Neurologists and end-of-life decision-making

The role of “protective paternalism”

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Most end-of-life care situations that neurologists mediate in intensive care units (ICUs) involve surrogate decision-makers for patients who have lost their capacity to make—or even weigh in on—such decisions. While a decision to limit life-sustaining treatment is optimally shared between a patient’s medical team and family, practical difficulties often complicate this dynamic.¹ Surrogates are understandably emotionally wrought and often are unsure of the patient’s own wishes for prioritizing prolongation of life vs pursuing comfort measures. Efforts of a medical team to communicate with and educate surrogates on a patient’s disease and prognosis may be ineffective. Moreover, a neurologist’s personal or cultural background may exert a strong influence on the extent and manner to which he or she involves families in end-of-life decision-making, especially when conflict arises. Data have been published on international variations of the degree to which physicians involve families in such decisions.² However, data specific to neurologists and ICU shared decision-making remain sparse.

In this issue of *Neurology® Clinical Practice*, Seeber et al.³ present the results of a qualitative study in which 20 Dutch neurologists were individually interviewed regarding personal experiences discussing limitations of life-sustaining treatment with surrogate decision-makers of critically ill patients. Participants were encouraged to discuss specific cases that went well, as well as interactions that were less than ideal. All members of the physician cohort were native to the Netherlands, but otherwise the interviewees were diverse in terms of their age, level of training, and location of practice. The authors found that as a whole their physician interviewees sought to elucidate treatment preferences from patients’ families and to work patiently with families to respect those preferences. However, despite Dutch law explicitly requiring that physicians seek consent from surrogates for all major treatment decisions, the interviewed neurologists seemed to agree that, in practice, the final “vote” in any “negotiations” that arise resides with the physician, and not the surrogate. The moral justification given by the neurologists for this practice is to reduce the suffering of a patient’s family by removing their burden of decision-making responsibility. The interviewees discussed strategies to provide emotional support and to avoid overt conflict between

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physicians and surrogates, but the neurologists were firm in their opinion that having the final say in these situations is critical for compassionately caring for families in crisis.

While it may be difficult to draw definitive conclusions on the majority opinion of Dutch neurologists from a sample size of 20 interviews, the study is an important contribution to the available literature suggesting that a paternalistic tendency towards end-of-life care may be more prevalent in Europe than in the United States.^{2,4} A study of 220 French ICUs in 2001 revealed that patients' families were involved in only 44% of decisions to limit life-supporting therapies.⁵ A 2003 study reported that 42% of Italian intensivists never or only rarely involved close family members of patients in the decision to forego ICU treatment.⁶ More recent evidence shows that attitudes in many European countries towards paternalism may be changing.⁷ Notably, although the neurologists interviewed by Seeber et al.³ did not endorse omitting families from these decisions, their subjects' consensus that the physician should have the ultimate authority in such situations is thematically consistent with some prior studies of European end-of-life care.

More recent studies from the United States have explored the spectrum of shared decision-making in which ICU physicians and patients' families may engage. White et al.⁸ audiotaped clinician–family conferences regarding life support in the ICUs of 6 hospitals and reported 4 distinct approaches that physicians employed in such meetings, ranging from “informative” or “facilitative” (on the more hands-off end of the spectrum) to “collaborative” or “directive” (on the more paternalistic end). In contrast to the aforementioned data from Europe, they found that the physicians in their US cohort frequently declined to provide a treatment recommendation to families, even when families explicitly requested their opinions. Complicating shared decision-making further is the fact that surrogate decision-makers have varying desires to bear the burden of decision-making⁹ and that physicians only infrequently explore a family's preference for involvement in decision-making before assuming their role.⁸

There is little debate that many families of neurocritically ill patients endure psychological suffering while working with medical teams to make choices among options that may only range from bad to worse. A growing number of studies have revealed that adverse psychological outcomes may persist in family members of ICU patients long after patients have been discharged or died.¹⁰ In an attempt to prevent these harms, some American critical care physicians choose to frame the family discussion by offering their opinion of the appropriate level of medical care, thereby permitting the surrogate to agree with the physician while freeing the surrogate of the psychological burden of rendering an independent decision.

The major question raised by the physician interviews conducted by Seeber et al.³ is whether the best way for neurologists to care for a family in decision-making distress is essentially to take away their decision. While such “protective paternalism” may be appropriate in truly futile cases (and may be instructive for US physicians), its ethical grounds become less justifiable in patients for whom a poor neurologic prognosis is possible but not guaranteed. It is these common and vexing situations in which a physician's belief of having the final say on life support may run a higher risk of having his or her personal values trump those of the surrogate and, by extension, the patient. A concerted effort to explore and confirm a surrogate's preference for being involved in life support decisions before determining one's own level of involvement should be a worthy goal for all neurologists, irrespective of nationality.

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