What are your chances of living two years? Doctors, cancer patients, differ

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Misunderstandings about prognosis between patients with advanced cancer and their doctors was common, in a study reported in *JAMA Oncology*, and the vast majority of patients didn't know that their doctors held different opinions about how long they might live.

"We've discovered two important things happening between oncologists

and patients with advanced cancer," said co-author Ronald M. Epstein, M.D., professor of Family Medicine, Psychiatry, and Oncology at the University of Rochester Medical Center, and one of the nation's leading authorities on doctor-patient communications.

"First, some patients might know the doctor's prognosis estimate but the patient chooses to disagree, often because they believe other sources," Epstein said. "And second, some patients think that their doctor agrees with their opinion about prognosis but, in fact, the doctor doesn't."

"When people think they'll live a very long time with cancer despite evidence to the contrary, they may end up taking more aggressive chemotherapy and agreeing to be placed on ventilators or dialysis, paradoxically reducing their quality of life, keeping them from enjoying time with family and sometimes even shortening their lives," Epstein added. "So it's very important for doctors and patients to be on the same page."

Researchers surveyed 236 patients with stage 3 or 4 cancer whose doctors "would not have been surprised" if they died within a year and half of whom died within 16 months. Fewer than five percent would be alive in five years, according to medical evidence. The 38 oncologists who treated these patients independently completed similar questionnaires to measure their own opinions about the patients' survival. Doctors were asked: "What do you believe are the chances that this patient will live for 2 years or more?" Whereas the patients were asked: "What do you believe are the chances that you will live for 2 years or more?" Additional survey questions gauged whether patients knew their prognosis opinions differed from their doctors, and to what extent treatment options were discussed in the context of life expectancy.

Among the 236 patients, 68 percent rated their survival prognosis differently than their oncologists. In nearly all cases the patients were

more optimistic than their doctors. Of the 68 percent, only one in 10 realized that their opinions differed from their oncologists.

The study results highlight a difficult communications issue that arises often when the conversation is about cancer. Discordance almost always leans toward patients being overly optimistic, Epstein said.

"Of course, it's only possible for doctors to provide a ball-park estimate about life expectancy—and some people do beat the odds," Epstein said. "Positive thinking by patients can improve quality of life. But when a patient with very advanced cancer says that he has a 90-100% chance of being alive in two years and his oncologist believes that chance is more like 10%, there's a problem."

The challenge, according to the researchers, is that talking about a cancer prognosis is not a straightforward exchange of information. It occurs in the context of fear, confusion, and uncertainty, and in the best cases it should be carried out in several conversations about personal values and treatment goals.

But when doctor-patient communication is poor, it can result in mutual regret about end-of-life circumstances. For example, nearly all of the survey participants said they wanted to be involved in treatment decisions. And 70 percent said they preferred supportive care at the end of their lives as opposed to aggressive therapy—but, the study authors pointed out, making an informed decision requires knowing when death is approaching.

Another important finding was that non-white patients were much more likely than white patients to have expectations about their prognosis that were out of synch with their doctors. However, the sample of non-white patients was small and included individuals from many different racial groups, which limited the researchers from drawing any conclusions.

The study had other limits, too, according to the authors. Researchers reported that they do not understand why discordant patients didn't know their oncologists' opinions and why it differed by race. The scientists believe several factors could have been at play, such as patients not wanting to discuss prognosis, or having poor recall, or avoiding talk of death because of personal beliefs.

The study concluded that having differing opinions—especially when both sides don't realize they differ—is a marker for inadequate communication and calls for an "urgent clinical and societal need" to better understand what it means to communicate well.

The University of Rochester Center for Communication and Disparities Research in the Department of Family Medicine is among the few academic centers to extensively study this issue and propose improvements. Previously the group pinpointed and studied compassionate words and actions by doctors that could be used to guide medical education. The Center is currently funded by the National Institutes of Health (NIH) to continue studying how to improve communication between physicians and patients with cancer.

Lead author of the *JAMA* paper, Robert E. Gramling, M.D., is a former associate professor at URMC who recently left to join the University of Vermont Medical Center as the Holly and Bob Miller Chair in Palliative Medicine at UVM. Gramling had been co-director of URMC's division of palliative care. Other co-authors from the UR and the Wilmot Cancer Institute include Paul Duberstein, Ph.D.; Kevin Fiscella, M.D., M.P.H.; Supriya Mohile, M.D.; Sandy Plumb, B.S.; and collaborators from the University of California, Davis, and Tulane University in New Orleans.

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