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REVIEW

## Social Ecological Perspectives of Tube-Feeding Older Adults with Advanced Dementia: A Systematic Literature Review

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### ABSTRACT

Dementia is a progressive, debilitating disease that often results in weight loss, malnutrition, and dehydration. Feeding tubes are often prescribed; however, this practice can lead to complications. The purpose of this systematic review was to examine the use of feeding tubes in elderly demented patients from a social ecological perspective. Results indicated that family members often receive inadequate decision-making education. Many health care professionals lack knowledge of evidence-based guidelines pertaining to feeding tube use. Organizational and financial reimbursement structures influence feeding tube use. Feeding practices for patients with advanced dementia is a complex issue, warranting approaches that target each level of the Social Ecological Model.

### KEYWORDS

Advanced dementia; social ecological model; tube feeding

## Introduction

Dementia is a progressive, debilitating disease that causes losses in functional and cognitive capabilities due to damage to the neurons in the brain (1). Alzheimer dementia, the sixth-leading cause of death in the United States (2) and the most common type of dementia, afflicted approximately 5.3 million Americans in 2015 (1). Estimates indicate that \$226 billion health care dollars were spent on dementia care and treatment in the United States in 2015, largely because patients with dementia often require hospitalization and institutionalized care (1).

Dementia is often associated with serious nutritional deficiencies as patients lose the ability to normally consume adequate nutrients. As the disease progresses, patients lose the ability to chew, swallow, and even recognize food and eating utensils (3, 4). They require time-consuming assistance with meals and ultimately experience weight loss, malnutrition, and dehydration (5).

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Therefore, in the United States, it has become common practice to place a feeding tube to provide artificial nutrition and hydration; a third of US nursing home residents with advanced dementia have feeding tubes for nutrition and hydration (6, 7). After a review of the literature, the American Geriatrics Society stated in a position paper that “feeding tubes are not recommended for older adults with advanced dementia,” as no concrete evidence exists to support long-term benefit to the patient, and it may even increase morbidity and mortality (6). While feeding tubes provide benefits for patients with many conditions, this practice is deemed ineffective and often causes a myriad of problems among patients with advanced dementia.

Despite scientific evidence against this practice, feeding tube use in this population is considered standard care among many health care professionals, leading practitioners to routinely recommend feeding tube placement without first considering the issue from a comprehensive approach. A strong need exists to consider this practice from the perspective of the Social Ecological Model, a health behavior model that explains behavior as the result of a dynamic relationship between multiple internal and external factors (8). The purpose of this systematic literature review is to explore feeding tube placement in older adults with advanced dementia from the Social Ecological perspective, including an examination of the individual, interpersonal, community, organizational, and policy levels of influence (8).

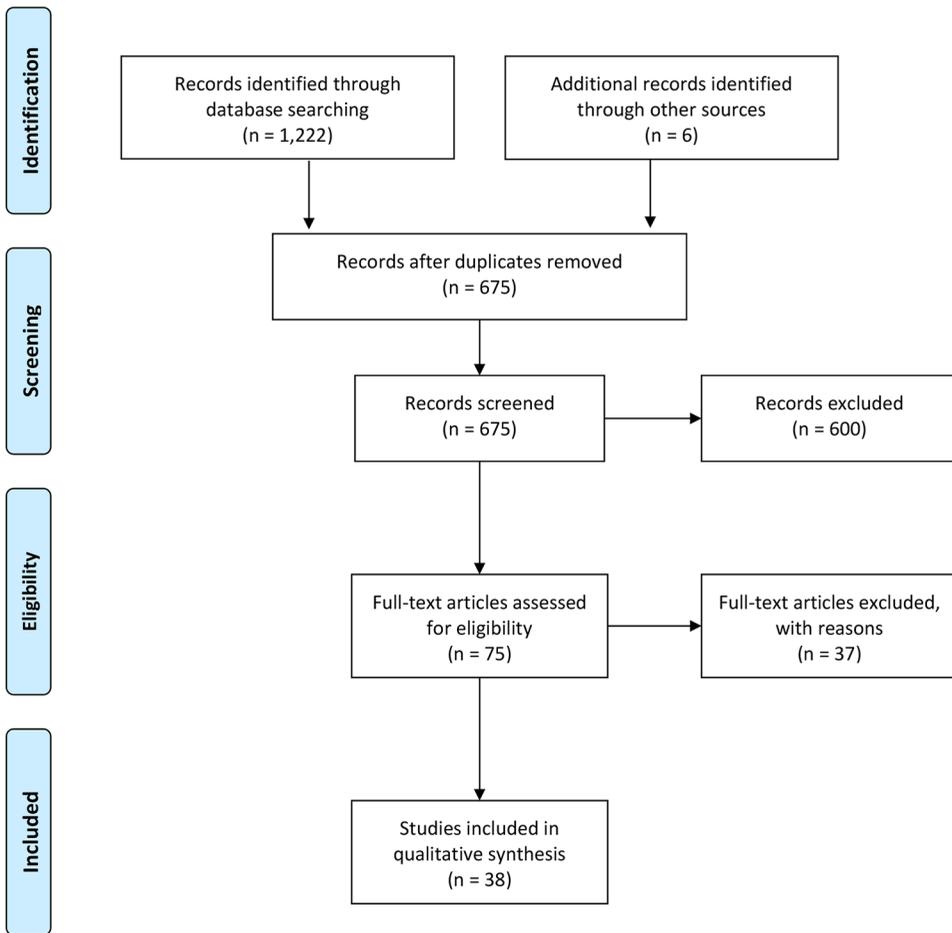
## Methods

A comprehensive literature search was conducted to identify studies pertaining to the five levels of the Social Ecological Model. This included searches of the ProQuest, PubMed, CINAHL Plus, and Cochrane databases. Publications from all countries were included, provided they were available in English. Peer-reviewed, original research studies published in scholarly journals were considered, including both qualitative and quantitative methodologies. Search terms included “dementia,” “cognitive impairment,” “feeding tube,” “artificial nutrition,” “percutaneous endoscopic gastrostomy,” “quality of life,” and “decision and elderly.”

## Results

Considering the advances in health care practices over the past decade, the search included studies published from 2005–2015, and returned 1222 publications. An additional six publications (published in 2002, 2003, and 2010) were included after a descendant search of article references.

The 2009 Preferred Reporting Items for Systematic Reviews and Meta-Analyses protocol was utilized to identify publications to include, as seen in Figure 1 (9). After the 553 duplicate studies were removed, remaining articles



**Figure 1.** Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) flow diagram.

were screened by type of publication, title, and abstract. All review articles and irrelevant articles were removed, leaving 75 articles.

The final step involved screening by full text to determine relevance to the scope of the review, which required that studies address one of the levels of the Social Ecological Model. A total of 37 articles were excluded at this phase, either because the article did not focus specifically on older adults with dementia ( $n = 16$ ), or the article focus did not fit within the scope of the review ( $n = 21$ ). Ultimately, 38 studies were eligible to be included in the review. No publications were added as a result of grey literature searches.

## Discussion

### *Individual considerations*

In considering the impact of a feeding tube on the individual level, the medical status of the patient must be considered as well as the patient's overall

quality of life. Because patients with advanced dementia have communication limitations, assessing quality of life is a challenge. In general, feeding tubes may fail to prolong life or improve clinical outcomes in this patient population.

Several studies explored mortality and complications that occurred as a result of feeding tube use in this population. One prospective, observational study demonstrated that 29.9% of participants were treated for pneumonia during the study period, and that this diagnosis was significantly associated with mortality ( $p = 0.003$ ) (10). Another study found similar results (11), where 15.5% of patients with a nasogastric tube and 7.9% of patients with a gastrostomy tube experienced aspiration pneumonia. Mortality in this cohort was 7.4% at 30 days, 19.4% at 6 months, and 23.1% at one year (11). Additionally, 24.5% of patients with nasogastric tubes had restraints to prevent them from removing the tube, and 62.2% of patients with nasogastric tubes had tube complications that required tube replacement (11). Among patients with gastrostomy tubes, 15.8% experienced infections at the tube insertion site. Overall, 14.8% of patients experienced diarrhea and 26.9% experienced constipation (11). Another study of tube-fed patients at home with dementia reported that 26.8% of patients were sent to the emergency department due to a malfunctioning tube, and 25.9% of patients were physically restrained to prevent tube removal (12).

In a prospective observational study, patients with a feeding tube were more than twice as likely to experience aspiration pneumonia when compared with orally fed patients (RR = 2.32, 95% CI = 1.22–4.40) (13). At three months, mortality among the orally fed group was 11.1%, and 41.9% among those fed via tube. Mortality increased to 27.8% and 58.1%, respectively, at six months. At both time periods, mortality was significantly higher among those with a feeding tube ( $p = 0.004$  and  $p = 0.012$ , respectively). Thus, aspiration pneumonia was more common and mortality was higher among patients who were tube fed (13). However, authors acknowledged that the tube-fed patients might have been more ill than the orally fed patients, which is an important limitation to consider. Thus, it is important to consider selection bias in these studies, as individuals with a feeding tube may have had it placed due to being at increased risk for developing aspiration pneumonia, and therefore may inherently be at greater risk for aspiration pneumonia than orally fed individuals.

One prospective study of nursing home patients found that tube-feeding complications were the most common cause of emergency department visits, comprising 47% of all visits (14). Authors concluded that the presence of a feeding tube is a significant predictor of hospitalization among this patient population ( $p < 0.10$ ) (14). Another study among nursing home residents with advanced dementia indicated that 64.1% of the 5209 older adults who received a feeding tube died within 1 year (15). Unfortunately, this study did not report on the cause of death of these individuals.

An examination of survival rates among residents with advanced cognitive impairment and newly developed eating difficulties concluded that the use of feeding tubes among patients with advanced cognitive impairment did not improve survival rates (16). Similarly, a retrospective study of nursing home residents measured survival and hospital feeding tube insertion rates based on Minimum Data Set assessments and Medicare claims (17). Overall, 29.5% of older, cognitively impaired patients died within a month of hospitalization and 52.2% died within 6 months. High rates of feeding tube insertion did not significantly improve patient survival (17). While this study did not explore indications for feeding tube placement, “pneumonia and other disease of lung” was noted as the primary admitting diagnosis, responsible for approximately 17%–20% of hospitalizations across facilities.

In a study of 67 older adults with dementia in Spain, Alvarez-Fernandez and colleagues measured several nutritional indices, including tricipital skinfold thickness, arm circumference, muscle area of the arm, hematocrit, cholesterol, albumin, and lymphocytes (10). Interestingly, the tube-fed individuals ( $n = 14$ ) had poorer nutritional values than orally fed individuals ( $n = 53$ ) in each of the above measures. Thus, the presence of a feeding tube was not associated with improved nutritional parameters (10).

The results of these studies reiterate the frequency of complications experienced by these patients, and provide insight into their quality of life. It is apparent that older adults with dementia may be subject to a number of complications and side effects related to feeding tube use, including increased mortality. Consequently, feeding tube use may negatively influence the patient’s quality of life.

### ***Interpersonal considerations***

Another level of the Social Ecological Model involves the interpersonal influences, which are the family members and caregivers of patients with advanced dementia. In many instances, they are responsible for making the health care decisions for the patient, and several studies have focused on how the use of feeding tubes affects these family members and caregivers.

One study examined how family members decide whether to use a feeding tube, their experience with the feeding tube, and their perceptions of the quality of end-of-life care for their loved one (12). Over half (55.3%) reported brief or no conversations about this issue with health care team members and 23.4% of family members regretted ever having the tube inserted. Other studies echo these results. One cross-sectional study of nursing home residents with advanced dementia and their health care proxies measured proxy satisfaction with the care provided at the nursing home (18). Tube feeding was negatively correlated with satisfaction with care ( $p = 0.02$ ), and, conversely,

greater proxy satisfaction resulted when the physician and proxy spent more than 15 minutes planning for end-of-life care ( $p < 0.001$ ).

In another cross-sectional study of 51 Chinese family caregivers of patients with advanced dementia, researchers investigated knowledge of caregivers about feeding tubes (19). More than a quarter of caregivers (26%) reported no knowledge and family members were unaware of an advanced directive from the patient regarding feeding tube use. Due to cultural norms regarding caring for one's aging parents, Chinese family members may be reluctant to forgo a feeding tube for a family member with dementia. Thus, understanding cultural differences in the way families make decisions about end-of-life care can influence how health care professionals deliver this important information. Cultural competence is essential in providing care to patients and their family members.

Knowing that the decision to insert or forgo a feeding tube for a loved one can be a difficult one for caregivers, several researchers have investigated interventions to reduce the difficulty in decision-making. Hanson and colleagues conducted a randomized controlled trial of 256 nursing home residents with dementia and their caregivers to investigate whether the provision of a decision aid pamphlet would improve decision-making for end-of-life feeding (20). Intervention group participants were significantly more likely to discuss feeding options with the health care team after receiving the pamphlet ( $p = 0.04$ ). They were also significantly less likely to feel conflicted about the decision, and displayed significantly more knowledge on the use of feeding tubes ( $p < 0.001$  in both cases). A follow-up qualitative study was conducted with the caregivers (21). After viewing the decision aid, caregiver knowledge of the advantages and disadvantages of feeding tube use improved significantly ( $p < 0.001$ ). Caregiver expectations were more consistent with medical evidence after viewing the aid and caregiver confidence in the feeding decision made for their loved one improved significantly ( $p = 0.016$ ).

In a study in Japan, researchers investigated the effect of a decision aid on the family members of 13 patients with dementia who were being considered for feeding tube placement (22). After working through the decision aid, decisional conflict among caregivers decreased significantly ( $p < 0.01$ ), and knowledge about feeding tube use improved significantly ( $p < 0.001$ ).

Another intervention study provided group education sessions to family members among 68 caregivers of African American dementia patients (23). Intervention group participants were provided with a four-week group education series on dementia and life-sustaining measures (mechanical ventilation, feeding tubes, and cardiopulmonary resuscitation) (23). Following the study, caregiver self-efficacy in making end-of-life care decisions for loved ones improved significantly in intervention group caregivers ( $p = 0.02$ ), but not control group caregivers ( $p = 0.11$ ).

In summary, caregivers bear a substantial burden in making decisions about end-of-life care. Health care practitioners can provide accurate information to families in a manner that is respectful and culturally appropriate to aid caregivers in reaching a decision that is most appropriate for their family and situation.

### ***Healthcare community considerations***

When considering the community level of the Social Ecological Model as it pertains to feeding tube use in patients with advanced dementia, evaluating the health care community is of particular interest because the knowledge and beliefs of the health care team can greatly impact the treatment. Usually, the physicians are the key decision-makers regarding initiating a feeding tube for these patients. However, physicians have reported that their decisions are influenced by other members of the health care team, including the nurses, registered dietitians, social workers, and speech-language pathologists (24). Thus, this section will explore research on the knowledge and beliefs of both physicians and other health care practitioners.

Shega and colleagues reported that few American physicians held current knowledge about the risks and benefits of using a feeding tube (24). Despite recommendations, the majority of physicians believed that feeding tubes would reduce the risk of aspiration pneumonia (76%), improve nutritional status (94%), and improve survival (61%). In another study, 62.4% of physicians believed that recurrent aspiration pneumonia in patients with dementia could be remedied using a feeding tube (25). Additionally, 44.7% of physicians considered tube feeding to be an appropriate treatment for unplanned weight loss, and 41.4% of physicians felt that it would improve nutrition-related laboratory values. A study of Japanese geriatricians reported that 46.8% of physicians considered dementia to be an indicator for a feeding tube, but 68% of geriatricians reported following no specific clinical guidelines related to tube feeding their older adult dementia patients (26). These studies suggest that physician knowledge may not be consistent with evidence-based guidelines.

Physicians around the world appear to be influenced by their own cultural norms and beliefs on the subject. One qualitative study compared physicians in Australia with those in the Netherlands and found that, while Australian physicians were more likely to allow family members to make nutritional end-of-life decisions, Dutch physicians were more apt to take personal responsibility for this decision-making (27). Authors attributed these differences to different cultural approaches to geriatric care and varying healthcare systems between the two nations. In a qualitative study in Japan, physicians reported that cultural norms favor family decision-making and deter physicians from allowing death without the provision of food and water (28).

Because of Japanese cultural norms, the legal system in Japan encourages physicians to recommend feeding tubes for patients with advanced dementia.

A study of physicians in the United States examined if race would predict physicians' recommendation (29). Results indicated that the race of the physician was more influential in predicting physician recommendations than the race of the patient. African American and Asian physicians more commonly recommended feeding tubes ( $p < 0.001$ ), and African American physicians recommended feeding tubes for African American patients more frequently than they did for Caucasian patients ( $p = 0.033$ ). This is consistent with prior studies indicating that African Americans are more likely than Caucasians to use feeding tubes in cases of advanced dementia (30). Authors suggested that cultural differences in views on death and dying might partly explain these findings, along with minority mistrust of the health care system and inadequate communication between minorities and health care providers regarding advance directives (30).

Authors have examined the role of the nurse in decisions about the use of feeding tubes. In a qualitative study of nurses in a nursing home setting, nurses expressed several common themes, including a lack of adequate knowledge on the current research, uncertainty about the legal and ethical implications involved in tube feeding these patients, and hesitance to provide education or direction to family members on this issue (31). Nurses in a qualitative study in Belgium ( $n = 21$ ) reported that they were hesitant to voice concerns and opinions regarding patient care because they believed that their input was not valued by physicians (32). One study described the intense emotions felt by nurses during the decision-making process because of their desire to "provide good care" to their patients (33). A study in Italy found that 59% of nurses reported feeling sadness regarding the decision to provide or forgo artificial nutrition and hydration to terminal patients with dementia (34). Professionals who did not receive training in palliative care or who specialized in geriatrics were 1.52 times more likely to agree with providing artificial nutrition and 1.7 times more likely to agree with providing hydration, while those who reported feeling sadness about patient deaths were more 1.41 times more likely to agree to provide artificial nutrition and hydration (34). These studies demonstrate that while nurses play an important role in caring for these patients, they may also be unclear about their role in the process, which could lead to emotional distress.

Speech-language pathologists (or speech therapists) are often consulted to determine whether a patient can safely continue eating and drinking by mouth (35). One study surveyed 731 American speech therapists and found that only 22% recognized that a feeding tube would not prevent aspiration pneumonia among individuals with dementia (35). Additionally, only 42.1% of the speech therapists felt confident in managing swallowing difficulties in patients with advanced dementia, and 55% reported recommending tube

feedings. In another study, 56% reported recommending feeding tubes for this population, 78% reported that the feeding tube would improve the nutritional status of the patient, and 43% reported that feeding tubes improve survival (36). Thus, the knowledge and practices of some speech-language pathologists appear to be inconsistent with current research and recommendations.

In a study on the knowledge and practices of Irish dietitians on feeding tube use in patients with dementia, 41% reported being involved in initiating tube feedings for these patients (37). Seventy-eight percent (78%) reported that there was no policy in their workplace on this issue. Additionally, 67% of dietitians reported that family members did not receive adequate information about feeding tubes and 58% felt that the medical team did not thoroughly discuss the use of a feeding tube with patients prior to tube placement. This emphasizes the need for evidence-based guidelines for nutrition professionals working with this patient population.

In many cases, social workers or social services staff members are charged with assisting nursing home patients and their family members with completing an advance directive, which includes patient's wishes regarding the provision of a feeding tube. In one study of 138 nursing home social services staff members in New York, 97% of respondents said they were responsible for having advance directive discussions with family members of patients (38). Only about half (52%) reported regularly discussing the risks and benefits of feeding tube use with families. When asked about their own knowledge of these risks and benefits, only 37% provided responses that were consistent with empirical research. In many cases, social services staff perceived that the medical directors and nursing directors make these decisions (45% and 25%, respectively) (39). This indicates that, according to this cohort, social services staff members may not be providing family members with adequate knowledge of tube feeding use, and that they may have insufficient training on the topic.

Several studies have examined personal feelings of healthcare professionals toward feeding tubes. Specifically, researchers have asked whether health care professionals would want a feeding tube for themselves if they became bedbound due to a terminal illness. Only 20% of speech therapists and 31% of dietitians said they would agree to a feeding tube for themselves if they developed advanced dementia (36 and 37, respectively). In a more recent study in of physicians and nurses in Japan, only 14.4% of reported wanting a feeding tube for themselves (40). Those who routinely worked with tube-fed patients were more likely to refuse a feeding tube for themselves ( $p = 0.014$ ). These studies show that while health care professionals may recommend feeding tubes for patients with dementia, few of them would agree to a feeding tube if they were in the same situation.

In summary of the multidisciplinary health care team's status on this issue, continuing professional education on nutrition and feeding in end-of-life care for practitioners who work with patients with dementia is needed.

### **Organizational considerations**

At the organizational level, research has indicated that certain facility characteristics are associated with frequent use of feeding tubes among patients with advanced dementia. In a cross-sectional study of cognitively impaired nursing home patients, researchers sought to identify patient and organizational characteristics associated with feeding tube use (30). All licensed nursing homes in the United States were included ( $n = 15,135$ ), 33.8% of cognitively impaired residents had a feeding tube, and nursing homes with higher feeding tube rates among cognitively-impaired residents were typically larger ( $>100$  beds), urban, and for-profit. These facilities did not usually have a specialized dementia care unit or a nurse practitioner or physician assistant on staff.

Another study published the same year analyzed tube feeding insertion rates among nursing home patients between 1995 and 1996 (41). They found that having a full-time speech therapist on staff at the nursing home was associated with increased rates of feeding tube insertion (OR = 2.06, 95% CI = 1.51, 2.82). Additionally, the lack of a specialized dementia unit, more licensed nurses with fewer nursing assistants, larger facilities, and a higher proportion of Medicaid beds were also associated with increased tube feeding rates.

Authors in two studies (41, 42) noted that patients without an advance care plan were more likely to have feeding tubes inserted. Facilities with specialized dementia care units may be better equipped to manage end-stage dementia and guide families through the decision-making process. Authors theorized that in organizations where advance care planning is encouraged, family and patient education is being provided and therefore fewer feeding tubes would be placed. Unfortunately, the relationships between feeding tube use and larger facilities, higher proportion of Medicaid beds, urban location, and for-profit financial structure are not well understood. The results of another study support these findings, indicating that urban nursing home residents were more likely to have a tube inserted than residents of rural facilities ( $p < 0.001$ ) (42).

In another study, two nursing homes in South Carolina were compared in order to better understand how differences in the culture of the facility resulted in different tube feeding rates among residents (43). In the high-use facility, 41.8% of patients with advanced dementia had a feeding tube. In the low-use facility, feeding tubes were used in only 10.7% of patients with advanced dementia. Researchers found vast differences in the culture of the two facilities. In the high-use facility, researchers observed only a few staff members available to assist patients with meals. Staff interviews revealed that many employees favored the use of feeding tubes to prevent aspiration pneumonia and avoid citations from regulatory agencies. In the low-use facility, the environment was more like a home setting and mealtimes were staffed with knowledgeable nursing assistants who were trained in feeding patients.

The low-use facility also encouraged advance care planning to address end-of-life care decisions. Researchers concluded that the culture of the organization could greatly affect feeding options available for patients with advanced dementia.

Because feeding tubes are usually placed while patients are in the hospital, researchers have investigated hospital feeding tube insertion data to identify characteristics associated with high tube insertion rates. One such study found that larger (>301 beds), for-profit hospitals associated with medical schools were more likely to place a feeding tube in a patient with dementia than smaller, rural hospitals not affiliated with medical schools (44). An additional study on the health care transitions of nursing home patients and rates of feeding tube insertion found that patients were more likely to receive a feeding tube when they experience multiple care transitions, such as being sent to the hospital for treatment (45). Several studies noted that having advance care plans lowers the likelihood of having a tube inserted during a hospital stay; therefore it is increasingly important that this information is communicated from the nursing home to the hospital when a patient is hospitalized (30, 43).

While the reasons for variations in tube feeding rates among hospitals and nursing homes are not fully understood, the use of feeding tubes in patients with dementia varies widely among health care facilities. This could be related to the corporate culture of the organization, which impacts the attitudes and beliefs of the health care providers who work there. Thus, researchers have emphasized the importance of educating the entire healthcare team in order to modify organizational culture (24).

### ***Policy considerations***

The final level of the Social Ecological Model is policy, which consists of the laws and regulations that govern health care systems. Health care policy is not only important in regulating health care and protecting patients, it is a critical component of the financial structures within the health care system. Further, legal systems may influence the practices of health care professionals. This section investigates how health policy, reimbursement, and legal considerations influence the decision to use a feeding tube in patients with dementia.

In the United States, the government reimburses nursing homes for various services provided to patients. In theory, patients with feeding tubes represent higher medical acuity, and therefore require increased monitoring and care. Because of this, facilities are reimbursed at higher rates for patients receiving tube feedings than they are for patients who eat by mouth (46). This situation is not unique to the United States; Japan and other countries have similar reimbursement structures (28). Unfortunately, this prompts the question of whether government reimbursement structures incentivize facilities for using feeding tubes.

To investigate the cost of caring for patients with feeding tubes, Mitchell and colleagues studied nutrition-related health care costs incurred by patients with

advanced dementia, half who were hand-fed by staff, and half who had feeding tubes (47). They found that it cost an average of \$2379 to provide nutrition care for a tube-fed patient over a 6-month period, while it cost \$4219 to hand-feed a patient for 6 months. This was due to the amount of staff time involved in hand-feeding the patients without a tube. Thus, facilities receive higher reimbursement rates for tube-fed patients, but caring for these patients actually costs less, both in terms of staff time/wages and supplies, than caring for similar patients who do not have feeding tubes.

After reimbursement rates increased for tube-fed patients in nursing homes in the United States, several researchers sought to investigate whether this affected tube-feeding rates across the country (46). While authors expected to find that the financial incentive associated with tube-fed patients led to an increase in tube-feeding rates, they found no significant changes in feeding tube rates after adjusting for confounders. However, this study considered less recent data (from 1993 to 2004). In light of more recent financial concerns, this issue should continue to be monitored, as current health care policy may inadvertently promote the increased use of feeding tubes in this patient population.

Long-term care regulatory structures in the United States may also influence feeding tube use. Guidelines for maintaining adequate nutrition and hydration among nursing home patients are rigorous. Because nursing homes can be penalized when patients with advanced dementia suffer from malnutrition, health care professionals may recommend feeding tubes for these patients even though there is a lack of evidence to support the use of feeding tubes for patients with advanced dementia (43, 48).

The legal system is another aspect of policy that may influence feeding tube use in older adults with dementia. Physicians in the United States have reported fear of legal action taken by family members for failing to recommend a feeding tube for a malnourished patient (24). Similarly, in Japan, physicians also reportedly fear legal repercussions if they do not offer a feeding tube to a terminally ill patient (28).

Thus, multiple policy-level factors can impact feeding tube use in patients with advanced dementia. Several researchers have called for policy reform and restructuring of reimbursement rates to address these issues (48). They reason that the quality of patient care could be improved if health care professionals made evidence-based recommendations for these patients, rather than making recommendations in an effort to maximize financial reimbursement for patient care, or out of fear of legal or regulatory penalty.

### **Conclusion: Strategies for health care professionals**

The use of feeding tubes in patients with advanced dementia is a complex issue, and this warrants multilevel approaches that target each level of the Social Ecological Model. In order for health care professionals to make the

best recommendations for their patients, they will involve family members and other health care professionals as well as address organizational norms and health care policies. Strategies for healthcare professionals are discussed next, and are summarized in [Table 1](#).

Patients with advanced dementia can make their wishes known to family members and health care professionals prior to or early in the disease process. Health care professionals can educate patients about end-of-life care options early on, before advanced dementia, if possible. The health care team should support individuals in making informed choices. In cases where patients with advanced dementia already have feeding tubes in place, health care professionals can support the individual by closely monitoring for adverse side effects and complications related to the tube. The health care team should carefully assess every individual and design a plan of care to meet the patient’s needs and desires.

At the interpersonal level, the health care team must begin end-of-life care discussions with family members and caregivers in the early phases of dementia, when possible. The interdisciplinary health care team must provide thorough, accurate, and culturally appropriate education to family members to reduce anxiety about the decision and increase communication.

From the health care community perspective, professionals must stay abreast of current research and evidence-based guidelines, and they must exhibit cultural competence. This can be accomplished by attending continuing education opportunities related to end-of-life care and advanced

**Table 1.** Strategies for health care professionals on the appropriate use of feeding tubes in patients with advanced dementia.

Individual Level	<ul style="list-style-type: none"> <li>– Educate patients about end-of-life care issues early on, before advanced dementia, if possible.</li> <li>– Support individuals in making an informed choice about whether they want a feeding tube.</li> <li>– Actively monitor for adverse side effects and address complications in tube-fed patients.</li> <li>– Carefully assess every individual and design a plan of care to meet the patient’s needs.</li> </ul>
Interpersonal Level	<ul style="list-style-type: none"> <li>– Discussions about end-of-life decisions need to take place with the caregivers in early phases of dementia, if possible.</li> <li>– Providing caregivers with adequate information about feeding options reduces decisional conflict and increases communication with the healthcare team.</li> </ul>
Health Care Community Level	<ul style="list-style-type: none"> <li>– Attend continuing education opportunities related to end-of-life care, advanced dementia, etc. ... in order to stay abreast of new research.</li> <li>– Share current research with colleagues.</li> <li>– Participate actively in the multidisciplinary health care team.</li> <li>– Education programs need to target the entire health care team, as multiple members of the team often provide input in clinical decision-making.</li> </ul>
Organizational Level	<ul style="list-style-type: none"> <li>– Support the development of evidence-based clinical guidelines within the organization.</li> <li>– Participate in quality improvement efforts.</li> <li>– Encourage hand-feeding and dementia care programs in the nursing home setting.</li> </ul>
Policy Level	<ul style="list-style-type: none"> <li>– Advocate for policy changes that will provide for financial incentives for facilities that successfully hand-feed patients instead of placing a feeding tube.</li> <li>– Support the development of evidence-based regulations.</li> </ul>

dementia, or by reading current research. Additionally, health care professionals can share current research with colleagues (49). Professionals need to be active members of the multidisciplinary health care team. The collaboration between health care professionals leads to improved patient care. Finally, inter-professional education programs should be developed to target the entire health care team, not just one discipline. Because multiple members of the health care team are often involved in clinical decision-making, it is important that the entire team have a current knowledge base on end-of-life care.

At the organizational level, health care professionals should support the development of evidence-based clinical guidelines and policies within the organization. Organizational quality improvement efforts are needed to reduce the insertion of feeding tubes in patients with dementia (50). Encouraging and participating in the development of specialty dementia care programs, patient and family education programs, and hand-feeding programs can influence the culture of the organization, which can provide for improved patient care.

Finally, from the health policy perspective, professionals must advocate for policy changes that impact reimbursement structures, regulatory agencies, and legal systems. Ideally, health care policy should provide for financial incentives for facilities that successfully hand-feed patients instead of placing a feeding tube. However, at a minimum, reimbursement structures should provide for similar reimbursement rates for all patients with advanced dementia, whether tube-fed or hand-fed. Healthcare professionals can support the development of scientifically sound regulations pertaining to elder care. Legal systems must protect health care practitioners in allowing patients and families to make their own end-of-life choices, especially if they decide to forgo artificial nutrition and hydration. Health care practitioners must be able to allow for death in the case of terminal disease without fear of legal repercussions.

Some limitations to the conclusions exist and should be noted, particularly regarding specific constructs. As the population in question, patients with dementia, have difficulty with communication, the research cannot directly explore the individual level of the Social Ecological Model and patient's quality of life. Therefore alternate variables, such as medical complications or mortality were used. Additionally, there is a paucity of recent research to support the organizational and policy level constructs in this area. This is concerning as any future organizational or policy changes designed to improve the quality of patient care should be well-supported and evidence-based. And finally, this area of research would be strengthened by controlled comparisons of United States versus international health care systems' policies and patient outcomes. There is much to learn from other health care systems regarding feeding patients with advanced dementia. However, until all variables are explored similarly in each country, it will be difficult to accurately draw conclusions on the most effective policies to implement.

In terms of future research, more work is needed at each level of the model in order to fully understand the many factors that influence this issue.

## Take away points

- The use of feeding tubes among older adults with advanced dementia may not be beneficial for these individuals. As this is a complex issue, health care professionals must treat each case individually.
- The Registered Dietitian is recognized as the nutrition expert and should lead the interdisciplinary healthcare team in providing patient care that is based on current evidence-based practice guidelines.
- Future interventions should target organizational and policy level influences that impact how individuals with advanced dementia are cared for.

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