

End-of-Life Decision Making, Quality of Life, Enteral Feeding, and the Speech-Language Pathologist

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If man be sensible and one fine morning, while he is lying in his bed, counts at the tips of his fingers how many things in this life truly will give him enjoyment, invariably he will find food is the first one.

Lin Yutang (zaadz, no date)

Introduction

A speech-language pathologist assessing swallowing function may determine that an individual is no longer able to meet his or her nutritional needs safely through oral feeding alone. The choice to initiate, withhold, or discontinue artificial nutrition and hydration (ANH) should be made by a fully informed decision maker, be it the patient or his or her substitute decision maker (SDM). As health-care professionals with specific knowledge of the issues leading up to the decision, speech-language pathologists have a crucial role in providing information and support. The Terry Schiavo case reminded us how emotional, challenging, and divisive these choices can be. Supporting patients and families through this process requires not only a solid grounding in dysphagia, but also a wide range of knowledge relating to the law, ethics, risk benefit analyses, and one's own values and beliefs. This knowledge must be balanced with compassion, courage, and sensitivity. The objective of this article is to present possible roles of the speech-language pathologist in these discussions.

Where We Are Now

In 1990, the United States Supreme Court's *Cruzan* decision appeared to interpret the 14th Amend-

ment to include ANH as a form of medical intervention (Kapp, 2002). Although there is no legal ruling on this issue in Canada, the Joint Statement on Preventing and Resolving Ethical Conflict Involving Health Care Providers and Persons Receiving Care (December 4-5, 1998) states, "The competent person has the right to refuse, or withdraw consent to, any care or treatment, including life-saving or life-sustaining treatment." Other countries such as Britain and Australia affirm this position (Ashby & Mendelson, 2004; Lennard-Jones, 1999). Over the last 15 years, legal consensus has confirmed ANH as a treatment. As such, it requires informed consent, prognosis with and without the treatment, and long- and short-term risks and benefits specific to the individual involved. In December 1991, the Patient Self Determination Act encouraged individuals to engage in medical directive planning and health-care providers to develop and disseminate formal policies regarding matters such as decisions about ANH, though this initiative has not met with great success (Gramelspacher, Zhou, Hanna & Tierney, 1997; Kapp, 2002). Studies looking at the quality of discussions between health-care providers and those making decisions about ANH vary considerably, but the great majority agrees that information provided to families is inadequate. O'Brien and colleagues (1995) reported only 12% of study participants had any discussion with health-care providers regarding enteral feeding preferences. Forty percent of respondents in a retrospective survey of decision makers reported they did not have time to discuss the decision with other family members (Callahan,

Haag, Buchanan, & Nisi, 1999). In an international study located in Boston and Ottawa, almost one-third felt the decision was unilateral—made mainly by the physician—and the majority reported the discussion with the physician took 15 minutes or less. Speech-language pathologists have an important role in ensuring that patients and their families receive adequate support in making their decision.

Challenges

Individuals with significant cognitive and communication impairments who require enteral feeding present the clinician with the most challenges (Covinsky et al., 2000). Through assessment, speech-language pathologists can assist SDMs in learning what their loved one's communicative gestures might or might not mean. We can work with other team members to reinforce the principles guiding the SDM process.

Speech-language pathologists need to be aware that discussion participants may tend to focus on "outlier" cases, situations such as Terry Schiavo's where there was tremendous dissension around the removal of a feeding tube. The vast majority of these discussions are concluded without the intervention of the courts. By stressing that our role is to provide information to allow for an informed choice and not to direct the decision itself, we reduce potential fear-born antagonism in the discussion process.

Although legal consensus defines enteral feeding as a treatment, the emotional value all cultures place on the sharing of food means that enteral feeding is not viewed as a treatment but as basic care by most patients and, indeed, many health-care workers. Food is synonymous with love and the giving of care (Critchlow & Bauer-Wu, 2002; Taylor, 1995). Participants in discussions about the initiation, withholding, or withdrawal of enteral feeding must recognize this, accepting the challenge it presents.

Simply introducing the concept that patients or their SDMs can have a say about enteral feeding can be difficult. In one study, 69% of nursing home residents surveyed believed doctors should make the most important decisions (O'Brien et al., 1997). In the large-scale SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), most participants did not discuss end-of-life decisions and most said they did not want to (Covinsky et al., 2000). Members of the health-care establishment may be seen with fear and distrust that negatively color useful discourse, as family members assume that raising the topic of enteral feeding may represent an attempt "give up" or "starve" their loved to save costs.

The medical-care team may have its own set of biases and preconceptions, and its members are well advised to consider how they affect interactions in these discussions. Our training has been directed towards the prolongation of life (Ashby & Stoffell, 1995), a goal at which we all eventually fail. Openness to the perspective that extending life is not necessarily the greatest good if it does not correspond to the patient's values is vital if health care providers are to adequately support these discussions.

Cultural Differences

Discussions relating to enteral feeding (and end-of-life decision making generally) are inherently value laden. Acknowledgment and exploration of patient values are crucial. Cultural diversity presents an increasing challenge in this area, particularly for care teams working in large urban centers. Speech-language pathologists are natural advocates in these situations and can help ensure that adequate translation services are provided to allow appropriate information to be exchanged.

There is a need to be informed of cultural difference, especially where it affects this area of speech-language pathology practice. A survey looking

at end-of-life care of 540 proxy respondents indicated that even after accounting for sociodemographic factors, there were significant differences in advance care planning and treatment decisions for Caucasians and African Americans with the latter less likely to have a living will and more likely to involve unconditionally prolonging life (Hopp & Duffy, 2000). In another study examining patient care preferences among non-Hispanic Whites, Hispanics, and African Americans, the latter two groups were more likely to want aggressive measures in the event of terminal illness, with the Hispanic group being in-between the two extremes (Caralis, Davis, Wright, & Marcial, 1993).

Some cultures do not automatically place a high value on individual self-determination. Speaking of the Chinese culture, Bowman and Hui (2000) state, "...the Confucian concept of relational personhood challenges the assumption that the patient should be given the diagnosis and prognosis and the opportunity to make his or her own medical decisions" (p. 1483). Echoing this, Blackhall and colleagues (1999) found that Korean Americans revealed a marked discrepancy between what they might want for themselves and what they might expect their children to decide. One lady said it would be her son's responsibility to decide because of *hyodo* (filial piety) and that he would likely choose to keep her alive even though she personally was opposed to such a choice. "It may be a contradiction, but it's the right thing to do, don't you think?" (p. 1785) she told the interviewer.

It is important to keep in mind that differences between individuals within a given culture may be greater than the differences between cultures. For this reason, the values of the patient and decision makers should not be assumed based on ethnicity alone. Complete knowledge of differing cultural norms is an insurmountable challenge, but a vigilant awareness that large differences exist, combined

with an openness to listen to and acknowledge the value systems of others will help in the discussion process.

Time

Finally, the greatest barrier to discussions about enteral feeding is an element none of us have enough of: time. Information about the risks and benefits of tube feeding for a given individual is complex, and families need time to digest information and discuss it amongst themselves. Decisions may change as the situation evolves and the discussions progress. Placement of responsibility for these time-intensive talks on one member of the health-care team virtually predetermines their failure. Speech-language pathologists working with doctors, social workers, ethicists, physicians, and nurses can provide the multidimensional support families require to make the best choice for their loved one.

What We Know, What We Don't Know

Speech-language pathologists are in a position to dispel some of the misconceptions around ANH. In a study completed in 2000, the most common reasons given for wanting enteral feeding were to prevent aspiration pneumonia (67%) and to prolong life (84%; Mitchell, Berkowitz, Lawson, & Lipsitz, 2000). However, feeding tubes cannot prevent aspiration of contaminated oral secretions or regurgitated gastric contents—both well-documented causes of aspiration pneumonia (Finucane & Bynum, 1996; Langmore et al., 1998; McClave et al., 2002). In fact, several studies have identified tube feeding as a risk factor for pneumonia (Langmore, Skarupski, Park, & Fries, 2002; McClave et al., 2002; Pick et al., 1996).

The causation of pneumonia is multifactorial, and speech-language pathologists must be wary of simplifying complex issues or providing certain answers where none exist.

Volume and nature of aspirated material, number and nature of oral flora, and host defense responses are all important and highly variable from individual to individual (Langmore et al., 2002; McLave et al., 2002; Pick et al., 1996).

Prolongation of life is given as a reason for beginning tube feeding, and its benefits are fairly well established for some groups, such as post acute stroke (Ciocon, 1990; Cummins, Marshall, & Burls, 1999). There remains a lack of good evidence for prolongation of life in other populations. Mitchell, Kiely, and Lipsitz (1998) studied over 5,000 institutionalized older people and found lower survival rates among tube fed residents even after adjusting for confounding covariates such as general health status and baseline cognitive function. End stage advanced dementia and terminal illness are often characterized by anorexia cachexia syndrome, where the generalized breakdown of homeostatic mechanisms results in decline even when provided with adequate calories and nutrients (Chouinard, Lavigne, & Villeneuve, 1998).

In addition to providing accurate information to family members about ANH and prolongation of life, speech-language pathologists need to be aware of issues relating to quality of life. The health-care team needs to work with families to educate them about possible negative consequences of ANH, so they can make an informed decision as it relates to their loved one's values. Evidence indicates decision makers are frequently not informed of the possible negative effects of tube feeding (Mitchell et al., 2000; Van Rosendaal, Verhoef, & Kinsella, 1999). Although serious complications such as erosion of the tube into pleural cavity and gastric perforation are rare (American Gastro-Enterological Association, 1995; Bastow, 1986; Finucane, Christmas, & Travis, 1999; Rabeneck, McCullough, & Wray, 1997), they can occur and may significantly reduce quality of life. The most reported nega-

tive side effect of enteral feeding is diarrhea, with incidence ranging from 2% to as high as 68% (American Gastroenterological Association). In addition to aspiration pneumonia mentioned above, other common complications include agitation and extubation (Ciocon, Silverstone, Graver, & Foley, 1988), the latter possibly in response to the restriction to mobility ANH presents. Reduced quality of life is confirmed by studies such as that done by Somogyi-Zalud, Likourezos, Chichin, and Olsen (2001), where surrogate decision makers rated the quality of life of their loved ones on ANH as poor to very poor.

Effects of Starvation and Dehydration

A misunderstanding of the natural physiological course of a life ending illness gives rise to the most sensitive area for discussion of enteral feeding. The choice not to insert a feeding tube may be seen as equivalent to "murder," by having the patient "starve to death," with the underlying assumption being that this will cause undue pain to the patient.

Speech-language pathologists, together with the health-care team, can inform decision makers about the process a body experiences when there is cessation of intake. In one report, caregivers indicated that they were unaware that loss of appetite occurs naturally in terminally ill patients and is part of the body "shutting down" in preparation for death (Critchlow & Bauer-Wu, 2002).

The belief that withholding hydration and nutrition at the end of life causes suffering is not supported by research regarding what happens physiologically when a body is deprived of food and fluids. Calorie deprivation from terminal starvation results in a partial loss of sensation, which may add to the patient's comfort during the dying process (Brody, Campbell, Faber-Langendoen, & Ogle, 1997; Critchlow & Bauer-Wu, 2002). Analgesia is also produced

through acidosis, hypernatremia, hypercalcemia, and cerebral anoxia that occur with terminal starvation (Printz, 1992).

End stage dehydration is associated with some advantages for the dying person. Anesthesia, reduced urine, decreased gastrointestinal fluids, and decreased pulmonary congestion have been reported as well as fewer episodes of nausea and vomiting, less coughing and chest congestion, reduced sensations of pressure in the periphery and pulmonary system, and reduced sensations of drowning and choking (Critchlow & Bauer-Wu, 2002; Taylor, 1995). In contrast, hydrating the dying person has been associated with complications such as increased pain, respiratory congestion, and edema (Critchlow & Bauer-Wu, 2002; Phillips et al., 1984). It is notable that before the 1980s, when long-term tube feeding became feasible, dehydration was the most common primary or secondary cause of death (Hoeftler, 2000).

Hospice workers have the privilege of working with the dying, and their insights in this area are valuable. In a study of hospice nurses, it was found that the more deaths a person witnessed, the more positive his or her attitude was toward terminal dehydration (Critchlow & Bauer-Wu, 2002). Andrews and Levine (1989) found that hospice nurses judged patients without ANH as appearing to be in less pain than those receiving ANH.

Patient reports of thirst in the dying process are a useful source of information for speech-language pathologists participating in discussion regarding ANH decision-making. McCann, Hall, and Groth-Juncker (1994) found that terminally ill patients did not generally experience hunger, and complaints of thirst and dry mouth were relieved with mouth care and sips of liquid in amounts far less than those needed to prevent dehydration. The majority in this study never experienced hunger or thirst, with those who did only experienc-

ing it initially. As part of the care team, speech-language pathologists need to reassure family members that if their loved ones appear thirsty, ice chips or sips of fluid may be offered. The decision to withhold ANH in no way means abandoning the patient, with physical discomfort reduced and patient dignity maintained.

The quality of the literature in this area must be acknowledged as limited. For obvious ethical reasons, there are no randomized controlled studies. Much of the observational literature is based on inference. Whereas the effect of dehydration on physiological mechanisms is known, the sensations of a given individual body will vary. What speech-language pathologists can do is keep abreast of current literature and pass on the information the studies provide, acknowledging their limitations along with lack of absolute certainty in this area.

Elements of an Ideal Discussion

It should be clear from the legal, ethical, medical, and human issues outlined above that health-care institutions need to have guidelines and policies that support and direct the process for decision making regarding ANH. Some elements will vary according to state laws and the nature of the patient population involved, but several elements will be shared.

Guidelines need to support the involvement of a variety of caregivers, acknowledging that these discussions frequently take place in stages over an extended time. Physicians must be kept informed of advanced care plans and should be involved as much as possible. However, primary responsibility for leading patients and families through discussions of values and treatment choices may rest on non-physician providers (Cantor & Pearlman, 2004), which could include nurses, social workers, ethicists, chaplains, and speech-language pathologists. For the team to

be involved effectively in these discussions the health-care institution needs to have mechanisms in place to give them the necessary educational tools. Policies and guidelines ensure these discussions happen earlier rather than later. Beginning the conversation about ANH before a crisis occurs, in situations when that is possible, allows a more gentle consideration of the multifaceted questions involved.

In situations where the patient is not of decision-making capacity with respect to the treatment, SDMs will be involved. These individuals will need to be identified and informed of the central guidelines of choice making on behalf of another: substitutive judgment and best interest standards. Facilitating the SDM's role in choosing what the patient would want for himself or herself, were he or she fully informed and able to speak, is a supportive function speech-language pathologists can perform that brings clarity to complex issues.

The information provided to the SDM or patient should be comprehensive yet manageable. Speech-language pathologists and the health care team need to be guided by the patient's "need to know" as well as their ability to absorb complex and emotionally daunting material. This establishes the locus of decision-making with the patient. An information package in lay language can be a valuable adjunct to (but not a replacement for) face-to-face discussion. In instances where the decision maker does not wish to discuss the issues, a brochure can be an invitation to discuss at a later time if desired or can be taken home and discussed with other family members in a home setting.

Decision makers need to be provided with a description of the proposed treatment, alternative treatments, and the prognosis with and without ANH. They need to have an understanding of the benefits and burdens of the decision to initiate,

withhold, continue, and/or withdraw enteral feeding. Finally, decision makers need to know they have the right to amend, temporarily withdraw, or revoke any decision with regard to ANH.

The information offered to the decision-maker should be comprehensive, reflecting the principle of patient autonomy. The ultimate choice should be made in the context of the value system of the individual involved. Consideration of these values is central to any discussion of ANH decision-making, and this applies not only to patients and families. Caregivers need to examine their own moral, cultural, and religious views about living, dying, dependence, and independence (Serradura-Russell, 1992). An unflinching and accurate appraisal is crucial if the team is to support families with neutrality and sensitivity. Caregiver biases can easily influence decision-making and promote guilt if the SDM feels the choices they are making are not supported.

Speech-language pathologists are naturally drawn into discussions about decision-making and ANH. As we repeatedly assess a deteriorating patient, we may be in the best position to alert the physician and team that a discussion should be initiated. Whereas these conversations are daunting and frequently emotional, we have a great deal to contribute. The discussions require considerable time, courage, knowledge, and sensitivity. We never have enough of the first, but by using the other three within the context of our teams we can help families manage these difficult decisions.

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- non-Hispanic Caucasian Americans.
- b. Most nursing home residents believe that they should be making their most important health-care decisions.
- c. Some cultures, such as Korean American, may expect a family member to make the decision to insert enteral feeding even though the patient him/herself is competent to make this decision.
- d. Most nursing home residents do not want to discuss end of life issues.

3. The significance of the United States Supreme Court's Cruzan decision as applied to enteral feeding is:

- Enteral feeding can be withheld.
- Enteral feeding can be initiated.
- Enteral feeding can be withdrawn.
- Enteral feeding can be withheld, initiated or withdrawn.

4. A SDM approaches the speech-language pathologist and asks if his/her loved one will benefit from having enteral feeding. Which is a documented benefit of enteral feeding?

- Elimination of the risk of aspiration pneumonia
- Prolongation of life in Alzheimer's dementia
- Prolongation of life in some post-acute stroke patients
- Reduction in diarrhea and agitation

5. If a feeding tube is withheld or withdrawn, the most likely result for the patient will be

- edema.
- increased hunger and thirst.
- increased analgesia.
- increased respiratory congestion.

Continuing Education Questions

1. Which of the statements below presents an insufficient reason for the speech-language pathologist's inclusion in discussions about end of life decision making, quality of life and enteral feeding?

- The speech-language pathologist has strong views on the subject.
- The speech-language pathologist has determined significant dysphagia issues that warrant the discussion of feeding tube placement.
- The speech-language pathologist is advocating for translation services for patients/SDMs who do not speak English.
- After reading this article, the speech-language pathologist can provide some evidence-based information about the risks and benefits of inserting, withholding, and withdrawing enteral feeding.

2. Which of the following is false?

- African Americans are less likely to have a living will than Hispanic Americans and