

Dealing with Uncertainty in a Time of Plenty

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It's the newest trend in medicine: "patient-centered care." Cynically, I think, "Isn't that what being a doctor has always been about?" But my curiosity brings me to a workshop, where two patients describe their experience of illness insightfully. One discusses her lymphoma diagnosis followed by breast cancer. She draws a picture in which she places herself at the center of a wheel with many spokes: internist, oncologist, hematologist, radiotherapist, psychologist, cardiologist, physiotherapist, social worker, nurse, pharmacist. "And the patient-centered bit?" she intones. "Well, I am in the center of the confusion. No one talks to each other; they all do their own thing and expect me to be the go-between." She holds up her voluminous medical diary. We clinicians nod knowingly, wanting to believe that we'd never be one of *those* doctors.

The second patient is older. In more measured tones, he delivers the same message regarding his 10-year history of prostate cancer, during which he's seen 12 experts. "First it was whether to have surgery, then hormones or radiation, now it's chemotherapy versus waiting." He reflects, "If you had told me at the start of my illness that more experts led to more confusion, I would have laughed. But now I get it. How can anyone reassure me about my health when they can't agree themselves?" As each appointment approaches, he's filled with dread because even the doctor doesn't know what to do about a supposedly common condition.

An audience member springs up. An oncologist in his late 50s,

he speaks with the kind of authority that can silence a room: "But your doctors don't agree because the data are not clear. It isn't their fault — do you understand that?"

The patient nods. "I do understand, actually, but there are ways of framing an answer so that the patient doesn't feel alone. I came out of many appointments feeling there was no one like me and that there wouldn't ever be an answer to suit me."

"That's my point," the oncologist presses. "When the data are poor, how can your oncologist truthfully tell what is best?"

"I understand that you can't make up an answer where there is none," the patient responds, "but it's the way you say it that counts. I think you'd find that a lot of patients can deal with uncertainty, provided it's explained properly."

"But I can't give you reassurance if I'm not reassured myself!" protests the oncologist. "If PubMed can't inform me, how can I educate you?"

The oncologist is becoming irate at the patient's inability to understand his simple logic. The patient shakes his head at the obtuse doctor. The convener intervenes, reminding us that the point is to keep the whole patient in mind and that patients seek reassurance that their doctors will work alongside them even in times of private doubt. It's hardly a surprising conclusion, but the oncologist is unconvinced. "Is that patient for real?" he mutters.

Indeed, both patient and doctor are for real, and both are troubled by the increasingly visi-

ble uncertainty present in clinical practice. The more medicine advances, the greater the glimpses we're allowed into the human body's complexities, and the more intrigued we are. We realize that there are layers upon layers of explanations, and it's sometimes exceedingly difficult to arrive at simple, understandable definitions of diseases and how they afflict us. Wasn't breast cancer thought to be one uniform disease? Who would have thought that peptic ulcer disease was caused by bacteria and not spicy food? Witness what happened to the children of women who took thalidomide. The phrase "Trust me, I'm a doctor" has become a quaint anachronism — for good reason.

So how can doctors deal with uncertainty in a time when knowledge is plentiful? How do we educate our patients well about what we know but avoid displaying hopelessness when we don't know?

First, we must acknowledge our own feelings. If we're uncertain about a complex diagnosis, decision, or therapy, we're probably not alone. But it's easier to disguise our realization that we don't have all the answers than to accept it and feel like fledgling physicians again. If you've been anointed an expert, how can you safely say you're not sure? The question "What would you do?" wouldn't be so frustrating if experts always had the answer. We shouldn't stop asking experts, but we must let patients know that many opinions do not erase uncertainty: they may attenuate it, even exacerbate it. "I don't know" is not a shameful admission; add

“but I’ll work on it,” and it can signal the beginning of a meaningful engagement. Our patients say this is what they hanker for.

Second, we must harness the available scientific evidence and avoid harping on the shortcomings of clinical trials. Carefully performed trials benefit us in many ways: they deliver information about patient characteristics, drugs, and what will or won’t work in the real world. They seldom crystallize what’s best for a particular patient but usually educate us about what will harm the patient. There is nothing constructive about dismissing the available evidence about a disease, paltry as it may be, without trying to build on it. The responsibility for enrolling patients in clinical trials belongs to us all. Sometimes the additional mandatory tests and biopsies, the delay in screenings when there’s clinical urgency, and the tricky logistics of traveling to a clinical trial center make it far simpler to avoid seriously considering a trial. Trials then attract only desperate patients, limiting doctors’ and patients’ enthusiasm. Yet the only way we’ll get answers to our increasingly sophisticated questions is by actively encouraging participation in trials.

Finally, we need to teach our-

selves how to communicate with our patients about uncertainty. Contrary to doctors’ common belief, we frequently fail to demystify diagnosis and management for patients. We lapse into jargon and sidestep detailed conversations, especially when the evidence is thin and there doesn’t seem to be much to say. As a clinician, I find that often, just as I think I understand something well enough, I’m bombarded by data that make me feel doubtful again. I know it’s rare that a brand-new piece of data will upend a therapeutic decision that has taken into account not just history, examination, and labs, but the whole patient context. But when inadequacy gnaws at us, it’s hard to be thoughtful, communicative, and tolerant of questions that seem designed to exploit this weakness. Ultimately, managing uncertainty comes down to managing one’s own angst.

An exhausted late patient of mine compared his list of chemotherapy options to a series of parallel lanes on an unending highway, when he wouldn’t have minded a progressively narrowing road leading to a dead end. His observation highlighted modern medicine’s constant search for another drug, another test, another opinion that just might save the

day. Myriad communication-skills courses aim to help us navigate uncertainty, but they generally focus on the patient’s experience: a good consult is distinguished from a bad one by how it made the patient feel. But we must also learn to feel compassion for ourselves, especially when the stakes are high and the answers not straightforward. Believing that it’s OK to feel lost in the murkiness of data or that we’re not alone in grappling with fundamental matters like the unfairness of suffering might allow us to appreciate that there are some aspects of our work over which we have less control than others. This appreciation, in turn, can help us communicate more effectively with our patients.

Good communication is about giving patients the confidence that their doctor is an advocate who won’t abandon them. That requires self-knowledge, perspective, and patience for ourselves. If patient-centered care is to fulfill its promise, we need to start redefining how doctors think.

Disclosure forms provided by the author are available with the full text of this article at NEJM.org.

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