Ethical Dilemmas

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The Case of Ms. D

Ms. D is a 39-year-old woman who has been diagnosed with a brainstem glioblastoma. Her prognosis is poor. Clinically, she presents with quadraparesis, moderate flaccid dysarthria, and moderate dysphagia. Throughout the assessment process she has performed within functional limits on all cognitively-based tasks. Upon examination of swallowing, Ms. D was found to be aspirating inconsistently on all consistencies of food/liquid. No use of diet modification or compensatory technique was effective in eliminating the aspiration. Use of an effortful breath hold did reduce the amount of aspiration on thick liquids and pureed foods.

Considering the severity and regularity of aspiration, Ms. D was given the recommendation that she take nutrition and hydration nonorally (NPO). She indicated that she had thought her situation through, however, and does not wish to stop eating and/or drinking.

Commentary

This case was presented in last quarter’s newsletter with the question “How might you proceed?” It is the first in a number of cases that will highlight ethically challenging clinical situations. The details of this first case admittedly were sparse in order to elicit a representative spectrum of commentary and questions. The lone respondent did address the paucity of medical facts in the case. Further information might help the clinician explain to Ms. D the risks and benefits of taking food and fluids orally versus through feeding tube. The respondent, a speech-language pathologist, mentioned the risks of aspiration, even though the route of feeding may be nonoral. Additionally, she recognized the fact that the patient’s current medical stability and mobility status could impact the risk of contracting respiratory complications secondary to aspiration.

The mention of the provision of more information is significant. In the literature discussing ethical decision-making, one of the hallmark guidelines by which clinicians and patients make decisions is that of informed consent. The term “informed” implies that all necessary information needed by the patient to make a decision has been provided. This concept traditionally comes from the legal notion that no one can “trespass” upon your person (touch you) without informing you and gaining your permission (Applebaum, Lidz, & Meisel, 1987). This concept respects the principle of autonomy. In health care, autonomy is the notion that each competent individual has the freedom to decide his/her course of treatment (Beauchamp & Childress, 1994). Autonomy is one of the four primary principles of health care ethics promoted by Beauchamp and Childress. The others include beneficence, the obligation to do good for our patients; nonmaleficence, the edict that we must not harm our patients; and justice, that all individual patients will be treated fairly. Sharp and Genesen (1996) indicate that ethical challenge is faced by the speech-language pathologist, particularly in dysphagia cases, when the concepts of beneficence and nonmaleficence appear to collide. The speech-language pathologist may view his/her obligation for nonmaleficence (recommending NPO status to a patient who is aspirating and in whom this is medically risky) as the beneficent (doing good by aiming to maintain optimum health status) action. The patient may, view the beneficent action (the “good” for her) as allowing her to make the choice to enjoy eating and drinking as long as possible, as in the case of Ms. D.
Questions

Let’s explore an important question in the case of Ms. D to help lead us to the ethically acceptable options in this vignette.

Does Ms. D have the capacity/right to make a medically questionable decision for herself?

As stated above, the notions of informed consent and patient autonomy deal with the competent patient. Competency is a legal status. In order for someone to be considered “incompetent” to make decisions and manage their affairs an adjudicated hearing must take place. In health care, a determination of this sort for every case is impractical (White, 1994). When physicians and health care teams seek shared decisions with patients (by the reciprocal action of the informed consent process) they will typically attempt to determine if the patient has decision-making capacity (DMC) for the task at hand. For this to occur patients must be able to comprehend their medical condition, the options presented, and the consequences of each choice (for treatment or nontreatment). They must also be able to convey a reasonable process of consideration on which they base their decision (Applebaum & Grisso., 1988; Lo, 1990).

Let’s say for the sake of this discussion that Ms. D was discovered to have adequate DMC. If this is so, she indeed has the right to refuse the placement of a feeding tube, even if she is at risk of hastening her death secondary to chronic aspiration. (Another complicating factor of this issue is that we currently have no empirical data indicating how much aspiration will equal a pneumonia and for whom). Let us also say for the sake of debate that Ms. D recognizes her difficulty swallowing and wishes the speech-language pathologist to remain involved to assist her in maximizing her swallowing potential. Further difficult questions are then raised.

Can/should the speech-language pathologist remain involved in the case?

Is the speech-language pathologist ethically/legally permitted to train strategies for swallowing, even if he/she knows the patient will aspirate?

References


Suggested Reading


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