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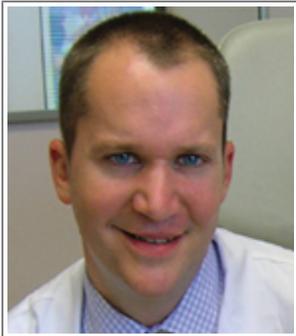
Don't Tell Me Anything Negative

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While on call over the weekend, I looked after one of my partner's patients who is approaching death from advanced, refractory ovarian cancer. She ended up in the ICU with what was believed to be a bowel perforation and sepsis, and I and the intensivists on the case felt that she could die within a few days. She was completely lucid despite her condition, and refused to discuss any treatment limitations, despite the fact that all of the physicians involved in her care agreed that her prognosis was terminal. When I tried to discuss these issues with her, she asked me not to talk about anything negative with her, because she needed to find something hopeful to hang on to. Decisions need to be made—should I just remain silent about them at her request? We can't really make any decisions without discussing negative things.

Dr. Helft Responds



Paul R. Helft, MD

This situation represents a difficult but all-too-common situation. One wonders how such a patient got to this point in her illness with so little apparent understanding of the trajectory of her disease. However, that is water under the proverbial bridge at this point.

This case seems to involve at least two ethical issues. The first is whether the patient's directive to you regarding communication represents a true "information advanced directive" which binds you in a way that does not permit communication about issues the patient perceives as overly negative. The second, larger issue is how to manage the conflict between what the clinicians feel is in the patient's best interest and her contradictory views of the goals of care.

Requests not to speak about negative information are usefully framed as symptoms of extreme emotional distress, as opposed to absolute rules. Moreover, there is evidence from research groups such as Terrance

Albrecht's group at Wayne State University that we only imperfectly predict what information is negative for any individual patient. So, how can we know for sure that anything we say might not be perceived as negative? Framing the patient's request this way suggests a different strategy for responding to her request. "Help me to understand more about why you feel that way" is a conversation opener for such a situation. By demonstrating emotional support and respect for how difficult the situation is, one can sometimes open a door little by little to empathic but franker conversations about information that is clearly negative but crucial to decision making. Also, recruiting other sources of emotional support, including family members (who may or may not feel similarly), psychosocial professionals, or chaplains, can aid in productively and respectfully handling such a request.

As for the second issue, a decision regarding life-sustaining therapies and the goals of treatment can only be reached effectively by providing enough time, engagement, and compassionate communication that the patient feels supported in her emotional crisis to a sufficient degree that her authentic preferences can come to align better with what is most likely to be in her best interest: a peaceful and dignified end-of-life period, protected as much as possible from technology and treatments that merely prolong the dying process.

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