Feeding Tubes: Three Perspectives

Rebecca Brashler, Teresa A. Savage, Debjani Mukherjee, and Kristi L. Kirschner

Percutaneous endoscopic gastrostomy tubes, or PEG tubes, look innocuous enough—narrow, plastic, pliable tubes, that when inserted into the stomach protrude approximately 3 to 5 inches and can be attached to a bag of liquid food. How can something so seemingly straightforward create so much controversy and evoke such intense emotion? It seems that part of the answer lies in the fact that nobody sees the same thing when they look at a feeding tube. This article will present three different views of gastrostomy tubes and challenge practitioners to think beyond traditional models. **Key words:** *decision-making, disability, ethics, feeding tubes,*

Percutaneous endoscopic gastrostomy tubes, or PEG tubes, look innocuous enough—narrow, plastic, pliable tubes that when inserted into the stomach protrude approximately 3 to 5 inches and can be attached to a bag of liquid food. How can something so seemingly straightforward create so much controversy? The answer, at least in part, lies in the fact that nobody sees the same thing when they look at a feeding tube. It is complicated further by the haunting reminders of Terri Schiavo, whose name will now be forever associated with decisions about feeding tube withdrawal. Many bioethicists continue to assert that the right to withdraw artificial hydration and nutrition is "a settled ethical and legal issue in this country."[1(p1631)] If health care providers and ethics consultants approach each new case as if the issue has indeed been settled, it may be impossible to clearly hear the perspectives of patients and family members who are grappling with the complexity of decisions around feeding tube placement and withdrawal. This article will explore three different perspectives on gastrostomy tubes—perspectives not of special interest groups or political camps but viewpoints that may be raised by individual patients and families struggling to make personal decisions about their treatment.

Perspective 1: PEG Tubes as Life-Sustaining Medical Interventions

> PEG tubes are placed for a variety of different clinical conditions, including dysphagia, prolonged illness, anorexia, neurologic/psychiatric disorders, oropharyngeal or esophageal disorders, or cancers, or increased nutritional needs that the patient is unable to meet with oral intake.[2(p22)]

The predominant medical view of feeding tubes maintains that they are life-sustaining medical treatments, similar to mechanical ventilators, and, as such, competent patients or their surrogates can choose to have them withdrawn in certain circumstances.[3,4] The US courts have largely upheld this view of feeding tubes and, since 1982, have stated that "separate rules were not required for decisions on withholding and withdrawing nutritional

Rebecca Brashler, LCSW, *is Assistant Professor, Physical Medicine & Rehabilitation and Medical Humanities & Bioethics, Northwestern University Feinberg School of Medicine, Chicago, Illinois.*

Teresa A. Savage, PhD, RN, *is Adjunct Assistant Professor, Physical Medicine & Rehabilitation and Medical Humanities & Bioethics, Northwestern University Feinberg School of Medicine, Chicago, Illinois.*

Debjani Mukherjee, PhD, *is Assistant Professor, Physical Medicine & Rehabilitation and Medical Humanities & Bioethics, Northwestern University Feinberg School of Medicine, Chicago, Illinois.*

Kristi L. Kirschner, MD, *is Associate Professor, Physical Medicine & Rehabilitation and Medical Humanities & Bioethics, Northwestern University Feinberg School of Medicine, and Coleman Chair in Rehabilitation Medicine, Rehabilitation Institute of Chicago, Chicago, Illinois.*

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support."[5(p937)] Justice Sandra Day O'Connor echoed this sentiment when she wrote in her concurring opinion for the Nancy Cruzan case that "artificial feeding cannot readily be distinguished from other forms of medical treatment."[6(p312)]

What are the arguments in favor of viewing feeding tubes as medical treatment? They need to be inserted by licensed medical practitioners in a health care setting and carry some risk of complication, such as bleeding and infection. Although table food can be pureed and placed through a gastrostomy tube, most people choose to use tube-feeding preparations that require a doctor's prescription and monitoring. Insurance companies will typically cover the costs of the feeding tubes, equipment, and the prescription feedings, which reinforces the classification of gastrostomy tubes as medical interventions.

The procedure to place a PEG tube is fairly straightforward and can usually be completed in approximately 20 minutes. The benefits seem obvious—the tube provides an alternative means by which complete nutrition and hydration, elements necessary for life, can be administered. Once the tube is in place and the feeding system stabilized, patients and family members can often be taught how to administer the tube feedings. However, one can find differing opinions within the medical literature as to whether PEG placement should be considered a high-benefit/low-risk intervention or whether the complications associated with these tubes are underappreciated.[2,7,8] In reality, the benefits and burdens of treatment can only be discussed in the context of the medical condition resulting in the need for a gastrostomy tube. The risk/benefit ratio of feeding tubes for medically stable patients with cerebral palsy, strokes, and head and neck cancers is judged to be quite favorable,[9–11] whereas there is a growing consensus in the medical literature that such is not the case for people with advanced dementias[12–14] or anorexia-cachexia syndrome (advanced cancer or AIDS).[15]

Perspective 2: PEG Tubes as Basic Humane Care

> It seems to me that our three basic needs, for food and security and love, are so mixed and mingled and entwined that we cannot straightly think of one without the others. So it happens that when I write of hunger, I am really writing about love and the hunger for it, and warmth and the love of it and the hunger for it; and then the warmth and richness and fine reality of hunger satisfied; and it is all one.[16(p353)]

Feeding tubes appear to evoke a much more visceral and emotional response than other medical treatments because they provide "food and fluid." Feeding issues often spark controversy in the United States as evidenced by the attention given to breast feeding, school lunches, fad diets, and obesity. Food in our society is intricately associated with love, sustenance, celebration, religious rituals, and daily customs. In this context, we hear people refer to the removal of tube feedings as "starving" someone. Yet we rarely refer to the removal of a ventilator as "suffocating" someone or the end of dialysis as "poisoning" someone.

Although health care providers often view feeding tubes as a straightforward clinical intervention, many patients and family members struggle with the meaning of feeding tubes in a social context. Their concerns can make it difficult to initially accept the need for artificial feeding mechanisms, and many are, at first, reluctant to agree to feeding tube placement. Many people share writer Sam Crane's worries that his son's need for a feeding tube would forever rob him of "the pleasure of taste and texture of food."[17(p134)] Another parent reported to researchers that she was so sensitive to the meaning of shared meals in a communal setting that she sent her child to school with a lunch despite her general inability to take in food orally because it preserved her ability to socialize with others.[18] Ethical issues surrounding feeding tubes are common for clinicians who work with patients and families struggling to balance the social and psychological importance of eating with the potential detrimental effects of aspiration pneumonia.[19,20]

Though there has been a growing consensus in this country that withholding life-sustaining treatment is morally equivalent to withdrawing such treatment,[21] in practice many health care providers, patients, and families feel otherwise, particularly when discussing feeding tubes. Although they may struggle with decisions to begin artificial feeding, they also describe deep angst at the thought of actively intervening to withdraw nutrition and hy-

dration. People who view feedings as an act of compassion will naturally view the removal of feedings as neglectful and inhumane. Tube feedings strike many people, including the late Pope John Paul II,[22] as inherently different from other medical interventions. Rather than viewing the surgical insertion of this medical device as life-sustaining treatment, some people maintain that feedings of any kind should be considered basic care and that the removal could be considered euthanasia by omission.[22]

Perspective 3: PEG Tubes as Disability Accommodations

> Disability activists must express our ridicule for the pathetic response of the nondisabled majority to these simple pieces of latex rubber. This case hinges on the fact that Terri uses a feeding tube, which to disabled people is no big deal—it's just another piece of adaptive equipment.[23]

The disability rights view holds that feeding tubes are simply an accommodation to disability. Similar to wheelchairs for those who cannot walk, feeding tubes provide access to nutrition and hydration for those who cannot eat orally. The tube in this perspective is analogous to a fork or a set of chopsticks.[24] This perspective—which many first became aware of during the Terri Schiavo case—perceives the denial or withdrawal of a feeding tube as a potential violation of an individual's civil rights. Furthermore, it raises questions about whether people with disabilities who require feeding tubes receive discriminatory treatment based upon their impairments.

The term "reasonable accommodation" as used in Section 504 of the Rehabilitation Act and the Americans with Disabilities Act (ADA) generally refers to employer-based modifications that allow a person with a disability to perform job responsibilities.[25] However, it is not difficult to see how the concept might be applied to individuals in need of feeding tubes. If the "essential function" of the gastrointestinal system is to digest nutrients and extract energy, then altering the method of moving the food from outside the body to the stomach could certainly be viewed as a simple accommodation that facilitates getting the essential job accomplished.

In a longitudinal study of families caring for a child with a gastrostomy tube,[18] parents describe in detail their shift from thinking about the tube as a medical intervention to viewing it as another piece of adaptive equipment. Parents in this study initially worried about measuring and timing food exactly as prescribed and following physician orders precisely. Later they began to relax these guidelines to allow for more spontaneous family activities and to think about it as "just food." Many people who use feeding tubes over time experiment with feedings and often move from the use of store-bought prescription products to blending and liquefying table foods. This change is often accompanied by a sense of empowerment and control over one's life that is a hallmark of the disability rights movement. Medical professionals are no longer viewed as the experts as patients and family members learn to make complex decisions in light of their day-to-day needs and intimate knowledge of their own bodies.

The disability rights perspective highlights as well the fact that people with inside knowledge of disability often have dramatically different views than those of the able-bodied majority. Although parents in Thorne's study gradually shifted to thinking about the feeding tube as a necessary piece of adaptive equipment, they still had to confront the negative reactions of others and learn to cope with the stigma associated with eating differently.[18] Anyone setting up a tube feeding for a child or for themselves in public would need to prepare themselves for stares and possibly even some indication that others viewed the process as bizarre. This awareness that people with disabilities view their needs and lives differently than those who lack experience with the insider perspective is a common theme in the disability studies literature.

Remarks

These three perspectives of PEG tubes are not mutually exclusive and have many areas of overlap. There are certainly other perspectives that could be added to this list. Most important is the realization that our perspectives shift over time and are influenced by life experiences and exposure to different viewpoints. The likelihood that the perspective of a health care professional will

closely match that of their patient/family member is questionable, which may be what sparks so much misunderstanding and controversy. Being aware of one's own perspective is particularly important because health care professionals' values influence the way they frame information and their willingness to offer various treatments.[26–28] Greater appreciation for other viewpoints and a willingness to view PEG tubes through another person's lens may increase understanding and the capacity for more productive communication. It is this communication that facilitates the true spirit and goals of informed consent.

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