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Introduction
Clinical management of dysphagia may range from minor modifications in positioning the patient, to significant restrictions in food textures, to recommending that the patient should not eat orally at all. Although most patients with dysphagia agree to follow the recommendations of the healthcare team, some patients elect not to. One study found that as many as 40% of patients with dysphagia who were capable of independent feeding chose not to follow all of the speech-language pathologist’s recommendations (Colodny, 2005).

Dysphagia specialists face complex ethical questions when a patient refuses recommendations for treatment. If the clinician facilitates unsafe oral intake, he or she feels responsible if the patient becomes ill or dies of respiratory complications. If the clinician discharges the patient without dysphagia services, he or she may worry about abandoning the patient.

To develop a strategy for managing patients’ refusals of treatment, a number of clinical, ethical, and legal issues should be considered. In order to simplify these issues, a series of clinical steps is discussed. First, clinicians should understand why the patient is refusing. Second, the team should assess the patient’s capacity to make an informed and rational decision. Third, the team should re-evaluate the proposed treatment plan in light of the new information obtained through discussion with the patient and/or the patient’s surrogate decision-maker.

Reasons Patients Refuse Treatment
Patients may not follow treatment recommendations for a variety of reasons. Clinical problems such as refusal to eat may be related to gastrointestinal distress or dental pain and should be ruled out by the care team.

The patient’s reasons for refusal should be considered. A direct discussion with the patient about why he or she is refusing treatment helps clinicians to understand the patient’s perspective. Patients are known to refuse treatment recommendations because of fear, denial, loss of independence, loss of pleasure associated with eating, family pressure, depression, financial concerns, lack of information, religious and spiritual beliefs, previous experiences, and many other possibilities (Berg, Appelbaum, Lidz, & Parker, 2001; Colodny, 2005; Jonsen, Siegler, & Winslade, 1998). When a clinician talks with a patient to learn his or her reasons for refusing treatment, the discussion often reveals that the patient has made a thoughtful and rational decision that reflects his or her personal preferences.

Sometimes patients who refuse treatment are considered “non-compliant” (Colodny, 2005). It is important to separate true non-compliance from a patient’s informed refusal of treatment. Non-compliance implies that the patient is uncooperative or difficult, whereas an informed refusal reflects a decision that the patient makes by balancing the benefits and burdens of the proposed treatment.

Informed Consent and Informed Refusal
Informed consent requires three primary components. First, the patient must be given clear and sufficient information to make a decision. Second, the patient must have the capacity to make an informed and rational choice. Third, the patient must be free to make the decision without coercion (Bernat, 2001). The notion of obtaining informed consent from patients is based in ethical and legal value for an individual’s right to make decisions that affect his or her body (Bernat).

Informed refusal is a necessary counterpart to informed consent. Courts have long upheld the rights of “competent” individuals to refuse treatment, even if that refusal will shorten their life (Berg et al., 2001).
Psychosocial Issues Related to Dysphagia

Competence and Decision-Making Capacity

When a patient refuses treatment, the health-care team must determine whether the patient is making a fully informed decision. Perhaps the most challenging of the three components of informed consent/refusal is deciding whether the patient has the cognitive capacity to make an informed choice. Although the term “competence” is often used, this term refers to a legal concept with broad implications for the patient’s financial and civic rights (Lo, 2000). While some families may proceed with time consuming and expensive legal competency hearings, more often in clinical settings the concept of decision-making capacity is used.

In order to demonstrate decision-making capacity, a patient must demonstrate the ability to:
1. Communicate choices,
2. Understand information relevant to the decision,
3. Understand the risks and benefits associated with the treatment and non-treatment options, and

Unlike competence, which is an overall assessment of a patient’s abilities to make all self-care decisions, decision-making capacity is specific to the patient’s ability to make the specific decision in question. A patient may have decision-making capacity for one decision, but lack it for another. Decision-making capacity is also determined on a continuum; a higher threshold is applied for life-threatening decisions than for minor health-related choices. For example, a more rigorous standard should be applied to obtaining consent for tube feeding than to obtaining agreement for a flu shot.

The Role of SLP in Determining Decision-Making Capacity

All clinicians make informal assessments of their patients’ ability to understand and agree to evaluation and treatment. It is relatively easy to identify patients who clearly have capacity and those who clearly lack it. However, when patients are able to communicate their preferences, but have cognitive disorders or barriers to communication, it can be exceptionally difficult to determine whether the patient meets all the requirements of decision-making capacity.

When a patient’s capacity is unclear, the health-care team must work together to determine whether the patient is able to agree to or refuse the proposed treatment. If the team is uncertain about the patient’s capacity, they should consult with a psychologist, psychiatrist, or ethics consultant for a more definitive assessment. Because all of the requirements of capacity involve communication, speech-language pathologists may play an important role in facilitating communication between the patient and other health professionals, particularly when the patient has a speech, language, or hearing impairment (Sharp & Payne, 1999).

Identify a Surrogate Decision Maker

When a patient lacks decision-making capacity, the care team must turn to others to make decisions about evaluation and treatment. If the patient has been declared incompetent by a judge, a legal guardian should have been named, and this person then makes decisions together with the health-care team. It is relatively rare that families pursue formal legal procedures, including guardianship. So, often the care team must determine who the appropriate decision-maker is.

State codes and federal policies allow for people to designate a surrogate (or proxy) decision-maker usually through assigning a Durable Power of Attorney for Health Care (DPAHC; Patient Self Determination Act, 1990; Uniform Health-Care Decisions Act, 1993). The DPAHC is not necessarily the same person that the patient has chosen to make financial decisions through a Financial Durable Power of Attorney. A DPAHC is authorized to make health-care decisions on the person’s behalf only in the event that the person lacks decision-making capacity. As long as the patient retains decision-making ability, the DPAHC should only be included in decision-making with the patient’s permission. When the team turns to the DPAHC, this person should be fully informed about the patient’s diagnosis, prognosis, and treatment options. The DPAHC should be encouraged to use a decision-making approach called “substituted judgment” in which he or she uses his or her knowledge of the patient’s values and preferences to arrive at a decision (Beauchamp & Childress, 2001).
If the patient has not named a DPAHC and now lacks the ability to execute the appropriate documents, a DPAHC cannot be formally appointed. However, many jurisdictions have developed a hierarchy for identifying decision makers when no one has been named. A hierarchy for identifying decision makers is proposed in the Uniform Health-Care Decisions Act as follows: legal guardian, spouse, adult child, parent, adult sibling, adult grandchild, close friend, and lastly, the guardian of the patient’s estate.

Some patients may have completed a living will, which is a document that allows a person to make written statements about his or her treatment preferences (Patient Self-Determination Act). For patients with dysphagia, questions about living wills arise when tube feeding is recommended and the patient has written his or her preference to forgo tube feeding. Living wills should be interpreted with care and caution. If the patient is able to communicate and states a preference to start tube feeding, the verbal statement will often be honored because it is preferable to err on the side of treatment, rather than non-treatment. If the patient lacks decision-making capacity, the DPAHC may be asked to interpret the living will along with the health-care team. In many states living wills only apply when the patient lacks decision-making ability and is terminally or irreversibly ill or permanently unconscious. If the team is uncertain about how to interpret a patient’s living will, they should seek an ethics consultation or discuss the specific case with an ethics committee.

Revisit the Treatment Plan

When patients can demonstrate all the components of decision-making capacity and continue to refuse treatment, clinicians should respect the patient’s decision. This respect stems from the ethical principle of respect for patient autonomy (Beauchamp & Childress, 2001). Patients’ rights to refuse medical intervention are supported through many court decisions (summarized in Berg et al., 2001). This right to refuse treatment is extended to surrogate decision-makers in most cases, although some exceptions arise, most often when a surrogate’s decision is contested by another family member (e.g., In re: Martin, 1995; Wendland v. Wendland, 2001).

When a patient (or surrogate) makes an informed refusal, the care team must re-assess the plan of treatment. When clinicians understand patients’ reasons for refusal, these reasons can often be addressed directly in a new plan of treatment. For example, if the patient’s primary reason for refusal is the taste of the thickening agent, the clinician can work in collaboration with the patient to find a more acceptable method to thicken fluids.

A patient’s informed refusal of tube feeding can be particularly challenging for clinicians because the recommendation is most often made to circumvent aspiration and/or malnutrition/dehydration. As the team reconsiders the treatment plan, it can be helpful to evaluate the data regarding outcomes associated with tube feeding. Many patients continue to aspirate oral secretions and are at risk for pulmonary complications from aspiration of stomach contents secondary to reflux (Callahan, 2000; Finucane & Bynum, 1996; Finucane, Christmas, & Travis, 1999; Rabeneck, McCullough, & Wray, 1997; Raha & Woodhouse, 1994). Surgically placed tubes also yield low, but real, risks for infection and other complications. The benefit of tube feeding has been questioned for patients with advanced dementia, as there is little empiric evidence that artificially administered food and water reverse malnutrition, bedsores, or lengthen life when compared with careful hand feeding (reviewed in Finucane et al, 1999; Post, 2001).

Services for Patients Who Refuse Therapies

When a patient decides to eat, despite known risks of aspiration or inadequate nutrition and hydration, the dysphagia specialist is likely to be concerned for the patient’s safety. Some clinicians may consider whether to continue to work with the patient under these circumstances. Understanding the patient’s goals for treatment and reasons for refusal of treatment can help to find a solution to which both clinician and patient can agree. Some patients who express concern about the loss of pleasure of eating associated with tube feeding are satisfied with a hybrid plan that allows some oral feeding at mealtimes coupled with tube feeding. While this plan places the patient at some risk, the
compromise allows both patient and clinician to meet their goals. The clinician should work with the care team to monitor the patient’s clinical status and provide education to the patient, family, and caregivers regarding the signs and symptoms of complications.

Dysphagia therapy should be continued as long as the patient agrees to therapy and as long as there are tangible goals for improved swallowing function. Discharging the patient is an option if the clinician (a) conscientiously objects to the patient’s choice and (b) finds another clinician who is equally qualified to take over the patient’s care. Abrupt discharge of the patient should be avoided in order to avoid abandoning the patient and to allow continued education and monitoring. Continuing a relationship with the patient also allows the patient to change his or her mind more easily after a choking event or onset of respiratory complications. Forcing a patient to accept treatment that he or she has stated he or she does not want is legally considered battery (Bernat, 2001).

Waivers

Some facilities have written waivers or “Against Medical Advice” forms that patients must sign in order to proceed with their desired plan of treatment. Like informed consent forms, informed refusal forms offer limited protection to clinicians and institutions. While a signature on an informed consent document provides some evidence that the patient agreed to an assessment or treatment, the signature does not necessarily show that the patient understood the plan and agreed without coercion (Berg et al., 2001). A carefully documented conversation with the patient is the most important aspect of accepting a patient’s informed refusal. The conversation allows the clinician to gauge the patient’s understanding of the proposed treatment plan and allows the patient to ask questions. Written forms present a considerable barrier for many patients, particularly those who are illiterate. Consent and waiver forms may be loaded with legal jargon, making the form difficult for any patient to understand. When waiver forms are used they should add to the conversation between patient and care team, but should not replace it (Berg et al.)

Preventive Ethics

Although not always possible, many of the ethical and legal concerns discussed here can be avoided. Speech-language pathologists and other dysphagia specialists can help to offset negative findings for patients by discussing the range of outcomes that might arise before the assessment occurs. Establishing the patient’s goals prior to an assessment may prevent confusion and conflict. For example, when a patient has already established a preference not to start tube feeding, the clinician may use this information to guide the assessment. The intent of the assessment remains the same, but the clinician may conduct some portions of the evaluation differently, such as making a copy of the videotape for the patient to review later or finding strategies that reduce aspiration, even if eliminating problems is not possible (Sharp & Bryant, 2003).

Obtaining the patient’s consent for an evaluation of swallowing may also reduce the potential for conflict following the assessment. Swallowing assessments are often ordered by physicians with little explanation given to the patient. Patients may not recognize that the swallowing evaluation could result in a recommendation for tube feeding. Other potential negative outcomes of swallowing evaluations include: cost, increased length of stay for additional tests or procedures, need to transport, and the findings may be inconclusive (Sharp & Bryant, 2003). Describing these possibilities along with the benefits of the assessments can reduce conflicts and allow the clinician to address the patient’s concerns and questions (Sharp & Bryant).

Developing institutional procedures for handling patients’ refusals of treatment also helps both clinicians and patients. Policies allow broad open discussions across disciplines outside an active crisis. When patients refuse treatment, clinicians may spend hours in consultation with other staff and researching solutions. Policies and procedures save time by mapping the steps that the clinician should take, help to identify the appropriate people to contact, and reduce practice variation across clinicians within the same institution.

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Wendland v. Wendland, 26 Cal. 4th 519, 28 P.3d 151 (Cal. 2001)
Psychosocial Issues Related to Dysphagia
Ethics and Quality of Life: Opposing Ideals?

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This article centers on two concepts: ethics and quality of life. *Ethos*, the Greek root of ethics, is defined as “the disposition, character, or fundamental values peculiar to a specific person, people, culture, or movement” (American Heritage Dictionary, 2000). *Ethics* is “the explicit philosophical reflection on moral beliefs and practices...a conscious stepping back and reflecting on morality” (Hinman, 2002). Quality of life can be defined as an individual’s consciously perceived positive and negative, cognitive, and affective experience (Næss, 1999; Næss, Masteekaasa, Moun, & Sørensen, 1987; Sorensen & Næss, 1996). Though very different in their definitions, ethics and quality of life both regard the person or people involved, circumstances surrounding the person or people, and time. Ethics and quality of life guide our profession. Clinical recommendations, therefore, are derived from the reciprocal relationship between our professional ethics (i.e., rules and standards of conduct) and what we want as the best quality of life for our patients (i.e., clinician perception), sometimes opposing each other in patient care.

Clinicians are faced with ethical dilemmas daily. One example of this is a school-based speech-language pathologist (SLP) who gets a referral from a 5-year old child’s parent to evaluate and treat /r/. After performing a full articulation assessment, the SLP chooses not to recommend treatment based on the child’s developmentally appropriate articulation, yet is strongly encouraged by the school principal to treat the student. A second example includes making decisions about the application or declining of a therapy technique when there is little evidence in the research literature to support the technique. We make these decisions in accordance with the information (or data) we collect and our clinical judgment, upholding what we perceive to be the best interests of the client at all times. SLPs who focus their practice in swallowing disorders constantly battle between what is clinically appropriate for the patient and the patient’s desires, sometimes in conflict with each other.

Let’s face it...food and drink are very important. We maintain health, socialize, entertain, and enjoy life with food and drink. Health and nutrition aside, I’m confident that if you were to reflect on your own life, you’d come to the conclusion that many fond, life-long memories are related to food and drink in some way, whether they are part of a campfire where you sang songs, told stories, and had s’mores, grilled dinner with some friends on a holiday weekend, had a hot dog at a particular sporting event, or took part in a toast at a wedding you attended. Maybe your reflections of food and drink are simpler, involving a box of popcorn you ate while watching a movie, licking a scoop of ice cream on a cone at the local hangout, chewing gum as you browse through shops at the mall, or sipping a soft drink from a vending machine on a hot summer’s day. Can you imagine no longer having the opportunity for these experiences? Have you ever thought about it? Food and drink—so much a part of our life, though often taken for granted—are now gone. Consider this case as an example that many clinicians face...

You receive an order to evaluate a patient who was just transferred to the hospital’s neurology unit from the emergency room 2 days earlier. Your chart review reveals a young, vibrant, and recently married patient who had a motorcycle accident that resulted in a closed head injury with diffuse brain trauma. After observing your patient at the bedside, you conclude that he is inconsistently able to answer yes/no questions and follow one-step directions. He remains alert and appropriate throughout the screening. The attending team follows your recommendations for a modified barium swallow study (MBSS) and writes the order. You meet your patient in Radiology the following day for the evaluation.

During the modified barium swallow study,
you notice gross aspiration with all food and liquid consistencies presented. After attempting several swallowing strategies in Radiology to address the physiologic impairments, you note that all were unsuccessful for preventing aspiration. Your recommendations are for the patient to have nothing by mouth and for the medical team to consider an alternative means of nutrition (e.g., PEG tube). Still disoriented and confused, your patient returns to his room with the same flat affect he has exhibited since the accident. You speak with the resident to discuss the results of the MBSS. He pages the attending physician who agrees with the feeding tube recommendation. You then return to the patient’s room to discuss your recommendations with the patient’s wife.

You explain to the patient’s wife that the food and liquids were given to her husband while viewing them under x-ray and that they were seen going into his airway instead of his esophagus. “In order to provide your husband with the best possible care,” you tell the patient’s wife, “we will need to keep your husband from eating and drinking by mouth for an extended period of time, but it is critical that he continues to receive nutrition. I am recommending to the doctors that they consider an alternative way of feeding him. In doing so, we are trying to promote his strength, improve his health, and reduce the risk of food and drink from going into his airway and into his lungs, ultimately causing an infection. The physician and I believe that a food tube, surgically placed into his stomach to bypass his mouth and airway, will give him the time he needs to recover and do so in a relatively safe manner. This means that he would not be getting a food tray or anything to drink. We’ll take another look at his swallowing ability once he has improved in our treatment sessions together.”

Visibly stunned by the information, the patient’s wife indicates that she has no questions. You place your report and recommendations in the medical chart, stating that the patient’s wife understands the results. You walk down the hall to find the patient’s nurse and discuss the results of the MBSS, then leave the unit to see another patient.

The next day, you arrive to see the patient in his room shortly after noon. Much to your chagrin, the patient has a tray of half-eaten puree food sitting on his bedside table. After speaking with the patient’s nurse, you learn that the PEG tube was refused, your recommendations were ignored, and an oral diet was ordered. Probing a little further, you discover that the patient’s wife had a heated discussion with the physician and demanded that her husband was not going to be fed through a tube. “Hmmm…” you think to yourself. “What on Earth happened, in the span of only 24 hours?!”

Where is the line between a clinician’s mandate to promote the patient’s health (i.e., the ethics principle equivalent of beneficence, or promoting the patient’s welfare) and a patient’s (or family’s) desires? Is there a point in the health care of a patient where the care provided can infringe on a patient’s quality of life? How much input does a patient effectively have regarding his/her own care, and under what circumstances? Unfortunately, there are no data to support straightforward answers to any of these questions. Worldwide and historically, health-care providers, ethicists, lawyers, and politicians have debated these and other questions. Yet, it was not until the 1990s that thinking was actually transcribed into laws and policy. Still with large gaps, the debate continues about a patient’s quality of life and his or her rights versus the patient’s needs as seen through a clinician’s eyes.

Many of these conflicts exist in speech-language pathology. Specifically regarding the care of a patient who has dysphagia, SLPs are constantly confronted by their ethics of practice set forth by the American Speech-Language-Hearing Association (and/or state legislature) and their own moral, cultural, and spiritual views related to life and death. SLPs may find their personal beliefs to be in conflict with guidelines and rules established by governing bodies.

SLPs who are competent in the diagnosis and treatment of dysphagia have the training, clinical judgment, and ongoing education necessary to inform patients about the risks and benefits of continuing oral feedings and make recommendations appropriate for therapeutic gain collectively with the physician. SLPs, however, are not trained in the physiological ramifications of withholding nutri-
cision and/or hydration. There is a gap between making the recommendation for non-oral feedings and the nutritional background necessary for making such a recommendation. This is perhaps one reason for the conflict between our professional ethics and our patients’ quality of life.

**Nutritional Considerations**

The ethical dilemmas associated with recommendations for feeding and dysphagia have been discussed in a number of articles throughout the past decade (Groher, 1990; Landes, 1999; Segal & Smith, 1995; Serradura-Russell, 1992; Sharp & Genesen, 1996). The authors’ intended focus primarily was to address ethical decision-making in speech-language pathology. Only one article has addressed the nutritional needs of the patient and the consequences of reduced nutritional intake, but in the absence of discussion associated with ethics (Kovar, 1997). In sum, no article, to this author’s knowledge, has addressed the physical and behavioral manifestations of malnutrition within the framework of ethical decisions and dysphagia diagnosis or therapy.

Dávalos and colleagues (1996) attempted to determine the prevalence of malnutrition in individuals with acute stroke after a week of hospitalization. Protein-energy malnutrition was seen in over 16% of patients entering the hospital for treatment, 26% of patients after the first week of inclusion, and 35% of patients after the second week in the study. Higher levels of stress, respiratory and/or urinary infections, bedsores, mortality, poor outcomes, and longer hospitalization were noted and related to malnutrition when compared with the properly nourished group (Dávalos et al.). The most important factors associated with malnutrition were stroke severity and the presence of dysphagia. Taking into consideration the advantages and disadvantages of early enteral nutritional support, the authors suggest that it might be wise to delay nutritional support until after the first week following stroke. This appears to be a reasonable approach, since a study by Barer (1989) found approximately 71% of patients with hemispheric stroke and dysphagia resolve to oral intake within one week of onset. Yet, knowing when to intervene in the face of disuse atrophy related to the gastrointestinal system is unclear. Dávalos and colleagues continued to say, however, that early enteral nutrition should be placed only in patients who are unable to swallow and are malnourished. SLPs are not trained to base our decisions of oral versus non-oral nutritional support based solely on the patient’s nutritional status. Additionally, we are not trained to understand changes in metabolism that may accompany different injury and disease states, ultimately affecting the urgency with which nutrition should be provided. SLPs are trained only to make recommendations based on the individual’s swallowing ability, safety if you will, with a specific consistency (texture) of food or liquid.

Support for enteral feedings is mixed, regardless of our recommendations and the patient’s diagnosis. Whereas some researchers believe that enteral feedings are cost-effective and necessary for patient recovery and maintenance of health (Annoni, Vuagnat, Frischknecht, & Uebelhart, 1998; Britton, Lipscomb, Mohr, Rees, & Young, 1997; Faries & Rombeau, 1999; Silani, Kasarskis, & Yanagisawa, 1998), others hold the opposing view (Chouinard, Lavigne, & Villeneuve, 1998; Ciocon, Silverstone, Graver, & Foley, 1988; Gillick, 2000). They believe that placing a tube for feeding may not show benefits due to the risks for aspiration, infection, and other complications. Despite the arguments either way, SLPs are still bound by ASHA guidelines (ASHA, 2001; ASHA, 2004) to recommend no oral feedings should it be deemed appropriate. But what is appropriate? The waters of ethics and therapy are muddied when a patient refuses alternative methods for feeding and wants to continue with oral intake.

**SLP’s Responsibilities**

It is compulsory that SLPs serve their patients with the “preservation of the highest standards of integrity and ethical principles” (ASHA, 2003, p. 185). Landes (1999) and Sharp and Genesen (1996) proposed different models to use for ethical decision-making. The specific purpose of these models was to assist SLPs (though probably appropriate for many medical professionals) in arriving at decisions for recommendations to patients.
caregivers, and the medical team concerning their patient’s dysphagia. Whereas these models are well constructed and easily implemented, one readily apparent caveat exists with these and any model of similar structure: personal bias. Personal beliefs play a role in our approach to therapy. For example, consider the clinician who is willing to implement a new therapy technique at face value based on marketing and the proper training as opposed to the clinician who is a bit more judicious to wait for more research to be released before making the decision to implement the technique.

Landes (1999) discussed the four primary principles of ethics (i.e., beneficence, nonmaleficence, justice, and autonomy), vis-à-vis Beauchamp and Childress (1994), as they apply to speech-language pathology and the care of patients who have dysphagia. Briefly, acting in the benefit of others (beneficence) while keeping harm from coming to patients (nonmaleficence) is the foundation of medical practice and therapies alike. Referring to the case above, the SLP made the recommendation for alternative feedings to the patient based on observed aspiration during examination. The SLP was acting in accordance with the principles of beneficence and nonmaleficence, that is, attempting to avoid harm (e.g., aspiration pneumonia, death) to the patient. Conversely, Landes points out that those patients who lose the pleasure of eating to the invasive placement of a feeding tube and perceive a loss of socialization at mealtime may feel that they suffer more harm than the good that can come from what may be a reduced risk of infection. In other words, the patient’s desires now pit quality of life against ethics. Justice, the third principle, is fair treatment for all patients. Continuing with the case, the SLP has made and will continue to make this recommendation to other patients with similar presentations, treating no two patients differently in fairness and objectivity for their diagnosis and treatment. The final concept is autonomy, or the patient’s prerogative to make choices based on his or her values (i.e., self-determination). The SLP must take into account what the patient’s goals are in therapy. Though it may not be in the patient’s best interest (according to the SLP) to refuse treatment, it is the patient’s definition of quality of life that guides his or her decisions and that decision needs to be respected. The recommendations for treatment need to be discussed with the patient, regardless of the final decision. SLPs need to discuss which method of alternative feeding should be chosen with the physician in light of the difficulties with swallowing function that compromise the patient’s health and well-being (e.g., aspiration of oral intake).

Setting aside the other three ethical constructs only temporarily, respect for autonomy seems to be at the center of ethical dilemmas associated with artificially administered nutrition and hydration, largely related to what patients perceive as a change in their quality of life. So what is “quality of life?” As stated earlier, it depends on who is thinking about it, the circumstances, and time:

Few terms have been defined in so many different ways as quality of life, and it is futile to search for the one and only correct sense of the term....So, in the most suitable sense, the concept of quality of life coincides with the value of the life for the person who is living it. High quality of life means having a good life, or a life worth living (Malmgren, 1997).

Difficult, too, is the permissibility by the SLP to respect this decision, notwithstanding our beliefs and research suggesting that harm may come to the patient provided the patient does not follow our advice. This is especially prominent with a patient’s desire to continue oral feedings in lieu of the recommendations by the SLP placed in the medical record. Even if the SLP and other members of the medical team believe that the best course of treatment is to provide alternative feedings until such time as the patient is capable of handling oral feedings, the competent patient still has the right to refuse that treatment. Unfortunately, there are no hard and fast answers to the question of what happens when the patient is readmitted to the hospital for complications due to oral feedings after refusing alternative feedings, or refusing to follow through on the strategies recommended by the SLP. By-products of these behaviors may include (but are not limited to) the constant return to healthcare services with a drain on medical resources and increased health problems for the patient due to repeated aspiration pneumonias.
Patients like the one in the case above are often left with compromised mental faculties. The combined beneficence and nonmaleficence side to the ethical equation is that SLPs will act in a manner to augment the patient’s abilities without causing harm to come to the patient. That is, SLPs will recommend alternative means of nutrition to augment health and keep the patient potentially safer than if he or she were to be fed orally. But how can clinicians know—beyond a doubt—that patients who are unable to express their wants and needs really do want therapy? The simple and inherently flawed answer, or assumption as it were, is that unless there is an advanced directive that prohibits treatment, it is assumed that therapy is desired to improve a patient’s quality of life. Given that enteral feedings are widely viewed as a therapy (Sullivan, 1993) instead of nourishment, physicians act similarly with patients who are non-autonomous and who do not have a surrogate.

In most cases of refusal for enteral feedings, a patient’s desires were upheld in courts of law (e.g., Cruzan v. Director, Missouri Department of Health, 1990; In Re Schiavo, 2000). Perhaps Albert Einstein was right when he stated, “It has become appallingly obvious that our technology has exceeded our humanity”(QuoteDB, no date) when issues like this need a court’s intervention. Here again, though, our patients are telling us, “You’ve made your recommendation. It’s my turn to make a decision.”

It seems as though ethical practice mandates a “do all I can until I’m told to stop” approach to treatment. The literature is replete with differing opinions on this subject, specifically related to placement of a feeding tube for artificial nutrition and hydration or the withdrawal or withholding of the nutrition and hydration itself (Fainsinger & Bruera, 1997; Gillick, 2000; Groher, 1990; Goodhall, 1997; Landes, 1999; McCann, Hall, & Groth-Juncker, 1994; Meisel, 1995; Melltorp & Nilstum, 1997; Meyers, 1985; Rabeneck, McCullough, & Wray, 1997; Segal & Smith, 1995; Sharp & Genesen, 1996; Sullivan & Young-ner, 1994). The argument of feeding tube placement for continued nutrition and hydration in diseases where no cure is available but death is not imminent (e.g., dementia) is weighed against prolonging a disease that does not have a cure and for which death is imminent (e.g., terminal cancer). Because the pendulum swings both ways, many conclusions in the research do not recommend strict methods of treatment. Rather, they suggest that the notion of quality of life is based on the patient’s needs and desires. Once the patient’s desires are determined, the treatment plan should be executed with everyone on the medical team made aware of it. Finally, there is an overwhelming assertion in these articles that no attempt at legislation or policy should be made that makes a global statement of who should have these measures placed, withdrawn, or withheld. Each patient and each patient’s disease process should be considered in isolation.

Conclusions

Patients are not given every piece of information available to clinicians, perhaps as a safety mechanism or the result of a situation in which time does not permit this type of dissemination. This is especially true when it comes time to make the decision of acceptance or refusal of artificial nutrition and hydration. Instead, future plans, dignity, and comfort are at the fore of patients’ and caregivers’ minds. Whereas some patients will choose no treatment, others will opt for every measure to preserve life, even seeking experimental techniques, each with his or her own reasons. It cannot be overstated that patients have the right to refuse medical treatment. It is now law that allows them to do so.

Each clinician practices differently, yet within his or her respective scope of practice. Philosophies even differ between institutions (e.g., nursing homes, hospitals, private clinics) within the same city, let alone between states. Nothing is a given or a constant; perhaps this is best. The United States and each state within have set forth guidelines for care along these lines, still allowing people the autonomy to choose the physician, the hospital, the clinician most aligned with their beliefs. Of course, given the structure of the laws and policies at present, it is strongly suggested that resolution of these issues be accomplished prior to the actual need for this kind of treatment. Views of medical treatment,
dying, and death should be discussed with loved ones when possible. Additionally, patients should consider completing living wills that will carry out their wishes, keeping in mind that a living will is sacrosanct until it is amended. This way, there is no question of what a patient truly wants in most circumstances. However, if a patient were determined to be non-autonomous by virtue of the inability to adequately express his or her needs, such as in the case above, alternative methods to carry out his or her wishes should be in place. Alternative methods present some difficulty, though. If an advanced directive or living will is not in place, the patient’s wishes can be quite difficult to enact and enforce.

The bottom line is that there is no bottom line. Each person is a new case and brings with him or her a new set of rules. The courts have stated some definitions for patient’s rights, but there is no legislature that mandates what is to be executed on a patient’s behalf. The lines between law, ethics, medicine, and therapy as they relate to artificial feedings are blurred at best. By keeping the lines of communication between disciplines open, perhaps the answers to these issues will come into focus.

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References


Psychosocial Issues Related to Dysphagia


Psychosocial Issues Related to Dysphagia
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 Amendment 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 assess-
ment, 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 dissen-
tion 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., 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., 1997). In the large-scale SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments), most participants did not discuss 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
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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; McClave 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 Gastroenterological 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 negative 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 (Hoefler, 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 experiencing 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 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 consider-
able 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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References


Psychosocial Issues Related to Dysphagia
Behavioral Treatment of Feeding Disorders

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Pediatric feeding carries with it the possibility of both medical and psychosocial difficulties. While normally developing youngsters typically progress through a series of developmental stages in feeding, there are those children who, for medical, developmental, or other reasons, fail to achieve adequate oral feeding. The estimates of incidence of feeding problems in normally developing children range from 25-45% (Burklow, Phelps, Schultz, McConnell, & Rudolph, 1998; Linscheid, 1998), while children with developmental delays are known to be at even greater risk (Burklow et. al.; Schwarz, Corredor, Fisher-Medina, Cohen, & Rabinowitz, 2001).

Classifications of feeding disorders have been variable, but frequent mention has been made of organic versus nonorganic feeding problems. Organic feeding problems have been conceptualized as those with underlying physiologic causes, while feeding problems related to such issues as environment, family dynamics, and/or psychopathology have been thought of as nonorganic in nature. More recent medical and psychological literature has acknowledged the necessity of taking a more complex approach to classification by examining the medical, anatomical, and behavioral components that often co-occur in children with feeding disorders (e.g., Burklow et al., 1998; Linscheid, 1998; Rudolph, 1994). Indeed, the complex medical and behavioral aspects of feeding disorders have been increasingly recognized. Budd and colleagues (1992) found that two-thirds of children with feeding disorders in their study sample could be characterized as having both physiologic/developmental and behavioral characteristics. Thus, behavioral assessment and intervention in the area of feeding disorders have become important parts of overall treatment.

Rudolph (1994) describes the various processes involved in feeding. For young children, feeding involves the experience of hunger and satiety, the provision or procurement of food, and ingesting and swallowing food, all conducted in the larger social context of family and peers. Parents (or other designated caregivers) have a primary responsibility to ensure that infants and young children are provided with appropriate sustenance. There is a natural parent-child interaction around feeding and food, and the inability to effectively feed an infant or young child can result in an emotionally charged parent-child interaction. Regardless of the specific cause of feeding problems, parents may have difficulty responding efficiently to a child’s negative feeding behaviors at mealtimes, whether these are refusals, disinterest, or an inability to tolerate oral feeding. In this way, interactions between parent and child may become negative and behavioral problems may develop secondarily or become entrenched. Parent-child interactions and behavioral issues then become a focus of intervention.

It is not only those children with clinically diagnosed feeding disorders who exhibit mealtime difficulties. The psychological literature indicates that mealtime behavioral problems in young children are common, with parents in two-thirds to one-half of normative samples reporting at least one mealtime behavioral problem. One-fourth of parents in normative samples report multiple mealtime difficulties. It appears that it is not the presence of mealtime behavioral problems, but rather the frequency of such, that differentiates clinical from normative samples (Crist & Napier-Phillips, 2001).

From a behavioral perspective, one could conceptualize a feeding problem in terms of skill vs. motivation. Skill represents physiological, anatomic and developmental ability to eat, while motivation refers to the environment and/or the interactions that either support or interfere with appropriate feeding. Many children require intervention in both of these areas and are seen by physicians, nurses, speech-language pathologists, occupational therapists, dietitians, and behavioral psychologists, among others. For the purposes of
the remainder of this article, the focus shall be on behavioral assessment and treatment of feeding disorders with the understanding that behavioral treatment is conducted in conjunction with one or more of the previously mentioned sub-specialists.

**Behavioral Assessment**

A detailed behavioral assessment seeks to examine the child in the context of overall psychosocial, developmental, and physiological functioning. This often begins with a clinical interview involving the parents and/or other relevant caregivers of the child, as well as the child. The clinical interview may elicit information such as the onset and nature of the specific feeding problems, feeding milestones and developmental history, medical history, mealtime and daily routines, and previous attempts at intervention (behaviorally or from other sub-specialists). Children are screened regarding general behavioral and emotional functioning.

Behavioral assessment may additionally include the gathering of parent report questionnaire data that could be useful in supporting or extending the information gathered during the interview. Questionnaire data may also reveal other areas of difficulty that are relevant to the feeding difficulties. Questionnaires might include a screening of behavioral and emotional difficulties, parent report of specific mealtime problems, and parent report of developmental functioning. Parents may also be asked to report on their own psychosocial functioning, which is useful in gauging, for example, stress and anxiety related to family mealtimes.

An observation of the child during a meal is a common component of a behavioral feeding assessment. Observations may be done “live” in the clinic, via videotaped meals from home, or both. Regardless of the method of observation, the clinician is looking to evaluate a typical meal in terms of the types of foods presented, the manner in which food is presented, the child’s behaviors and the parents’ response, and the interaction between parent and child throughout the meal.

During the interview and the observation, feeding behaviors are reviewed in detail. Feeding behaviors could include, but are not limited to, acceptance of bites, verbal refusals, spitting, emesis, and crying. Behaviors are analyzed by breaking them down and examining the antecedents (triggers), the specific actions that compose the behavior itself, and the consequences or the outcomes of the behavior. This process allows the therapist to better understand how a behavior is elicited and maintained and, thus, how best to intervene to facilitate behavioral change.

**Behavioral Treatment**

Behavioral interventions have long been empirically supported in terms of psychosocial treatments for feeding disorders (e.g., Babbitt et al., 1994; Palmer, Thompson, & Linscheid, 1975). Specific behavioral techniques might include: use of feeding structure, manipulation of hunger, contingency management, shaping, and parent training. These techniques will be discussed in more detail.

At the initiation of treatment, data from the assessment are used to establish baseline functioning (in order to track change) and to set treatment goals. General treatment goals often include:

- Decreasing behavioral problems at meals
- Decreasing parent stress
- Increasing pleasurable parent-child interactions
- Increasing oral intake or variety of oral intake
- Advancing texture
- Increasing the structure and routine of mealtime

Additionally, specific behaviors are often chosen and targeted for increase or decrease/ extinction. Thus, detailed behavioral programs are designed to address individual behaviors as well as to further the general goals of treatment.

Depending on the child and the nature of the problem, interventions may be conducted with the individual child, the child and parents, parents alone, or in some combination thereof. Ongoing consultation with other sub-specialists involved in the child’s care is necessary in order to appropriately understand the child’s needs and abilities and design behavioral interventions. Throughout the course of treatment, utilizing baseline data and ongoing data collection, progress is tracked by monitoring calories consumed, weight gain/loss,
frequency of problem behaviors, and frequency of desired behaviors.

**Feeding Structure**

One of the most basic behavioral feeding interventions is the implementation and improvement of feeding structure and routines. Parents are encouraged to consistently adhere to routine meal and snack times. It is recommended that meals last for a set period of time (dependent upon the child’s abilities and developmental level) and that children be dismissed from the table not based on food consumption, but rather based on elapsed time. Depending on the individual situation, children are typically required to accept in front of them some type of food or liquid presentation (regardless of whether they will consume it). This helps parents to set limits that are reasonable and easily enforced (e.g., sitting at the table as opposed to eating) and teaches children to sit at the table with their family, regardless of whether they are interested in eating. Sitting at the table, in turn, allows for ongoing exposure to food and drink, as well as to social interaction at mealtime. Parents are typically advised that the child is not dismissed from the table at the end of the meal unless or until he/she is sitting quietly in the chair, lest crying, tantrums, and refusals be inadvertently reinforced by escape from the table.

**Manipulation of Hunger**

Behavioral feeding interventions are likely to be facilitated by the presence of hunger, which is manipulated through the use of structure as well as by decreasing supplemental feedings. Parents are asked to provide calories through food or liquid only at scheduled meals and snacks, regardless of whether the child ate at the previous meal. Grazing is discouraged. Dietitians and physicians make decisions about the need to decrease or change the schedule of supplemental feeding in order to create as much hunger as possible while still maintaining adequate nutrition and hydration.

**Contingency Management**

After analyzing behavior in terms of antecedents and consequences, a behavior therapist may choose to use methods of contingency management. Contingency management refers to the manipulation of the consequences of behavior, that is, changing the outcome of behavior in order for it to be encouraged or discouraged. Reinforcement is the strengthening of a behavior by applying a stimulus or a consequence immediately following the behavior (this may also be referred to as positive reinforcement, as it involves the application of a reinforcer). The applied stimulus or consequence is referred to as the reinforcer. Reinforcers can be tangible (e.g., stickers) or intangible (e.g., attention). In the case of young children, parent attention and interaction may provide extremely strong reinforcement of either desirable or undesirable behavior.

Negative reinforcement is the *removal* of an aversive stimulus or consequence in order to strengthen a behavior. An example of negative reinforcement in a feeding situation is a caretaker’s *removal* of the spoon as a consequence to a child’s verbal refusal. In this example, the refusal is *strengthened* by the consequence of spoon removal. We can say that the refusal has been negatively reinforced (made stronger). It is important to note that negative reinforcement is not punishment. Punishment is defined as a stimulus or a consequence that weakens behavior. Punishment can be difficult to implement because, in order for it to be effective, it must be perceived as highly aversive. A common rule of behavior therapy is to use reinforcement before punishment.

In utilizing contingency management, therapists may attempt reinforcement of tastes, sips, bites, or targeted volumes of food/drink. It may also be important to reinforce behaviors that are related to the acquisition of oral feeding, such as sitting calmly at the table. Conversely, certain behaviors may be targeted for extinction. These might include crying, refusals, or emesis. One method of extinction is to identify a behavior’s reinforcer and then to remove it. For example, if it is determined that parent attention is reinforcing a tantrum, parent attention would be removed. The therapist would teach the parent how to safely ignore the behavior in order to decrease and extinguish it. Another method of extinction is to provide reinforcement to a competing behavior and remove reinforcement from the targeted behavior. Taking
the preceding example, the parent would ignore a tantrum (remove the attention reinforcer) and attend to a quiet behavior (apply attention as a reinforcer).

**Shaping**

Shaping is the method of changing behavior by reinforcing successive approximations of the desired behavior. In the situation where there is a large gap between the currently exhibited behavior and the desired behavior, it is useful to move slowly and methodically toward the goal. This method is useful, for example, in the process of teaching new skills or introducing new tastes and textures. A child who does not use utensils might first be reinforced for picking up an empty spoon, then for dipping the spoon into food, next for bringing spoon to mouth, and finally for inserting the spoon with food into his/her mouth. A child who drinks only juice might be moved toward water consumption by slowly diluting the juice with water over time.

**Parent Training**

Early in treatment, it is important that parents are educated regarding behavioral interventions in terms of theory and application. Topics to be covered include, but are not limited to, how negative behaviors develop and become reinforced, how to analyze and track behavior, and basic behavioral interventions. Provision of written information can be helpful to parents in this phase. Once behavioral interventions begin, it is also helpful to provide written handouts detailing the behavioral plan so that it is more likely to be implemented effectively and consistently in the home.

Therapist modeling of a behavioral intervention is a crucial aspect of parent training. This can be followed by therapist coaching of parents as they implement the intervention with their child. Modeling and coaching can be done with all parties in the same room, or with one of the parties observing (via one-way mirror or video monitor). For example, one method of effective parent training is first to have the therapist teach and model the intervention with the child. The parent may then be asked to implement the intervention in the room alone with the child (to approximate the in-home interaction), while the therapist watches from outside the room and coaches via a microphone transmitting to an earpiece worn by the parent. This then removes the therapist from the interaction while allowing the parent to implement the intervention under the direction of the therapist. Therapist modeling and coaching help to ensure that parents better understand how to effectively utilize and implement behavioral interventions outside of the office setting. In-session review of videotaped meals from home can serve as a check on the manner in which behavioral interventions are being applied at home and can also help parents see more clearly the interactions between themselves and their children.

**Intensive Behavioral Intervention**

In some instances, the use of outpatient treatment alone may not result in the desired improvement in oral feeding. Certainly there are situations where the feeding difficulties are so severe or complex and the resistance to feeding is so strong that a more intensive approach to treatment is warranted. Additionally, there are children who do not have easy access to behavioral feeding treatment and who live too far away from the clinic to participate in regular outpatient treatment.

Intensive behavioral feeding intervention can be conducted in a day treatment format or in an inpatient setting. The specifics of the programs may differ from location to location, but, in general, intensive programs are designed to allow a high frequency of and more intense interactions with a behavior therapist. If medically appropriate, supplemental tube feedings are significantly decreased or stopped during the behavioral program and the child is monitored closely regarding nutrient and fluid intake. It is important that reduction or elimination of supplemental feeding is done under the supervision of experienced therapists and other treatment providers and that it be paired with behavioral intervention, as children may not eat (or may not eat enough) for several days. Drastic reductions in supplemental feeding without appropriate supervision and without the behavioral component of the intervention may not be successful.

Generally, in the beginning of an intensive behavioral program, treatment goals are developed and agreed upon by parents and clinicians. Goals
of treatment may include complete oral feeding, texture advancement, or initiation of consistent oral feeding (in conjunction with supplemental tube feeding). There is usually a period where the child is fed directly by a therapist or by a technician trained in behavioral feeding. The behavior therapist designs a treatment plan that is implemented at each feeding session. These interventions are used to move the child progressively toward the treatment goals. The parents are then intensively trained to continue the intervention once the basic treatment goals have been met. Typically there is some level of outpatient follow up to address difficulties as the family transitions to feeding back in the home environment.

Intensive behavioral feeding programs may differ in their requirements for admission, but typically there is some requirement for medical and nutritional stability, along with medical clearance for oral feeding. The child should be judged safe for oral feeding and not at risk for aspiration. There should be clear communication and agreement between therapists and families with regard to treatment goals and the types of interventions applied. Additionally, there should be agreement regarding the need for, and access to, follow-up behavioral therapy services.

One example of an intensive behavioral feeding program is the inpatient behavioral feeding program at Children’s Hospital of Wisconsin, located in Milwaukee, Wisconsin. The inpatient behavioral feeding program is part of the Wal-Mart and Sam’s Club Feeding and Swallowing Center and is run and staffed by behavioral psychologists. Children are accepted into the program based on readiness for oral feeding (demonstrated oral skills without risk for aspiration), medical and nutritional stability, and identification of behavioral factors affecting oral feeding. Family distance from the treatment program and prior attempts at outpatient therapy may also play a role in the decision to admit to the inpatient feeding program.

Prior to admission, each child is examined and cleared for intensive behavioral intervention by a representative of each of the feeding subspecialists on the team (physician, dietitian, speech-language pathologist, and psychologist). At that time, the team, in conjunction with the parents, identifies treatment goals for admission. Parents are also briefed ahead of time regarding the nature of and expectations of the program. Specifically, parents are informed that it is generally a 2-week program utilizing a behavioral approach to feeding. Weight loss during the program and slow weight gain in the months following discharge is expected, and the team preference is for children to enter the program with some excess weight to allow for these occurrences. Children are fed three times per day, 7 days per week, and at least one parent is required to be present at all mealtimes. Any supplemental feeding are eliminated (or significantly reduced) during the inpatient program, with the exception of fluids to prevent dehydration.

At the initiation of the program, all meals are fed by PhD level behavior therapists experienced in behavioral feeding interventions. During this phase of treatment, behavioral interventions are used to progress the child toward the identified treatment goals. Once behavioral problems have been reduced and the child has attained or is close to attaining treatment goals, parents are transitioned into the feeding of their child. A dietitian works closely with the treating psychologist to monitor caloric intake (calculated daily), weight maintenance or loss, and hydration.

Initially, parents are asked to sit quietly in the room observing as the therapist feeds the child. The parent then begins gradually feeding the meal directly while the therapist observes in the room. The parent is next asked to feed his or her child while the therapist is out of the feeding room and observing via video monitor. During this phase of treatment, parents are coached with the use of a wireless radio receiver placed in their ear. The therapist observes the feeding interaction and provides direct feedback and instruction. The child is discharged once he/she has stabilized with parents providing the feeding intervention.

Outpatient therapy is provided through the Feeding, Swallowing and Nutrition Center at Children’s Hospital of Wisconsin or, if a family is not located close to the clinic, by a local behavior therapist in consultation with the treating inpatient therapist. Outpatient follow-up is felt to be
critical as many children and families experience some level of behavioral difficulty as they transition home. Behavioral follow-up sessions are often conducted in conjunction with a dietician and provide close monitoring of behavioral interventions, maintenance of behavioral goals, and caloric intake and growth. Follow-up sessions with physicians and speech-language pathologists are scheduled as needed by an individual child. Follow-up sessions are tapered off as the children become nutritionally stable and behavioral problems in relation to oral feeding become minimal or nonexistent.

**Summary**

Feeding problems are not uncommon in young children, and a subgroup of children exhibit a number of feeding-related problems. Increasingly, professionals are recognizing the complex contributions of medical, anatomical, developmental, and behavioral factors in children with feeding disorders. Behavioral treatment is one treatment approach that is used to address feeding problems in young children. This type of treatment is usually applied in consultation with other knowledgeable professionals. As described above, behavioral assessment and intervention can be a complex process and require well-trained professionals. In the case of behavioral feeding interventions, behavioral therapists must be experienced and knowledgeable in general behavioral therapy, treatment of early childhood feeding disorders, child development, and medical issues related to feeding. Access to an interdisciplinary team experienced in treating children with feeding disorders is also critical. The interdisciplinary team approach allows recognition and treatment of the complex contributors to feeding disorders, behavioral factors included, and provides children and families with coordinated and comprehensive care.

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**References**


Psychosocial Issues Related to Dysphagia

Food for Thought: The Impact of Dysphagia on Quality of Life

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Dysphagia is a disorder with not only physical but also psychosocial and emotional consequences. While speech-language pathologists should be aware of and sensitive to this reality, our literature contains a paucity of studies exploring the experience of dysphagia from the perspective of patients and their caregivers. For this article, we interviewed three individuals who have had significant dysphagia (all secondary to brainstem injury), as well as the mother of a fourth person, a young man with dysphagia resulting from brainstem injuries sustained in a motor vehicle accident. These interviews exposed the significant quality-of-life implications of dysphagia, with respondents devoting as much or more time to discussing the social, emotional, and psychological consequences of dysphagia than to describing nutritional or respiratory concerns. One person said that one year following the onset of his health crisis, the swallowing problem remains the biggest issue affecting his quality of life. The mother of the young man, who is also paraplegic, described his swallowing problem as “devastating to the point where it’s even difficult to describe” and asserted that dysphagia has affected her son’s quality of life even more than his inability to walk.

Societal ignorance about swallowing disorders contributes to the negative impact that dysphagia can have on quality of life. When asked “What is the one thing you would most like other people to understand about dealing with a swallowing disorder?,” our interview candidates expressed the wish that others would recognize that medical problems can mean that some people cannot swallow their saliva and secretions, and must spit them out into tissues, or cough and “hawk” to clear secretions throughout the day. They described feeling stigmatized when others look at them pointedly, or move away in the apparent belief that their secretion-clearing behaviors indicate a contagious illness. One person described difficulty finding discrete ways to dispose of the many tissues used each day when out in public places. Another person wished that others would understand the great effort and concentration required to chew and swallow. She said that trying to listen and swallow at the same time can create enough of a distraction to launch an attack of coughing.

Amidst such circumstances, it is hardly surprising that all of those interviewed said that their social lives were severely disrupted by their dysphagia. One person said, “My social life was nil during the first two and a half years following surgery. I was housebound most of the time, except for doctors’ appointments and rehab sessions. I missed several parties, weddings, retirement events, and get-togethers…. Currently, I have been gradually phasing into the social circle again…taking into consideration my limitations and impairments.” Another person said, “We used to go to restaurants to celebrate events—birthdays and special occasions. We don’t eat out anymore. On the odd occasion we have gone to a fast food restaurant. But it is awkward.” He said that social visits with people other than close family must occur between meal times, with the result that “you tend not to visit much.” When people decide to eat out despite their swallowing difficulties, attempts to explain the situation to restaurant staff can prove exceedingly difficult. “There are many times when [our son] feels upset, depressed, and humiliated in restaurants. Waitresses and waiters just don’t understand. They ask why he’s not going to eat, or why he doesn’t need a glass of water, or why he doesn’t need cutlery.” Another person commented that, “Even other family members, aunts and uncles and cousins, they don’t understand the whole scenario. They know that he’s fed by a tube...
but they seem to feel that he can take liquids…. I have to remind everyone in [his] life that he doesn’t swallow…. Every time we have a prescription, I have to remind the pharmacist. I have to ask, ‘Does it come in a liquid? Is it a capsule that can be separated, or can it be crushed?’”

Clearly, individuals with dysphagia are not the only ones whose quality of life is affected. The people closest to them also feel the effects of the dysphagia. The mother we spoke to stated, “The maternal instinct is always to feed your children, and when you can’t do that there’s part of you that seems quite empty. Because I can’t do that for [my son], I feel somewhat inadequate, and it makes me feel very sad. And I do have some real problems with that from time to time. I do have some real depressing days and hopeless feelings that I try to deal with.” She stated that professional counseling has been greatly beneficial in dealing with such issues.

The individual with dysphagia is constantly reminded that he can’t eat; food and evidence of the pleasure of eating, is everywhere. Whether watching T.V. or a movie, listening to the radio or reading a newspaper, walking down a street where the smells of food are spilling out of a restaurant—even in one’s dreams at night—food is unavoidable. This constant reminder is also present at home, and may affect personal relationships. The wife of one man that we interviewed said, “At first I was anxious about eating in front of him, because I felt guilty that I was eating and he couldn’t. So I would eat in the kitchen and he would be in the family room, and then I thought, ‘Well gee, that is normally a time when you can get together and talk.’ So I said to him, ‘Would it bother you if I came in and ate where [you are]?’”, and he said, ‘No.’ So we’re doing that now…. I still feel guilty eating in front of him, especially if it’s something he really liked before.” Similar feelings of guilt were echoed by the mother we interviewed, who said “Other members of our family, his siblings and their partners, become upset by celebrating with food in front of [him]… we often have some tears and remorse.”

People also said that the need to follow a strict feeding regimen interfered significantly with their opportunity to lead a normal social life. “A great part of my daytime is consumed just trying to obtain proper and sufficient nutrition to keep me going. Eating is tiresome and inefficient. I can handle only a teaspoonful at a time, and have to chew slowly and stay focused and concentrate as I eat. By the time I finish a small meal and clean up, there is not much time to do other things in between meals, and I am quite tired by then.” Another person, using enteral feeding for nutrition, stated that 6 hours of every day are taken up in this one activity, and that other activities must be planned around feeding. He said that there often just isn’t enough time in the day to do other things.

Going out for the day when reliant on tube feeding can be an undertaking requiring an enormous burden of pre-planning and organization. One person explained that nutritional supplements and bottled water, a pill crusher, and medications must be packed, a viable battery pack for a continuous feed system must be checked, and an emergency kit must be constantly replenished. She said this “has altered our life to the point where everything has to be thought out completely ahead of time…. The whole routine of our life has changed.” Going out is also difficult because the tube feedings can cause nausea.

A good night’s sleep, so essential for good quality of life, may also be interrupted by dysphagia. One may be awakened by coughing spells throughout the night; this is likely to interrupt sleep for spouses/partners as well. One person told us that aspirating at night means hard work the next day to “clear his lungs.” He said this leads to a lack of energy and the need to nap. He described a strategy of placing tissues in his mouth overnight to soak up saliva that can’t be swallowed while he sleeps, as well as positioning considerations used to limit aspiration at night: “I have a wedge, I have a pillow so I don’t roll on my back, and I have a foam pad underneath me so I don’t slide down off the wedge, and a pillow on the other side too so I don’t roll too far that way either. So it’s like sleeping in a box. And when you travel you can’t take everything with you.”

With regard to experiences in the health-care system, one person commented that he appre-
ated the apparent efforts made by allied health-care professionals to “push the doctor” to order more tests and to do more on his behalf. One person expressed disappointment that the speech-language pathology services he had received had focused more on speech than on swallowing. Advice from medical professionals regarding the decision to have enteral feeding is often reported to be far from sufficient. One person described a situation in which he was first left with the impression that there was no option other than insertion of a percutaneous endoscopic gastrostomy (PEG) tube, and then surprised when his gastroenterologist later asked, “Are you sure you want this?” Another person said that his questions about PEG tubes received conflicting answers depending on which health professional he spoke to; one surgeon even refused to see him to answer his questions.

One person provided some valuable food for thought for clinicians regarding feedback after treatment sessions. She said that after each therapy session, she received encouraging feedback, which emphasized every small positive event. Although this was clearly well-intentioned, it left her completely unprepared for an ultimately unsuccessful outcome. The individual stated that although the speech-language pathologist stated very clearly at the outset that there was no way to know whether treatment would be effective, the final result was devastating after the many positive comments received throughout the block of treatment. Clearly, we must remember to balance our efforts to motivate clients with awareness that the outcome may not be what they or we are hoping for. We must also recognize that clients and families may be facing significant life adjustments due to other components of their health situation. The mother of the young man said that as a consequence of the catastrophic accident, “We’re told where we can live, how much money we have to live on, where we can go, what we can do, who we can hire to help us, everything. Our whole life revolves around permission from the insurance company.” She felt that the insurance adjusters “go to great lengths not to meet [her son]” in order to maintain objectivity, but that this was perceived by the family as a lack of compassion in the system.

All the people interviewed stressed the importance of a positive attitude and a sense of humor in coping with swallowing difficulties. One person said his experience gave “new meaning to the term, ‘brown bagging it’” when he carried around a “spit cup” (for clearing secretions) in a brown paper bag. He made up a song about “Granddad and his Gevity” (a nutritional supplement) that he used to entertain his grandchildren during his feedings. He refused to be embarrassed in public, placing his need to take feedings as paramount. “I started playing golf again, though of course, riding in a cart. I took along a funnel, a can of Gevity and a couple of bottles of water. I didn’t find it embarrassing to be seen doing something unseemly in the presence of others to take the nourishment I needed.” One person spoke of the importance of having “a ‘can-do’ attitude: …whatever we have to do, we’ll do it.” Another spoke about dealing with only one thing at a time and considering each situation as just one “moment in time that may change,” and in this way, maintaining a belief that things will improve. One somewhat surprising coping strategy used by one person was to watch cooking shows and keep lists of foods he planned to eat when the dysphagia resolved.

Speech-language pathologists who work with individuals with dysphagia see evidence of its profound impact on quality of life every day. With the expectation that the incidence of dysphagia will rise with the aging demographics, it is important that greater attention be devoted to this issue in our literature, particularly in light of recent research highlighting the phenomenon of noncompliance by patients with the swallowing recommendations made by speech-language pathologists (Colodny, 2005). Although our interventions are designed first and foremost to facilitate swallowing safety and efficiency, the fact is that patients are frequently inclined to disregard our recommendations (Colodny). It may be that we have not fully recognized the negative impact that our well-intentioned recommendations might have on quality of life. Further research in this area could provide valuable information to assist clinicians in making recommendations that balance swallowing safety with quality of life considerations and might facilitate
patient compliance with swallowing recommendations. Attention to this area in the literature might also provide information that could be used to further the education of the public on swallowing disorders, which is sorely needed to alleviate the social difficulties encountered by our patients and clients.

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Reference