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The family conference
End-of-life guidelines at work for comatose patients

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Most patients in prolonged coma will ultimately remain unconscious, survive disabled, or die. It is incontrovertible that the dignity of these patients will be compromised, and limiting life-sustaining treatment for comatose patients is often taken into consideration. Such decisions are made by physicians and families or their surrogates and rarely involve a hospital ethics committee. Families endure an emotional struggle filled with sorrow, fear, and even guilt. However, the decision to let go—with maximal comfort—is the most common cause of death in comatose patients.

In this issue of Neurology, the American Academy of Neurology (AAN) reaffirms their prior position of following the patient’s own preference for healthcare through living wills, advanced directives, or after wishes voiced to families or surrogate decision makers are made known. The AAN does not dictate withdrawal of life-sustaining treatment in prolonged comatose patients. A position that would endorse only withdrawal of life-sustaining treatment clearly interferes with the autonomy of the patient or those making decisions for the patient. The AAN reemphasizes the need for education of its members and to promote better understanding of patient preferences for medical care. However, most insistently, the AAN opposes any restriction of end-of-life decisions. With the introduction of multiple state bills—that would require actual proof of the patient preference—a troubling trend has emerged. Rather than being directed by a consensus agreement of family members, such a level of proof would almost certainly be followed by a court challenge. The AAN position—and most guidelines of professional organizations, including the American Medical Association—advise against involvement of the courts. Surely, courts can never truly solve a physician—family or family discord and can, in fact, deepen the division.

The neurologist’s ability to protect the patient’s autonomy and honor the patient’s wishes hinges on the “family conference.” How do these “end-of-life” discussions proceed? Who leads these discussions? Who is qualified? A family conference usually includes a representative of the clergy, nurse, social worker, attending neurologist, and all involved family members. Although everyone involved may be inclined to share their thoughts, it is advisable to agree on a single major communicator—usually the attending physician. After full disclosure of the patient’s medical and neurologic condition, estimate of prognosis, and cognitive capacity, and the possible futility of medical or surgical interventions is made, the family is asked what the patient’s wishes were.

Families should be given an explanation of the success rate and complexity associated with resuscitation, but the physician should avoid needless detail. The family should have an understanding of the accumulating costs of intensive care if a major advancement of level of care is pursued. It is important to point out that the presence of an advance directive is an indication that the patient had a desire to limit medical care if permanently disabled. In contrast, the absence of an advance directive must not be understood as an indication that the patient wanted all possible medical care (the number of patients with an advance directive remains small). The attending physician of a patient with a devastating neurologic illness will have to come to terms with the futility of care and take the responsibility to address the facts with the family. Those families who are unconvinced should be explicitly told they should have markedly diminished expectations for what intensive care can accomplish and that withdrawal of life support or abstaining from performing complex interventions is more commensurate with the neuro-
logic status. This should be communicated unambiguously, honestly, and with deep compassion. Withdrawal of care is not “hands off.” Physicians should continue providing comfort to the patient and, when appropriate, communicate frequently with the family.

The skills needed to lead a family conference are substantial and part of high-quality care. The dynamics of the interaction between physician and families are crucial, and the outcome of these interactions is determined by certain characteristics of the parties involved (figure). Some physicians believe in flawed data on prognostication and interpret all poor outcomes as a result of a self-fulfilling prophecy. They believe other physicians give up too often and too early. These physicians remain hopeful despite all odds and may always see something optimistic in bad news. Unsure physicians are pessimistic when patients do not awake and neuroimaging confirms the devastating damage to the brain, but think they see signs of improvement every day. They often focus on details of daily care and not prognosis. In other situations, physicians do not wish to confront the issue or explore families’ understanding—the “I do not want to talk about it” phenomenon. The adroit physician will have a tenacious approach, is avowedly academic, has searched for facts, and stands guarded. Years of experience leading family conferences are needed to reach this ideal qualification. In reality, it is likely that some physicians are unsure 1 day and convincingly clear another day. It also depends on the underlying illness.2,3

A similar spectrum is present in families. There are realists who understand the gravity of the situation and know that prolonged care of a comatose patient is futile. Fighters are family members who may never have been confronted with such decisions but feel they can pitch in with the help of their close community. For them, to do everything possible is what medicine is all about. This group also comprises those who are willing to “sacrifice themselves” for the patient no matter how much care they will require long term—missing the point that they are making the decision for the patient and not for themselves—and those who will put trust in “the miraculous recovery.” Within these extremes are those who are unsure, procrastinate, or have heard about unexpected recoveries—the “according to someone who heard it from someone else” phenomenon.

We do not make a moral judgment here, but the reality is that one can easily imagine that certain physician–family combinations may be productive and lead to a resolution of these always painful situations, whereas other combinations can lead to postponement of necessary decisions (figure). Withdrawal of care in a hopelessly injured comatose patient may lead to a conflict when family members disagree and when attending physicians do not wish or know how to proceed with conviction.

There are few data and considerable variation on how physicians should discuss withdrawal of life-sustaining treatment. A recent study found that physicians based their decisions not only on the patient’s chance to survive the hospitalization, but also on quality of life, their own perception of patient’s best interest, and evidence that treatment may not be consistent with patient’s wishes. Most recently Curtis et al. provided a glimpse into the family conference with disturbing results.2-7 Missed opportunities to explore families’ wishes and to explain key tenets of palliative care, emphasizing the patient will not be abandoned, occurred in about one-third of the taped conferences (the study included 14% neurologists). More alarming is a recent intensive care unit study in which the decision to limit support was solely made by physicians in 16% of patients who were admitted to a medical intensive care unit and had no decision-making capacity or available surrogate decision maker.8

Prospective data regarding discussion on level of care in the neurosciences intensive care unit and other intensive care units in patients admitted with catastrophic neurologic disease are needed to train future generations of neurologists. Communication skills can be divided into teachable segments, and a recent prospective controlled trial involving residents at Duke University showed improved skills in these palliative care conversations after training.9,10 More research is necessary to understand how a family or family–physician relationship can become adversarial, sometimes requiring intervention of the courts.

References

Figure. Family–physician interactions determined by personal values, clinical experience, and personalities.


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