that forgoing tube feeding from severely demented patients is morally right maintain that if patients are unable to consume food orally, and are not tube fed, the cause of their death is the underlying end-stage dementia itself and not the lack of nourishment. They also hold the view that the artificial means of feeding and hydrating patients are the same as any other medical intervention. Tube feeding is

⁴⁹ Dickey [1986].

⁵⁰ Rosner [1993].

⁵¹ Wanzer, Adelstein, Cranford, et al. [1984]; Siegler, Weisbard [1985].

⁵² *Ibidem*, p. 129.

⁵³ Callahan [2000] p. 80–82; Cantor [1993] p. 17–18.

⁵⁴ Rosner [1993].

⁵⁵ *Ibidem*; Kunin [2003].

not the natural way of eating; it is an invasive intervention that requires medical and nursing skills and has adverse effects and complications. The use of a nasogastric tube entails suffering, as is well known for conscious patients, and much more so for cognitively impaired patients, who may keep trying to pull the tube out in a way that requires the use of physical and chemical restraints. The use of PEG (percutaneous endoscopic gastrostomy tube) is also associated with some complications such as infection at the site of the PEG, diarrhea, nausea and vomiting, and aspiration pneumonia.⁵⁶ Tube feeding satisfies only the biological requirements for nourishment, but not any other aspect of eating (i.e., psychological, social, and cultural). Furthermore, those who argue that tube feeding is unacceptable, argue that intervention that sustains the life of patients who cannot achieve life goals is futile. In contrast, the opponents of withholding artificial nutrition contend that the cause of death in these cases is starvation; that tube feeding is feeding, and the distinction between food and fluids administered by a feeding tube and intravenous line, and food and fluids given or taken orally is artificial and inappropriate; and that the lives of individuals with advanced dementia are equal to and worth no less than the lives of others.

It should also be noted that until relatively recently there was no reliable medical evidence regarding the benefits of tube feeding *vis-à-vis* no tube feeding for severely demented patients. It is important to note that for ethical reasons, no randomized controlled studies have been conducted to assess the effect of tube feeding on morbidity and mortality in this population. Despite the wide use of feeding tubes for patients with advanced dementia, up until 2009 the potential beneficial or harmful effects were not clearly recognized. At that time, a Cochrane review of the existing studies was done to evaluate the outcome of enteral tube nutrition for older people with advanced dementia who develop problems with eating and swallowing and/or have poor nutritional intake. The authors of the review concluded that although there is insufficient evidence to suggest that enteral tube feeding is beneficial in patients with advanced dementia, data are lacking on the adverse effects of this intervention.⁵⁷ Not until 2012 was a comprehensive prospective cohort study published, based on research carried out from 1999 to 2007 on 36,492 nursing home residents with advanced cognitive impairment from dementia and new eating problems. The sample included all of the nursing homes in the U.S.⁵⁸ This study found that the insertion of PEG (percutaneous en-

⁵⁶ Schwartz, Barrocas, Wesley, et al. [2014].

⁵⁷ Sampson, Candy, Jones [2009].

⁵⁸ Teno, Gozalo, Mitchell, et al. [2012].

doscopy) tubes did not significantly affect survival, nor did the timing of the insertion relative to the onset of an eating problem affect survival. In the following years clinical guidelines put forth by the leading professional bodies both in America⁵⁹ and in Europe⁶⁰ discouraged the use of feeding tubes in patients with advanced dementia and instead promoted the use of careful hand feeding. Indeed, a large study conducted in the U.S. reported that among nursing home residents with advanced dementia, PEG insertion rates declined from 8.6% in 2000 to 3.1% in 2014 among white residents and from 37.5% to 17.5% among black residents in the same period.⁶¹ Nevertheless, the conclusion that comfort hand feeding is equal to PEG tube feeding is not unanimously accepted. For example, some scholars⁶² have raised methodological concerns regarding the analysis and interpretation of the results of that comprehensive U.S. study.⁶³ In addition, a recent case-series reported a high median survival among patients with whom PEG insertion was performed while they were in a relatively good nutritional condition.⁶⁴ Such reports raise doubts as to whether comfort feeding is as effective as PEG feeding for all patients, or there may be cases in which the patient might live longer if fed by PEG.

In light of this controversy, it would be advisable to define the goals of treatment and make the medical decisions accordingly. In the end-stage dementia there is no chance of restoring health and normal functioning and eliminating disease, so the goals are to provide care and respect for the patient, thereby alleviating suffering. It should be determined which form of care would best serve these goals for any individual patient.

As for the goal of care, intuitively, hand feeding is much more compatible with care than tube feeding. However, there are cases in which patients seem agitated with hand feeding.

The goal of respect for the dignity of the severely demented patient deserves special attention, because of the high value placed by Western society on cognition as an integral aspect of an individual's dignity, in accordance with the Kantian reading which sees dignity as based on rationality.⁶⁵ However, in a previ-

⁵⁹ American Geriatrics Society [2014].

⁶⁰ Volkert, Chourdakis, Faxen-Irving, et al. [2015].

⁶¹ Mitchell, Mor, Gonzalo, et al. [2016]. Note the marked difference in the use of tube feeding between white and black residents due to different cultural attitudes to end-of-life care.

⁶² Wiki Journal Club [2015]; Lynch [2016].

⁶³ Teno, Gozalo, Mitchell, et al. [2012].

⁶⁴ Gingold-Belfer, Weiss, Geller, et al. [2016].

⁶⁵ Hayry [2003]; Prainsack, Buyx [2011].

ous volume of this journal, Oliver Sensen discussed the applicability of Kantian respect for people who are not in full possession of their rational capacities, such as elderly demented people.⁶⁶ Sensen claimed that Kant conceives respect as a maxim of not exalting oneself above others, and that this attitude should be independent of what the other is like, and whether he or she is a rational being. This interpretation presents a different approach toward the concept of dignity because it does not claim that rationality is a prerequisite for dignity. But, as with the goal of care, the kind of actions this implies depends on the individual case.

Other interpretations that extend Sensen's approach to the concept of dignity relate to all human lives being created in the image of God, and having a human genome.⁶⁷ In this regard, it would be worthwhile to refer to two authorities from different cultures who follow the principle of the equal worth of all human lives:

(a) Nordenfelt has described four notions of human dignity: the dignity of merit, the dignity of moral or existential stature, the dignity of identity, and the universal human dignity (*Menschenwürde*).⁶⁸ The basic notion of dignity (*Würde*), which is the basis for all human rights, pertains to all human beings to the same extent and cannot be lost as long as the person exists. By definition, the dignity of persons with advanced dementia in this sense is definitely preserved. "According to this interpretation, loss of dignity cannot be used as an argument for euthanasia in persons with severe dementia."⁶⁹

(b) Menachem Elon, the (former) vice-president of the Israeli Supreme Court, refers to Paul Ramsey's claim that the phrase "dying with dignity" is a contradiction in terms,⁷⁰ and stresses that "there is a conflict between the death of a person and the dignity of a person. By contrast, the life of a human being is itself the dignity of man, and there is no conflict between the life and dignity of man, nor could there be a conflict."⁷¹

In accordance with the concept of dignity for every human life, and in light of the value of solidarity, decisions about life-sustaining treatment for patients with advanced dementia should be made on a case-by-case basis, as they are for any other patient, in consideration of the medical implications of the intervention

⁶⁶ Sensen [2014].

⁶⁷ Hayry [2003]; Prainsack, Buyx [2011].

⁶⁸ Nordenfelt [2004].

⁶⁹ Gastmans, De Lepeleire [2010] p. 84.

⁷⁰ Ramsey [1974] p. 48.

⁷¹ Civil Appeal [1993].

that might best serve the goals of care for the individual patient. There is no definite 'right decision' in this regard, and we simply have pointed out what factors should be taken in consideration. For those who accept the claim that there is no evidence that artificial nutrition prolongs life or reduces suffering in patients with advanced dementia, care should be provided to relieve hunger or thirst symptoms, prevent pressure ulcers or aspirations, and comfort feeding should be applied unless there are compelling reasons to prefer tube feeding in an individual case. Such an attitude, focusing on basic care, comfort, and love towards the patient was described by the British literary critic and writer John Bayley in his book, *Iris and Her Friends*, regarding the last days of the life of his wife (the novelist Iris Murdoch, who suffered from Alzheimer's disease):

She had grown steadily weaker. Without bother or fuss, as if someone she trusted had helped her to come to a decision, she stopped eating and drinking. Gentle pressure from those kind nurses, but no insistence. No horror of being put on a drip.⁷²

Yet, for those who believe that withholding tube feeding might hasten the death of the patient if he or she is undernourished, artificial nutrition and hydration should be provided, after thorough consideration of the risks and complications and side effects of the intervention.

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⁷² Bayley [2000] p. 270.

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