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END-OF-LIFE CARE

HOW YOU CAN HELP STRESSED SURROGATES



PHOTO BY TYLER MALLORY

Early talks about end-of-life care could help ease the burden on surrogates, says Daniel Sulmasy, MD. He is studying the effect of nurse-led discussions with families such as Patrick Johnson, who has pancreatic cancer, and his wife, Deborah. "I don't think we can make [stress] go away and make it all pretty," Dr. Sulmasy says. "But there are some things that can make it better."

The grief that comes with losing a parent, spouse or sibling after a long illness can be devastating. But there is an additional burden for family members involved in making end-of-life care decisions on behalf of loved ones.

Sleepless nights in the intensive care unit often are followed by sleepless nights at home. Surrogate decision-makers can be haunted by lingering doubts about whether they made the right choices for family members or may feel guilty about those decisions, research shows. Surrogates often feel anxious and depressed, and are at significant risk for posttraumatic stress disorder.

And the distress is slow to fade.

One in three surrogates carries a lasting emotional burden related to these decisions, according to a systematic review published March 1 in the *Annals of Internal Medicine*.

The heart-wrenching surrogate experience is expected to grow more common as the country's population ages, bringing a rising incidence of conditions such as dementia and Alzheimer's disease

Family members who make life-or-death decisions for loved ones are at high risk for anxiety and depression. Here's how to ease the strain.

STORY BY KEVIN O'REILLY

that degrade patients' decision-making capacity. And despite decades of urging from physicians, lawyers and others, most patients fail to complete advance directives to help guide care should they lose the ability to make health decisions. Even when directives are completed, they often fail to cover every potential option.

While making consequential health care decisions for a loved one will never be easy or stress-free, an emerging body of evidence shows that there are some steps physicians and hospitals can take to help ease the strain on surrogates. Physicians can help, experts say, by taking the time to talk with families about their loved ones' values, listening to

their concerns and questions, and sharing responsibility for the final decision.

FOCUSING ON FAMILIES

Surrogate decision-making compounds the emotionally trying experience of caring for a critically ill family member, says Alexia Torke, MD, assistant professor of medicine and geriatrics at the Indiana University School of Medicine in Indianapolis.

"There is evidence that just having a family member in the hospital is stressful, but being involved in the decision-making is even more stressful," says Dr. Torke, whose research focuses on the ethical challenges of caring for adults with diminished decision-making capacity. "Making life-or-death decisions for oneself can be hard, but at least it's for you. ... Making the decision for someone else is just a very different, very weighty kind of thing."

Too often, physicians think only about how to proceed with patient care and fail to acknowledge the strain on families, says J. Randall Curtis, MD, MPH, professor of medicine at the University of Washington School of Medicine and section head of pulmonary and critical care medicine at Harborview Medical Center, both in Seattle.

"In the U.S., we have been very driven by the idea of patient autonomy and putting the patient first as the sole focus of our attention," Dr. Curtis says. "A lot of the time, physicians are trained to communicate with family members the way they communicate with colleagues. They don't take into account the stress that family members are experiencing. They aren't trained in how to communicate with family members and provide support to them in this process of being surrogate decision-makers."

That lack of training translates into discussions with families that delay decisions and worsen surrogates' stress, says Douglas B. White, MD, who has conducted studies of how physicians communicate with families about withdrawing life support.

"We need to have a more careful exploration of patients' values than what doctors usually do," says Dr. White, director of the Program on Ethics and Decision Making in Critical Illness at the University of Pittsburgh Medical Center. "We know from audio-recorded conversations of doctors and families that physicians will ask, 'Has your loved one ever told you what they would have wanted in this situation?' The family says, 'No,' and the conversation stops. That's a really thin conception of the person."

Physicians should go further, Dr. White says, and ask family members if the patient ever discussed similar situations, or expressed opinions about needing assistance with basic activities of daily living, or being kept alive without the ability to interact with others.

Too much of the thinking about end-of-life care has focused on decisions — whether to withdraw life support, for example — rather than on the patient as a person, says Daniel P. Sulmasy, MD, PhD, associate director of the University of Chicago's MacLean Center for Clinical Medical Ethics. This focus has a ripple effect on surrogates, he says.

"Martin Luther King said, 'Keep your eyes on the prize.' For us as the physicians, and for the fam-

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ily, the prize is the patient,” Dr. Sulmasy says. “Part of the problem is that bioethics has abstracted from the person to the decision. It’s not about decision-making. It’s about the person. The decisions are meant to serve the person.”

Dr. Sulmasy says surrogates’ distress can be ameliorated not only by focusing on the patient’s expressed preferences, but also by discussing his or her best interests in the current clinical situation. Doctors can take an active role in that discussion and recommend how to proceed.

Dr. White also says physicians should not shy away from offering recommendations. He co-wrote an April 1 study in the *American Journal of Respiratory and Critical Care Medicine* stating that nearly 90% of 230 surrogate decision-makers surveyed about continuing intensive medical treatment said they wanted to hear the physician’s opinion or share responsibility for the choice with the doctor. Too often, Dr. White says, patients will ask doctors what they believe should be done, and physicians will dodge the question for fear of being too paternalistic.

“Physicians should take some responsibility to be moral participants in the decision-making process,” he says. “That’s a very different model from one where the families decide what to do and the doctors just implement it.”

“The thing not to do is just say, ‘I’m just a fact provider. I’m a fact technician.’ There are doctors who behave that way, and there are things lost — and there may be danger for the patients — when we are not willing to walk with the families through this.”

PROVIDING VALUE

Sharing a decision-making journey with families involves more than just telling them the clinical facts and leaving them to mull things over, Dr. Curtis says. His research team has developed a five-step mnemonic to help physicians and other health professionals talk with families of critically ill patients.

The VALUE process advises doctors to:

TIPS ON TALKING WITH FAMILIES

Family members called upon to act as surrogate decision-makers for loved ones often must make heart-wrenching choices without the aid of advance directives or other guidance. Here is one model for how physicians can help surrogates navigate this tricky terrain:

Acknowledge the stresses of the situation and the difficulty of the task; attend to the surrogate’s needs.

“It must be very difficult to see your loved one so sick.”

Discuss the patient as a person; explore interpersonal, moral, religious, familial and psychological values; understand substantive treatment preferences and process considerations, such as who should decide and how.

“Tell us about your loved one.”

“Has anyone else in the family ever experienced a situation like this?”

Share your understanding of the patient’s clinical circumstances and prognosis.

“All of that is important for us to know as we face the current situation.”

“Here is what is wrong.”

“This is what is likely to happen.”

Determine what the patient’s real interests are, given the patient’s values and current circumstances.

“Knowing your loved one, what do you think would be the most important for him/her right now? Avoiding pain? Having family members here?”

Share your understanding of the options and offer recommendations based on clinical experience, tailored to the particular patient’s real interests.

“Here’s what could be done.”

“This is what we would recommend, based on what we know and what you’ve told us about your loved one.”

Use your best judgment for the patient as a unique person in context of his/her relationships, values, known wishes, interests, given the circumstances and options.

“Knowing your loved one, does our recommendation seem right for him or her? Do you think another plan would be better, given his or her values, preferences, relationships?”

SOURCE: “SUBSTITUTED INTERESTS AND BEST JUDGMENTS: AN INTEGRATED MODEL OF SURROGATE DECISION MAKING,” *THE JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION*, NOV. 3, 2010

- Value comments made by the family.
- Acknowledge their emotions.
- Listen to their concerns.
- Understand the patient as a person.
- Elicit family questions.

The strategy was used as part of a randomized controlled trial involving 126 families of dying patients in 22 French ICUs whose results were published Feb. 1, 2007, in *The New England Journal of Medicine*. Families who had longer conferences

with physicians where the VALUE communication strategy was followed were less stressed, anxious and depressed than families with shorter conferences and standard conversations, the study found. They also were less likely to have PTSD.

“Just saying ‘I know this is hard’ can be an enormous relief to family members,” Dr. Curtis says.

Logistics also make a difference. Family conferences should be scheduled regularly so misunderstandings are avoided and changes in patient prognoses do not come as a shock. Families should have a quiet, clean place to meet and talk things over.

“We really need to have hospital spaces where families have room to be in there with patients, not just a chair but a cot to encourage relatives to stay there,” says Jason Karlawish, MD, professor of medicine and medical ethics at the University of Pennsylvania School of Medicine and director of the Penn Memory Center. “We need a space to meet with families that’s a respectful, quiet place, not the house staff lounge where there’s the residue of last night’s Chinese dinner.”

Advance care planning also can help. The *Annals* study found that families of patients with advance directives experienced less stress, so physicians should continue to urge patients to plan ahead — not just for themselves, but for their loved ones.

Dr. Sulmasy is testing an intervention in which nurses meet with patients with stage III or IV cancers and their likely surrogate decision-makers. They discuss potential health decisions and whether the patient and family member have similar ideas about what the patient would want. They also share views on how much deference should be given to a patient’s preferences, compared with considering the family member’s and doctor’s best judgment.

The start, experts say, is to acknowledge some responsibility for the well-being of surrogate decision-makers.

“We can never take away the stress of having a critically ill loved one,” Dr. Torke says. “But we can mitigate that stress and help people have a positive adjustment to the terrible things that have happened.” ♦

7 WAYS TO ADDRESS DISTRESS

These are the most common sources of emotional strain reported by surrogate decision-makers and some strategies for mitigating them.

Unsureness about patient’s preferences: Engage in advance care planning with patients during routine annual exams and when there is a decline in functional status or more frequent hospitalizations. Emphasize to patients that planning ahead is important not only for themselves but to ease the potential burden on their loved ones.

Discomfort with hospital environment: Hospitals, and intensive care units in particular, can be confusing and distressing to families. Employ a patient navigator to help patients understand how the ICU works, what the machines do and who is caring for their loved ones.

Logistics of decision-making: Make sure that families have enough time to make decisions by communicating with them about potential decisions before crisis strikes. Give them a quiet place where they can talk things over and think in peace. When pressed for time, surrogates are likelier to make poor decisions and feel distressed afterward.

SOURCES: DAVID C. WENDLER, PHD; “SYSTEMATIC REVIEW: THE EFFECT ON SURROGATES OF MAKING TREATMENT DECISIONS FOR OTHERS,” *ANNALS OF INTERNAL MEDICINE*, MARCH 1

Poor communication by clinicians: Physicians, nurses and other members of the health care team should be on the same page communicating with families about how their loved ones are faring. Regularly scheduled family conferences can help avoid misunderstandings.

Conflict among family members: Identify conflicts among siblings or other family members, many of which can be resolved by ensuring that everyone shares the same understanding of the patient’s prognosis. Conferences can help ensure that the health care team sends a consistent message to all family members.

Sense of sole responsibility for decision: Share responsibility for decisions by talking through options and the patient’s values and making recommendations, which can help relieve some of the surrogates’ burden.

Uncertainty or guilt over decisions: Express support for surrogates’ decisions and how they arrived at them. Let family members know it is common to feel guilt and other distressing emotions related to the experience and advise them to consider seeking counseling or spiritual support.