Communicating With Seriously Ill Patients

Better Words to Say

Steven Z. Pantilat, MD

WORDS MATTER. WHAT CLINICIANS SAY AND HOW they say it hugely affect patients.[1-3] Communicating about emotionally and medically complex topics such as advance care planning, preferences for care, prognosis, and death and dying is challenging. Doing so requires clinicians to attend to their own and the patient's cognitive reactions, tone, affect, and nonverbal cues.[4-6] Communicating goals of care is so important that in California it is now the law.[7] Although poor communication may harm patients by leading to unwanted invasive procedures, generating unnecessary anxiety, or creating feelings of abandonment, good communication can improve outcomes for patients and their families by promoting shared decision making and addressing patient concerns.[1,2,8]

A recent study described a novel communication model and a process through which it could be adopted by clinicians.[9] The 4 parts of this model include seeing communication as a process that unfolds over many conversations, taking a patient-based approach to understand the patient's values, making recommendations, and using positive and negative role models and experience to develop an effective personal approach to communication. Such role modeling can take the form of recommendations for specific words to say to facilitate clear communication.[6,10,11] Many of these recommendations can be used daily to prevent poor communication and unfortunate choices of words that can create unintended and negative consequences.

In this article, 4 common and problematic phrases are parsed; their potentially negative effects on patients, families, and clinicians are described; and in their stead, a lexicon aimed at improving communication based on clinical observations is modeled. While no data report how often these phrases are used or the effectiveness of the alternative lexicon, clinical observation can provide a useful evidence base for such recommendations and serves as a source of innovation.[12]

"There Is Nothing More to Do"

"There is nothing more to do" is commonly heard from the intensive care unit to the clinic. Well-meaning clinicians use this phrase to advise patients and families that no further treatments can be mustered to cure the illness. In that limited sense it may be true that "there is nothing more to do," but difficulty arises because clinicians rarely articulate the culminating phrase "to cure the illness." Thus, the patient and family hear the disheartening message that the clinician has nothing left to offer.

There are several problems with this statement. First, it is simply not true. There is always something that can be done for the patient, despite an inability to achieve cure. The fact that many clinicians are unprepared to provide palliative care and are unaware of options other than attempts at cure may contribute to the widespread use of this phrase.[13] For patients who are very near death, however, there is much that can be done, including symptom management and psychosocial support, to ensure comfort and ease suffering.

Second, this phrase locks the patient and physician in an unnecessary tug-of-war: the patient insists, "There must be something to treat this cancer," and the physician responds, "There is nothing more to do." The tensions increase as patient and clinician become increasingly resolute. A phrase that acknowledges the patient's hope and expresses the physician's desire to help, such as "I *wish* there were something we could do to cure your illness," might defuse the conflict.

Third, "there is nothing more to do" can feel to the patient like abandonment. A patient could reasonably deduce that if there is nothing more to do, then the physician's role, responsibility, and relationship with the patient have ended. Far from the physician's role ending, it is arguably increasingly crucial to maintain the relationship once the physician has concluded that cure is not possible.[14] Fourth, this phrase cements the clinician's mistaken belief that there is nothing left to offer. This denies the patient meaningful support and treatment of symptoms and deprives the clinician of the gratification and meaning that can come from caring for patients at this stage of illness.

Removing "there is nothing more to do" from the lexicon and replacing it with the caring statement, "I *wish* there were something we could do to cure your illness," as

Author Affiliations: Palliative Care Program, Division of Hospital Medicine, Department of Medicine, University of California, San Francisco.
Corresponding Author: Steven Z. Pantilat, MD, Box 0903, University of California, San Francisco, 521 Parnassus Ave, Ste C-126, San Francisco, CA 94143-0903 (stevep@medicine.ucsf.edu).

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suggested by Quill and colleagues,[11] followed with, "Let's focus on what we *can* do to help you," is preferable in many ways. First, it is true. Every clinician wishes to provide a curative treatment. The absence of a cure is not due to the clinician's lack of desire to provide one or to withholding such treatment, but rather to the limits of medicine and science. The "I wish . . . " statement demonstrates that the clinician is on the patient's side and drops the rope in the figurative tug-of-war. The proactive "Let's focus on what we *can* do" demonstrates that the clinician has an important role to play, with treatments to offer, and will stay engaged until the end. The suggested phrases not only model specific language, but by having the clinician address options, encourage a more detailed discussion of what can help.

"Would You Like Us to Do Everything Possible?"

Whether asked of patients or family members, "Would you like us to do everything possible?" elicits a single, reflexive answer: "Yes." This phrase is often heard regarding an acutely ill or terminally ill patient but also is used in other settings. Clinicians use this phrase in a well-meaning attempt to engage in shared decision making and to understand the patient's preferences for care. The difficulty is that it likely evokes a radically different scenario for clinicians than for patients. To the clinician, "everything possible" may include intensive care, mechanical ventilation, vasopressors, and the complete armamentarium of medical interventions. Patients and families may imagine a different set of interventions, ie, those designed to relieve pain or distress or achieve a particular goal. Miscommunication occurs because clinicians and families silently complete the phrase very differently. The clinician may be thinking but not saying, "I can do these things, though I don't really think they will improve the quality of the time left." Family members may unconsciously complete the clinician's statement with, " . . . which would help you achieve your goal." Each party believes the other has understood the practical application of the conversation, but an unintended mismatch between the spoken offer and the unspoken assumptions may lead to conflict when interventions that are not consistent with the patient's goals are instituted.

"Would you like us to do everything possible?" is simply an inartful question. More effective is to begin by asking, "How were you hoping we could help?" Many patients and families will be able to answer this question directly. For example, a patient with end-stage heart failure with acute pneumonia and dyspnea might respond, "Make my shortness of breath better," "Give me that tube and breathing machine," or "I am dying; please help me." Other patients and families may respond with a blank stare, unaware of the range of potential interventions, or may simply say, "Help me." Regardless of the response, the clinician should ask additional questions and offer options to clarify the patient's preferences and goals. Starting with an open-ended question and continuing with options sets the stage for an accurate understanding of the patient's preferences, elucidates and manages expectations about the efficacy of the available options, avoids any misunderstanding about the meaning of "everything possible," and encourages the patient to share emotions and concerns. By reorienting the conversation to promote patient and family input, this statement serves as more than a model phrase and could promote improved communication.

"Stop the Machines"

When discussing goals of care, clinicians often must address the issue of withdrawing or withholding interventions aimed at prolonging life. This clinical decision is often summarized to patients and families as, "We will stop the breathing machine and the antibiotics and if his heart stops we won't try to resuscitate." At that point, families will likely be thinking, and may ask, "You mean you're just going to stop?" The problem with the clinician's framing of the change in care in this manner is that it focuses on what will *not* be done, rather than on the care that will be provided. It is not so much the word "stop," or even withdrawing interventions; "stopping" is often precisely what the patient and family want. There is also no ethical dilemma in withholding or withdrawing unwanted interventions. Although these actions may feel different to the clinician, both are ethically permissible and consistent with accepted medical practice.[15] The concern is with the exclusive focus on stopping, which suggests an aftermath devoid of care. This singular emphasis on stopping fails to acknowledge and detail how the clinician intends to refocus both the biomedical and psychosocial plan of care with measures intended to provide comfort rather than prolong life.

When discussing the withdrawal of mechanical ventilation, the clinician can say, "To respect his wishes, we will stop the breathing machine and use medicines to make his breathing comfortable." Similarly, a discussion of cardiopulmonary resuscitation can be articulated as, "If your heart stops, we will let you die peacefully." Each of these phrases provides not only alternative words to say but reframes the act of stopping into one of actively promoting the patient's goals, and the former further explains the new treatments that will be instituted.

Discussions With Consultants

When clinicians converse with consultants, they often use the phrase "withdrawal of care" to communicate an idea similar to "stop the machines." What clinicians seem to mean is that they believe it is appropriate to withdraw life-sustaining interventions. This phrase, however, reinforces the idea that the only real way to care for the patient is with treatments focused on survival. Clinicians should avoid the shorthand "withdrawal of care," and instead say, "Withdrawal of mechanical ventilation and vasopressors and in-

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stitution of comfort measures," which accurately reflects the speaker's intent and reminds all clinicians caring for the patient that their care will continue.

Conclusion

Communication is a powerful instrument to convey the myriad forms of caring and is an important tool. Banishing phrases like "There is nothing more we can do," "Would you like us to do everything possible?" "Stop the machines," and "withdrawal of care" and replacing them with phrases that truthfully communicate the care that clinicians are able and ready to provide promotes clear understanding, elicits patient concerns that can be discussed, and emphasizes the enduring nature of the patient-physician relationship. A new lexicon that provides models for effective communication may lead to fewer misunderstandings, improved care, and increased satisfaction for patients and clinicians. Phrases with potentially pernicious consequences should be replaced with better words.

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