

## Rethinking Conversations on Prognosis and Life Expectancy

Heather Boerner, December 14, 2018

Not that long ago, **Juliet Jacobsen, MD**, had for a patient a woman with cancer. The patient did not want Jacobsen to talk about life expectancy. At all. Ever.

She didn't want to talk about time-based prognosis when she was diagnosed. She didn't want to talk about it when the cancer spread. She didn't want to discuss it when she stopped treatment or enrolled in hospice. The same was true when she signed a do-not-resuscitate order.

*"We were able to make all those decisions without her having to know if she had 6 months, 3 months, or 3 days left," said Jacobsen, of Massachusetts General Hospital, Brigham and Women's Hospital, and the Harvard School of Public Health, in Boston. "The idea that you have to have specific information to have decision-making conversations" just isn't true.*

And that's good news, because two recent articles suggest that discussing life expectancy and prognosis are tough on both sides of the doctor-patient relationship. And that means, suggest palliative care specialists, that *physicians may need to redefine what a successful prognosis discussion looks like*, using shared decision making and patient-centered approaches.

### **Life Expectancy? No Thanks.**

If we are going to talk patient-centered, it's important to know what patients want. Therefore, **Nancy Schoenborn, MD, of the Johns Hopkins University School of Medicine**, Baltimore, Maryland, and colleagues *asked more than 1000 older adults with chronic illnesses when and how they wanted to talk to physicians about life expectancy.*

These are her patients, said **Schoenborn**, a primary care physician who works with people who are "older and often sicker and at various points of this decline toward end of life."

The study *was published* in the November/December issue of the *Annals of Family Medicine*.

What she found was that *59.4% of the 878 respondents didn't want to talk about life expectancy at all if life expectancy was 10 or more years. And 87.7% did not want physicians talking to family or friends about it either.*

Patients' interest changed, however, when life expectancy dropped to 2 years. Then, 55.8% of patients wanted their doctor to talk to them about it.

Still, like Jacobsen's patient, *16.5% of respondents didn't want to talk about life expectancy even when it dropped to 1 month.*

This all made sense to **Schoenborn**, in a way — after all, people with chronic conditions who aren't facing something like cancer don't necessarily need to have these conversations. They are important for physicians, however, as they have a bearing on some preventive screenings 10 years from end of life.

*What did surprise her was the answer to another question: Would patients be open to a physician asking if the patient wanted to have the discussion? Nearly 60% of patients said absolutely not.*

"Before this study, that's what we were proposing," she said — *"telling patients, 'This is something we ask everyone about, is it OK if we ask you if you're open to the conversation?'"*

The answer left her wondering, "If a patient doesn't want to be offered, what's a clinician to do?"

## Hope and Concern

One answer comes from a [recent article](#) published in *JAMA Internal Medicine* that **Jacobsen and colleague Joshua Lakin, MD, of Massachusetts General Hospital and Harvard Medical School**, authored. The pair suggest another way of handling the tension between a patient who doesn't want to have the conversation and a physician who feels it's their duty to do so.

In that tug of war, the pair wrote, "Put down the rope."

"The problem is not a patient who cannot accept the prognosis, nor is it the pessimistic clinician who has given up hope," they write. "The problem is the disease, which is advancing despite everyone's best efforts."

In [the article](#) (*\*softening our Approach to Discussing Prognosis*), the pair suggest couching prognostic and life-expectancy conversations in "I" statements that pair a physician's hope ("I am hoping that you will have a long time to live with your heart disease") with concern ("but I am also worried that the time may be short, as short as a few years"). These statements allow for the uncertainty of prognosis and also put the patient and provider on the same side against the disease.

[*\*Softening Our Approach to Discussing Prognosis*

[Joshua R. Lakin, MD<sup>1,2</sup>](#); [Juliet Jacobsen, MD<sup>3</sup>](#)

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*We tend to cringe when we hear "So, how much time do I have, doc?" Yet prognostic discussions are a core skill of being a compassionate physician, preparing patients and families to live with serious illnesses, and enabling informed medical and personal decisions. The first challenge of prognostic communication is the inherent and unavoidable uncertainty, that the exact trajectory of health (or illness) is unknowable. Thus, clinicians are inaccurate prognosticators, overestimating by up to a factor of 5.<sup>1</sup> We have difficulty making accurate short-term time-based prognostic estimates for common diseases, such as congestive heart failure, and can be off by as much as 1 to 2 years.<sup>2</sup> Compounding this uncertainty, we worry about upsetting our patients with too much or unwanted information. On one hand, patients say that they want to know their prognosis and report that it is one of their highest priorities.<sup>3</sup> On the other hand, patients also say that they are unsure about how much they want to know and give mixed messages about how much they want to talk about it.<sup>4</sup> As one patient said, "I ask the question, and then I don't want to know the answer. But the question is out there, and then I am devastated." Uncertain about the information and not wanting to cause emotional harm, we hesitate to talk with patients about their futures. We watch colleagues hesitate with statements such as "Well, I don't have a crystal ball" or "You know I can't tell you that," or "Only God knows," or "We are very bad at predicting this sort of thing." But we also worry that our patients do not have the prognostic information that they need, however imprecise. And perhaps worse, we worry that patients perceive that we cannot handle the tough discussions they need from us.]*

## Talking Values, Not Time

But for patients who don't want to talk about length of time at all, there are other options, especially when discussing preventive screenings, **Robert M. Arnold, MD, of the University of Pittsburgh**, told *Medscape Medical News*.

"The goal isn't to tell people what they don't want to know. It's to help people cope with where they are," said **Arnold**, who has studied physician communication and end-of-life care for decades.

Instead of telling patients that you want to discontinue cancer screenings because life expectancy has dropped to 10 years, Arnold suggests weighing out the benefits and risks of such screenings with patients, without discussing time left.

"I'd talk around it," he said, and be willing to talk directly about life expectancy if that develops in the conversation. "You can say, 'I don't think it makes sense to keep doing colonoscopies. Do you want to talk about it?'"

**Schoenborn** agreed, saying that she suspected that the path moving forward involves exactly that kind of risk-benefit analysis. And, she added, exacerbations and hospitalizations give physicians a reason to bring it up.

It's this long-term relationship with a patient that offers another option, said **Lakin**. In a fee-for-service world, where physicians have little time with each patient, taking the conversation bit by bit may be better.

*"If a patient is having notable changes in their disease, if they are reaching landmark moments in progression," that's the moment to start mapping out the kind of care they want going forward. Even if you never give a timeline, you can talk about what a patient wants to do if hospitalizations happen again. You can share how the disease usually progresses. And you can, through shared decision making, give patients real options that take into account "what's important for them."*

*"Those are the moments," he said, "to realign care."*