

Study reports ethnicity does not predict type of end-of-life care patients want

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Ethnicity does not predict the type of end-of-life care people want, according to a study by researchers at Stanford University School of Medicine

"There is so much generalization and stereotyping by physicians about how ethnic minorities want everything done, irrespective of how effective these treatments might be at the end of life," said VJ Periyakoil, MD, a clinical associate professor of medicine at Stanford and lead author of the study, which will be published online Nov. 18 in the *Journal of Palliative Medicine*. "I decided that we needed to go into their communities and ask them what they want."

The study found that ethnic minorities want conversations with their physicians about quality end-of-life care, but numerous barriers, including poor communication and finances, often get in the way.

Helena Kraemer, PhD, professor emeritus of biostatistics in psychiatry, is senior author of the study.

The researchers interviewed 315 people of multiethnic backgrounds—including 117 white Americans, 38 African Americans and 160 Asian Americans—over the age of 50 from cities across the San Francisco Bay Area. They found that all participants valued high-quality end-of-life care. A majority, 61 percent, said there were barriers to receiving high-quality care for members of their ethnic group.

The inequalities in health care that occur across ethnic and socioeconomic groups persist well into end-of-life care, the study said, with seriously ill [ethnic minority](#) patients being disproportionately affected by poor-quality care.

"In reality, it is more of a socioeconomic issue than an ethnic issue," said Periyakoil, an expert in

palliative and end-of-life care.

Education level tied to participant responses

For the study, medical interpreters accompanied the Stanford researchers into community-based senior centers in Fremont, Palo Alto, San Francisco, San Jose and Walnut Creek to help conduct interviews in the participants' preferred language. In addition to English, interviews were conducted in Spanish and five Asian languages—Burmese, Hindi, Mandarin, Tagalog and Vietnamese.

The 191 participants who reported barriers to getting quality end-of-life care were asked to describe the biggest barriers, which were, in order of how often they were cited: finances and health insurance; physician behavior; communication problems with doctors; family beliefs; health system barriers; and cultural/religious barriers.

A comparison of the various ethnic groups interviewed showed no significant differences in how they ranked these barriers.

But education level was found to have a significant influence. Participants with no formal education found financial issues to be most challenging, followed by a communication chasm between doctors and patients. Participants with any other level of education (elementary, high school or more) identified doctor behaviors as being the biggest barrier.

The majority of participants ranked lack of finances and inadequate medical insurance as the biggest barrier, according to the study.

"Lack of basic health access continues to plague the poorest in the nation," the study said, adding that 43 percent of all Americans reported cost-related problems in getting needed health care.

Communication barrier

Poor communication with physicians was the second-most-common barrier reported by [participants](#). They felt that "doctors were just too busy to initiate conversations," and that "doctors were either unaware of, or insensitive to their cultural/spiritual needs," causing patients to shy away from "intensely personal" end-of-life conversations, the study said.

"If a patient says, 'I'm praying for a miracle,' there's the concern that the doctor might say something insensitive," Periyakoil said. "You can't tell patients that miracles are unlikely to happen or question their faith and beliefs. Physicians need to be sensitive to religious and cultural beliefs and support them to the extent possible."

Participants also reported an inability to understand medical terminology, language barriers and family members with differing beliefs about death and dying.

"Most people don't know that at some point most of us will lose our ability to make [health-care](#) decisions at the end of life," Periyakoil said. When this happens, a family member is usually required to step in as a proxy decision-maker.

"Making medical decisions for a loved one takes mental fortitude and a deep understanding of the patient's values and preferences for care" Periyakoil said. "It's a profound responsibility choosing whether a person dies at home or in a hospital, what types of treatments to attempt or forego, and when to limit or withdraw burdensome interventions and allow a natural death. I've seen far too many families split apart due to the trauma of this decision making. In fact, the only right decision is what the patient wants."

Providing culturally competent [end-of-life care](#) is becoming more essential as the United States is poised to become a nation whose majority population is made up of minorities by 2044, the study said.

The fragmented health system, which doesn't train doctors to communicate effectively with their

patients about end-of-life choices, is the underlying larger problem that is in need of an urgent solution, the study said.

More information: online.liebertpub.com/doi/full/10.1089/jpm.2015.0403

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