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1 in 3 surrogate decision-makers carries lasting emotional burden

A new study finds that advance directives ease stress when making treatment choices for others.

By KEVIN B. O'REILLY, amednews staff. Posted March 14, 2011.

A third of surrogate decision-makers experience stress, guilt and other upsetting emotions related to their role in determining a loved one's care, according to a March 1 *Annals of Internal Medicine* systematic review of 40 studies.

The emotional burden on surrogate decision-makers often lasts for months -- and sometimes years -- after the treatment choice, researchers found. One study cited in the review found that stress levels of surrogates were comparable to those of people who experienced construction disasters or lost their homes to fire.

The circumstances of decision-making have an impact on how deeply surrogates are affected, the review showed. Having an advance directive that specifies the patient's wishes substantially reduces surrogates' stress, and achieving consensus with other family members and the care team also helps.

The study offers another reason for doctors and hospitals to encourage patients to complete advance directives, said David Wendler, PhD, lead author of the *Annals* study.

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

"We had always thought about documenting your wishes and knowing what the patient wanted as a protection and a benefit for the patient," said Wendler, head of the Unit on Vulnerable Populations at the National Institutes of Health Clinical Center's Dept. of Bioethics. "This study suggests that there is an additional benefit as a protection for the family. Just leaving decisions up to the family may well be counterproductive and make it harder on the family, not easier."

Yet most patients lack advance directives. According to figures cited in a Nov. 3, 2010, commentary in *The Journal of the American Medical Association*, estimates range from 5% to 25% of the population who have these documents.

"We have to recognize that despite 30 years of asking people to fill out advance directives, it is still a small proportion of the population that has done so," said Daniel P. Sulmasy, MD, who co-wrote the *JAMA* commentary. "That can't be the total solution to the problem. This new study points us in the direction of looking at better ways of talking to surrogates and better ways of involving the surrogates in the decision-making process that might ameliorate some of the stress."

Physicians should take a more active role in helping surrogates and not shy away from making clinical recommendations, said Dr. Sulmasy, associate director of the University of Chicago's MacLean Center for Clinical Medical Ethics. But first, he said, must come the recognition that being a surrogate decision-maker is no easy task.

"This is not a simple cognitive exercise for the surrogate," Dr. Sulmasy said. "It pays to pay attention to the psychological and even the spiritual needs of surrogates who are making these decisions if we are going to have optimal care for the patient."

ADDITIONAL INFORMATION:

WEBLINK

"Systematic review: the effect on surrogates of making treatment decisions for others," *Annals of Internal Medicine*, March 1 (www.ncbi.nlm.nih.gov/pubmed/21357911)

"Substituted Interests and Best Judgments: An Integrated Model of Surrogate Decision Making," extract, *The Journal of the American Medical Association*, Nov. 3, 2010 (www.jama.ama-assn.org/content/304/17/1946)

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