Variations in decisions for care of patients with brain injury 'disturbing'

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Treatment decisions involving patients with severe brain injury vary widely between medical institutions and appear to be more driven by hospital and physician practices and priorities. In an article appearing today in the *New England Journal of Medicine*, physicians at the University of Rochester Medical Center (URMC) argue that providers must take steps to develop a process of communication and decision-making that gives greater weight and voice to the informed preferences of patients and their families.

"The decision whether or not to continue aggressive medical treatment for patients with severe brain injury requires tough discussions about the benefits and burdens," said URMC neurologist Robert Holloway, M.D., co-author of the article. "Such decisions are often made without a clear understanding of the patient's medical prognosis and with suboptimal input from the patient and family. The possibility that decisions of this magnitude are being overly influenced by factors other than patient values and preferences informed by an understanding of the medical options and potential outcomes should make us cringe."

It is estimated that up to 60 percent of deaths in patients with a severe brain injury resulting from a stroke, trauma, or cardiac arrest are related in some manner to a decision to withdraw treatment. These cases are unique compared to other forms of treatment withdrawal because patients with brain injuries who receive aggressive life-sustaining treatments sometimes continue to live for months or years. However, outcomes can be difficult to predict early in the treatment process and

can range from an early death, to survival with extreme physical and cognitive disability, to the possibility of substantial recovery of cognitive function.

Decisions about treatment continuation or withdrawal are often made without clear input from the patient who is often too impaired to participate. Ideally patients would have made their wishes know in advance, but most have not. In these instances where there is medical uncertainty about prognosis and a lack of clear direction from the patient, the treatment culture and practices of a hospital (and even an individual physician) may play the greatest role in influencing treatment. Financial incentives may also matter as hospitals are highly reimbursed for interventions such as tracheosotomies - a breathing tube surgically inserted in the windpipe - which in some circumstances enhance recovery and in others make stopping treatment even more difficult.

The consequence of these potentially conflicting incentives and priorities is a "large and disturbing variation" in how these decisions are approached, with some hospitals electing to aggressively treat all cases while others lean more toward advocating early withdrawal of treatment.

The right approach, the authors contend, should be a mix of three treatment approaches: 1) some early tracheostomies for patients with a good prognosis to allow them to begin rehabilitation earlier; 2) some time limited trials of continuing aggressive support to see if the patient's neurological situation can clarify; and 3) some early withdrawals of treatment for patients with poor prognosis who clearly would not benefit from this type of intervention under these circumstances. The best hospitals would have a combination of these approaches depending on clinical circumstances and patient preferences.

The authors contend that one of the keys to successfully navigating this decision-making process is to create an environment of open

communication between medical teams (neurology, neurosurgery, palliative care) and the patient and their family.

"You not only need to understand the clinical situation with all its uncertainties, but you also need to understand patients' values and preferences in light of their medical prognosis," said Timothy Quill, M.D., a co-author of the article and director of the URMC Center for Ethics, Humanities and Palliative Care. "Sometimes the prognostic evidence is clear enough for decisions to be made. But in those situations where the clinical outcomes are uncertain, evidence-based medicine may need to take a back seat to preference-based medicine."

These conversations are challenging under the best of circumstances, but they have recently been clouded by the highly-charged debate over health care reform. Specifically, the authors point to the need to "get well beyond 'death panel' rhetoric to a more systematic conversation about the potential of invasive medical treatments to do good and to harm patients toward the end of life."

Provided by University of Rochester Medical Center

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