Feeding Tube Use in Advanced Dementia: Current Considerations

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Purpose and Overview

Feeding tubes are alternatives to oral feeding in patients with a variety of conditions that prevent proper chewing or swallowing, and have been commonly used to provide nutritional support to patients with advanced dementia. The purpose of this talk is to discuss the current research, the importance of shared decision-making, and certain policy implications associated with feeding tube use in persons with advanced dementia. Healthcare providers who care for patients with advanced dementia in any capacity should be aware of the current body of literature regarding feeding tube use in persons with advanced cognitive impairment, and research efforts should continue to move forward in identifying predictors of morbidity and mortality in feeding tube placement.

Objectives

1. To review some of the current research that has been done on feeding tube use in persons with advanced dementia.
2. To discuss current policy implications of the growing body of literature on feeding tube use in advanced dementia.
3. To discuss the importance of shared decision-making between caregivers and health care providers when discussing feeding alternatives in this population.

Introduction

In 1979, Drs. Micheal Gauderer and Jeffrey Ponsky devised the percutaneous endoscopic gastrostomy (PEG) procedure, as a method to insert feeding tubes in infants and children who had feeding and swallowing difficulties.[1,2] These children, who ranged in age from 4 months to 18 years, had diagnoses of severe hypoxic encephalopathy, severe laryngotracehomalacia, and complex neurological syndromes. All were unable to swallow and had previously been feed by nasogastric tubes. Because of their disease states and certain musculoskeletal deformities, these patients were considered of high anesthetic and surgical risk. In an attempt to avoid or lessen

surgical complications, Gauderer and Ponsky developed what was considered a safer alternative to open laparotomy. The percutaneous endoscopic gastrostomy procedure did not require general anesthesia in most cases, and was associated with only minimal discomfort in the post-operative period. The procedure was also relatively simple to perform and faster than traditional methods. Gauderer and Ponsky went on to follow the clinical course of the first 150 patients who had undergone the procedure over time. In the 50 children and 100 adults who received PEG tubes from June 1979 to May 1982, they found that morbidity associated with the procedure was low (10%) and that there were no procedure-related deaths.[3] Complications included minor infections and extrusion of the tube, but hemorrhage, peritonitis, and other more serious complications did not occur. Consequently percutaneous endoscopic insertion of feeding tubes became an effective and commonly used alternative to open laparotomy and a more permanent and stable alternative to nasogastric feeding tubes. [3] Since the time of its creation, PEG tube insertion has been adapted as a technique for use in conditions that affect chewing and swallowing for both children and adults. Adults with conditions that affect chewing and swallowing, such as stroke, head and neck cancers, and various neurodegenerative processes may be candidates for PEG tube placement.

The frequency of PEG tube placement has been estimated to be more than 200,000 annually;[4] however, the circumstances associated with feeding tube placement are not without controversy – particularly among patients with conditions that leave little hope for improvement. This controversy extends to feeding tube placement in persons with advanced dementia. These patients are bedbound, nonverbal, and exhibit difficulties with swallowing. Though their condition is irreversible with no chance of recovery, their disease trajectory can be prolonged. Family members and caregivers are then faced with making decisions on how their loved ones' nutritional needs will be met. Feeding tube placement is sometimes offered as an alternative. It should be noted that the creators of the percutaneous endoscopic gastrostomy procedure did not intend for it to be a method of end-of-life care for patients. [1,2] In fact, when interviewed regarding the Terry Schiavo case, Dr. Ponsky remarked that, "Too often the tubes are used in patients with no potential for recovery." Ponsky also stated that, "Once [feeding tubes] are in, it's so emotionally difficult to take it out and let someone die."[2] Placement of feeding tubes in this population may create an ethical dilemma, as the research suggests that there is no real benefit and potential risk associated with the use of PEG tubes in these frail elders – particularly at the end of life. As a result, health care providers must assist caregivers in making informed decisions about feeding tube use in persons with advanced dementia. A caregiver's choice to place or forgo placement of a feeding tube in their loved one should involve shared decision-making, be individualized, and the information health care providers use to enrich discussions about feeding tube placement should be based upon the current evidence.

Nutrition

For patients who rely on enteral nutrition as their source of nutrients, certain things must be taken into account. Some studies suggest an improvement in laboratory values, including blood count, renal function, electrolytes and hydration status when

compared to controls,[5] and increased weight and maintained serum albumin when an in-house low-cost formulation was used,[6] while other studies have shown that micronutrient deficiencies and malnutrition exist despite provision of adequate calories and protein in chronically ill patients that receive tube feeds.[7] Other complications of tube feeding have been cited. Research suggests that refeeding syndrome and hyperphosphatemia may occur in long-term care elderly who received nutrients via NG tube.[8] Furthermore, development or underdiagnosis of diabetes has been noted in up to 44% long-term care residents who received tube feeds,[9] and long-term care residents who have complex physical disabilities who are fed using PEG or NG tubes may be at higher risk of low bone mineral density and development of metabolic alkalosis.[10,11] Certain enteral formulations may result in loose stools; however, fiber-containing formulas may help to resolve that issue.[12] Research has noted the effectiveness of having a registered dietician involved in the care of these patients,[13] and given the complexities associated with tube feeding, a registered dietician should be included in the multidisciplinary team if possible.

Colonization

Antibiotic resistance is an emerging public health issue that hospitals and health care systems must face, and though the threat of antimicrobial resistance is most prevalent in the hospital setting, it has been noted in the community and long-term care settings as well. An estimated 85% of serious MRSA infections are associated with health care exposure, but nearly 14% of the infections are community-associated.[14] Given that long-term care residents with feeding tubes are often transported to hospitals for care, health care providers in the long-term care setting should be mindful of possible colonization of certain bacteria and how to reduce spread of antimicrobial-resistant organisms in their facilities. Among the antibiotic-resistant organisms most commonly found in long-term care populations are multidrug-resistant Gram-negative bacteria, methicillin-resistant *Staphylococcus aureus* (MRSA), and vancomycin-resistant enterococci (VRE),[15] and feeding tubes use may increase risk of colonization among patients who have them. Studies have shown that tuboenteral (PEG and NG tube) feeding in elderly patients receiving care in nursing and skilled nursing facilities may be associated with oropharyngeal colonization with bacteria such as resistant strains of *Pseudomonas aeruginosa*.[16] Oropharyngeal colonization of Klebsiella, Proteus, and MRSA has also been detected in patients with NG and PEG tubes who reside in skilled nursing facilities and community nursing homes.[17,18] Infection control programs may significantly reduce bacterial contamination associated with enteral feeding,[19] and long-term care providers should use this information to create strategies that will reduce spread of antimicrobial resistance in their facilities.

The Epidemiology and Clinical Course of Dementia

Alzheimer's disease is the most common type of dementia, and is thought to account for 60-80% of cases. Though vascular dementia is the second most common form and accounts for about 10% of all cases, other types of dementia are less well known. Those who are diagnosed with Dementia of Lewy Bodies can experience visual

hallucinations and develop parkinsonism. Patients with frontotemporal dementia are often younger in age, exhibit changes in personality and behavior, and may have some preservation of cognition. Other dementias may be associated with clinical conditions. For instance, patients with Parkinson's disease may also develop cognitive impairment. Persons with normal pressure hydrocephalus may have a triad of symptoms that includes gait abnormalities, urinary incontinence, and cognitive impairment. Additionally, Creutzfeldt-Jakob disease, a rare neurodegenerative disease, may present later in life and be rapid in its course. Given that Alzheimer's disease is most common, it is most commonly recognized, and more detail regarding the epidemiology of this dementia is known. There are estimates that up to 5 million individuals aged 65 and older in the United States have Alzheimer's disease, and 13.8 million people are projected to have dementia by the year 2050.[20] The length of survival from symptoms onset is variable and prognostication is difficult. Research suggests that the median survival after the onset of dementia can range from 3 to 9 years.[21-23] Though prognosis is often difficult to determine, validated measures have been created that can sometimes help clinicians in determining the stage of dementia – particularly when patients are no longer able to complete a mental status evaluation. One tool that is used is the Functional Assessment Staging (FAST) tool (See Table 1). This validated tool is composed of seven major functional levels that correspond with global levels of cognition and functional capacity.[24] For instance, deficits in a person's ability to perform complex tasks of daily life is indicative of mild dementia (FAST stage 4), while limited intelligible vocabulary (FAST stage 7b) and loss of ambulatory ability (FAST stage 7c) are characteristics noted in severe dementia patients. This tool is commonly used to assist in determining hospice eligibility for patients with Alzheimer's and other dementias, and is recommended by the National Hospice and Palliative Care Organization for this purpose, as it identifies the progressive steps and sub-steps of functional decline that persons with dementia often face.[25] Additional "sentinel" events preclude a poor prognosis in dementia patients. Development of pressure ulcers (particularly stage III or IV), sepsis, pyelonephritis, and aspiration pneumonia are examples of those events. Dysphagia is often a harbinger of aspiration and aspiration pneumonia, and is indicative of progression of disease. Alzheimer's disease is sixth leading cause of death in the United States and is the fifth leading cause of death among people aged 65 years and over.[23] The disease trajectory of Alzheimer's disease is one of a non-reversible, progressive functional decline, and as the disease progresses clinical complications will likely be encountered. For instance, in a study of 323 nursing home residents with advanced dementia (as defined by a Mini-Mental State Examination score of 5.1 ± 5.3) who were followed for 18 months, researchers found that 54.8% of the residents died during the study period. The probability of a resident developing an eating problem was 85.8%, and the probability of a resident having at least one episode pneumonia was 41.1%.[21] The trajectory of events for persons with advanced dementia is further complicated by weight loss, pressure ulcers, and nutritional concerns, which then necessitate discussions about feeding options.

<u>Perceived Benefits of Feeding Tube Insertion in Advanced Dementia</u>

Eating problems like oral dysphagia (pocketing of food), pharyngeal dysphagia (delayed swallowing and aspiration) often mark the progression of dementia, and feeding tubes are often placed as a means to provide nutrients to patients with severe dementia who have difficulty with chewing and swallowing. In a study of more than 100,000 US nursing homes, 34% of nursing home residents with advanced cognitive impairment had feeding tubes.[22] The circumstances that drive these decisions are multifactorial. Some health care providers may believe that feeding tube insertion and enteral nutrition will serves as a benefit to patients with advanced dementia. In a study of nearly 200 primary care physicians, researchers found that a great number of those physicians believed that PEG tube insertion benefitted patients with advanced dementia in the following ways: reduction of aspiration pneumonia (76%), improvement in pressure ulcer healing (74%), survival (61%), nutritional status (94%), and functional status (27%). More than half of these physicians felt that use of PEG tubes in advanced dementia was the standard of care.[26] Misperceptions about tube feeding in advanced dementia among other health care professionals have also been identified. In a study of more than 1000 speech-language pathologists, researchers found that only 22% of them recognized that tube feeding in advanced dementia is unlikely to reduce risk of aspiration, but 70% were willing to consider recommending oral feeding despite high risk of aspiration in this population.[27] These misconceptions may certainly spill over to caregivers when decisions are made to place feeding tubes in the loved ones.

The studies noted above have identified common perceived benefits to feeding tubes in advanced dementia. Though there is some thought that feeding tube placement will reduce the risk of aspiration in this population, studies have shown that patients with feeding tubes are still at risk of aspiration and the development of aspiration pneumonia.[28,29] Studies have shown that up to 22.9% of nursing home residents with PEG tubes aspirate, regardless of method of administration (continuous versus intermittent infusion),[30] jejunostomy (PEJ) tube placement does not protect against aspiration pneumonia in patients known to aspirate,[31] and that the presence of a nasogastric or gastric tube is a risk factor for development of nosocomial pneumonia among elderly in the long-term care setting.[32] An alternative to feeding tube placement that should be considered is careful hand feeding.[33-35] Though in the long-term care setting, this alternative may be hampered by cost[36] and facility staffing issues, the data suggests that this may be a viable alternative to tube feeding in older adults with advanced dementia.[34] In addition to the notion that tube feeding reduces the risk of aspiration and aspiration pneumonia in advanced dementia patients, it is thought by some as a way to assist with pressure wound healing, and improve survival. There are observational studies that do not support these assertions. Studies have shown that PEG tube insertion in nursing home residents with advanced cognitive impairment does not affect survival. In a study of more than 30,000 nursing home residents with advanced cognitive impairment, neither feeding tube insertion nor the timing of insertion relative to the development of eating problems was associated with improved survival among the cohort.[37] The data suggests that tube feeding does not prevent the development of pressure wounds or assists with wound healing. There is evidence that PEG tubes are not associated with prevention or improved pressure ulcer healing and

may be associated with increased risk of pressure ulcers among nursing home residents with advanced cognitive impairment.[38]

Morbidity, Mortality, and "Burdensome Transitions"

Those who have dementia often reside in the long-term care setting. In fact, up to 67% of dementia-related deaths occur in these nursing facilities.[39] Given that up to 34% of nursing home residents have feeding tubes in place, the "natural history" of feeding tube utilization in this population is often born out in long-term care. Geographic variation of feeding tube insertion also exists, and burdensome transitions have been identified among advanced dementia patients who have feeding tubes in place. A study was conducted to examine the natural history of feeding tube insertion in this population, including the incidence, circumstances of insertion and post-insertion health care use. The study revealed that while the overall incidence of feeding tube insertion was 53.6 per 1000 elderly nursing home residents, there was wide state-by-state variation in incidence across the United States (2.1 per 1000 for Utah up to 108.3 per 1000 residents for Mississippi). Feeding tube recipients were more likely to be younger, male, and racial and ethnic minorities were much more likely to receive feeding tubes than white subjects. Two thirds (68.1%) of all feeding tubes were inserted during an acute care hospitalization, and the most common primary diagnoses were aspiration pneumonia, dehydration, and dysphagia. The overall 1-year mortality rate was 64.1%, with a median survival of 56 days after insertion.[40] Health care transitions, or transfers to or from any health care setting (hospital, emergency room, inpatient rehabilitation facility, nursing home, inpatient hospice, etc.) may be considered "burdensome" for persons with severe dementia. The likelihood of needing to make one of these transitions is increased when feeding tubes are placed. Complications such as tube dysfunction, clogging[41] , dislodgement, and infection[42] may occur, requiring emergent evaluation and inpatient hospitalization.[40] Furthermore, regions with higher rates of these health care transitions among nursing home residents are much more likely to have higher rates of feeding tube insertion in the population.[43]

Costs Associated with Feeding Tube Use

Healthcare costs associated with feeding tube use must also be considered. Studies have revealed that though tube-fed nursing home residents generate a higher daily reimbursement rate from Medicaid and require less expensive nursing care than hand-fed patients, tube-fed patients incur increased Medicare costs due to the expense associated with initial placement and acute management of complications (i.e., hospitalizations and emergency room visits).[36] Small-bore feeding tubes have been associated with increased costs because of the need for radiographs, unsuccessful placements, fluoroscopy, and complications.[44] Higher feeding tube insertion rates have been noted in for-profit hospitals,[45] and nursing homes residents who reside in for-profit nursing homes have a greater likelihood of feeding tube use.[22] Research has shown that one year hospital costs were $2224 higher in nursing home residents with feeding tubes than those without a feeding tube, and those with a feeding tube were more likely to spend more time in an intensive care unit.[46] Though healthcare providers' first

concerns should be for patients and their families, our current climate of economic uncertainty may play a very important role in improving evidence-based shared decision-making around feeding tube placement.

Perceptions of Family Caregivers

While the complications associated with feeding tube use can create increased healthcare costs, they can be equally if not more costly to patients and their families or caregivers. Caregivers are often faced with the challenging decision of feeding tube placement for their loved one, and some have expressed concern about the decision-making process. Family members have reported that discussions with healthcare providers about feeding tube insertion were either abbreviated or did not occur, and they have sometimes felt pressured by the physician to insert a feeding tube.[47] They have also noted that their loved one was often pharmacologically restrained, and they were less likely to report excellent end-of-life care.[47] Opportunities to improve shared-decision making surrounding feeding tube insertion exist, and efforts are being made to improve communication about feeding tube insertion among patients, family caregivers, and healthcare providers.[48-50] Researchers conducted a randomized trial that tested the effectiveness of an audiovisual decision aid that provided information about dementia, feeding problems in dementia, and the advantages and disadvantages of feeding tubes or assisted oral feeding options among 255 surrogate decision makers for nursing home residents with advanced dementia and feeding problems. After review of the decision aid, intervention participants had improved knowledge about feeding tubes, decreased expectation of benefits from tube feeding, and reduced decision conflict. Furthermore, surrogate decision makers reported more certainty in their decision to opt for oral feeding instead of tube feeding after reviewing the decision aid.[50] Community organizations have also created guidelines and established protocols that address feeding tube insertion in advanced dementia. The Rochester Community-wide Percutaneous Endoscopic Gastrostomy (PEGs) Workgroup) created a practice guideline that recommends the following actions be taken prior to making a decision about PEG placement: 1) conduct a comprehensive assessment looking for reversible causes of inadequate nutrition; 2) review the medical evidence as it relates to tube feeding/PEGs; 3) discuss the evidence with the patient, health care agent or family member; 4) elicit family/patient understanding of the present medical condition; and 5) discuss the benefits and burdens of tube feeding and whether this would be consistent with the patient's wishes. They further recommend that if tube feeding is utilized, specific goals should be developed and time intervals for reviewing whether these goals have been achieved should be considered.[49] The creation of decision aids and establishment of protocols that take into account caregivers may decide to have a feeding tube placed is important, and periodic review of the goals of care with caregivers is also valuable.

Future Research

While there is an extensive amount of research about feeding tube use, including indications for placement, complications associated with placement, and outcomes for

patients with advanced dementia, there is more work to be done. Research regarding feeding tube use among patients with advanced cognitive impairment is largely observational. Though there is substantial evidence that feeding tube insertion does not promote wound healing, improve survival, or prevent aspiration pneumonia in this population,[37,38,51,52] researchers should consider the possibility of randomized controlled trials to either strengthen or refute these findings if they can be done in an ethically responsible way. Also, members of underrepresented groups more often choose feeding tubes as an option for nutritional support.[53] The reasons for this dynamic should be explored, and interventions should be designed to enhance culturally-sensitive shared-decision making for patients and families of diverse racial/ethnic groups

Implications for Policy Formation

The American Geriatrics Society

The American Geriatrics Society (AGS) is a not-for-profit organization of more than 6000 health professionals dedicated to improving the quality of life of all older adults. A part of the vision of AGS is to guide public policy through advocacy so that policy supports improved health and health care for seniors. In 1993, AGS drafted a position statement on feeding tube use in advanced dementia and reviewed the document in 2005. The statement was updated and revised in 2013 because of the publication of several sentinel studies that describe the natural history of feeding tube use in this population, and has been vetted extensively by experts in the fields of geriatrics, gerontology, and long-term care. This guideline recommends consideration of careful hand feeding instead of feeding tube insertion, while realizing that individual-centered approaches should be a part of the care plan for all older adults with advanced dementia. Additionally, the guideline emphasizes the responsibility of all members of the healthcare team caring for residents in long-term care settings to understand any previously stated wishes regarding tube feeding and to incorporate these wishes into the care plan.[54]

Choosing Wisely

Current research and practice have had other direct implications on policy formation. *Choosing Wisely*®, an initiative of the American Board of Internal Medicine (ABIM) Foundation, was designed to help physicians and patients engage in conversations about the overuse of tests and procedures and support physician efforts to help patients make smart and effective care choices.[55] Through *Choosing Wisely*®, leading specialty societies have created specialty-specific lists of “Things Physicians and Patients Should Question,” which are evidence-based recommendations that should be discussed to help make wise decisions about the most appropriate care based on a patient’s individual situation. Consumer Reports, the nation’s leading independent non-profit consumer organization, has also joined the campaign in an effort to help disseminate information and educate patients on making wise decisions.[55] Both the American Geriatrics Society and the American Academy of Hospice and Palliative

Medicine have included recommendations against the use of percutaneous feeding tubes in patients with advanced dementia among their contributions to the *Choosing Wisely*® campaign.[56] Instead, both organizations recommend assisted oral feeding as an evidence-based approach to providing nutrition for patients with advanced dementia.[56] These and other programs are not only important in terms of policy formation, but they assist healthcare workers in providing evidence-based information to patients and families who must make the decision to insert or forgo the use of a feeding tube.

Conclusion

The decision to place a feeding tube is a complex one for patients, caregivers, and healthcare providers. Those who are charged with the decision of whether or not to place a feeding tube should be fully informed of the risks, benefits, and alternatives to feeding tube placement. Alternatively, health care providers should be aware of the needs of patients with feeding tubes in the long-term care setting; they should work closely with nursing and dietary staff to make sure that the appropriate tube feed is used, and complications such as infection and aspiration are minimized if possible. If a feeding tube is placed for clinical condition that is likely not reversible such as advanced dementia, these patients should be reassessed periodically, and the goals of care should be readdressed. Continued research efforts should assess the possibility of clinical trials in this area and creation of culturally-sensitive shared decision-making interventions. Policy-makers should continue to implement programs and policies that will enhance patient-provider communication. The ultimate goal for healthcare providers should be to assist patients and their caregivers in making informed decisions that focus specifically on the patient's quality of life.

Table 1. Functional Assessment Staging

Stages	Characteristics	Clinical Diagnosis
1	No objective or subjective functional decrement	Normal Adult
2	Subjective forgetfulness	Normal Aging
3	Deficits noted in demanding occupational and social settings	Mild Cognitive Impairment
4	Deficits in performance of complex tasks of daily life	Mild Dementia
5	Deficient performance in choosing proper attire and assistance is required for independent community functioning	Moderate Dementia
6	A. Needs help with putting on clothes B. Needs help with bathing C. Needs help with toileting D. Urinary incontinence E. Fecal Incontinence	Moderately Severe Dementia
7	A. Ability to speak limited to six words in an average day B. Ability to speak limited to a single word C. Loss of ambulation D. Inability to sit E. Inability to smile F. Inability to hold head up	Severe Dementia

Adapted from Sclan et al, International Psychogeriatrics, 1992;4:55-69.

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