

ETHICAL PERSPECTIVES IN NEUROLOGY

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The practice of neurology presents a series of ethical challenges for the clinician. These rarely have simple or straightforward solutions, but require careful consideration by the neurologist. This section of *CONTINUUM*, written by colleagues with particular interest in the area of bioethics, provides a case vignette that raises one or more ethical questions related to the subject area of this issue. The discussion that follows should help the reader understand and resolve the ethical dilemma.

NOTE: This is a hypothetical scenario.

A 42-year-old woman with ALS diagnosed 2 years earlier came to the ALS clinic with the specific request that she have a percutaneous endoscopic gastrostomy tube (PEG) inserted. She had attended the ALS clinic only sporadically and had relied on alternative medicine for the management of her disease. The patient declined to discuss end-of-life issues when these were brought up during the visit. Since she was no longer able to swallow adequately, the PEG procedure was medically indicated. As her vital capacity was 50% of predicted, she met the respiratory guidelines (Miller et al, 1999) for performing this procedure with minimal risk of respiratory failure. She had decision-making capacity and provided consent for the procedure after a full discussion of potential risks and benefits, including the fact that the need for intubation and ventilatory assistance were potential outcomes following the procedure. The PEG insertion was complicated by the need for intubation and she required mechanical ventilation and intensive care unit (ICU) care. She was eventually weaned from the ventilator, extubated, and transferred from the ICU to a ward bed. Now, because of bulbar dysfunction, she was no longer capable of producing understandable speech. The health care team used a mechanical device to communicate with her, which, although effective, required much time. When her respiratory function continued to deteriorate, she indicated a desire to have a tracheostomy and be placed on long-term ventilation as she did not want to die. Once more, the patient resisted attempts to engage in a discussion of end-of-life issues. There was no known family or surrogate. No community facility was currently available that would be able to provide long-term ventilatory care for her, and she could not have home ventilation because she lacked family support, and she did not have the financial resources to obtain private care to support home ventilation needs. Thus, the only option was to provide long-term ventilatory support in the ICU until she died.

COMMENT

- The neurologist involved with this patient knows from experience that deciding on the course to follow in this situation will be difficult. He has many ethical issues to

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consider, and his personal values, which may be in conflict with those of the patient, are likely to impact his decisions. Further reflection leads him to identify the following ethical questions that must be considered:

- (1) Will the patient be able to maintain her autonomy and capacity as her disease progresses?
- (2) Will a time come when the provision of life-prolonging care may be seen as causing the patient to suffer?
- (3) As the patient's disease progresses, will the quality of her life deteriorate to the point that it will be judged that continuing life-prolonging care is futile?
- (4) When health care resources are limited, can we justify expending so many resources to support this patient who has no hope of recovery?

DISCUSSION

- ALS is a progressive, fatal, neurodegenerative disease for which no effective long-term treatment is currently available. In 1999, the American Academy of Neurology published guidelines for care of the patient with ALS (Miller et al, 1999) (**Appendix**).

Since then, several publications have focused on this topic (Andersen et al, 2005; Andersen et al, 2007; Bradley et al, 2004; Guerrier, 2006; Heffernan et al, 2006; Mitsumoto and Rabkin, 2007; Payne, 2005). The AAN guidelines and the other publications outline the following common themes for physicians who are caring for patients with ALS: (1) respect the patient's autonomy, (2) provide timely and accurate information to assist the patient in decision making, (3) initiate discussions about end-of-life decisions and care, (4) use a team-based model (when feasible) for health care needs, and (5) include the family in decisions and care.

The AAN guidelines stress the need patients and families have for timely information for decision making delivered well in advance of major management crossroads, especially for respiratory care and for discussions regarding advanced directives. Mitsumoto and Rabkin (2007) describe the burdens and satisfaction family members may experience as well as the financial costs that may be incurred when caring for a loved one with ALS.

The application of these practice parameters to individual cases may, however, become challenging when the patient does not participate in a way that allows these principles to be followed. In such instances, the neurologist will eventually have to decide what to do and when a situation of uncertainty arises can be aided by referring to the ethics literature. A practical general approach to apply in ethical decision making is outlined by Hébert (1995). In *Ethical Issues in Neurology*, Bernat (2008) outlines a general approach to resolving ethical issues (chapter 6) and includes a discussion specifically focusing on the patient with ALS (chapter 14).

Autonomy and Capacity

- This patient is currently judged to have capacity and has made a request for a medical intervention that will definitely prolong her life. This intervention is considered appropriate for patients in her situation (guidelines), and she has made the decision autonomously. Up to now, she has resisted attempts to engage in

discussions about end-of-life issues, and she has not appointed anyone to act as a surrogate decision maker for her. While it would certainly facilitate her care plan if this information were known, a key feature for making autonomous decisions is that the decisions are made free from coercion. Thus, it is ethically inappropriate to attempt to put pressure on the patient to make these decisions.

As her disease progresses it is possible that she will lose capacity as a result of the development of cognitive impairment, which can vary from mild cognitive dysfunction to dementia. Ringholz and colleagues (2005) report that 51% of patients with ALS had cognitive impairment compared with 5% of controls, and 15% of a subset of patients with ALS met actual criteria for frontotemporal dementia. Another possibility is that because of the loss of all ability to communicate, it will no longer be possible to determine whether she still has capacity.

Lacking an advanced directive or a surrogate decision maker, a mechanism must be put in place to determine how to proceed should these circumstances develop.

Communication Failure and Moral Distress

- Mitsumoto and Rabkin (2007) list the following caregiver responsibilities to the ALS patient with advanced disease who is cared for at home:
- Increasing levels of assistance with nearly all activities of daily living
 - Increasing physical demands in providing care as the patient's ability to communicate diminishes and it becomes less safe to leave the patient alone, and
 - Taking on an increasing emotional burden as the disease progresses
- When the patient lacks family to provide support, the health care team becomes responsible for providing the type of support within the hospital setting.

With progression of her disease, it is anticipated that the patient may eventually become “locked-in” and be no longer capable of communicating with her external environment. In such a scenario, it is likely that there will be disagreement about what will be the appropriate course to follow. Some members of the health care team may believe that the care they are providing is actually harming the patient, and yet they have no way to influence the care decision about continuing her life-prolonging treatment. This creates the experience of moral distress for the caregiver. Most of the information on this phenomenon comes from the nursing literature.

Nathaniel's definition of moral distress, as quoted by Austin and colleagues (2005) follows:

Moral distress is the pain or anguish affecting the mind, body or relationships in response to a situation in which the person is aware of a moral problem, acknowledges moral responsibility, and makes a moral judgment about the correct action; yet, as a result of real or perceived constraints, participates in perceived moral wrongdoing.

These authors believe that moral distress may be manifest in nurses as feelings of frustration, anger, anxiety, guilt, and physical symptoms such as sweating, shaking, headaches, diarrhea, and crying. One outcome of this for the nurse is the loss of ability to give good patient care and eventual development of “burnout,” with the nurse leaving the nursing setting altogether. Other members of the health care team are likely to experience the same feelings.

Quality of Life and Futile Care

- No universal agreement seems to exist as to what the term *quality of life* means, and decisions about withdrawal of care on this basis are always dependent to some extent on the values of the decision maker.

Beauchamp and Childress (2008) state, “The principle of nonmaleficence does not imply the maintenance of biological life, nor does it require the initiation or continuation of treatment without regard to the patient’s pain, suffering, and discomfort.”

They further state, “when quality of life is sufficiently low and an intervention produces more harm than benefit for the patient, caregivers may justifiably withhold or withdraw treatment.”

Bernat (2008) comments on medical futility as follows:

The essence of futility is overwhelming improbability in the face of possibility. An act is futile if the desired outcome, while empirically possible, is so unlikely that its exact probability may be incalculable.

Medical futility exists when a treatment or hoped-for benefit may, on the best evidence available, be predicted not to help a patient’s medical condition. The therapy may not be able to provide benefit to the patient either because it is highly unlikely to produce the desired physiologic effect or because it produces the physiologic effect that does not confer benefit to the patient.

As the patient’s disease will inexorably progress, a time will be reached when it may appear that providing continuing life-supportive care to the patient is harmful. At this point, it may be considered ethical to withdraw life-sustaining medical care. As it is likely that the patient may no longer be able to communicate, it will be impossible to know whether she is able to comprehend how the next step in her treatment will affect her.

Justice

- The management of medical resources is an everyday concern for physicians practicing in Canada (and probably other countries as well), where some medical services, especially of the type required for the maintenance of a patient with ALS on long-term ventilation, are in limited supply. Thus, any decision about placing this patient on long-term ventilation will be questioned by both health care providers and the staff who are responsible for administrative decisions about use of in-hospital resources.

The publication titled “Medical Professionalism in the New Millennium: a Physician Charter” (ABIM Foundation et al, 2002) lists the principle of social justice as one of its three fundamental principles. It states:

The medical profession must promote justice in the health care system, including the fair distribution of health care resources. Physicians should work actively to eliminate discrimination in health care, whether based on race, gender, socioeconomic status, ethnicity, religion, or any other social category.

Expanding on this principle under the heading “Commitment to a Just Distribution of Finite Resources,” the document states:

While meeting the needs of individual patients, physicians are required to provide health care that is based on the wise and cost effective management of limited clinical resources. They should be committed to working with other physicians, hospitals, and payers to develop guidelines for cost-effective care. The physician’s professional responsibility for appropriate allocation of resources requires scrupulous avoidance of superfluous tests and procedures. The

provision of unnecessary services not only exposes one's patients to avoidable harm and expense but also diminishes the resources available for others.

This statement does not, however, provide guidance as to what to do in this situation. Cassell and Brennan (2007), commenting further on this topic, state:

The Physician's Charter on Medical Professionalism maintains that among other responsibilities, physicians must be committed to managing medical resources. This responsibility is controversial largely because it can be seen as in conflict with the more traditional altruistic commitment of the physician to the patient. Moreover, control of cost is inextricably linked to the business interests of insurers. Physicians ask, is this really our responsibility?

The answer is yes. Physicians can not [*sic*] afford to ignore the profound logic of the link between care for individual patients and the costs of care. The more costs, the more likely many individuals will be without good insurance, and research clearly shows that their health will suffer. It is impossible to avoid the fact that physicians live and work in the medical commons and bear responsibility for it.

In trying to adjudicate various claims, it is important to distinguish between ordinary and exceptional situations, eg, a pandemic. The University of Toronto, Joint Centre for Bioethics Pandemic Influenza Work Group has addressed these issues. Work group members highlight that under normal circumstances all patients have an equal claim to receive the health care they need. They also comment that even under circumstances of a pandemic, the process by which decisions are made must be open to scrutiny and the basis on which decisions are made should be publicly accessible. Thus, justice requires that the health care system provide for this patient's needs.

ETHICALLY PERMISSIBLE ACTIONS IN THIS CASE

- ▶ After reflecting on the various issues that have been outlined in this section, the attending neurologist decides that, due to the complexity of the various ethical issues that currently as well as in the future will impact on care decisions, it is inappropriate for him to make these decisions unilaterally. He will require assistance in deciding what will be the best ethically permissible plan to care for the patient now and as her disease progresses inexorably and leads to her death. He then makes contact with the ethics committee in his hospital and requests that a formal ethics consultation be held.

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