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PROFESSION

Surrogate decision-makers' dilemma on end-of-life care requires more input from doctors

Physicians and hospitals adhere too strictly to a protocol that leaves such choices exclusively to family members, an article's co-author says.

By KEVIN B. O'REILLY, amednews staff. *Posted Nov. 15, 2010.*

Choosing treatments for patients who cannot do so for themselves puts surrogate decision-makers in an unenviable position. The situation requires that physicians navigate a careful path in offering recommendations while respecting surrogates' and patients' wishes, according to two recent medical journal articles.

"Data have shown that the stress of being a surrogate decision-maker is equivalent to the kind of scores people get on psychological instruments when their house just burned down," said Daniel P. Sulmasy, MD, PhD, co-author of a Nov. 3 commentary on surrogate decision-making in *The Journal of the American Medical Association*.

Physicians and hospitals have failed surrogate decision-makers by hewing too closely to a protocol that delegates these life-and-death choices entirely to family members, Dr. Sulmasy said.

The hands-off approach to surrogate decision-making "leaves them hanging in the wind, saying, 'It's your decision,' " said Dr. Sulmasy, associate director of the University of Chicago's MacLean Center for Clinical Medical Ethics. "This is not like a menu in a restaurant. They need and ought to have some guidance in these decisions."

Leaving choices in the laps of surrogates is especially problematic because they often do not have an advance directive to help them decide, said Dr. Sulmasy, professor of medicine and ethics in the University of Chicago's medical and divinity schools. Only 5% to 25% of patients have such documents, the *JAMA* article said. Even when advance directives are available, they often fail to cover the precise clinical situation at hand.

40% of surrogates want to share responsibility with physicians for making medical decisions about life-sustaining treatment.

"You get these questions like, 'Would the patient have wanted a dopamine infusion at 2 micrograms per minute if they were in a coma and in addition had Alzheimer's disease and pneumonia and were in the ICU?' " Dr. Sulmasy said. "No one's thought about those things, and trying to guess what the person would have thought is a nearly impossible exercise."

Exploring patients' values can help physicians make appropriate clinical recommendations, Dr. Sulmasy said.

"What we want is for you to tell us about your mother as a unique person in these circumstances," he said. "Would she value having family members around her? Would she want to be awake as long as possible, and how would she balance that against being in pain? Then from there we can make exact decisions that serve the actual interests of the patient."

The University of Chicago Medical Center is teaching the new "substituted interests" model of decision-making to medical residents, who carry laminated cards with guidance on talking with surrogates.

Making the final call

Surrogates may benefit from more input from physicians, but most want to make the final care decisions themselves, according to a study published online Oct. 29 in the *American Journal of Respiratory and Critical Care Medicine*.

The researchers surveyed 230 surrogate decision-makers for incapacitated patients on ventilators in four intensive care units at the University of California, San Francisco, Medical Center. They were asked who should make the final call about whether to continue intensive treatment for a loved one "with a very small chance" of surviving. Not all patients at the time of the survey were declared to have a small chance of survival.

Only 5% to 25% of people have advance directives.

More than half of surrogate decision-makers said they preferred to "make the final decision," while 40% wanted to "share responsibility" for the decision with a physician. Only 5% said doctors should make the final decision.

"What we've unmasked is that surrogates' answer is very different for value-laden decisions," said Douglas B. White, MD, the study's lead author. "People often don't want to give up control of these decisions to physicians."

There is no inherent conflict between using a different process to explore incapacitated patients' values and leaving the final decision in surrogates' hands, Dr. White said. And nearly all of the surrogates surveyed wanted physicians' recommendations about what to do.

"Physicians should simply plan -- when going in to talk with a family -- that the family will want to hear their opinion," he said.

This content was published online only.

ADDITIONAL INFORMATION:

Sharing decision-making

Interviews with 230 surrogate decision-makers in ICUs found that a majority prefer to have the final say about whether to continue intensive medical treatment for a loved one who no longer could make care decisions. However, they also wanted physician input. Few wanted

physicians to take charge. Here is a breakdown of surrogates' preferences on sharing life-sustaining therapy decisions with physicians:

44% want to make the final decision after considering a physician's opinion.

40% want to share the decision responsibility with a physician.

11% want to make the final decision.

3% want a physician to make the final decision after considering the surrogate's opinion.

2% want a physician to make the final decision.

Source: "An Empirical Study of Surrogates' Preferred Level of Control over Value-Laden Life Support Decisions in Intensive Care Units," *American Journal of Respiratory and Critical Care Medicine*, published online Oct. 29 (**www.ncbi.nlm.nih.gov/pubmed/21037019**)

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"Substituted Interests and Best Judgments: An Integrated Model of Surrogate Decision Making," *The Journal of the American Medical Association*, Nov. 3 (**jama.ama-assn.org/cgi/content/full/304/17/1946**)

"An Empirical Study of Surrogates' Preferred Level of Control over Value-Laden Life Support Decisions in Intensive Care Units," *American Journal of Respiratory and Critical Care Medicine,* published online Oct. 29 (**www.ncbi.nlm.nih.gov/pubmed/21037019**)

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