

Patient-doctor ethnic differences thwart end-of-life conversations

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Credit: Petr Kratochvil/public domain

Most doctors balk at talking with seriously ill patients about what's important to them in their final days, especially if the patient's ethnicity is different than their own, according to a new study by researchers at the Stanford University School of Medicine.

The study, to be published in *PLOS ONE* on April 22, is based on [questionnaires](#) answered anonymously by 1,040 [medical residents](#) in their last year of training.

End-of-life conversations help clarify for doctors what matters most to patients in their waning days of life, said VJ Periyakoil, MD, the lead author of the study and a clinical associate professor of medicine at Stanford. "What are their hopes, wants, needs and fears? Do they want to die at the hospital on a machine? Do they want to die at home? We can't know unless we have a [conversation](#)," she said.

By default, Periyakoil said, doctors generally offer patients every possible treatment for their condition, regardless of its impact on their quality of life. "Doctors need help from their patients in having these conversations," she said.

The survey took place between 2010 and 2012 at two [academic medical centers](#): Stanford Hospital & Clinics (now called Stanford Health Care) and the Veterans Affairs Palo Alto Health Care System. The response rate was 84 percent. It included staff from 11 medical specialties. Most respondents were in internal [medicine](#) (29 percent), surgery (19 percent) or pediatrics (14 percent).

The survey asked doctors if they had encountered any barriers to conducting effective end-of-life conversations with seriously ill patients and families, and if yes, to what extent conducting these conversations with those of a different cultural or ethnic background was challenging. It also asked doctors to list the top three barriers they faced in conducting effective end-of-life conversations.

"I knew that the percentage of doctors who encountered barriers for having end-of-life conversations would be high, but I was surprised by how high," Periyakoil said. Of those surveyed, 99.99 percent reported

barriers, with 86 percent rating them as very challenging.

Medical interpretation a sticking point

The researchers categorized the barriers encountered by doctors according to subject and identified the top six. Starting with the most severe, these categories were 1) language and medical interpretation issues; 2) patient's and/or family's spiritual beliefs about death and dying; 3) doctor's ignorance of patient's cultural beliefs, values and practices; 4) patient's and/or family's cultural differences in handling the truth and making decisions; 5) patient's and/or family's limited health literacy; and 6) patient's and/or family's mistrust of doctors and the health-care system.

All of these barriers are more likely to affect patients who are ethnic minorities who speak a different language than the doctor, Periyakoil noted, further exacerbating the health disparities they encounter.

The survey responses provide details about these problems and suggest some solutions. The survey revealed, for example, that the greatest barriers physicians face when engaging in these conversations is communicating with patients with whom the doctor shares no common language. Responders noted that medical jargon is difficult to translate, as equivalent words may not exist, and approximations can lead to misunderstandings. Technical terms, such as cardiopulmonary resuscitation, and idiomatic phrases, such as "heroic measures," that crop up in end-of-life conversations can confuse even people proficient in English. And while medical interpreters can help, doctors in the study said that interpreters are not always immediately available, and involving them is time-consuming and can interfere with the doctor-patient relationship.

Even fluent English speakers commonly misinterpret doctors' words, the

authors of the study write. "Even commonly used words can mean very different things to different people," they write. "For example, oncologists often use the word 'cure' to indicate five years of cancer-free survival. However, to cancer patients and families, the word 'cure' means eradication of cancer and restoration of normal health."

Periyakoil contends that all doctors should be trained in conducting end-of-life conversations in a respectful and culturally effective manner. Health-care organizations need to develop ways to systematically identify patients with limited English proficiency by screening them on entry into the system—for example, asking the question, "Is a language other than English spoken at your home?"—and adequately reimburse doctors for longer appointments with patients necessitated by the need for interpretation, suggested Periyakoil. It is also important to train doctors and medical interpreters to work together efficiently, she said.

More training for physicians

To help address the other issues, many of which stem from doctors' lack of knowledge about patients from different cultures and faiths, the researchers recommend training throughout the physicians' education and career.

None of this will be easy, said Periyakoil, which is why she thinks doctors need patients' help.

"Doctors are very good at doing what we are trained to do: Prescribing medications, doing procedures—but not to communicate," she said. "It is ironic that we don't train doctors to communicate but expect them to be master communicators."

"We need the patient to hold the doctor's hand and walk with them," she added.

As the United States population becomes more diverse, overcoming communication barriers is especially important, she said.

"The United States will be majority minority in 2034, and 30 years is not a long time for the nation to change," she said. "In order for us to give the best quality care for everyone, we need to avoid burdening and overtreating people who will not be benefited. Conversation is the secret sauce of providing care tailored to the patient's goals and values. But doctors are reluctant, not trained and not paid to have these conversations. Patients need to make it easy to have these conversations."

Looking for a way to bring up the topic? Periyakoil would start with this: "Doctor, let me help you talk about some things that matter most to me." Then, she suggested, make your desires clear and explain what you value. Do you want every medical intervention regardless of the pain and affect on the quality of your life? Or is avoiding pain your main priority?

To help patients start this conversation, she has created a template for a letter [patients](#) can fill in and share with their [doctors](#). It's available at <http://med.stanford.edu/letter.html>.

For herself, Periyakoil plans to say, "I want you to do everything you can to help me live well. But when my time comes, please let me go gently."

Provided by Stanford University Medical Center

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