

What Do Patients Want? Help in Making Effective Choices

Usually, I want to be a rational patient. To do that, my physicians need to help me understand the probability and magnitude of the good and bad things that can happen to me, as a result of taking—or rejecting—possible treatments.

By “understand,” I mean having cognitive control over the issues that are so important to me. I want not only to hear the facts, but also to be able to integrate them into what I already know about the topic (recognizing that some of what I know is wrong and will have to be replaced by better knowledge). I want to be fluent enough to explain my decision to myself and my family.

To tell the truth, I'd also like to have emotional control over the decision. As hard as it might be, I'd like to be at peace with the decision. I want to be able to live with my choice—and its consequences. If things turn out badly, I don't want to add the insult of second guessing to the injury of what has already occurred.

I realize that this can be a tall order. So let me reflect on it now, when I'm not mired in the tensions of an actual choice, and I can be more sympathetic to the constraints on my physician's reality. I do know, in principle, that my physician does not have unlimited time, unlimited knowledge, or unlimited patience for me, especially when decisions have to be made and I might not be at my most reasonable.

What's Likely To Happen?

There's nothing worse than being blindsided by an adverse effect that no one has mentioned—at least not in a way that sunk into my consciousness. On the other hand, not much is going to sink in if lots of far-fetched improbabilities are piled on. I realize that this puts physicians in a bind. So here is what seems like a reasonable compromise: Give me a complete list of possibilities of what might happen with each relevant treatment and with no treatment at all. After that, let's focus on the real risks (but still allow me to bring up the not-so-real ones, if they stay on my mind).

Then, I want some numbers. Possibilities are not probabilities. And one person's “probable” is another person's “likely” or “50–50 chance.” I know that I don't have a precise gut feeling for 3.2% or 32% (not to mention 0.00032%). Still, if you don't give me a chance, I can't even get close. Nor can I start to learn. Over time, I've developed some intuition for a 30% chance of rain (and a 1 in 300 chance of a National League Central Division title). So don't treat me as hopeless, forcing me to divine the number under your verbal label. I may decide to think qualitatively, but that should be my prerogative.

Furthermore, I want to know how good those numbers are. I would love for them to be certainties (unless, of course, they deny me the chance to hope). However, I'm setting myself up for major regrets if I don't learn just how big the gamble is (or that there is no gamble at all). Therefore, tell me how much medicine knows about my condition and about the effects of possible treatments. Tell me, too, how much medicine is likely to know in the not-too-distant future. That way, I can decide whether I want to suffer the consequences of waiting in return for the benefits of learning the results of experiments conducted on others. That doesn't sound very nice, but hey—it's my life.

What's It Likely To Be Like?

Of course, probabilities are only half the equation. I also need to understand the full meaning, for me, of the events to which they are attached. You may have seen so many cases of stroke, diabetes, tendinitis, angina, and so on that the full set of attendant problems is second nature to you. However, it's probably news to me. It might never occur to me that I will have trouble sleeping, feel uncomfortable in public, have constant reminders of my condition, experience moments of panic, or need special efforts to protect my family's health or financial security. Don't assume that I know what you know about what these events entail.

One place where, unfortunately, you may not be able to help me as much is with knowing how these events will feel, should they occur (or should their possibility continue to shadow me). Pain, embarrassment, anxiety, chronic fatigue, addiction—it's hard to know what they're really like without having been there. Even then, they may affect people differently. Still, from your experience, you can provide the outside view of how people behave when they are suffering or enjoying the consequences of a procedure. You may also be able to connect me with individuals so they can relate the inside view of those who have gone before me (or at least with records of their accounts).

One way to project myself into these possible future worlds is to have a coherent "mental model" of how my health works. If I understand some of the physiology, I may be better able to imagine the symptomatology. Seeing the interconnection of effects may help me to integrate the pieces of my personal puzzle and to anticipate my ability to adjust to bad outcomes (or enjoy good ones). Knowing some of the science should also make me more realistic about my prospects by limiting my options for special pleading. That is, it should close some of the loopholes that I would otherwise create for myself to avoid facing the hard reality of what generally happens.

How Do I Decide?

If I am candid with myself I realize that when I ask for more facts about my prospects, my real uncertainties are about my own values. That is, I do not know what I want, having seldom faced such fateful choices. You can help me determine where my uncertainties lie by asking me whether more information (e.g., results of another diagnostic test or data from another study) could, conceivably, alter my choice. If my choice isn't "sensitive" to such information, then I should be thinking about what matters to me rather than about what might happen.

If my challenge is indeed figuring out what trade-offs I want to make, consultation with you, my personal physician, can be particularly valuable but also particularly difficult. It may be tempting for you to tell me what you would do in my stead. That is a useful perspective, as long as I know how you are like me and unlike me and I feel no pressure to accept your hypothetical choice. It may also be tempting for you to tell me what you think I would choose if I understood the circumstances fully and could reflect fully on my prospects. That, too, is a useful perspective, as long as I know how you know me better, and worse, than I know myself—and I feel no pressure to follow this recommendation, either.

Now, here I face a quandary. On the one hand, I'd like advice that is as personal as possible, using my values applied to my circumstances. On the other hand, that leads to quite an abstract inference. That is, figuring out what is perfect for me means that the advice is, by definition, unique. I would need to have a lot of faith in my reasoning ability to believe that I can think my way through to the right decision, working from first principles. Thus, it would probably also help me to hear some other people's stories, following their reasoning as they make choices and their experiences as they live with the consequences. I can then try to locate myself in this space of stories, reflecting on ways in which I am like and unlike those persons.

What Are the Bounds of the Decision?

That's what I need. I realize, though, that it is a lot to ask. In a typical appointment, you don't have the time to give me all the help that I need. Even if you did, I might not have the cognitive or emotional capacity to absorb it all. The only way around these limits is to conceive of decision making as being distributed over time rather than occurring at one intense moment of truth.

There is a run-up to most decisions, during which I sort out my priorities and familiarize myself with the facts. You, or your professional organizations, can help me by producing materials (written, video, or Web based) that will help orient me. I don't want a core dump of things that physicians routinely consider, but material selected according to my decision-making needs, as I've just described them.

There is a denouement to most decisions as their consequences play out. Here, all I'm asking is for you to stick with me. Help me to integrate what has happened into what we've discussed beforehand. Help me to understand the element of luck in both good and bad outcomes. Help me to complete my mental model of my condition so that I can be better prepared for future decisions. And, by all means, don't stop returning my calls if things go

poorly. As frustrated as I may be, it will be even worse if you abandon me. If we've done a good job of framing the decision, my frustration should be tempered by knowing what kinds of promises you were making regarding the outcomes—and regarding our relationship.

Suggested Readings

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