You Can't Get What You Want: Innovation for End-of-Life Communication in the Intensive Care Unit

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Family meetings to establish care goals for patients in the intensive care unit (ICU) are inherently challenging due to asymmetries of information between physicians and families, complicated family dynamics, mixed messages from providers, and uncertainty about prognosis and preferences (1, 2). How we communicate during these meetings—specifically the words we choose—may interfere with our ability to determine patient preferences and goals. One word that may be particularly problematic is the use of the word “want.”

Consider the following example from an audio recorded family meeting. A 78-year-old woman had a massive left middle cerebral artery stroke and cervical spine fracture from a subsequent fall. She is intubated and has a cervical traction halo, although she does not have cord compression, because of the magnitude of cerebral ischemia, she has at least 50% mortality and will be severely disabled with hemiplegia and aphasia if she does survive. A skilled intensivist clearly and accurately describes her overall prognosis and asks the surrogates to consider two options: proceed with aggressive life-supporting treatments or emphasize comfort. He says, “Our goal, in this situation is to do what she would’ve

wanted, if we could ask her. And we can’t ask her, so we have to ask the people who knew her best. And that’s why I’m coming to you. So, I think it’s a . . . you know, a decision that the medical team needs to make, in conjunction with the family, to do what . . . what all of you think that (she) would’ve preferred, if she could choose.”

This is state-of-the-art communication for preference-sensitive treatment decisions. Rather than simply deciding for the patient, the intensivist has embraced the ideals of shared decision making—identification of a choice, presentation of options contextualized within prognostic information, and a phrase to encourage deliberation (3): what would she want? Despite this, the conversation sputters as the family has trouble grounding the decision in medical reality. Her daughter says, “I think there’s hope in there, because she does move around and . . . we think she’s gaining, that she’s coming back and everything,” while another chimes in, “She wants it. She’s fighting. She wants it.” By the end of the meeting, the family is clear they do not like seeing her in her current state, and “that if the good Lord wants to take her,” it might be time to let her go, but the intensivist has not heard

them talk at all about what is important to the patient given her overall condition.

When we are trying to elicit information about patient preferences to recommend treatments that will align with their values we routinely ask family members, “What would she want?” This approach is specifically endorsed by the Society for Critical Care Medicine (4). In our study of conversations between intensivists and surrogates in five ICUs in two California hospitals from 2006 to 2008 (5, 6), physicians eliciting goals and preferences use the word “want” in more than 70% of these instances to engage surrogates in deliberation. Unfortunately, asking about wants can lead to worse decision making and less information about the patient’s values.

The question of what the patient would want is flawed in several ways. First, it encourages the family to reflect on treatments, like life support or comfort care, rather than goals. The intent of asking what a patient wants is to initiate a discussion about the patient’s values. Instead, the question focuses on medical strategies directing surrogates to contemplate what the patient would choose, rather than discuss the value of different outcomes.

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The intensivist stresses his objective “is to do what she would have wanted” and implies the key consideration is a specific treatment or care plan rather than an invitation to join a critical discussion about trade-offs and outcomes. Like a waiter asking what a person might want on the menu, this narrows the response by directing attention to specific treatments.

Second, it can shut down discussion; once the family makes a choice, what else is there to say? The intensivist now has three responses: agree with their choice; attempt the difficult task of talking the family out of their decision; or invoke a fair process review to resolve intractable conflict (7). None of these options allow the intensivist access to the family’s deliberative process. Even if the answer is deeply considered, when intensivists are not privy to this reasoning, they are unable to learn more about what is actually important to the patient. A simple declaration from the family about what the patient wants without supporting information about why this might be aligned with her goals might seem as though this decision is not well thought out. Once the family has expressed a choice, it is much harder to talk them out of it (8), and the process becomes contentious rather than shared.

Third, want is aspirational and evokes fantasies. When we ask patients or their surrogates what they want, we release the constraints of the decision-making context and allow consideration of possibilities outside the boundaries of clinical reality. Just as “What do you want to be when you grow up?” inspires children to believe anything is possible, “What would your mom want?” suggests that alternative clinical states or outcomes exist. As we witnessed in the family meeting, loved ones respond with desires that are familiar, “She wants it (to live).” It is hard to imagine this patient’s family saying “Mom would want to die,” and so they invoke a higher power to express this unwanted option: it is God who wants her. They talk about the things

she wants and what they want (for her to get better) without confronting the real question about how she would value her new and very serious disability.

In turn, families’ assertions that the patient wants to live are often interpreted as a request for continued life-sustaining treatment and translated into an action plan of prolonged critical care. Although declarations like “she wants to live” reveal nothing about how much a patient would value long-term mechanical ventilation, tracheostomy, or the associated loss of independence, the assertion is taken to mean the treatments are desired and the associated outcome is valuable.

Similarly, when we ask surrogates, “Do you want us to do everything we can?” we encourage an affirmative answer. Most people want to live, want to breathe, and want to get better. Only the savviest of surrogates can resist the temptation to answer “yes” and go on to engage in deliberation about whether continued life-prolonging measures will achieve the patient’s goals. Many patients would prefer to avoid burdensome interventions with a low chance of success or consider a strategy that prioritizes symptom management over life prolongation. However, want questions ask for a statement of inclination, and patients and their family members are unlikely to concede they are eager to assume a great loss. Asking what the patient would want prompts decision makers to use intuition and emotion to make a decision without pushing them to do the harder work evaluating possible health states (9).

Intensivists ask about wants in a genuine effort to promote shared decision making. It is such a natural question it is used reflexively, almost without thinking because it is embedded in everyday speech and the desire to seek out patients’ values. Although want is just one word, this word matters. We believe there are better words that would encourage surrogates to think deeply about their loved one’s values and

goals. Instead of asking what their mother would want, the intensivist could ask the patient’s family, “What would your mom say about her serious illness?” or “What would your mom think about all of this?”

These questions help surrogates avoid reliance on the emotional consequence of their decision and allow them to examine other important aspects of the clinical situation. In using “say” or “think” the intensivist encourages the family to balance their feelings with a more analytical approach at a time when emotions run high. Others have used this strategy in different settings to help patients manage their affective and cognitive reactions and improve decision making (10, 11).

Furthermore, questions like “What would she say?” cannot be answered succinctly and demonstrate that the physician is asking the patient or family to engage in deliberation, to weigh options, and evaluate trade-offs from the perspective of what is important to the patient. Focusing on what they think she would say or think about her serious illness prompts family members to consider their loved one’s values and to talk about what the patient has said or the kinds of experiences she has enjoyed in the past.

Innovations that improve the way we communicate will require small tweaks and firm attention to the words we use. By recognizing the impact of these words, we can help families consider strategies that reflect their loved one’s preferences and values. The conversation in our example might have been different had the intensivist said, “Tell me what your mom would say about living with this bad stroke and a broken neck?” ■

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