Swallowing and Swallowing Disorders (Dysphagia)

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Ethical Dilemmas

The Case of “Mr. E”
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“Mr. E” is a 39-year-old gentleman who has been diagnosed with a large bilateral cortical glioblastoma. His prognosis is poor. Clinically, he presents with motoric involvement of all limbs (left greater than right), a moderate flaccid dysarthria, and moderate dysphagia. Throughout the assessment process he has demonstrated moderate-severe cognitive communicative deficits including reduced attention, orientation, and memory as well as anosognosia. Upon examination of swallowing, Mr. E 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, Mr. E was given the recommendation that he take nutrition and hydration non-orally (NPO). He indicated that he did not wish to stop eating and/or drinking, however, and physically resisted the attempt of the physician to insert an NG tube for provision of nutrition and fluids.

If you have read the most recent issues of this newsletter you may have seen the discussion surrounding the case of “Ms. D.” The case of Ms. D led us to conclude that a competent patient has both the right to accept and to refuse medical treatments offered. Ms. D’s vignette was similar to Mr. E’s in all but one respect. Ms. D possessed decisional capacity and had the ability and right to exercise self-determination and either accept or refuse an alternative means of nutrition and hydration based on personal weight of the benefits and burdens of this treatment (Jonsen, Siegler & Winslade, 1992).

The Patient Who Lacks Decision-Making Capacity

Patients (individuals) are assumed competent until proven legally incompetent to oversee their healthcare, personal or financial affairs. The process of adjudicating a patient incompetent is a time intensive one. It is a safeguard that is necessary in some cases. More often physicians use the less formal method of determining if the patient has decision-making capacity (DMC). Provided the patient has rigorously satisfied the criteria of DMC, the patient can even refuse lifesaving or life-sustaining treatment. A patient is said to possess DMC if he or she understands all the information given regarding diagnosis and treatment alternatives, is able to consider these alternatives and comprehend and weight the consequences, and is capable of expressing a rational choice (Applebaum & Grisso, 1988). Some definitions include the ability to attend to this information and adequately remember it over time (Lo, 1990; Freedman, Stuss & Gordon, 1991). DMC is typically determined for a patient’s task specific judgment. Competence (or incompetence rather) is a more global assertion.

We know that as long as we have exercised sound practice as clinicians, have explained the treatment options and the consequences to the patient, and the patient is a competent individual, he or she has the right to refuse the treatment options we suggest.

How should we proceed when the patient lacks the DMC to consent to or refuse treatment?

The case of Mr. E is just such a case. In addition to his anosognosia, evaluation revealed that Mr. E does not have the adequate sustained attention to process and comprehend the serious nature of his swallowing deficits and the consequences (namely aspirating and illness) that could arise from refusing an alternative means of nutrition and hydration.

In the case of a patient who is medically inca-
pable of making decisions, the physician/clinician should look to any advance medical planning that was done by the patient or to a surrogate who can best represent the wishes of the patient.

**Advance Directives**

The use of advance directives grew out of controversy surrounding use of life-sustaining treatment in the case of a patient in permanent coma (Singer & Siegler, 1991). The use of an advance directive allows an individual to prospectively describe what they might wish for their medical care in certain situations if he or she were to ever lack DMC. An advance directive is a legal document and is only valid when written while an individual is competent. In other words, a minor child or an individual with advanced dementia for instance would not be able to make an advance directive.

Although types of advance directives vary from state to state, there are two general forms. The first is the Living Will (LW). The LW varies in utility for specific conditions and decisions based on the legislation of each state. In general this document allows persons who are in a terminal condition (again defined differently in each state) to express the kind of medical treatment they may want if they become incapacitated.

The Durable Power of Attorney for Healthcare (DPAHC) is the second general advance directive form. The DPAHC allows patients to name the individual they prefer to make medical care decisions for them if they become incapable of doing so. The DPAHC is a more powerful document and usually takes precedence over the LW. Alternatively, if an individual had both a LW and a DPAHC, the medical team would speak to the proxy decision-maker which would allow the patient more flexible interpretation of what his or her wishes might be. It should be noted that it has been estimated that only 4% to 17.5% of the population of the United States has made an advance directive (Paridy, 1993).

**Surrogate Decision-Makers**

It is important to note that the DPAHC (or, in the more likely event that there was no advance directive made, the proxy or surrogate decision-maker (SDM)) is obliged to exercise certain standards when making decisions for the patient. The first standard that should be employed is Substituted Judgment (Beauchamp & Childress, 1994). Substituted judgment occurs when the SDM, who is obliged to place him/herself in the patient’s shoes, attempts to make the decision the patient would have made. The SDM does this by recalling past conversations with the patient in which the patient may have stated his or her wishes for medical treatment in specific cases. The SDM might also extrapolate what the patient would want done by reflecting on the patient’s behavior in certain circumstances.

If there were no analogous situations or conversations from which to draw a conclusion of what the patient’s authentic choice may have been for a particular decision, the SDM should then use the standard of best interest of the patient to aid decision-making (Beauchamp & Childress, 1994). The best interest standard mandates that SDMs weigh the available options and choose what they believe to be the most beneficial for the patient by weighing the burdens and benefits of various recommended treatments.

When an individual has not named a DPAHC and does not have a LW, physicians usually turn to family members as the informal (but widely used and often most appropriate) SDM. When there is unresolvable conflict among the family members or there are other special circumstances, the medical team may go to court to name a guardian for the patient. In most cases, however, the physician consults the family in decision-making. Some states have adopted legislation to aid them in selecting a SDM for incapacitated patients in certain strict incidences to avoid having to go to court each time these situations arise.

**The Case of “Mr. E” - Conclusions**

As we look again at the circumstances in Mr. E’s scenario we see that he lacks decision-making ability and will require a SDM to ascertain if an alternative method of nutrition (i.e. G-tube) should be placed.

Choices made by SDMs are largely treated as those of competent patients. That is, if all the options and consequences of treatment and non-treatment are fully understood, the SDM has the right to accept or refuse intervention. An exception to this would be if the SDM was not making decisions on behalf of the patient’s authentic wishes or in their best interest (Beauchamp & Childress, 1994).

Mr. E had a DPAHC; namely, his wife. After discussing the diagnosis of dysphagia and the risks and benefits of nutrition/hydration intake alternatives, Mrs. E chose to have a G-tube placed. Using the principle of substituted judgment, Mrs. E knew that Mr. E would not wish to risk becoming gravely ill while he was still able to enjoy his family. She
did also concede that he would want to attempt to eat some things by mouth because he loved food. She spoke at length with the speech-language pathologist and the physician regarding the risks and benefits of taking restricted consistencies by mouth using special techniques. Following their exhaustive conversation, it was decided that an effortful breath hold technique would be trained and Mr. E would be fed pureed and thick liquids with supervision and close monitoring for clinical signs of aspiration and its complications. This constituted a trial intervention because Mrs. E decided that if Mr. E became ill, the oral feeding would be discontinued.

Although it is indicated here that shared decision-making occurred primarily with Mrs. E, Mr. E was considered and the treatment alternatives were presented to him as well. All patients, even those who lack DMC, should be consulted whenever possible when making decisions regarding their care, and every effort should be made to assist their comprehension of the harms and benefits of the proposed alternatives.

When medical decisions requiring informed consent are made, clinician’s documentation of all conversations, determinations and provisions should be thorough and immediate (Jonsen, Siegler & Winslade, 1992). Although it has been demonstrated that the patient with DMC has the right to accept or refuse treatment and that the SDM has the right to accept or refuse intervention for a patient who lacks DMC, it is the obligation of the clinician to ensure that the process of informing the patient and/or SDM of all pertinent information has been completed accurately. When physicians acquire informed consent from a patient to perform a procedure (such as a bronchoscopy) patients are required to sign a form indicating that they have been told of all the possible harms and advantages, that they understand these and that they will not hold the physician or the institution liable should they incur a harm that was discussed. As speech-language pathologists dealing with patients with dysphagia, we see cases such as Mr. E’s where the patient (or proxy) chooses a medically risky alternative. Documentation of decisions such as these is extremely important. Some institutions may have a policy that the patient or their SDM sign a release form. It is best to consult your supervisor or the legal counsel at your institution.

References


