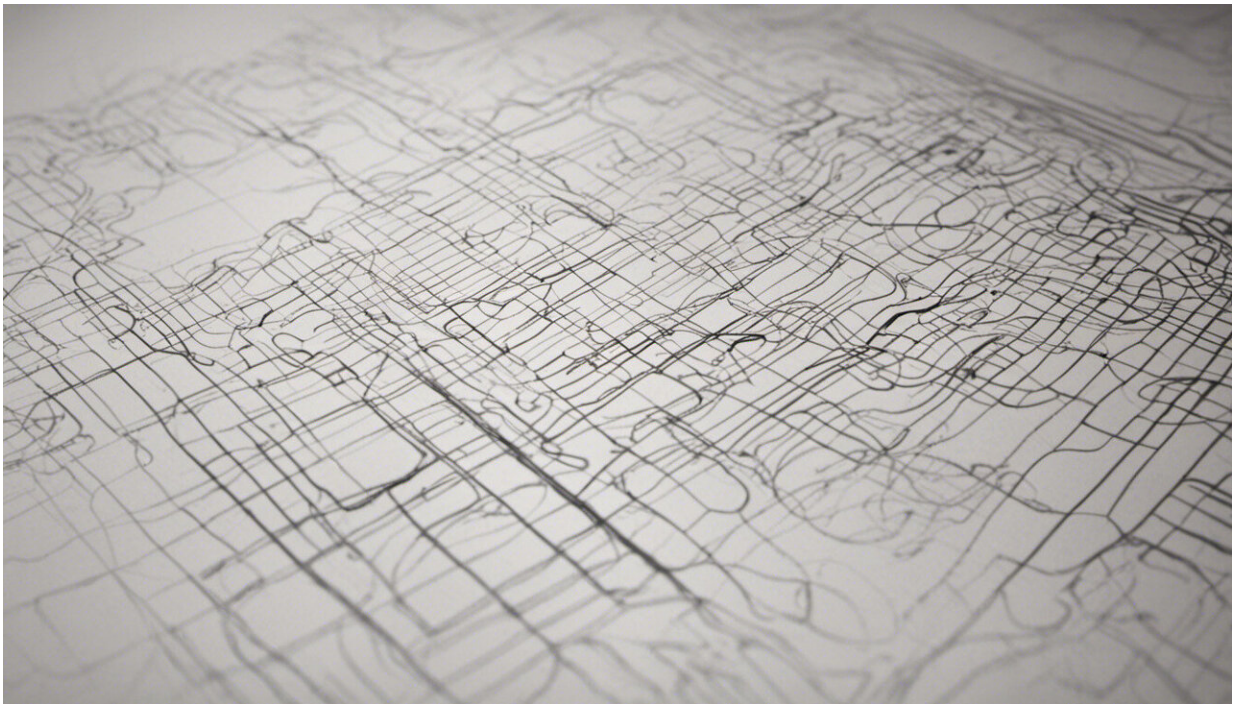


Making the tough medical decisions with patients

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Should I have surgery for prostate cancer? What are the pros and cons of taking a statin? Should I get a mammogram?

These questions are just a few examples of decisions that patients have to make every day, sometimes with solid research to support one option,

and in other cases, little or no data at all to guide them. In an opinion piece published Jan. 14 in the *New England Journal of Medicine*, Dr. Terri Fried, professor of geriatrics at Yale School of Medicine, explores the issue of "Shared Decision Making—Finding the Sweet Spot." YaleNews talked to Fried about her innovative approach to arriving at decisions in the best interest of patients; the following Q&A has been edited.

Why did you decide to address the issue of shared medical decision making?

This has been a long-standing interest of mine. I was inspired by what I had observed in terms of clinical interactions and decided that this was a topic that needed to be addressed in a way that would get people's attention and get people talking.

In part, there's been more of a spotlight in the last few years on this need to do shared decision making. It was my concern that perhaps we weren't doing it in a way that always best served the interest of the patient.

How do you define shared decision making?

Shared decision making in its broadest form is a process by which the clinician ensures that the voice of the patient is represented in the healthcare decision that is being made.

In the NEJM perspectives piece, you say that, 'the role the patient is asked to play in the process is frequently not appropriately matched to the clinical circumstances.' What do you mean?

Doctors cite that they involve patients in the decision in a wide variety of ways. On one end of the spectrum, the clinician lays out the potential treatment options for the patient and says, 'here are the options, you decide'—in essence giving all the responsibility for the decision to the patient.

At the opposite end of the spectrum, the clinician makes a strong recommendation—'this is what you ought to do'—and leaves it to the patient to accept or reject that recommendation. At that end of the spectrum, the clinician might not even give the alternatives but may give only the decision that the clinician thinks is correct.

There's recently been increasing recognition that patients themselves vary in terms of which of those approaches they prefer. But what's less recognized is the need to think about matching that spectrum of decision making to the clinical circumstances at hand. What I mean is that from clinical experience, I've observed that clinicians are more likely to hand the decision over to the patient if the clinician isn't sure what the right answer is, and that usually occurs when we either don't have good data, or we don't have any data, or we have conflicting data.

The reason why that is not a very good match of the decision making style to the clinical scenario is that it's really hard to make decisions under uncertainty. If the clinician can't come up with the right answer, why do we think the patient is going to be able to do that?

That's why my recommendation is that under circumstances in which the clinician isn't sure what to do, he or she ought to model for the patient how to think through the scenarios, including incorporating uncertainty: 'I'm not sure if treatment x is going to give you a better outcome than treatment y, but let me tell you what my best guess is, and what I'm basing that best guess on, and then let's think about how that might fit with what you tell me is most important about this decision.'

The alternative happens when we have very good data and we're able to predict with a fair amount of certainty what the result of specific decision is going to be. If we know what's going to happen, it's easy for the clinician to think he or she has right answer to a clinical question and tell the patient that this is what he or she ought to do. However, it may be that the outcome we can know with certainty is not what is most important to the patient.

What are the risks of leaving a decision that involves several options up to the patient, as many clinicians do?

When there is a lot of uncertainty about the outcomes of those different options, there is some evidence that the patient feels both increased burden and responsibility. What that can lead to, if things don't go well, is cause a lot of regret on the part of the patient, which only makes a bad outcome worse. There's also the possibility of the patient saying, 'I don't want this responsibility. This isn't how I want to make this decision.'

Don't some patients simply want to be told what to do?

That's a really good question. When you unpack that a little bit, there's actually two parts to making a decision. We have focused on the part about who actually makes the decision. But there's another part, which is being given information about all the available treatment options. And while there's a fair number of patients who say, 'I don't want to make the decision,' virtually all patients say, 'I do want all the information you have to give me.' When the physician makes a strong recommendation at the expense of letting the patient know what other options are available, the physician is not doing what the patient wants.

You mentioned prostate cancer. Can you think of an example from your own experience or something you observed of this problem coming up?

It happens all the time in geriatrics. Because so many of our patients are not represented in clinical trials, we rarely have a very good or strong database for making our decisions. Even things that are more straightforward for the younger patient, like a surgery for a cancer, in our patients—frail patients, patients with multiple chronic conditions—the risks can be much higher. I find that I am often talking with patients about what the downsides might be of different treatment options because it's really important to find out from our patients how they feel about those downsides.

Normally we make decisions based on the idea that we're going to choose the option that's going to extend the patient's life. But our older patients frequently tell us 'if it's going to extend my life, but it's not going to be a good quality of life—I'm not going to be independent, I'm not going to have good cognitive function —that's not what I want.'

Your piece talks about patient's values. How should their values play into decision making in your opinion?

I think values need to be a part of the equation much more frequently than they currently are. What I mean by that is if we look at the flip side of uncertainty, doctors frequently give patients strong recommendations based on treatment guidelines that say if, for example, the patient's risk of heart disease is x over the next five years, the patient should get a statin. But what we know is that that number x makes a difference to people. Some people don't think it's worth it to have to take a pill every

day if you're going to reduce their risk by a small amount. That decision, as clear cut as it seems, depends on how much the patient values a certain amount of risk reduction versus the burden of having to take that pill every day.

What kinds of preferences and priorities do patients express that may conflict with a clinician recommendation?

I think statins are a good example because they are so ubiquitous. We hear this all the time. There are patients who experience side effects from the medication and what I hear is 'my doctor tells me I have to take this medication because it's reducing my risks of a heart attack. But what I care about is being able to do my walk every day and this pill is making my legs hurt, so I can't do my walk.'

That's a good example. Anything else come to mind?

The bottom line is recognizing that there are issues that can be more important to patients than extending their life. It's most relevant for our older patients but I hear it even from younger folks —that there are circumstances in which extending life is not the most important priority. It comes up a lot in terms of, for example, giving palliative chemotherapy to patients with cancer. So the thought in that case is that even if we can't cure the cancer, if we can give the patient a few more months, it's something that we ought to be doing. But the patient needs to know what life with that chemotherapy is going to be like because a number of them will say 'If the chemo is going to make me feel worse, that's not what I want.'

What other scholarly/research project are you

working on now?

My research is closely linked to issues we've discussed. I have two main projects. One is a project in which we're working to develop ways to engage people earlier in the process of advance care planning. Advance care planning is the process by which individuals think about what's important to them down the road when they're not going to be able to participate in [decision making](#) because of serious illness, so that they can communicate with their loved ones and physicians about what matters to them most. The other project is looking at medication among older [patients](#) who are taking multiple medications to clarify what the potential risks and harms of those medications are, and to make sure that we're maximizing the benefits of what we're prescribing for those individuals.

More information: Terri R. Fried. Shared Decision Making—Finding the Sweet Spot, *New England Journal of Medicine* (2016). [DOI: 10.1056/NEJMp1510020](#)

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