



To Feed or Not to Feed

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Advancements in evaluation and treatment of dysphagia would seem to make treatment decisions more clearcut.

However, the decision process is complicated by factors brought to the clinical setting by both clinician and patient. Lack of appreciation for these factors or unwillingness to address them can limit the evaluation and result in services inconsistent with the patient's wishes and values. These factors include: (a) the cultural and social significance of eating; (b) medical judgments about patient mental status, treatment burdens, prognosis, and risk of aspiration; and (c) patient directives, treatment refusals, and definitions of quality of life. Each set of factors must be considered in treating individuals with swallowing disorders. A discussion of these factors and practical recommendations for addressing them have been developed jointly by a speech-language pathologist and a bioethicist.

Serradura-Russell (1992) pioneered efforts to delineate dilemmas encountered by the speech-language pathologist in treating dysphagic patients. She addressed benefits and burdens of treatment and tube feedings, and their impact on patients' refusals to accept intervention. The speech-language pathologist, in her opinion, should be instrumental in providing the patient with alternative care options and implications of these decisions. Her article has served as a resource in formulating our thoughts and designing this article.

Cultural and Social Considerations

In most cultures, eating and feeding are not simply intended for the physiological purpose of providing nutrients. Eating, especially sharing a meal with family and friends, is a primary way of initiating and maintaining human relationships (Farb & Armelagos, 1980). Eating and sharing food can be powerful

symbols that evoke positive images, feelings, and memories.

Similarly, not to eat and not to feed can evoke negative images and thoughts. *Starvation*, *famine*, and *fasting* express situations associated with absence of food, and can call forth disturbing or at least unpleasant remembrances. Even fasting, often freely chosen, can have negative attachments, because it is usually occasioned by a desire to repent from sin, to be purified from evil impulses, or to protest social ills (Rogers, 1976).

Because food is associated with familiar human experiences and encounters, the provision of food can become a measure of humanness and care. Not providing food can be a sign of inhumanity and cruelty. Health professionals, patients, and families are not immune from cultural meanings associated with food and eating. They also are sharers in cultures, readers of history, worshipers in religions, and participants in communities. They can have many and even conflicting cultural images associated with food, eating, and not eating. These images accompany clinicians and await them as they engage in decision making at the patient's bedside.

What is Possible: Medical Judgments

Decisions about what form nutrition should take, or whether it should be provided at all, are influenced by medical judgments, especially regarding diagnosis and prognosis. These judgments define more clearly the problems and potential solutions for patient care plans. Medical assessments and judgments about a patient's mental status, a treatment's burdens for the patient, prognoses, and risks of aspiration are principal areas of attention that help the health care team ascertain what is possible for the patient.

Mental Status

The patient's mental status can both clarify and cloud whether and how to provide nutrition. Mental status directly affects the degree of patient participation in health decisions. Its decline affects a patient's ability to make decisions about proposed treatment, and influences swallowing safety because the patient may not be able to exercise appropriate precautions or follow directions.

The greatest difficulty arises in determining whether mental status is impaired and, if so, what degree of impairment prohibits or restricts patient participation in decision making. The ability to exercise autonomy can vary from patient to patient, depending on age, mental ability, presence of dementia, and degree of

cognitive, affective, or psychiatric dysfunction. For some patients, ability to participate in decisions can vary from day to day or hour to hour.

When a patient's ability to make health care decisions is in doubt, an assessment by members of the health care team is appropriate. Within the physician-patient relationship, the primary physician has ultimate responsibility for determining a patient's ability to participate in decision making. Nevertheless, the physician may benefit from observations and assessments by the speech-language pathologist, neuropsychologist, primary nurse, a liaison psychiatrist or social worker if available, and other ancillary staff such as a hospital chaplain.

Cognitive skills to be looked for include the abilities to communicate choices, understand relevant information, appreciate the medical situation and its consequences, and manipulate information rationally (Applebaum, 1988). If lack of intact mental status can be reversed, and if time allows, attempts should be made to restore the patient's ability to make decisions prior to decision making.

Serradura-Russell (1992) discusses dilemmas that arise while attempting to provide nutrition to demented patients. She points out that health professionals who are expected to feed demented clients can be placed in distressing quandaries. Are they force feeding patients against their wishes? Have the family and relevant health professionals discussed the options and their implications? Have the burdens and benefits of the nutritional management plan been weighed from the patient's perspective? Assessing and clarifying a patient's mental status, and trying to maximize the patient's ability to make decisions, do not directly answer these and other questions. But the assessment and resulting clarification can provide a starting point for ethically supportable decisions.

Treatment Burdens for the Patient

Treatment burdens of feeding a patient can be emotional and physical, as well as financial. For example, a patient may have strong feelings about tube feeding. Being unable to express feelings due to dementia or other impairments does not necessarily mean that the patient is unaware or unaffected by what is being done.

Regarding physical burdens, the lack of pleasure from tasting and smelling food may be significant for a patient. The pleasure that is derived from eating often drives the patient's desire to continue intake. Also, naso-gastric tubes can be a constant irritation and discomfort to sensitive tissue.

Scofield (1991) expresses concern about inappropriate and unwarranted use of feeding tubes. Regarding emotional and physical burdens, he comments that tube feeding regimens increase a patient's isolation, can lead to psychosocial deterioration and withdrawal, and can make it more difficult for patients to regain lost function. To reduce emotional and physical burdens of feeding tubes for patients, he gives a two-fold recommendation: (a) feeding tubes should be used only when medically indicated, and (b) decisions about how to provide nutrition should be determined by the least restrictive alternative for the patient.

Prognoses

The issue of medical prognosis is complex. Differentiation must be made regarding prognosis for the patient's specific medical condition(s), for swallowing ability, and then the overall prognosis. Decisions made for and with a patient who is not expected to recover medically but who could recover swallowing ability would be different from decisions made for a patient expected to recover medically but not to recover swallowing ability. A different set of decisions could be made if both the patient's medical condition and dysphagia are not expected to recover, or if decline in either of these areas is an anticipated outcome.

Serradura-Russell (1992) discusses the impact of acute change in medical status with little or no expected recovery. A major difficulty here is that acute change often necessitates decisions and actions prior to clarity of prognosis. Further, initial actions taken may be unknowingly discordant with patient wishes. Once the prognosis can be determined (after the acute phase of illness is over), questions may be raised as to whether tube feedings or nutrition in general are medically appropriate. Serradura-Russell emphasizes that a speech pathologist is never in a position to decide to stop tube feedings and that the health team, together with the family, should analyze the situation and make the appropriate decisions.

Risk of Aspiration

One criterion medical professionals use to assist decisions for oral intake or tube feeding is the presence or absence of risk of aspiration. However, this risk is not always clear. A patient may be able to avoid aspiration but be at significant risk for aspiration under less than favorable conditions such as decreased alertness, poor positioning, or distractions within the eating environment. Aspiration can occur both silently and inconsistently, making the assessment even more complex. Finally, there

are patients who aspirate, consistently or inconsistently, and who are able to avoid infection.

A trial of oral intake and waiting to see if infection or aspiration pneumonia develops could be medically appropriate. For the patient who lacks ability to make decisions, such trials may be problematic, depending on the presence or absence of patient advance directives or surrogate.

Oral intake is not the only feeding scenario that places a patient at risk for aspiration. Tube feedings can be refluxed and aspirated (Ciocon, 1990; Groher, 1990). Lo and Dornbrand (1992) emphasize that modern advancements and medical technologies should be used to benefit patients, and that tube feedings should not be considered “ordinary” care, used automatically without assessing benefit. The issue is not the nature of the technology, but whether benefits of the technology for the patient outweigh burdens, such as risk of aspiration.

Occasionally, surgical interventions are appropriate to manage aspiration, such as a tracheostomy (Blitzer, 1990; Groher, 1984; Logemann, 1983), a total laryngectomy (Cannon & McLean, 1982), a laryngotracheal diversion (Tucker, 1979), or placement of an anti-aspiration stent (Eliachar et al., 1987). Surgical intervention should be considered in light of the different levels of prognoses. A patient may wish to forgo surgery if it is irreversible or the benefit is not reasonably certain. Because some interventions are experimental, the patient may decline to participate. Finally, the patient’s comorbidities may increase the risk for complications during or after surgery.

What is Permissible: Patient Decisions and Actions

Decisions regarding oral feeding and artificial nutrition are affected not only by the cultural significance of eating and by medical judgments, but also by patient participation in the decision process. Patients communicate what is permissible according to their values, goals, and perceptions of risks, benefits, and quality of life. This communication does not take place independent of the other two sets of factors, but interdependent with them and within the context and dynamics of intimate (usually family) relationships (Nelson, 1992).

Patient Self-Determination and Directives

The value of freedom and self-determination has become a significant part of health care decision making. Patients are encouraged (and have come to expect) to be involved in the

process of informed consent to recommended treatments. Their degree of involvement often is dependent on the gravity of risks for the proposed procedure, their ability to make health care decisions, and the acuteness of the illness. If a patient can give informed consent, the same patient also can give informed refusal.

In general, the wishes of a competent adult patient ought to be solicited and honored. If ability to make decisions is clearly absent or remains in doubt, the patient’s advance instructions, either in writing (Annas, 1991) or given orally, as well as assistance of a surrogate, may be helpful. Without advance directives, surrogate, or legal guardian, health professionals must do what they perceive to be in the “best interests” of the patient.

Patient Refusals

The question arises whether decreased oral intake or repeatedly pulling a naso-gastric tube are the patient’s way of communicating treatment refusal (Groher, 1990; Lo & Dornbrand, 1992; Quill, 1992; Serradura-Russell, 1992). This has recently been argued most forcefully for patients with decreased mental status. More importantly, is force-feeding or repeated reinsertion of a tube a cruel treatment? Quill (1992) has indicated that in one study, restraints were used with 63% of incompetent patients who were receiving tube feedings in order to keep the tube in place. Questions of treatment objectives, patient wishes, and distresses and discomforts for patients arise in such situations.

Patients may also refuse evaluations, treatments, or diagnostic procedures (e.g., videofluoroscopy or fiber-optic exam) that would allow documentation of aspiration. Ethical quandary may be heightened for health professionals when a refusal is given by a patient who is mentally competent and who may have greater potential to benefit from the outcome.

Refusal of treatment by patients lacking intact mental status is harder to interpret. The presence of family members or other surrogates may help to discern patients’ verbal and nonverbal communications. Surrogates may also be able to provide a context for decisions by recounting patients’ values, lifestyle, and previous conversations about health and personal definitions of quality of life. Written advance directives may also help the decision process. Presumptions either to forgo or continue oral feedings or artificial nutrition should not drive the decision. Medical judgments of benefits and burdens, and patient wishes and values (if known), should be brought to the forefront of the decision process.

Quality of Life

Ultimately, how the patient defines quality of life creates the context for what is permissible from the patient's perspective. Does the patient prefer oral intake to tube feeding despite the risks undertaken? Does the patient prefer decreased caloric intake and gradual nutritional depletion rather than tube feeding? Does the patient want life prolonged at any cost, or must a minimum level of function and cognition exist before continuation of life is considered acceptable?

Recommended treatment may be perceived differently by a patient than by health professionals. A patient may view or experience continued oral intake and swallowing maneuvers as laborious, painful, or simply not worth the effort. The patient may see tube feedings as a needless means of prolonging life, pain, and delaying the inevitability of death, which may be preferred to the burdens of treatment.

In a similar way, a patient may have treatment preferences after weighing the risks of aspiration. A patient might decide to accept the risk of aspiration and refuse placement of a feeding tube. A second-level question can then emerge whether to treat an occurrence of aspiration pneumonia when the patient agreed to accept such a risk by continuing oral intake. If the response is affirmative, then one could ask how many times treatment should be provided for recurrences of pneumonia.

Health professionals may have difficulty allowing patients to define quality of life for themselves, or to refuse recommended treatment, or to assume risks thought to be too great. Reverse situations also cause difficulties, that is, when patients or their families choose to prolong life despite poor prognoses. It is difficult for health professionals to diagnose a medical problem, recommend solutions, and then allow patients or their representatives to choose, especially when the choice is not preferred by the health professionals.

In summary, decision making concerning oral intake and alternative forms of nutrition can be complex. Medical science provides some clarity when diagnostic results are definitive and prognoses are known. However, uncertain or unstable medical and mental status add to the complexity of the decision process. Advance directives and identification of surrogates are useful means to facilitate decisions which are medically justified and consistent with patient wishes.

No perfect set of guidelines or "golden rules" exists that will solve all dilemmas and apply to every case. Each patient must be assessed individually in light of medical diagnoses and prognoses, the patient's mental

status, swallowing abilities and risks, and the patient's wishes, goals, and definition of quality of life.

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