Tube feeding: Prolonging life or death in vulnerable populations?

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Abstract
Tube feeding can be an appropriate and effective means of providing nutrition for individuals who are unable to achieve adequate nourishment orally because of various medical problems. However, the delivery of nutrients by tube feeding can cause ethical dilemmas in cases where the effectiveness of tube feeding diminishes and medical complications increase. The decision to tube feed is often influenced by regional and cultural preferences, as well as the high cost of providing mealtime assistance. The effectiveness and appropriateness of tube feeding has been the subject of much debate as it applies to those with severe cognitive impairments and those who are in a persistent vegetative state (PVS). Recent research shows that in these vulnerable populations, tube feeding alone does not necessarily prevent malnutrition and risk of infection or improve functional status and comfort. While advanced directives allow an individual to make decisions about his or her care at the end of life, court cases and religious doctrine examine the individual’s right to autonomous decision making in opposition to preserving the sanctity of life. As long as the outcome of this debate is largely undecided, the process of dying may be prolonged for those who can no longer advocate for themselves.

Keywords: Enteral feeding, tube feeding, ethics, persistent vegetative state, dementia, palliative care

Introduction
Nutrients are introduced into the body in two ways: by enteral feeding through the digestive tract, and by parenteral feeding through a tube inserted in a vein in an arm or leg (peripheral line) or through the chest wall in a larger vein closer to the heart (central line) (ASPEN, 1995). While most individuals independently ingest food orally, tube feeding can be an effective method of providing nutrition via the digestive tract to an individual who is unable to obtain adequate nourishment because of various medical problems: a cognitive compromise, a hypermetabolic state or a physical impairment. Furthermore, persons with significant mental health problems that impede their volition to eat may be nutritionally supported while aggressive, life-saving treatment is initiated. An exhaustive body of literature supports the use of tube feedings to sustain life, support rehabilitation and improve the quality of life for many individuals. The value of tube feeding is not contested for the majority of persons who receive this treatment. However, in certain vulnerable groups of persons who are near the end of life and cannot advocate for themselves, the effectiveness of the nutrients delivered by tube feeding diminishes while medical complications increase,
thus causing ethical dilemmas for providers, families and patients. Two such vulnerable populations are those with severe cognitive impairments and those who are in a persistent vegetative state (PVS) and have lost all cognitive neurological function but have retained noncognitive (brainstem) function.

Enteral or tube feeding is a medical procedure to deliver nutrients through a thin nasogastric tube inserted through the nose, through a gastrostomy or percutaneous endoscopic gastrostomy (PEG) tube through the wall of the abdomen directly into the stomach, or through a jejunostomy or percutaneous endoscopic jejunostomy (PEJ) tube into the small intestine. Nutritionists and health care providers may refer to enteral or parenteral feeding as, “medical nutrition and hydration”, whereas ethicists tend to use the phrase “artificial nutrition and hydration” to describe the dilemma imposed by the medicalization of feeding. Using the term “medical” rather than “artificial” obfuscates the real meaning, as feeding someone through a tube is the delivery of nourishment rather than “medicine.” When the tube is withdrawn, the individual does not suffer an exacerbation of a disease, but instead suffers potentially from malnutrition, dehydration and perhaps death (Smillie, 2003). In most societies there is a moral imperative to feed those who are unable to feed themselves. This is especially true among African Americans, who demonstrate a significantly higher rate of tube feeding when this intervention could be deemed medically futile, as in the case of persons with severe cognitive impairments or PVS at the end of their life (Gessert et al., 2000; Mitty, 2001). Thus, an ethical dilemma develops within many Western societies regarding the appropriate use of tube feeding to prolong life and determining when tube feeding is in fact prolonging death. This article seeks to clarify these questions with regard to adults and older adults in two highly vulnerable populations: those with severe cognitive impairment and those in a PVS.

Use of tube feeding

Tube feeding has been used for centuries, and a series of published articles on its benefits began to appear in the middle of the 19th century (Harkness, 2002). Initially tubes were inserted through the nose, mouth or rectum to deliver nourishment, which was usually some type of pureed food in a liquid slurry. The feeding tube also has nefarious attributes ascribed to it: in the 1800s and early 1900s, tube feeding was sometimes used as a tortuous method of delivering food to persons held as prisoners, such as the suffragettes in Holloway and Perth Prisons. Interestingly, the Prisoner’s Temporary Discharge on Ill Health Act, or the “Cat and Mouse Act,” was legislated by the Asquith government in 1913 in response to acts of nonviolent civil disobedience by the Women’s Social and Political Union, whose members protested through hunger strikes. These women were initially discharged from prison because of potential malnutrition but were then returned to jail, only to be harshly force-fed using tubes.

Today, feeding with tubes is deemed an appropriate method to provide nutrition during a period of rehabilitation or for an extensive time when there is little possibility of functional improvement and the individual’s quality of life would suffer if food were withheld. Tube feeding is commonly used in certain medical conditions: impairment of the neuromuscular pathways, such as after a stroke; structural or connective tissue diseases, such as esophageal cancer or sarcoidosis; mental health problems, such as anorexia or major depression; hypermetabolic states caused by burns or sepsis; and for those who simply cannot eat because of a mechanical problem such as being ventilator dependent. The only contraindication to tube feeding is obstruction of the gut (Haddad & Thomas, 2002). Tube feedings can be the sole source of nutrition or might supplement an individual who
can still ingest some food but not in adequate amounts based on their caloric needs. The nutrition supplied in enteral feedings ranges from a diet prepared in a blender at home that approximates to the food in the usual diet, to a prepackaged canned liquid that is based on caloric and nutrient needs of individuals with certain health problems, for example diabetes or cystic fibrosis.

Insertion and maintenance of feeding tubes is not benign. For very short-term problems, a tube can be inserted through the nose into the esophagus, ending in the stomach. This delivery method is problematic as it is painful, often causing throat irritation and associated pain in the eustachian tubes, as well as desensitization, which affects swallow function and pneumonia risk. In a descriptive study of the perception of pain and discomfort for 16 common procedures or experiences delivered in the past seven days among hospitalized patients ($n = 165$), Morrison and colleagues (1998a) found the “pain” rating for tube feeding was third, following only the drawing of blood for arterial blood gases (via a puncture in the palmar side of the wrist) and the placement of a central line (an incision below the clavicle). Patients experienced more discomfort than pain from the tube and ranked tube feeding first in “discomfort,” followed by mechanical ventilation and restraint use.

When the medical team anticipates more long-term use of tubes, a surgical procedure is required to open the abdominal wall while an endoscope is inserted through the mouth, down the esophagus to assure proper placement of the tube in either the stomach or jejunum. An external small-bore tube is then inserted and fixed in place. The presence of a new orifice from the digestive tract to the skin increases the potential for infection and may allow a backflow of enzymes and other digestive fluids that can cause skin irritation.

Short-term or long-term tube feeding is often recommended for patients who are at risk for aspiration (food or liquid entering the lungs through the airway instead of entering the stomach through the esophagus). For many of these patients, adequate nutritive intake can be achieved with tube feeding while protecting them from developing aspiration pneumonia. However, individuals who are tube fed are still at risk of acquiring pneumonia through aspiration of regurgitated gastric contents from the tube feeding and aspiration of saliva rich in bacteria (Langmore et al., 1998).

In fact, Rabeneck et al. (1996) showed that after 11 months, 15% of US veterans with PEG tubes developed aspiration pneumonia. In a separate study, Oyogoa et al. (1999) evaluated three groups of patients (those with severe disease, such as late-stage cancer or serious pulmonary disease, those with neurological disorders, and those specifically with head and neck cancer) to determine which group had the best outcome from PEG tube placement. After following 100 patients for 30 days, the researchers found that the group with severe disease fared worst, with 85% succumbing to their disease within a month, compared to 30 and 15%, respectively, in the other groups. Four percent of the total sample died directly from the procedure itself. Thus, for certain medical disorders, use of tube feedings many not add time or quality to life. Despite the myth that to deny food and fluids at the end of life causes a painful death, it has been recognized for over a decade that persons who are cognitively intact until death report a sense of satiety, while eating only increases their discomfort causing bloating, nausea and vomiting (Schmitz, 1991; McCann et al., 1994; Ellershaw, 1995).

Use of tube feeding in persons with severe cognitive impairment

Tube feeding can occur across the continuum of health problems: from the person with a sudden stroke who temporarily loses the ability to swallow and requires enteral feeding for nutrition support while aggressive speech therapy is initiated, to the person with an oral
cancer who is having reconstructive surgery and may be able to resume oral intake, to the person who has severe neurological impairment and is not expected to return to oral feeding. It is this last state that is ethically problematic, especially in two groups of people—those with severe cognitive impairments and those in a PVS. Until the mid-1990s, a sketchy base of evidence existed that demonstrated the value of tube feeding at the end of life, especially as it might contribute to the quality of life. Necessarily, this was not a group of persons on whom a randomized control trial of tube feeding versus alternative feeding could be attempted. A seminal article published in 1999 by Finucane and colleagues reviewed the literature regarding the efficacy of tube feeding for persons with severe cognitive impairments, that is Alzheimer’s disease and other dementias. By evaluating the extant research, they were able to show the absence of methodologically sound studies to support the assumptions regarding the efficacy of tube feeding in this population, assumptions including: tube feeding alone does not prevent aspiration pneumonia, tube feeding does not prevent the consequences of malnutrition, survival was not improved, improvement of pressure ulcers was questionable, risk of other infections (besides pneumonia) was not reduced, functional status was not improved, and patient comfort was not improved and usually made worse. The authors concluded that “a comprehensive, motivated, conscientious program of hand feeding is the proper treatment” (Finucane et al: 1369) and conjectured that ease of use, decreased time, and family and healthcare provider misunderstanding contributed to use of tube feeding rather than hand feeding.

In the late 1990s and early 2000s more researchers began to use the national nursing home database, the Minimum Data Set (MDS) mandated in both the US and Canada, to begin to answer questions regarding why residents (term used in lieu of “patients” to designate persons living in nursing homes) were tube fed rather than hand fed. This database is able to generate quarterly prevalence data on 300 items including eating issues. Among all nursing home residents in the US (n = 1.41 million), recent data demonstrate that 50.3% of residents require minor assistance with eating and another 34.4% require constant assistance (CMS, 2004a). Among this same population, 7.1% are tube fed (CMS, 2004b). When facilities in Boston were compared with those in Ottawa, it was concluded that within the Canadian facilities only 10.9% of residents with dementia were tube fed compared with 60.4% in Boston (Mitchell et al., 2000). Aronheim et al. (2001) found wide regional variation in the US in the use of tube feeding in residents with severe cognitive impairments, with a rate of 7.5% in the state of Maine and 40.1% in Mississippi. Within the state of Kansas, Gessert et al. (2000) found that certain characteristics in the population (n = 4997) were more likely to predict tube use; odds ratios (ORs) showed that swallowing problems (OR 5.4), urban location (OR 2.9), non-white race (OR 2.7), stroke (OR 2.5) and absence of dementia (OR 2.5) were predictive of tube use. Of those dependent in all activities of daily living, 74% used tubes and 80.1% of those with either chewing or swallowing problems had tubes. Mitchell et al. (2003) also found that nursing home characteristics—larger, for-profit homes in urban areas without a nurse practitioner—placed residents at higher risk for tube use.

Provider factors also influence choice of tube feeding at the end of life. In a mailed survey of physicians (n = 195), most of whom had had experience caring for persons with dementia who had a PEG tube (87%), the majority believed that PEG tubes decreased the rate of aspiration pneumonia, increased survival, improved nutritional status and promoted healing of pressure ulcers (Shega et al., 2003). Over 62% of the physicians underestimated the rate of mortality after tubes were inserted, and 60% stated that other professionals influenced their decisions (e.g. speech-language pathologists, nurses and nutrition support teams). Only 28% had read any recent literature on tube feeding and dementia.
Issues related to feeding persons in nursing homes and at home

Care of people with dementia is costly, especially when that care requires assistance at meals. Older data (Shook & Beck, 1992) show that feeding takes significantly longer with cognitively impaired residents (32 min) than with those who are physically impaired (15 min). In a time-and-motion study in 35 nursing homes in which observations were categorized into 44 discrete caregiver activities, feeding assistance took the longest total time of all activities per day, 56.3 min. When heavy-care residents (those requiring assistance with all activities of daily living) were analyzed separately, the amount of time spent feeding these residents rose to 76.4 min daily (Roddy et al., 1987).

The cost of feeding may influence institutional decisions to use tube feeding. In most states, the US federal reimbursement is higher for care of tube fed residents than for hand fed residents; thus, the incentive to use tubes may be increased. In a retrospective study of residents who had either a PEG or a PEJ tube \( (n=11) \) versus matched residents who required manual assistance with eating \( (n=11) \) over 6 months, the tube fed residents were found to be more expensive to care for, but those costs were related to hospitalization for tube placement and complications directly related to tube feeding or swallowing problems, such as severe upper gastrointestinal bleeding or aspiration pneumonia: $9373 ± (SD) 5592 for tube feeding vs. $5178 ± 1821 for manual feeding. However, excluding these preventable costs, the cost of tube feeding in terms of staff time was much lower and was the least expensive care rendered: $2379 ± 1032 for tube feeding vs. $4219 ± 1545 for manual feeding, with staff spending 25.2 ± 12.9 min on tube fed residents vs. 72.8 ± 16.5 min for those without tubes (Mitchell et al., 2004).

Mealtimes in nursing homes may also be influenced by both regional and institutional culture. Kayser-Jones (1981) compared life in two nursing homes, one in Scotland and the other in California, and found that residents in the Scottish home unanimously agreed that food was to their satisfaction, compared with only 15% in the US home. Mealtimes were a pleasant, social experience in the Scottish home, whereas the US home’s meals were depicted as unattractive and unappealing. Upon completion of this work, Kayser-Jones conducted several ethnographic studies to examine the institutional culture of nursing home meals and use of tube feedings. Conclusions from these studies demonstrated that tube feedings were sometimes used as a threat against residents who ate slowly or consumed smaller amounts (Kayser-Jones, 1990), that inadequate staffing was linked to poor care, including insufficient time to assist residents at meals and risk of dehydration (Kayser-Jones, 1997; Kayser-Jones et al., 1999), and that caregivers focused more on the task of feeding than on the process of meals when working with residents who had cognitive impairments (Kayser-Jones & Schell, 1997). Amella (1999, 2002) found that the quality of the interactions that persons with dementia experienced with nursing home caregivers influenced their ability to eat or be fed and the level of resistance they offered to food. These studies indicate the need for greater understanding of the process of meals, including the influence of the context and the need for adequate, appropriately trained staff.

In an attempt to increase the number of staff available to assist at meals, the Centers for Medicare and Medicaid issued a change in regulations on September 26, 2003, allowing reimbursement for staff training as “feeding assistants” for a total of 8 hours. This change is intended to “provide more residents with help in eating and drinking and reduce the incidence of unplanned weight loss and dehydration” (Federal Register, 2003: 55528). While this rule change answers some of the mealtime staffing ratio issues, it has been criticized for not addressing the complexities of residents’ needs during meals (Pear, 2003).
Mealtime management for people with severe cognitive impairments who live at home has received scanty attention. In two qualitative, community-based studies, family members of persons with late-stage dementia were interviewed regarding ways they were assisted with meals (Amella, 2003a,b; Keller, 2003). Keller found that most families reported their loved one displaying a variety of behaviors at mealtime and were managing by “trial and error,” with female spouses reporting more burden associated with meals and keeping their husbands healthy. Amella found that while all caregivers clearly articulated a “plan” for meals, they offered few options or strategies when the plan did not work. These families dreaded the time when their loved one would no longer accept food from them. However, they were hesitant to consider nursing home placement for this problem, as all stated that staff would never take the necessary amount of time for feeding. While most said they would not consider placement of a tube for feeding, they were unsure exactly what they would do if their loved one actively resisted or refused food. At this time, evidence does not point specifically to feeding problems as a reason to place an individual in a nursing home. While decline in functional and cognitive status was cited in recent studies, more likely predictors were socio-economic: lack of active social support, unmarried, living in an urban area, poverty, gender (males in Canada, females in US and Germany), and being a member of a minority group (US) (Kliebsch et al., 1998; Aarsland et al., 2000; Kersting, 2001).

Use of tube feeding in persons in a persistent vegetative state (PVS)

Tube feeding provokes several familiar ethical arguments concerning the individual’s right to autonomous decision making and the sanctity of life versus preservation of quality of life. In persons in a PVS, the quality of life and sanctity of life issues arise more dramatically than in older persons with severe cognitive impairments, and research is less likely to inform health practice. Persons in a PVS are more likely to be young, not having completed any advanced care planning such as documentation via a Living Will or a Durable Power of Attorney for Health Care (sometimes called Healthcare Proxy); often these cases arrive in the courts.

Within the US, the recent case of Theresa Schiavo, age 40, brings this controversy again into the spotlight (Oranksky, 2003). The result of a myocardial infarction at age 26, following a potassium deficiency, Schiavo was in a PVS for years. In 1998, her husband brought legal measures to remove her feeding tube, and in November 1998 he was granted that right. However, this move was opposed by her parents. The parents have since sued and brought the case to the attention of the courts and the Florida legislature, which passed a law signed by Governor Jeb Bush outlawing the removal of Schiavo’s tube (Charatan, 2003). This law, House Bill No. 35-E, was passed on October 21, 2003, and states:

The Governor shall have the authority to issue a one-time stay to prevent the withholding of nutrition and hydration from a patient if, as of October 15, 2003: a) that patient has no written advanced directive; b) the court has found that patient to be in a PVS; c) that patient has had nutrition and hydration withheld; and d) a member of that patient’s family has challenged the withholding of nutrition and hydration.

(Full text available at: http://election.dos.state.fl.us/laws/03laws/ch_2003-418.pdf)

Since the passage of this law, a guardian has been appointed by the court and Theresa Schiavo remains in a PVS in a Florida hospice. However, on September 23, 2004, the Florida Supreme Court unanimously overruled the law and supported the lower courts’
decisions (Goodnough, 2004). The case is pending in the federal Circuit Court and Schiavo’s fate is still uncertain.

The Schiavo case was escalated into the sanctity of life arena by a statement on March 20, 2004, by Pope John Paul II, who, while attending a conference on ethical dilemmas concerning incapacitated patients, stated, “The evaluation of the probability, founded on scarce hope of recovery after the vegetative state has lasted for more than a year, cannot ethically justify the abandonment or the interruption of minimal care for the patient, including food and water” (as quoted, Associated Press, 2004). It is believed he was referring to the removal of Schiavo’s tube feeding and stated that this was euthanasia. However, Sheehan (2001) notes in the Catholic press that there is no need to provide:

medically assisted nutrition and hydration to those whose failure to eat or drink is part of the last stages of dying, such as with terminal cancer or advanced congestive heart failure. In these cases, the burdens of medically assisted nutrition and hydration are extremely high and benefit is minimal. These treatments could potentially cause premature death and increase suffering (p. 27).

In opposition to the Schiavo case is the case of a 22-year-old woman in the UK who suffered severe brain injury and quadriplegia following a motor vehicle accident and was judged to be “little beyond the vegetative state” (McMillan & Herbert, 2000: 198). Because no hope of recovery was given, the courts were petitioned to remove her feeding tube. Permission was granted pending a neuropsychological examination, which revealed that the patient was able to consistently give the same answers to questions using a buzzer system, and thus the request was denied. This individual was followed for five years and is now living in the community, completely dependent on caregivers. She is able to eat soft foods, can speak, and has short-term recall. Clearly some would question the quality of her life, but she states that she wishes to live.

The right to autonomy in decision making is exemplified by the case of Elizabeth Bouvia, a 28-year-old woman with cerebral palsy and quadriplegia, who, after living in the community with personal attendant service, underwent several significant personal losses and declined physically because of severe arthritis. While hospitalized, she refused to eat because of nausea and vomiting, and based on her previous attempt to starve herself, a feeding tube was inserted against her will. When Bouvia sued to remove the tube, the court initially upheld the physician’s decision but later reversed on appeal. Bouvia’s right to autonomy was determined to trump the need to keep her alive, and the feeding tube was withdrawn (Bouvia v. Superior Court, 1986). As of 2002, Ms Bouvia was still alive and living in the community. (For other recent cases concerning tube feeding insertion or removal in California case law, see http://www.dickinson.edu/endoflife/LawCA.html.)

Advance directives and tube feeding

The right to determine care at the end of life was legislated with the Patient Self-Determination Act, which became effective in December 1991. The individual’s right to autonomous decision making through advance directive documents is established by state laws in three ways: (1) Durable Power of Attorney for Health Care (DPAHC), which is a written document that establishes the right of designated proxies to use substituted judgment to carry out another’s wishes if he or she lacks decisional capacity; (2) a Living Will, which gives specific instructions regarding terminal care; and (3) special state legislation that establishes advance health care directives (Gunter-Hunt et al., 2002). Most
state laws require that artificial nutrition and hydration be addressed in specific language within these advance directive documents, and unlike other preferences regarding aggressive treatment such as cardiopulmonary resuscitation, the refusal to be tube fed must be specifically stated within the advance directive. Gunter-Hill et al. (2002) established a discrepancy among the states regarding language concerning refusal of artificial nutrition and hydration: 49% of states with DPAHC require that language be completed regarding tubes, and 66% of those states with Living Wills and 100% of those states with special legislation required advance directives. Lack of standardization in laws makes tube feeding the default treatment, which is particularly worrying in our aging and mobile society. In addition, the sentinel SUPPORT study (SUPPORT Principal Investigators, 1995) showed that physicians were unlikely to follow hospitalized patients’ advance directives and that many patients were reported to die in pain.

Healthcare professionals are required daily to address issues of withholding and withdrawing therapy that prolongs life. A series of federal court decisions resulted in enhancing this communication between healthcare providers and their patients (Caralis et al., 1993). In the well-known US case, Cruzan v. Director, Missouri Department of Health (1990), Nancy Cruzan was left in a PVS after a motor vehicle accident. Her parents sued to remove her feeding tube. While her room-mate recalled an earlier conversation where Ms Cruzan stated she would not want to live like this, the US Supreme Court, while acknowledging the incompetent person’s right to refuse treatment, stressed the importance of written evidence before allowing surrogates to authorize the termination of life-sustaining treatment. The justices described advance directives, both Living Wills and DPAHC, as important documents that may help to resolve legally and ethically challenged cases.

The role of culture in tube feeding

Many families make important healthcare decisions in the midst of a medical crisis. Unfortunately, most of them are inadequately prepared for the decision-making responsibilities that are associated with enteral or parenteral feeding. This is due in part to Western society’s reluctance to realistically address issues of declining health, dying and death. Consequently, many individuals have difficulty thinking about, discussing and preparing for decisions related to feeding and hydration that will directly impact their health status (Bailly & Depoy, 1995; Forbes et al., 2000; Pearlman et al., 2000). The idea of a loved one becoming unable to care for themselves or make decisions regarding feeding is unpleasant and conversation on the subject is often avoided. As a result, vital healthcare decisions are often made under stressful conditions without the benefit of thoughtful, detailed and clear discussions between the person and family members. Culture and ethnicity also play a vital role in the decision making process about enteral and parenteral feeding, but culture is frequently overlooked when discussions about feeding are initiated.

The United States Congress funded an investigational committee in 1999 to examine the disparities in the types and quality of medical care received by racial and ethnic minorities and non-minorities in the United States. The committee’s literature review yielded over 600 citations between 1992 and 2002. Minority patients were found to receive lower quality and intensity of medical care and diagnostic services across a wide range of acute and chronic conditions. In the studies where variables of sociodemographic, insurance status and clinical factors were controlled, racial and ethnic differences were generally attenuated, but rarely disappeared entirely. Collectively, the findings from this committee support the hypothesis that race and ethnicity significantly impact the quality and intensity of medical care an individual receives (Smedley et al., 2003).
Thomas (2001) defines culture as a unified set of values, beliefs and standards of behavior shared by a specific population. The manner in which a person accepts, orders, interprets and understands their experiences throughout their entire life course is part of what defines culture. Perkins et al. (2002) add that, most importantly, culture is transmitted on an unconscious level from generation to generation. Eventually this unconscious process influences one’s day-to-day behavior and often ensures one’s survival. Differing ethnic cultures share many similar values. Yet, differences do exist that can lead to conflict if the healthcare professional is unaware or unwilling to recognize these differences. Awareness of and sensitivity to cultural and historical differences become extremely important when discussing hydration and feeding choices.

To understand the impact that culture plays on healthcare decisions, one has to look no further than the culture of African Americans in the US. This culture faces many challenges within the healthcare system, including access to appropriate medical care and resource-intensive care when facing end-of-life decisions. However, when comparisons based on race or ethnicity are made with other cultures, many in the African American culture are more likely to desire prolonged and expensive treatments such as tube feeding, regardless of their stage of illness, and to choose aggressive treatments if permanently unconscious (Morrison et al., 1998b; Crawley et al., 2000; Dupree, 2000; Hopp & Duffy, 2000; Perkins et al., 2002). Advance care directives for hydration and nutrition have been promoted as a means to improve decision making. But the rate of completion remains surprisingly low in the general US population and even lower among African American groups (Morrison et al., 1998b; Crawley et al., 2000; Dupree, 2000; Hopp & Duffy, 2000; Perkins et al., 2002). Influenced by historical and contemporary events of slavery, abuses in medical experimentation, economic injustices, racial-profiling practices and a disproportionate number of incarcerations reflect the general loss of trust and credibility of the healthcare system by African Americans. As a result, any nutritional treatments or interventions are often embraced (Crawley et al., 2000).

Mistrust among the African American population regarding the healthcare system stems from six major sources according to Dula (1994). These sources have an indirect impact on the medical care decisions many African Americans make about enteral or parenteral feeding. These six sources include: the origin of slavery medical experimentation and research; the well-known Tuskegee syphilis experiment, which serves as a symbol of how many white medical professionals disregarded the sanctity of black lives; the debacle of sickle cell screening in the 1970s; the discovery of the 1970s blatant sterilization abuse, in which the national government began subsidizing family planning clinics, that has led to eugenic overtones; the indifference and disregard for federal funding when acquired immunodeficiency syndrome (AIDS) spread to the African American community in the 1980s, leading to a resurfacing of beliefs that the government did not value the lives of African Americans and other minorities; and the most recent events of violence research that resulted in two incidents regarding a national conference on violence and a “Violence Initiative” that was sponsored by the Department of Health and Human Services. As a result, suspicion was raised throughout the African American community on the motives of this type of research (Dula, 1994). After examining these sources of perceived mistrust, it becomes easier to understand how any nutritional treatments or interventions presented to African Americans are often embraced (Crawley et al., 2000). In addition, while decision making among African Americans with regard to end-of-life care varies with individual history, religiosity and income status, a large number of people regard advance directives as a means to legalize neglect, to deny treatment and to commit genocide. Furthermore, this culture’s strong religiosity is reflected in its propensity to continue
aggressive treatment and care and a desire not to authorize do-not-resuscitate (DNR) orders (Mitty, 2001). Thus, the use of tube feeding within this and other racial/ethnic and cultural groups deserves further exploration.

**Position statements**

Several bodies representing professional groups have addressed the issue of tube feeding. The United Nations High Commissioner of Human Rights (High Commissioner, 2000) recognizes the right of all persons to have food; however, in a search of UN documents relating to provision of food and fluid, no document could be found relating to the use of artificial nutrition and hydration for those persons in either a PVS or with severe cognitive impairments. The American Academy of Hospice and Palliative Medicine (AAHPM, 2001) supports the use of hydration and nutrition:

> [W]hen a person is approaching death, the provision of artificial hydration and nutrition is potentially harmful and may provide little or no benefit to the patient and at times may make the period of dying more uncomfortable for both patient and family. For this reason, the AAHPM believes that the withholding of artificial hydration and nutrition near the end of life may be appropriate and beneficial medical care. (2)

The American Medical Association (2003) asserts that its members will assure “that preferences for withholding or withdrawing life-sustaining intervention will be honored. Whether the intervention be less complex (such as antibiotics or artificial nutrition and hydration) or complex and invasive . . .” (5). The Hospice and Palliative Care Nurses Association (HPNA) (2003) developed a position statement on the use of artificial nutrition and hydration in which they address the point at the end of life when persons resist foods or are unable to take foods because of dysphagia or other problems. While not advocating either using or not using tube feedings, the HPNA recommends counseling patients, families and caregivers concerning the benefits and burdens of this intervention, as well as advocating advance care planning concerning this issue. The American Nurses Association (2003) echoes these sentiments in their position statement by recognizing that providing food and fluids is not the same as artificial nutrition and hydration, and decisions regarding initiating or continuing tube feeding should be made by the patient or surrogate. For nurses, whose professional ethic is to provide care, the differentiation of managing symptoms at the end of life through spoonfeeding and offering sips of water and ice or through enteral/parenteral feeding is significant: to do one is to offer comfort, yet to do the other is to potentially cause harm (Amella, 2003a,b).

**Conclusion**

Tube feeding is generally recognized as an effective method of delivering food and fluids to individuals who would benefit from short-term use during rehabilitation or for long-term provision of nutrition in those whose quality of life is improved by this intervention. However, when the benefit is low and the burden is high, such as in persons with severe cognitive impairments or PVS, there are few grounds on which to sustain this argument. Currently, the alternative to tube feeding, namely hand feeding, is not always supported within some long-term care facilities as the cost is deemed too high and reimbursement is low. Additionally, in larger population studies, patterns of use seem less dependent on patient characteristics/needs and more on institutional and regional factors such as cost,
time, staffing, ownership of the facility, and area of the country. Methods of addressing feeding issues at home are less well studied. The ability to make advance directives regarding all aspects of end-of-life care including tube feeding is legislated, yet having these wishes honored is not uniformly guaranteed from state to state in the US or even by providers.

The ways in which individuals, families and groups make decisions about the method of feeding at the end of life vary widely and cause ongoing ethical and legal dilemmas. Individuals and families may be in conflict among themselves and with legal and religious authorities regarding the initiation, continuation or refusal of tube feeding. Racial/ethnic and cultural groups may make decisions predicated on prior experiences, such as disenfranchisement by the medical establishment, value systems that differ from the dominant paradigm or deeply held religious beliefs. However, professionals can be guided by organizations that introduce policy statements to guide beneficent actions in end-of-life care. As long as inconsistency and disparity exist in legislation, care provision and among minority groups, dying will be prolonged for some and those who care about them will also suffer.

References


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**Biographical Notes**

Elaine Amella and James Lawrence are both Geriatric Nurse Practitioners. Dr Amella is the Associate Dean for Research at the College of Nursing at the Medical University of South Carolina, USA, and her research and teaching focus on end-of-life care for persons with dementia and other vulnerable groups. James Lawrence is completing his doctoral degree and is focusing on racial/ethnic issues in end-of-life decision making. Suzanne Orr Gresle is a Speech Language Pathologist who is working on her doctoral degree specializing in the diagnosis and treatment of swallowing disorders.