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 provides a case vignette that raises one or more ethical questions related to the subject area of this issue. The discussion that follows, written by colleague(s) with particular interest in bioethics, should help the reader understand and resolve the ethical dilemma.

NOTE: This is a hypothetical case.

A 32-year-old woman slips and falls from a 10-foot ladder at work. Her coworkers immediately find her awake and attempting to mouth words, but not capable of moving her limbs and barely breathing. When paramedics arrive 5 minutes later, she is unconscious and not breathing, and they intubate her using spinal precautions. At the hospital, she opens her eyes spontaneously and appears to attend when spoken to. She can blink when asked but cannot move her limbs. She has no sensation below the neck. She is ventilated and not generating any spontaneous respiratory movements. When asked about pain, she seems to indicate by using blinks and facial gestures that her neck pain is severe.

Sedative medications and narcotic analgesics are administered while imaging studies are obtained. CT of the cervical spine reveals a burst fracture of the atlas, with bony fragments and soft tissue within the spinal canal. MRI obtained 3 hours after the injury reveals severe compression of the upper cord, with T2-signal hyperintensity, indicating severe cord edema.

She is admitted to the surgical intensive care unit (ICU). Because the patient has been sedated, the ICU attending physician and neurosurgeon approach the patient's husband and her parents. The neurosurgeon indicates that the patient's prognosis for recovery is poor and that she is likely to be permanently quadriplegic. He recommends urgent surgery to decompress and stabilize the upper cervical spine in order to minimize the patient's pain and to maximize the chances of some recovery.

To the neurosurgeon's surprise, the patient's husband and her parents unanimously refuse surgery. Moreover, they express their certainty that under these circumstances the patient would refuse *all* life-sustaining therapy. The patient's husband has durable power of attorney for health care decisions ("health care proxy" in some states) for his wife and specifically requests that her ventilator be stopped and that she be allowed to die. The patient's husband and parents previously have had detailed conversations with

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her about disability, and in the past she has specifically stated that she "would rather be dead than be a quadriplegic." When the surgeon suggests waking the patient and discussing the matter with her, her family refuse, claiming, "We know what she would want, and we're not going to put her through that. She would definitely not want to go through the trauma of finding out about her condition. If she could comment right now, she'd tell you the same thing."

COMMENT

(1) When a patient lacks competence due to the administration of sedatives and narcotics, and if competence can be restored by reversing the sedation, are there circumstances in which it is ethically permissible for the surrogate to insist the patient remain sedated? Are there circumstances in which it is ethically permissible for the health care team to refuse the surrogate's request?

(2) When is surrogate consent required, and what types of decisions can surrogates make for patients?

(3) If a patient is competent, is it acceptable to conceal knowledge of her condition from her, in order to spare her psychological harm?

SURROGATE DECISION MAKING WHEN PATIENT CAPACITY CAN BE RESTORED

▶ It is a well-established principle that patients who lose decision-making capacity (competence) retain all of the rights in regard to health care decisions they possessed before they lost capacity (Meisel and Cerminara, 2004). Naturally, the challenge is to estimate what the patient's wishes would be. Ideally, patients will have specified their wishes in advance. However, in practice there is often a mismatch between the conditions in the advance directive and the patient's actual clinical circumstance, so that uncertainty or ambiguity exists. Physicians must usually rely on surrogates to make decisions for patients who lack capacity. A surrogate is someone who knows the patient well enough to try to estimate what the patient would want in a given situation. That is, the surrogate's job is to try to make the decision that the patient would have made, if the patient were able. Patients can specify in advance who they wish to be their surrogates through documents such as a durable power of attorney for health care decisions. Surrogates do not have decision-making authority over competent patients except in the rare circumstance in which a competent patient explicitly yields authority to the surrogate.

In the case described above, the patient lacks decision-making capacity *only* because she is sedated, and there is good reason to think that she would regain decision-making capacity if the sedation were reduced. Respect for the patient's autonomy requires the physicians to attempt to restore her capacity (while simultaneously treating her pain) so that they can inform her of her condition and ask her whether she wishes to make decisions for herself, or whether she wishes for her husband to make decisions for her. Especially when it comes to decisions with irreversible consequences, such as withdrawal of life-sustaining therapies, physicians should not consider proceeding without attempting to consult with the patient herself.

In the critical care setting, there is often a limited window of opportunity for a treatment, such as surgical decompression of the spinal cord, to be beneficial. Thus

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there are circumstances when the doctrine of emergency treatment will influence the traditional beneficence/nonmaleficence analysis strongly in favor of treating. One will not have the opportunity to reconsider later, since the surgery cannot significantly impact neurologic recovery after this critical period has passed. Likewise, a decision to continue the ventilator is reversible, but a decision to forgo it is not.

This explains why most health care professionals would consider it acceptable to have the patient's husband consent for surgery, but not acceptable to honor his refusal, at least not without first consulting the patient. One certainly should be unwilling to take the irreversible step of stopping the ventilator without consulting her.

PROTECTING THE PATIENT FROM PSYCHOLOGICAL HARM

▶ This patient's husband and her parents have argued that it is in the patient's best interests to discontinue her ventilator and allow her to die without consulting her because knowledge of her spinal cord injury and awareness of her neurologic deficits would cause significant psychological distress. This is a rationale that is sometimes advanced by families to protect patients in the setting of conveying news about a fatal illness like some cancers or neurodegenerative disease such as ALS. It is common in some cultures to conceal a diagnosis from a patient out of concern for the patient's psychological well-being.

In the United States, most physicians and ethicists are uncomfortable with this practice since it conflicts with the principle of respect for autonomy, and most consider it unacceptable (Beauchamp and Childress, 2001). While such an approach might be considered for patients from a culture where this practice is accepted, it cannot be reasonably considered if the patient comes from a culture and tradition in which honesty and disclosure directly to the patient is the norm, as it is in most of North America. In the absence of a specific reason to think that disclosure would cause severe and irreversible psychological harm, it should be the practice to include patients in their own medical decision making and to be prepared to respond to any emotional or psychological distress that the patient or family may have.

This does not mean that patients are required to make their own decisions in all circumstances. Autonomous patients may legitimately choose not to have certain types of information revealed and can ask that someone else make decisions for them. When a concern is raised about the type of information a patient may want to know, one can involve the patient in deciding what that information would be. For example, one is permitted in some cases to ask the patient, "How much specific information do you want to know?" This puts the patient in the position of controlling the flow of information, so if the patient "opts out" of the decision-making process at this point, this is still consistent with the principle of respect for autonomy.

COMPETENT REFUSAL OF LIFE-SUSTAINING THERAPY

▶ Generally speaking, patients with decision-making capacity have the right to refuse any medical therapies, including surgeries and life-sustaining therapies such as ventilator support. Physicians, in turn, are generally obligated to honor such refusals (Beauchamp and Childress, 2001).

Certain conditions should apply, however, before refusal of life-sustaining therapy is considered legitimate and informed. The patient must be able to understand her current condition and its prognosis, as well as the treatment alternatives available to her. She must

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be able to understand the potential risks and benefits of the alternatives and be able to make a choice between the alternatives. Finally, the patient's decision must not be coerced (Bernat, 2002).

In the case described, the patient's decision-making capacity has not been assessed, and she has not been informed of her condition, her prognosis, or the treatment alternatives (eg, surgery versus no surgery). But if she were awakened and found to be competent, and she refused surgery and ventilator support as her family predicted she would, what should the physicians' response be?

There is no single or simple answer to this question. The most general response is to say that such an important and irreversible decision should not be made until one can be very confident that the patient fully understands her situation and has an accurate understanding of what her prognosis actually implies. In the acute setting, one is wise to be cautious in assessing the patient's decision-making abilities even if she appears fully cognitively intact. In the hours and even days after a sudden and unexpected serious illness, the psychological stress of adjusting to the new situation can also cause patients to make decisions that they may later consider hasty (Patterson et al, 1993). It is also well recognized that patients and caregivers tend to underestimate quality of life with disability, so an argument can be made that patients' treatment refusals in the acute setting should be met with efforts to persuade and educate, rather than immediate treatment withdrawal (Cushman and Dijkers 1990; Peterson et al, 1993).

Much will depend on the particulars of a given case, but whenever concern about the legitimacy of treatment refusal or consent exists, caregivers should seek input and assistance from other sources, including ethics consultants, social workers, chaplains, and psychiatrists. Ethics consultation in particular is an effective way to ensure that all of the parties that should be involved in decision making have had appropriate input.

CONCLUSION

- When faced with a request by a surrogate to forgo life-sustaining therapy for a patient who lacks decision-making capacity solely because of the administration of sedative agents, physicians should not feel obligated to *immediately* honor the request without discussion. Because the patient in the case lacks capacity only because of medication effects, the team should attempt to restore her capacity before agreeing to the irreversible decision to withdraw ventilatory support. The physicians should attempt to persuade her surrogates of the need to wait until the patient's capacity is restored and assessed and the prognosis is better understood.

  Because of the limited time window for surgical decompression, the physicians may reasonably insist that surgical decompression and stabilization of the spine be performed, as the risk of further harm to the spinal cord is small, and there is a real, although small, chance of benefit. Since this would mean proceeding with surgery despite the surrogates' refusal (assuming the patient had not been awakened and refused the surgery herself), the physicians should call for immediate advice and consultation from the ethics service and the hospital counsel. It is very likely that an emergency request for a judicial order to treat the patient would be needed.

  Overriding the surrogates might, at first, seem to be a violation of the principle of respect for autonomy. But in rare circumstances such as these, this action can be properly viewed not only as protecting the patient's life and health, but also as defending the patient's right to make informed decisions about life-sustaining treatments for herself, which shows greater respect for her autonomy.

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REFERENCES AND SELECTED READINGS

Beauchamp TL, Childress JF. Principles of biomedical ethics. 5th ed. New York: Oxford University Press, 2001.

Bernat JL. Ethical issues in neurology. 2nd ed. Boston: Butterworth-Heinemann 2002.

Cushman LA, Dijkers MP. Depressed mood in spinal cord injured patients: staff perceptions and patient realities. Arch Phys Med Rehabil 1990;71(3):191–196.

Ditunno JF Jr, Formal CS. Chronic spinal cord injury. N Engl J Med 1994;330(8):550–556.

Meisel A, Cerminara KL. The right to die: the law of end-of-life decision making. 3rd ed. New York: Aspen Publishers, 2004.

Patterson DR, Miller-Perrin C, McCormick TR, Hudson LD. When life support is questioned early in the care of patients with cervical-level quadriplegia. N Engl J Med 1993;328(7):506–509.

Sensky T. Withdrawal of life sustaining treatment. BMJ 2002;325(7357):175–176.

Whiteneck GG, Charlifue SW, Frankel HL, et al. Mortality, morbidity, and psychosocial outcomes of persons spinal cord injured more than 20 years ago. Paraplegia 1992;30(9):617–630.

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