Ethical Issues in Palliative Care

Oral Nutrition or the Ability to Speak: The Choice Faced by a Cancer Survivor

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Abstract
Patients with head and neck cancer often suffer from breathing, speaking, and eating deficits, which negatively affect their quality of life. These patients are often observed to repeatedly contract aspiration pneumonia, resulting in prolonged hospital stays. To help prevent aspiration pneumonia, enteral nutrition is often provided. Although this method helps avoid pneumonia, patients need to give up eating by mouth. Because oral intake of food is closely related to patient quality of life, abandoning eating results in a strong internal conflict. This report describes the case of a cancer patient who experienced repeated aspiration pneumonias after neck surgery. The patient required enteral nutrition to avoid repeated bouts of pneumonia. However, the patient opted for laryngeal closure surgery to regain the ability to take food orally, at the expense of his voice. The patient’s choice caused an ethical conflict for the attending medical professionals, highlighting the need for physicians to communicate with their patients to understand their patients’ sense of values.

Key Words
Ethics, quality of life, head and neck cancer, communication

Introduction
Patients who undergo head and neck cancer surgery often suffer from difficulties in swallowing and speaking. The severely weakened swallowing function often leads to repeated accidental aspirations, which tend to lead to aspiration pneumonia. Consequently, postsurgical enteral feeding is often required to avoid the development of aspiration pneumonia.

For the treatment of persistent aspiration, several surgical options are available. These procedures primarily are used for patients with neurological deficits such as amyotrophic lateral sclerosis or cerebrovascular disease. These patients are prone to repeated bouts of aspiration pneumonia, and surgery is normally performed to sustain the patient’s life. Although the patient is able to take food by mouth...
with a greatly diminished risk of aspiration, the procedure necessitates breathing through a stoma and the sacrifice of the patient’s voice. A small number of patients with head and neck cancer suffer from severe swallowing deficits after surgery, and intensive radiation therapy often negatively affects eating. Surgery to prevent or minimize repeated aspirations also is appropriate in these cases. This report describes a patient who experienced problems associated with enteral nutrition and desired surgical intervention that would allow him to return to oral food intake, although he was aware of the possibility of other side effects. The ethical dilemma facing his attending medical professionals, as a result of his desires, also is described.

**Case Description**

This report describes the case of a 74-year-old cancer patient who was diagnosed with Stage II tongue cancer (T2N0M0) at the age of 66 years. The patient underwent tongue segmentectomy and radical neck dissection (Levels I–III). Three years later, malignant disease was found in his throat. The patient underwent tonsillectomy to remove the mesopharyngeal cancer (T1N0M0) and was subsequently treated with radiation and chemotherapeutic agents. As a result of the intensive treatment, there have been no recurrent tumors. However, these treatments negatively affected the functioning of the patient’s throat. A weakened pharyngeal constriction was detected in his throat by a speech and language pathologist. Over time, the patient developed repeated, accidental aspiration pneumonias that resulted in prolonged hospital stays. Eventually, it was necessary for the patient to begin an enteral nutrition program to minimize the risk of repeated pneumonias. Although the enteral nutrition kept the patient alive, he reported a diminished quality of life. A nutritionist estimated the total energy intake that was necessary to maintain his weight; his nutritional requirements necessitated several hours of nutritional infusions daily, resulting in his eventual hesitation to receive the infusions. This led to a gradual weight loss. Although evidence of recurrent cancer or physical comorbidities, such as a thyroid dysfunction, were not detected, his weight decreased to less than 40 kg while taking enteral nutrition. He indicated that he had almost lost his reason for living because his energy levels had decreased and he was not enjoying life anymore. His desire to eat again was so strong that he requested surgery to enable oral food intake, although he was aware that he would permanently lose his voice.

**Ethical Analysis**

There are several surgical options for the treatment of intractable aspiration, including total laryngectomy, laryngotracheal separation surgery, and laryngeal closure. Laryngeal closure surgeries have been performed widely over the past several years. Total laryngectomy is a relatively invasive procedure associated with high morbidity rates. Additionally, both total laryngectomy and laryngotracheal separation surgeries are associated with high incidences of pharyngocutaneous fistula. Laryngeal closure was opted for in this case because it was the least invasive procedure. This technique helps people with swallowing difficulties avoid aspiration pneumonia and allows them to take meals by mouth. However, the technique was developed for patients with chronic neurodegenerative disorders, such as amyotrophic lateral sclerosis, to prevent aspiration pneumonia and to prolong life. The technique was not developed to improve the quality of a patient’s life.

Although there would be little hesitation to perform this technique when necessary to preserve life, this case was different because the procedure was being considered to improve the patient’s quality of life. Several reports in the literature have focused on the ethical aspects of enteral nutrition and oral food intake. However, the situation in this case was different from those discussed in the literature. The ethical dilemma in this case arose because of the patient’s desire to take food orally, and it was difficult to know which choice would provide him with the best quality of life. One procedure would allow oral intake and result in the loss of his ability to speak, whereas not performing the procedure would require that the patient continue to give up oral food intake. Some surgical tracheoesophageal perforation methods retain the patient’s ability to speak; however, in this case, the patient’s
Laryngeal tissues were thought to be too weak to allow such treatment. The lack of any measurement tools to guide the decision made it difficult to determine which route would be best for the patient, from either a medical or an ethical point of view.

To compound the difficulty in making a decision regarding the most appropriate treatment modality, postsurgical loss of voice also is related to a diminished quality of life, as the patient has a greater difficulty communicating with others. A recent quality-of-life study focused on patients who underwent laryngectomies and showed that impaired communication and social activities were negatively correlated. The study also indicated a relationship between loss of voice and feelings of depression and anxiety. Because of the surgery, it was necessary for the patients to live everyday with the stress caused by their limited ability to communicate. Thus, in the present case, the medical professionals had to determine if the benefits of laryngeal closure outweighed its adverse effects. The patient insisted that in instances when communication was necessary, he could use an electronic speech device. He also argued that he would rapidly get used to life without speaking because he was not a very talkative person.

Food is taken by mouth for a number of reasons. The most important reason is the intake of calories and nutrients essential for preserving life and maintaining health. However, eating food also is strongly correlated with quality of life. Tasting delicious food makes us happy and provides opportunities to meet people and share comfortable experiences with others. A famous Japanese cooking expert, Yoshiko Tatsumi, said:

Modern medicine tends to resort to gastric fistula, using infusion or putting holes in our bodies. But we should rather value the importance of giving “through the mouth,” shouldn’t we? But humans don’t eat for the sake of taking in calories, nor do we usually think about how many grams of proteins we should take in. We’ve always eaten for good taste and enjoyment, haven’t we? In my view, what patients eat is not nutrition. Eating is the most basic activity for a human to be human.

Similarly, the patient described in the present case felt that daily enteral nutrition was not acceptable and that it took him away from his sense of being human.

Although the patient’s opinion was considered, it was necessary to assess whether he accurately understood his own situation and whether he had the capacity to make an accurate assessment. To aid in this determination, a psychiatrist met with him and conducted a semistructured interview, according to a reliable strategy. The questions in the interview were related to several concepts of competence, as described in the medical ethics literature. The interview was designed to address the following aspects: 1) ensure that the patient understood that he had a right to decide; 2) obtain evidence of the patient’s own choice; 3) ensure that the patient did not waver; 4) ensure that the patient understood the expected benefits, expected risks, alternative treatments, risks expected from no treatment, and benefits expected from no treatment; and 5) ensure that the patient had a desire to get better. The results of the interview showed that the patient was free of mental illnesses such as depression and cognitive dysfunction and possessed sufficient ability to judge his own situation. The patient also understood that he had a right to decide his own treatment and that there were benefits and risks associated with either choice, including the possibility that enteral nutrition might still be needed after surgery to supplement his intake. During the following two months, the patient considered the benefits and risks of his treatment plan and discussed these with his family. His wife was supportive and, although not knowing how her husband might change after surgery, agreed with his decision to undergo laryngeal closure surgery.

**Case Resolution**

The decision to perform the laryngeal closure procedure was made because medical personnel were unable to determine the best route for the patient, and they were influenced by his strong desire and their knowledge that the patient understood the associated risks. After the surgery, the patient regained the ability to take food by mouth. Although his swallowing difficulties necessitated supplementary enteral nutrition, he was able to enjoy the taste of food again. The patient also felt that he was
able to communicate with others sufficiently well through writing. The patient felt that the surgery helped him to regain a sense of being human, even several months after the surgery.

**Comment**

Sustaining life is an important goal of medicine. However, an outcome that is good for one person may not be optimal for another. Therefore, we need to consider each patient’s views on quality of life while helping the patients to make decisions regarding their long-term outcomes. Medical professionals need to communicate with their patients to become aware of the individual’s sense of values and to share the patient’s treatment goals.

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**References**


