

Enteral Nutrition and Dementia Integrating Ethics

Denise Baird Schwartz, MS, RD, FADA, FAND, FASPEN

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Abstract

This narrative review highlights topics related to feeding patients with dementia, including the use of ethical principles and legal precedents; specifies guidelines and practice recommendations; provides an option to assist in applying the recommendations, such as comfort feedings instead of enteral nutrition; promotes the use of early advance care planning to achieve medical therapies based on an individual's wishes; and provides 3 case studies to demonstrate the clinical application of the information presented in the article. Enteral nutrition guidelines and recommendations have been developed by the American Society for Parenteral and Enteral Nutrition and the Academy of Nutrition and Dietetics for individuals with dementia. Predominately these guidelines and recommendations focus on patients with advanced dementia due to the dysphagia and progressive disease process. Despite the research and recommendations to forgo enteral nutrition in advanced dementia, the practice continues. The detailed case studies, integrating an interprofessional approach, provide tools for clinicians to incorporate ethical principles and address the communication aspect when dealing with families and surrogate decision-makers for individuals with advanced dementia. (*Nutr Clin Pract.* 2018;33:377–387)

Keywords

dementia; feeding; enteral nutrition; tube feeding; ethics; dysphagia; advance directives

The focus of this narrative review is to provide information about background concepts in dementia including a discussion of advanced dementia and dysphagia as well as ethical principles and legal precedents associated with dementia. This review highlights the guidelines and recommendations for patients with dementia and discusses options to assist in applying the recommendations, such as providing comfort feedings instead of enteral nutrition and promoting the use of early advance care planning to achieve medical therapies based on an individual's wishes. Case studies are used to illustrate clinical application of the information. The American Society for Parenteral and Enteral Nutrition and the Academy of Nutrition and Dietetics have been instrumental in developing guidelines and practice recommendations for enteral nutrition that includes individuals with dementia and incorporating an interprofessional approach in the clinical setting.^{1–3} However, conflict still exists between the recommendations for enteral nutrition in individuals with advanced dementia and actual clinical practice.

Dementia

The word *dementia* is derived from Latin words and the word itself due to unfavorable cultural beliefs about dementia can result in individuals avoiding diagnosis and treatment. The *Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition* has stopped using the word *dementia* and instead uses the phrase “major neurocognitive

disorders.”⁴ Mild neurocognitive disorder has been added to the *Diagnostic and Statistical Manual of Mental Disorders–Fifth Edition*, paralleling the World Health Organization International Classification of Diseases of mild cognitive disorder.⁵

Dementia and mild cognitive impairment are identified by a decrease from a prior cognitive level. In dementia, the decline affects activities of daily living or social functioning compared with mild cognitive impairment, where the individual can still engage in complex activities, such as paying bills or taking medication. Dementia can be preceded by mild cognitive impairment. There are many different types of dementia—Alzheimer's disease is the most common, and vascular dementia is the next most common followed by dementia with Lewy bodies.⁶

From the Providence Saint Joseph Medical Center, Burbank, California, USA.

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Corresponding Author:

Denise Baird Schwartz, MS, RD, FADA, FAND, FASPEN,
Providence Saint Joseph Medical Center, Burbank, 3950 Laurel
Canyon Blvd, Studio City, CA, USA.

Email: denisebairdschwartz@gmail.com

The *Lancet* Commission on Dementia Prevention, Intervention, and Care met to merge the evolving knowledge as to what should be done to prevent and manage dementia.⁶ Dementia is a global issue and occurs predominately in individuals aged 65 years or older. In 2015, about 47 million individuals worldwide were living with dementia. Noted in the *Lancet* Commission report was the need for all professionals working in end-of-life care to be aware of and consider dementia in their planning and communication because one third of older people now die with dementia. Some of the key components from the *Lancet* Commission addressing dementia are detailed in Table 1. Several components focused on the importance of individualizing care, essentially patient-centered concerns with respect for autonomy, family involvement, and the importance of planning for decision-making options.

Advanced Dementia Concerns

For individuals with advanced dementia, there is little evidence that nutrition support can reduce the risk of aspiration pneumonia, prolong life, or improve nutrition status or quality of life.^{2,7} Several aspects of advanced dementia including immobility and being bed bound contribute to the risk of aspiration, which, in addition to having impaired immunological function, can increase patients' risk of pneumonia, urinary, and other infections.⁸ Difficulty swallowing and decreased appetite are also common in advanced dementia.⁹

The European Association of Palliative Care defined optimal palliative care for people with dementia and stressed the importance of adapting care goals for the individual throughout the course of the dementia.¹⁰ In the consensus report, the following recommendations included several components: (1) optimization of person-centered care, (2) the use of communication and shared decision-making, (3) tailored treatment of symptoms and providing comfort care, (4) setting realistic care goals, (5) advance care planning, (6) continuity of care, (7) psychosocial and spiritual support, (8) education of healthcare team members, and (9) society and ethical issues.

Dysphagia

Dysphagia is the medical term involving the symptom of difficulty swallowing. In advanced dementia, both oral and pharyngeal dysphagia have been reported.¹¹ Oral dysphagia deals with the pocketing of food in an individual's cheek. Pharyngeal dysphagia can result in aspiration and may result in pneumonia.

Dysphagia and malnutrition were found to be significantly associated in a cross-sectional, multicenter study of 53 Austrian hospitals involving 3174 hospitalized patients aged 65 years or older.¹² The incidence of dysphagia among these patients was 7.6%. Dysphagia occurrence level ap-

peared low when compared with other studies involving individuals aged 65 years or older, ranging from 9%–15%.^{13,14} In the study, malnutrition was defined as an acute or chronic condition that resulted from an energy imbalance or lack of energy, protein, or other nutrients that resulted in measurable and adverse effects on the body composition, function, and clinical outcomes. A malnutrition diagnosis incorporated the following 2 components: (1) unintentional weight loss >6 kg during the past 6 months or >3 kg during the past month and/or (2) a body mass index <20 kg/m². Of the patients who suffered from dysphagia, 37% were malnourished. For those patients exhibiting dysphagia the following nutrition interventions were started: food and fluid texture modification (32.2%), dietitian referral (31.4%), energy and/or protein-enriched diet alteration (27.3%), nutrient intake monitoring (21.5%), enteral nutrition (19.4%), and addition of high-energy snacks (15.7%). Nearly a quarter of the patients did not receive a nutrition intervention. Dementia was 1 of the 4 medical diagnosis groups that were significantly associated with dysphagia.¹² Although patients or their legal representatives were notified of the study in writing and orally, a signed written informed consent was required, and approval from the hospital ethical committee was obtained; however, the study did not address the ethical issue of whether to provide enteral nutrition for the patients with dementia nor was the dementia severity indicated.

For patients with severe (advanced) dementia, dysphagia can occur with the progression of the disease, which can then result in malnutrition. For nutrition support clinicians managing an individual with malnutrition, the treatment options could include all of the nutrition interventions from oral diet modification to enteral nutrition. However, this is where ethical principles should be applied for the decision-making process.

Enteral Nutrition

Enteral feeding includes the use of oral supplements; however, for this article enteral nutrition will be used to denote nutrients provided through tubes. Enteral nutrition tubes can be either short term, such as a nasogastric feeding tube, versus a long-term enteral access device, also referred to as gastrostomy tube or percutaneous endoscopic gastrostomy tube.

The use of long-term access devices for the provision of nutrition in advanced dementia varies between countries and within them.¹⁵⁻¹⁷ In Israel, Bentur et al¹⁵ studied older people with advanced dementia primarily living in nursing homes with the use of a cross-sectional survey of caregivers. Of the 117 individuals studied, 26% had feeding tubes. The individuals with feeding tubes required greater use of restraints, problems with swallowing, and emergency room visits when compared with patients without feeding tubes. Individuals with feeding tubes were more likely to have

Table 1. *Lancet* Commission on Dementia Components Specific to Autonomy, Family Involvement, and Planning for Decision-Making Options.⁶

Component	Component Description
Individualize dementia care	Good dementia care spans medical, social, and supportive care; it should be tailored to unique individual and cultural needs, preferences, and priorities and should incorporate support for family caregivers.
Plan for the future	People with dementia and their families value discussions about the future and decisions about possible attorneys to make decisions. Clinicians should consider capacity to make different types of decisions at diagnosis.
Protect people with dementia	People with dementia and society require protection from possible risks of the condition, including self-neglect, vulnerability (including exploitation), managing money, driving, or using weapons. Risk assessment and management at all stages of the disease is essential, but it should be balanced against the person's right to autonomy.
Consider end of life	A third of older people die with dementia, so it is essential that professionals working in end-of-life care consider whether a patient has dementia because they might be unable to make decisions about their care and treatment or express their needs and wishes.

legal guardians. Bentur et al¹⁵ noted that dependent on the country, the healthcare delivery site, religion, cultural, historical, and ethical reasons contributed to the variance in the use of long-term access devices for enteral nutrition in advanced dementia. Di Giulio et al¹⁶ retrospectively analyzed treatment practices for the last month of severely demented elders in 7 Italian long-term care institutions with >200 beds. Of the individuals, 29 (20.5%) received enteral nutrition. Teno et al¹⁷ conducted a mortality follow-back survey of individuals whose relative had died from dementia in 5 U.S. states with varying feeding tube use. Minnesota and Massachusetts were selected due to their lower tube feeding rates in the patient population previously identified. Alabama, Florida, and Texas were selected due to their higher feeding tube prevalence. For Texas and Florida, only hospital referral regions with the highest rates of feeding tube prevalence were analyzed. Nearly 11% of the 9652 individuals dying with dementia had a feeding tube.

For patients in these studies, it would have been helpful to know if advance care planning had been completed prior to the progression of the dementia to an advanced state. Although it is not known whether advance care planning done soon after the diagnosis of dementia changes outcomes or improves the quality of death, individuals with dementia, and their family and friends, find advance care planning discussions helpful. The value of these plans is in the ongoing process and discussion with the individual and family members rather than completing a written advance care plan.^{18,19}

Ethical Principles

Healthcare ethical principles should be considered before providing nutrition support for an individual with dementia. These principles, which are internationally recognized,²⁰ include the following: (1) autonomy, to honor the individual's

right to make their own decisions; (2) beneficence, to seek the good for the individual; (3) nonmaleficence, to do no harm; and (4) justice, to be fair and treat all individuals alike. The difficulty occurs with achieving autonomy when providing enteral nutrition, a medical treatment, for a person with dementia. The clinician's goal with the enteral nutrition for all individuals would be to achieve maximum benefit with minimum harm or burden, incorporating the person's wishes for their healthcare. The goal for optimum person-centered and patient-centered care is to achieve good communication, incorporating an interdisciplinary healthcare team approach with the individual/family/surrogate decision-makers. In the United States, respect for autonomy means that an individual with intact decisional capacity is allowed to make healthcare decisions about his or her treatment and care. However, if the person is unable to make decisions about his or her treatment, an informed designated surrogate represents the individual for healthcare decisions.²¹ Legislation has evolved for dealing with individuals who are unable to make decisions about their treatment.

Landmark Ethics Cases and Outcomes

Three landmark ethics cases and outcomes depicted in Figure 1 advanced the incorporation of respect for autonomy of individuals with dementia for their healthcare. The results of these cases from 1975–2005 have greatly benefited individuals and their families when the individuals are unable to speak for themselves.²² These unfortunate accidents of young women in their 20s intensely depicted the problem of the individual unable to speak for himself or herself. The issues were possibly heightened as a result of their youth. Sequentially, the cases added to the growing awareness of healthcare clinicians, hospitals, and the general public and supporting legislation to deal with individuals

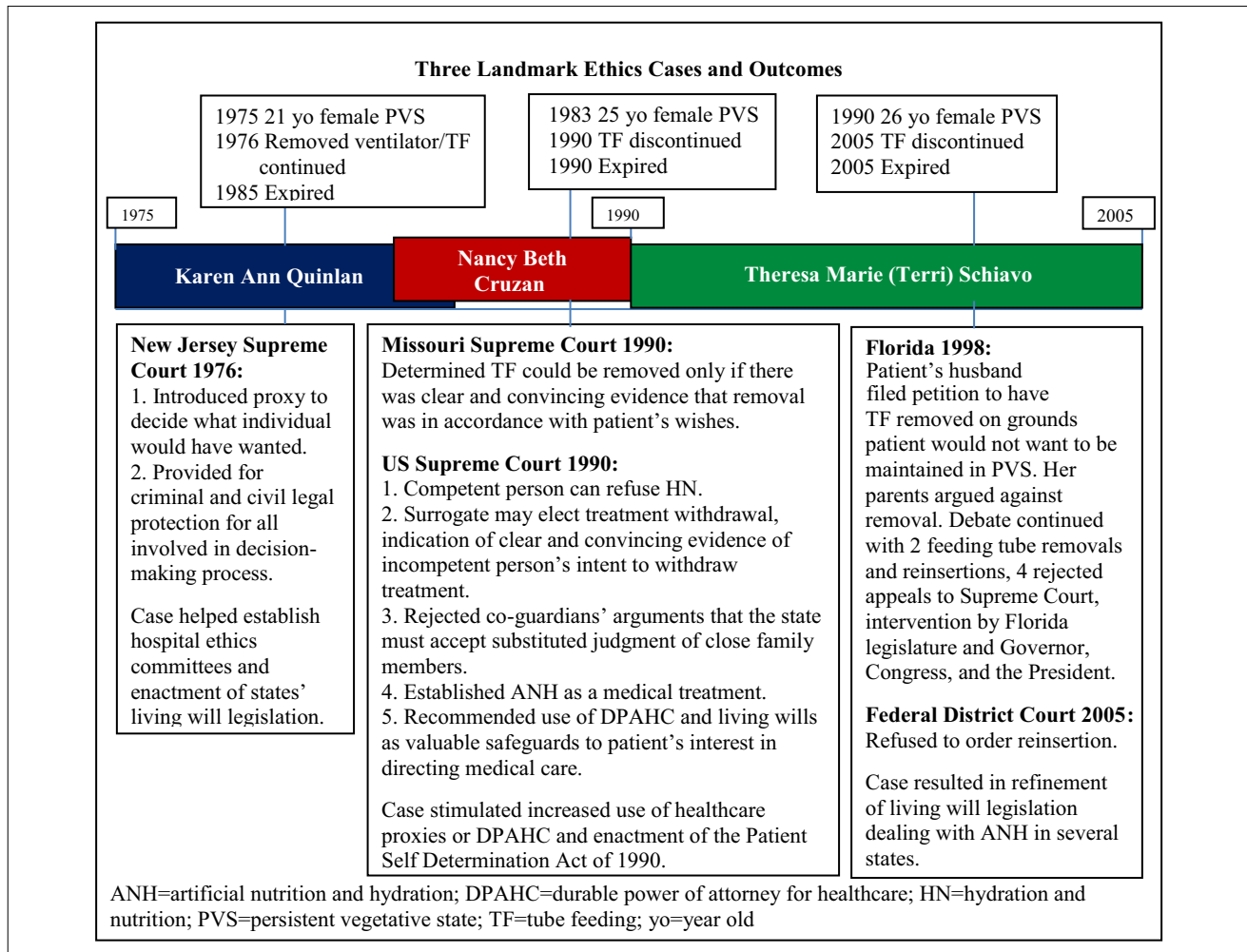


Figure 1. Landmark ethics cases and outcomes timeline.²²

who could no longer communicate their wishes. These cases helped establish hospital ethics committees and enactment of states' living will legislation, stimulated increased use of healthcare proxies or durable power of attorney for healthcare and enactment of the Patient Self Determination Act of 1990, and resulted in the refinement of living will legislation dealing with artificial nutrition and hydration in several states.

The Patient Self Determination Act of 1990

The Patient Self Determination Act of 1990 requires hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations to (1) inform patients of their rights under state law to make decisions concerning their medical care, (2) periodically inquire as to whether a patient completed an advanced directive (AD) and document the patient's wishes regarding

their medical care, (3) not discriminate against persons who have an AD, (4) ensure that legally valid ADs and documented medical care wishes are implemented to the extent permitted by state law, and (5) provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and ADs. In addition, the Patient Self Determination Act of 1990 directs the Secretary of Health and Human Services to (1) arrange with the Institute of Medicine of the National Academy of Sciences for a study assessing the implementation of directed healthcare decisions and (2) develop and implement a demonstration project in selected states to inform the public of the option to execute ADs and a patient's right to participate in and direct healthcare decisions.²³ The Patient Self Determination Act of 1990 along with the 3 landmark ethics cases and outcomes provide background for the enteral nutrition and advanced dementia findings, conclusions, and recommendations.

Enteral Nutrition and Advanced Dementia Findings, Conclusions, and Recommendations

The current literature does not support the use of enteral nutrition in patients with advanced dementia,^{1-3,7,14,24,25} as shown in Table 2. Careful total assisted oral feeding is the preferred method of feeding unless the person is too confused to focus on food and liquids. Common healthcare concepts addressed focused on the importance of advance directives, surrogate decision-makers, and effective family counseling. Families should be made aware that advanced dementia is a terminal illness, and enteral nutrition will

not stop the disease progression. Some of the barriers to discussions about end of life or essentially quality of life and goals for an individual with limited remaining life revolve around healthcare professionals and family communication issues, religion, and cultural values.

Despite the literature not supporting the use of enteral nutrition in advanced dementia, the nutrition therapy continues to be used in this patient population. Healthcare clinicians in both hospitals and long-term care facilities should develop a process that is interdisciplinary, collaborative, proactive, integrated, and systematic to facilitate decision-making that engages the patient, family, significant others,

Table 2. Enteral Nutrition and Advanced Dementia Findings, Conclusions, and Recommendations.

Article	Concepts/Pertinent Findings/Conclusions
Sampson EL, et al. Enteral tube feeding for older people with advanced dementia. <i>Cochrane Database Syst Rev.</i> 2009. ⁷	Implications for practice: Despite the large number of patients receiving this intervention there is insufficient evidence for the effectiveness of enteral feeding for older people with advanced dementia on survival, QOL, nutrition and pressure ulcers, function and behavioral or psychiatric symptoms of dementia.
Barrocas A, et al. A.S.P.E.N. ethics position paper. <i>Nutr Clin Pract.</i> 2010. ¹	<ol style="list-style-type: none"> 1. ANH may not provide any benefit and may have associated risks in patients with severe dementia. 2. Many states in the U.S. require “clear and convincing evidence” to forgo ANH in decisionally incapacitated patients without documented ANH preferences. 3. For patients lacking decision-making capacity, the healthcare professional has an ethical and legal obligation to reference an AD or discussion with the authorized surrogate decision-maker, whether appointed through mechanisms of a DPAHC, court or statutory processes. 4. Surrogate decision-makers (including but not limited to family members and/or significant others) should be given the same considerations as individual patients with decision-making capacity.
Hanson LC. Tube feeding versus assisted oral feeding for persons with dementia: using evidence to support decision-making. <i>Ann Longterm Care.</i> 2013. ²⁴	<ol style="list-style-type: none"> 1. The literature supports the view that PEG tube feeding in patients with dementia is not beneficial in terms of forestalling morality or improving QOL. 2. Assisted oral feeding is better accepted both by patients and by their families during the patients’ declining months of life. 3. After reviewing the body of evidence, it is advisable for clinicians to provide effective counseling to the families of persons with advanced dementia, helping to support the choice of assisted oral feeding in the late stage of this disease.
Schwartz DB, et al. Practice paper of Academy of Nutrition and Dietetics: ethical and legal issues of feeding and hydration. <i>J Acad Nutr Diet.</i> 2013. ³	<p>Advanced dementia:</p> <ol style="list-style-type: none"> 1. Individuals with end stage dementia normally lose interest in food/fluid, become too confused to focus on meals, may refuse to eat by turning their heads away from food or clamping their mouths shut. 2. Numerous studies found no evidence that enteral tube feeding provides any benefit for individuals with dementia in terms of survival time, mortality risk, quality of life, nutrition parameters, physical function, or improvement or reduced incidence of pressure ulcers. 3. Studies indicate that feeding tube insertion in nursing facility residents with dementia was associated with poor survival and a significant increase in the use of healthcare services after insertion. 4. Individuals with dementia and/or their families do not always understand that dementia is a terminal illness and a tube feeding will not stop the disease progression. Rather than enteral tube feeding, the preferred intervention for providing nutrition for individuals with advanced dementia is usually total assistance with oral feedings.

(continued)

Table 2. (continued).

Article	Concepts/Pertinent Findings/Conclusions
American Geriatrics Society. American Geriatrics Society feeding tubes in advanced dementia position statement. <i>J Am Geriatr Soc.</i> 2014. ²⁵	<ol style="list-style-type: none"> 1. When eating difficulties arise, feeding tubes are not recommended for older adults with advanced dementia. Careful hand feeding should be offered because hand feeding has been shown to be as good as tube feeding for the outcomes of death, aspiration pneumonia, functional status, and comfort. 2. Moreover, tube feeding is associated with agitation, greater use of physical and chemical restraints, healthcare use due to tube-related complications, and development of new pressure ulcers. 3. Efforts to enhance oral feeding by altering the environment and creating patient-centered approaches to feeding should be part of usual care for older adults with advanced dementia. 4. Tube feeding is a medical therapy that an individual's surrogate decision-maker can decline or accept in accordance with advance directives, previously stated wishes, or what it is thought the individual would want. 5. It is the responsibility of all members of the healthcare team caring for residents in long-term care settings to understand any previously expressed wishes of the individuals (through review of advance directives and with surrogate caregivers) regarding tube feeding and to incorporate these wishes into the care plan. 6. Institutions such as hospitals, nursing homes, and other care settings should promote choice, endorse shared and informed decision-making, and honor preferences regarding tube feeding. They should not impose obligations or exert pressure on individuals or providers to institute tube feeding.
Schwartz DB, et al. A.S.P.E.N. special report: gastrostomy tube placement in patients with advanced dementia or near end of life. <i>Nutr Clin Prac.</i> 2014. ²	<ol style="list-style-type: none"> 1. The decision to withhold or withdraw tube feeding in end-stage illness is supported by current scientific evidence. 2. Advanced dementia should be seen by the healthcare team as a terminal illness, and healthcare team members should clearly communicate this perspective to the patient's family, significant others, caregivers, and/or surrogate decision-makers. 3. A thorough discussion should take place with the patient, family, significant others, caregivers, and/or surrogate decision-makers. The conversation should cover the most updated evidence-based findings regarding short-term and long-term risks, burdens, and benefits. 4. Alternatives such as assisted oral feeding and other innovative oral interventions should be thoroughly explored and discussed with the patient, family, significant others, caregivers, and/or surrogate decision-makers. 5. The autonomy of the patient or surrogate decision-maker should be respected. Emphasis should be placed on functional status and QOL. An essential aspect of the process involves cultural, religious, social, and emotional sensitivity to the patient's value system. A time-limited trial of nasogastric feedings may be considered if a decision to proceed in the future with a G-tube is made. 6. The final informed decision should be reached via an approach, including family, significant others, caregivers, and/or surrogate decision-makers. 7. Clinicians in healthcare institutions, both hospitals and long-term care facilities, should develop a process that is interdisciplinary, collaborative, proactive, integrated, and systematic in order to facilitate decision-making that engages the patient, family, significant others, caregivers, and/or surrogate decision-makers. The process should promote AD that provide healthcare based on the patient's wishes and best interest.

(continued)

Table 2. (continued).

Article	Concepts/Pertinent Findings/Conclusions
Druml C, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. <i>Clin Nutr.</i> 2016. ²⁰	<ol style="list-style-type: none"> 1. If the risks/burdens of a therapy outweigh the potential benefits, the physician has the obligation of not providing (withholding) the therapy. 2. Nutrition therapy for older patients is frequently intended to ensure a permanent supply of nutrition and hydration up to EOL. Justification for such a treatment should be critically reviewed at regular intervals. 3. For patients with advance dementia priority should always be given to careful eating assistance/feeding by hand. 4. Even if the patient is not legally competent in accordance with civil law, he/she might be still capable of expressing his/her wishes and participating in the decision-making process. 5. In case a patient is unable to give consent and make judgments, the representative (dependent on the countries law and practice) makes the decision. If the representatives' decision is delayed, the physician should start AN according to evidence based medical indication. 6. In the absence of an effective statement of the patient's will in a specific situation, one should proceed in accordance with the patient's presumed will. The patient's authorized representative is obliged to determine the patient's presumed will. 7. QOL must always be taken into account in any type of medical treatment including AN. 8. A medical treatment, which does not provide any benefit or has become disproportionate can be withdrawn or withheld. 9. Providing nutrition against the will of the patient who is able to give his/her consent or make judgments (enforced feeding) is generally prohibited.

AD, advance directives; AN, artificial nutrition; ANH, artificial nutrition and hydration; DPAHC, durable power of attorney for healthcare directive; EOL, end of life; PEG, percutaneous endoscopic gastrostomy; QOL, quality of life.

caregivers, and/or surrogate decision-makers. The process ought to provide options for comfort feedings instead of enteral nutrition and to promote continued communication and advance care planning along with an advance directive that provides healthcare based on the patient's wishes and best interests.

Comfort Feedings

Although studies suggest that enteral nutrition does not improve survival or reduce the risk of aspiration, enteral nutrition is frequently used in patients with dementia. Many nursing home residents do not have specific orders documenting their wishes about the use of enteral nutrition. In the nursing home, reasons that may contribute to individuals not having a designation about enteral nutrition use may include (1) orders to not allow artificial hydration and nutrition might be incorrectly interpreted as a "nothing by mouth" order, which families and/or surrogate decision-makers would have difficulty accepting and (2) the administration of the nursing homes may fear regulatory penalties because of the patient's possible weight loss, although the use of feeding tubes could imply that everything possible is being done. To deal with both of these issues in healthcare facilities, Palecek et al⁹ suggest the use of a "comfort feeding only" order.

The "comfort feeding only" order includes continued attempts with careful hand feeding and a stopping point if

the individual appears distressed. Feedings are goal oriented to provide comfort and are not invasive compared with a feeding tube. Care plan for a patient with a "comfort feeding only" order involves continued interaction for meticulous mouth care, socialization, and therapeutic touch with the person, not just feeding attempts. Speech pathologists and occupational therapist are skillful in recommending food and fluid modification, along with proper body positioning for optimum oral-intake attempted feedings. The interaction could encompass refocusing of the family and significant others with alternatives to food for nurturing and providing love and compassionate care for the person.

Advance Care Planning

Advance care planning is a process that ideally should be started early in life, 18 years and older, and entails ongoing communication between an individual and a decision-maker who would be able to express the person's healthcare wishes if that person became unable to speak on his or her own behalf. An advance directive is a written document that could include the person's specific wishes for life-sustaining treatments, including tube feedings, and designation of a surrogate decision-maker. This document can be changed by the individual at any time as his or her life and health status changes. National Healthcare Decisions Day²⁶ is a useful resource and exists to inspire, educate, and empower

the public and providers about the importance of advance care planning.

The use of a Physician Orders for Life-Sustaining Treatment (POLST) form is an approach to improve end-of-life care for individuals in the United States. The process encourages providers to speak with patients and create specific medical orders to be honored by healthcare providers during a medical crisis. A POLST is completed based on conversations between patients and healthcare professionals about goals of care, quality of life, diagnosis, prognosis, and treatment options. Communication and completion of the form gives seriously ill patients more control over their end-of-life care, involving medical treatment of extraordinary measures, including feeding tubes. The POLST is printed on bright pink paper and signed by both a patient (or designated surrogate decision-maker) and physician, nurse practitioner, or physician assistant. The National POLST Paradigm²⁷ is a voluntary system that provides documents and can facilitate a process that honors patient medical treatment wishes through portable medical orders.

Although the completion of advance care planning documents is important, an essential part of the process is ongoing communication between the healthcare provider and the patient or surrogate decision-maker. Management of the completed advance care planning documents from the individual's home to various healthcare facilities, acute and chronic, and between these institutions requires a systematic process. An example of this procedure was presented as part of an intensive care unit healthcare communication process early in the hospitalization with a healthcare clinician sitting down with the family in the patient's room to develop a connection with the family and the importance of providing healthcare based on the patient's wishes.²⁸ A single-blind cluster randomized clinical trial with 302 nursing home residents aged 65 years or older with advanced dementia and their family decision-makers in 22 facilities developed an intervention communication process.²⁹ Intervention for the decision-makers consisted of a Goals of Care video decision aid viewed with researchers and a structured discussion with the nursing home care team. To prepare the clinical staff for the goals of care discussion, the investigators trained the nurses, social workers, therapists, and nutritionists who create the care plans. Although the physicians and nurse practitioners were invited to these discussions, they rarely attended. The Goals of Care decision aid intervention was found to be effective to improve the quality of communication for families of nursing home residents with advanced dementia and to improve elements of palliative care. Hospital transfers were reduced for these individuals without any adverse survival effects. Nursing home physicians or nurse practitioners completed an order set comparable to a POLST more often for residents in the intervention group.

Clinical Approach

Ideally, the clinical approach to determine the nutrition treatment plan for an individual would incorporate the benefits vs the risk/burdens ratio of a pending nutrition therapy, the person's decision-making capacity to accept medical treatment based on their healthcare wishes, or the designated decision-makers ability to represent the patient's wishes. There are several options to consider for optimizing the communication process between the healthcare providers and the family/designated decision-maker before the placement of a long-term feeding tube for a patient with advanced dementia. Suggested options include (1) use of a checklist for decision-making prior to gastrostomy tube placement^{2,30} as the example shown in Figure 2; (2) apply principles of an informed consent process³¹ that include disclosure, comprehension, voluntary choice, and authorization; (3) palliative care consult to assist with complex decision-making; and (4) completion of a POLST after a thorough discussion between the healthcare provider and the family/designated decision-maker.

Case study 1. A 74-year-old woman was admitted from home to the intensive care unit with an acute stroke. Earlier that year she was diagnosed with mild cognitive impairment. As part of the intensive care unit healthcare communication process, on the second day of hospitalization her nurse sat down with the family in the patient's room to further address the healthcare process and to develop a connection with the family. Her family lived nearby and checked on her daily, where she lived alone. She had been able to care for herself and drive a car prior to this hospitalization. During the current hospital stay, a swallow evaluation, including a video swallow study, was performed by a speech pathologist. The results of the swallow study indicated that the patient was able to achieve safe swallow with modified fluid and food consistency initially. A follow-up evaluation was scheduled by the speech therapist to determine if the patient would be able to progress to thin liquids and a regular diet without the food consistency modification vs remain on the prescribed diet.

The physician spoke with the patient and the family members as to the future if her swallowing became impaired and would she be willing to accept placement of a feeding tube for nutrition. Her physician explained the change in her condition could mean a temporary nasogastric feeding tube or a long-term enteral access device requiring surgical placement. The patient did not have an advance directive designating her healthcare wishes and had not selected a proxy decision-maker if she was unable to speak for herself. Therefore, this was an excellent time to discuss the importance of advance care planning while the patient was capable of making decisions for herself. The social worker gave the patient and the family an advance directive form and

Clinical indication	Presumed oral intake will provide insufficient nutrition and/or is unsafe due to possible aspiration for period greater than 4 weeks on nasogastric tube feeding? <input type="checkbox"/> Yes <input type="checkbox"/> No
Swallow evaluation	Was a video swallow study completed? Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, when? _____ Was this abnormal? specify _____
Consistent with patient's wishes	Is use of G-tube consistent with patient's preferences, as supported by patient's quality of life goals? Yes <input type="checkbox"/> No <input type="checkbox"/>
Preferences obtained	How have patient's preferences, goals and values been obtained? (check all that apply) <input type="checkbox"/> Discussed directly with patient <input type="checkbox"/> Discussed with patient's surrogate (for patient lacking decision-making capacity) <input type="checkbox"/> Documented in patient's advance directive and/or POLST form <input type="checkbox"/> Other (specify): Surrogate Committee formed to make decision on patient's behalf
Preferences documented	Are patient's preferences, goals and values formally documented in medical record or Surrogate Committee? Yes <input type="checkbox"/> No <input type="checkbox"/> If yes, date: _____
Medical condition stable	Is patient's medical condition expected to remain stable to discharge? Yes <input type="checkbox"/> No <input type="checkbox"/>
Expected survival time	Is patient expected to survive for at least 30 days post G-tube placement? Yes <input type="checkbox"/> No <input type="checkbox"/>
Primary driving force for G-tube	<input type="checkbox"/> Patient preference <input type="checkbox"/> Family preference <input type="checkbox"/> Physician <input type="checkbox"/> Skilled nursing facility requirement; facility name _____ <input type="checkbox"/> Other _____
Conditions present	Are any following conditions present? (check if condition is present) <input type="checkbox"/> Serious coagulation disorder <input type="checkbox"/> Status post cardiac arrest with poor neurological function after 48-72 hours <input type="checkbox"/> Extensive tumor infiltration of stomach <input type="checkbox"/> End stage dementia (bed-bound, incontinent, nonverbal, dysphagia with history of aspiration) <input type="checkbox"/> Multi-organ failure greater than 3 organs non-reversible <input type="checkbox"/> Stage 4 cancer with life expectancy of less than 6 months <input type="checkbox"/> Significant intracranial bleed with expected permanent ventilator dependence <input type="checkbox"/> Complete obstruction of bowel <input type="checkbox"/> Marked peritoneal carcinomatosis <input type="checkbox"/> Severe ascites <input type="checkbox"/> Peritonitis <input type="checkbox"/> Severe psychosis <input type="checkbox"/> Other _____ Clearly limited life expectancy, specify _____
Recommendation	Based on above answers is patient appropriate for G-tube? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> If No, recommend consults for discussion/decision-making with patient, family, caregiver, surrogate decision-maker for feeding option needs by: <input type="checkbox"/> Dietitian <input type="checkbox"/> Speech-Language Pathologist <input type="checkbox"/> Pharmacist <input type="checkbox"/> Palliative Care <input type="checkbox"/> Ethics

Figure 2. Checklist prior to gastrostomy tube (G-tube) placement or other long-term enteral access device placement. POLST, Physician Orders for Life-Sustaining Treatment. Printed with permission. Schwartz DB, Barrocas A, Wesley JR, et al. A.S.P.E.N. special report: gastrostomy tube placement in patients with advanced dementia or near end of life. *Nutr Clin Pract*. 2014;29:829-840.

reviewed the content with them. Due to several questions about enteral nutrition, a nutrition support clinician was asked to discuss aspects of this type of nutrition therapy with the patient and family.

After further discussion with her primary care physician, the patient decided to select her older daughter as her decision-maker. The daughter understood her mother's wishes to not receive cardiopulmonary resuscitation nor to be placed on a ventilator, but the patient was not certain about whether to allow the use of a feeding tube. Therefore, continued discussion between the daughter and her mother

over time would be very helpful. The mother decided at this point in her life she would allow a temporary tube feeding, with the intent of progressing to an oral diet when her swallowing ability improved. However, the mother indicated that she never wanted to be institutionalized in a state where she did not know her own family members and on a long-term feeding tube. Of course, if her mother changed her mind the advance directive could be redone, but these were her current healthcare wishes. The patient's daughter felt comfortable with her ability to articulate her mother's wishes if her mother's mental ability declined and

she was not able to speak for herself. The daughter realized that her mother valued autonomy above all else.

Case study 2. An 85-year-old man developed severe chest pains while residing in a board-and-care facility. He was transferred to an acute care hospital and diagnosed with a myocardial infarction. During hospitalization, his respiratory status deteriorated and he required intubation and ventilator support. After 10 days, his mentation remained altered and he failed weaning trials from the ventilator. The patient had a history of alcohol abuse, but was able to function at the board-and-care facility. Prior to hospitalization, he was ambulatory and able to answer simple questions. According to the healthcare providers at the board-and-care facility, there were no family members identified, and no visitors were reported during his 6 months at the facility.

The hospital social worker was unable to locate any family members to assist in healthcare decisions. The hospital bioethics committee was contacted to arrange for an ethics surrogate meeting to assist in decision-making on behalf of the patient. In addition to the primary care physician and patient's nurse, the following individuals were asked to participate: social worker, chaplain, nutrition support clinician, community member, risk management personnel, pulmonologist, and primary care physician. The goal of the surrogate meeting was to assist in the healthcare decision-making in the best interest of the individual as his clinical status evolved. At the meeting, the patient's case was presented by the primary care physician and the pulmonologist. The ethics principles were addressed in the discussion and applied. Due to not knowing the patient's prior healthcare wishes, the emphasis was placed on beneficence, to seek the good for the individual; nonmaleficence, to do no harm; and justice, for fair distribution.

A future tracheostomy, gastrostomy tube placement, and transfer to a long-term care facility would be required if the patient's mentation remained altered and he continued to require mechanical ventilator support. The other alternative would be to provide comfort care with compassionate extubation to allow the natural course of the clinical condition to occur. At the initial meeting, the surrogate committee discussed the aspect of changing the patient's code status in the best interest of the individual to not attempt resuscitation if the patient had a cardiac arrest and to not escalate any medical treatments. The surrogate committee agreed to meet next week to further discuss treatment options. The following day the patient's status deteriorated, progressing into renal failure, and his respiratory status declined with further increasing ventilator support needs. The next day, the patient cardiac status declined, and the patient died that afternoon. The patient's nurse, social worker, nutrition support clinician, and chaplain were with the patient during his passing and provided compassionate care in the hospital room.

Case study 3. This was the third hospital admission in 6 months for a 79-year-old woman with aspiration pneumonia and advanced dementia. She was cared for by family members in their home. The primary spokesperson was her son, who spoke Armenian and English. The son's wife and the patient's 2 daughters provided her care. These individuals only spoke Armenian. The patient had not spoken for several years and was refusing food the past few weeks. Unfortunately, the patient's weight continued to decrease. She sustained a 10% weight loss in the past 3 months. The patient was at 80% of her ideal body weight and had a stage III dermal ulcer. Upon physical examination, her abdomen was found to be distended and firm.

A palliative care consult was ordered when the patient was admitted due to the anticipated complexity of the decision-making process and the concern for communication with all the family members. Fortunately, the palliative care physician director spoke several languages, including English and Armenian. This was beneficial as the palliative care director was able to communicate with the other family members and not have the son as the translator of healthcare information. Family members are not optimum translators as they can sometimes unintentionally alter the communication between healthcare professionals and other family members. Awareness of cultural sensitivity can enhance optimum communication between the healthcare professionals and the family.

The goal of the healthcare team along with the palliative care team was not to convince the family to make any specific healthcare decisions, but to assist the family collaboratively make decisions in the best interest of the patient. This is done by informing the family in understandable language the benefit vs risk/burdens of medical therapies or the omission of a medical therapy. From a clinical standpoint, the patient was exhibiting malnutrition and end-stage advanced dementia. Nutrition support was not deemed to be warranted based on her clinical status and review of a checklist for decision-making prior to gastrostomy tube placement. The risk/burdens outweighed any benefit that she would derive from nutrition support. Fortunately, with the assistance of the palliative care team, the family recognized that performing cardiopulmonary resuscitation or placing their family member on mechanical ventilation would not be in the best interest of the patient. Therefore, an order was written indicating to not attempt resuscitation. A POLST form was completed indicating no cardiopulmonary resuscitation (CPR), ventilator, or artificial nutrition.

Conclusion

Enteral nutrition guidelines and recommendations have been developed by the American Society for Parenteral and Enteral Nutrition and the Academy of Nutrition and

Dietetics for individuals with dementia. Predominately, these guidelines and recommendations focus on patients with advanced dementia due to the dysphagia and progressive disease processes. Ethical principles should be applied when considering the use of enteral nutrition for individuals with advanced dementia. Landmark ethics cases and outcomes have provided useful tools for dealing with the healthcare of individuals who can no longer speak for themselves. Research articles support to forgo enteral nutrition in advanced dementia and an alternative would be to consider comfort feedings by mouth. The decision by the surrogate decision-maker is optimally supported by the use of advance care planning. Despite the research and recommendations to forgo enteral nutrition in advanced dementia, the practice continues. Case studies provide tools for clinicians to address the communication aspect when dealing with families and surrogate decision-makers for individuals with advanced dementia.

Statement of Authorship

D. Schwartz contributed to conception/design of the research; D. Schwartz contributed to acquisition, analysis, or interpretation of the data; D. Schwartz drafted the manuscript; D. Schwartz critically revised the manuscript; and D. Schwartz agrees to be fully accountable for ensuring the integrity and accuracy of the work. D. Schwartz read and approved the final manuscript.

Supplementary Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

References

- Barrocas A, Geppert C, Durfee SM, et al. A.S.P.E.N. ethics position paper. *Nutr Clin Pract*. 2010;25(6):672-679.
- Schwartz DB, Barrocas A, Wesley JR, et al. A.S.P.E.N. special report: gastrostomy tube placement in patients with advanced dementia or near end of life. *Nutr Clin Pract*. 2014;29(6):829-840.
- Schwartz DB, Posthauer ME, O'Sullivan Mailet J. Practice paper of Academy of Nutrition and Dietetics: ethical and legal issues of feeding and hydration. *J Acad Nutr Diet*. 2013;113(7):981.
- Blazer D. Neurocognitive disorders in DSM-5. *Am J Psychiatry*. 2013;170(6):585-587.
- World Health Organization. *International Statistical Classification of Diseases and Related Health Problems, 10th Revision*. Geneva, Switzerland: World Health Organization; 2016.
- Livingston G, Sommerlad A, Orgeta V, Costafreda SG. Dementia prevention, intervention, and care. *The Lancet*. 2017;390(10113):2673-2734[http://doi.org/10.1016/S0140-6736\(17\)31363-6](http://doi.org/10.1016/S0140-6736(17)31363-6)
- Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev*. 2009;2:CD007209. <https://doi.org/10.1002/14651858.CD007209.pub2>
- van der Steen JT, Meuleman-Peperkamp I, Ribbe MW. Trends in treatment of pneumonia among Dutch nursing home patients with dementia. *J Palliat Med* 2009;12(9):789-795.
- Palecek EJ, Teno JM, Casarett DJ, et al. Comfort feeding only: a proposal to bring clarity to decision-making regarding difficulty with eating for persons with advanced dementia. *J Am Geriatr Soc*. 2010;58(3):580-584.
- van der Steen JT, Radbruch L, Hertogh CPM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med*. 2014;28(3):197-209.
- Mitchell SL. Advanced dementia. *N Engl J Med*. 2015; 372:2533-2540.
- Eglseser D, Halfens RJG, Schols JMGA, et al. Dysphagia in hospitalized older patients: associated factors and nutritional interventions. *J Nutr Health Aging*. 2018;22(1):103-110.
- Chen PH, Golub JS, Hapner ER, et al. Prevalence of perceived dysphagia and quality-of-life impairment in a geriatric population. *Dysphagia*. 2009;24(1):1-6.
- van der Maarel-Wierink CD, Meijers JM, De Visschere LM, et al. Subjective dysphagia in older care home residents: a cross-sectional, multi-centre point prevalence measurement. *Int J Nurs Stud*. 2014;51(6):875-881.
- Bentur N, Sternberg S, Shuldiner J, Dwolatzky T. Feeding tubes for older people with advanced dementia living in the community in Israel. *Am J Alzheimers Dis Other Demen*. 2015;30(2):165-172.
- Di Giulio P, Toscani F, Villani D, et al. Dying with advanced dementia in long-term care geriatric institutions: a retrospective study. *J Palliat Med*. 2008;11(7):1023-1028.
- Teno JM, Mitchell SL, Kuo SK, et al. Decision-making and outcomes of feeding tube insertion: a five-state study. *J Am Geriatr Soc*. 2011;59(5):881-886.
- Robinson L, Dickinson C, Bamford C, Clark A, Hughes J, Exley C. A qualitative study: professionals' experiences of advance care planning in dementia and palliative care, "a good idea in theory but . . ." *Palliat Med*. 2013;27(5):401-408.
- Sampson EL, Thuné-Boyle I, Kukkastenvehmas R, et al. Palliative care in advanced dementia: a mixed methods approach for the development of a complex intervention. *BMC Palliat Care*. 2008;7:8.
- Druml C, Ballmer PE, Druml W, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clin Nutr*. 2016;35(3):545-556.
- Barrocas A, Schwartz DB. Ethical considerations in nutrition support in critical care. In: Seres DS, Van Way CW III, eds. *Nutrition Support for the Critically Ill*. Switzerland: Springer International Publishing; 2016:195-227.
- Schwartz DB. Ethical considerations in the critically ill patient. In: Cresci G, ed. *Nutritional Therapy for the Critically Ill Patient: A Guide to Practice*, 2nd Ed. Boca Raton, FL: Taylor & Francis; 2015:635-652.
- Patient Self Determination Act of 1990, HR 4449. www.congress.gov/bill/101st-congress/house-bill/4449. Accessed October 16, 2017.
- Hanson LC. Tube feeding versus assisted oral feeding for persons with dementia: using evidence to support decision-making. *Ann Longterm Care*. 2013;21(1):36-39.
- American Geriatrics Society. American Geriatrics Society feeding tubes in advanced dementia position statement. *J Am Geriatr Soc*. 2014;62(8):1590-1593.
- National Healthcare Decisions Day. www.nhdd.org. Accessed October 20, 2017.
- National Physician Orders for Life-Sustaining Treatment. <http://polst.org/>. Accessed October 20, 2017.
- Schwartz DB, Olfson K, Babak B, Barrocas A, Wesley JR. Incorporating palliative care concepts into nutrition practice: across the age spectrum. *Nutr Clin Pract*. 2016;31:305-315.
- Hanson LC, Zimmerman S, Song MK, et al. Effect of the goals of care intervention for advanced dementia: a randomized clinical trial. *JAMA Intern Med*. 2017;177(1):24-31.
- Schwartz DB, Barrocas A. Ethics and law. In: Mueller C, Lord LM, Marian M, McClave SA, Miller S, eds. *The ASPEN Adult Nutrition Support Core Curriculum*, 3rd Ed. Silver Spring, MD: American Society for Parenteral and Enteral Nutrition; 2017:785-804.
- Grady C. Enduring and emerging challenges of informed consent. *N Engl J Med*. 2015;372(9):855-862.