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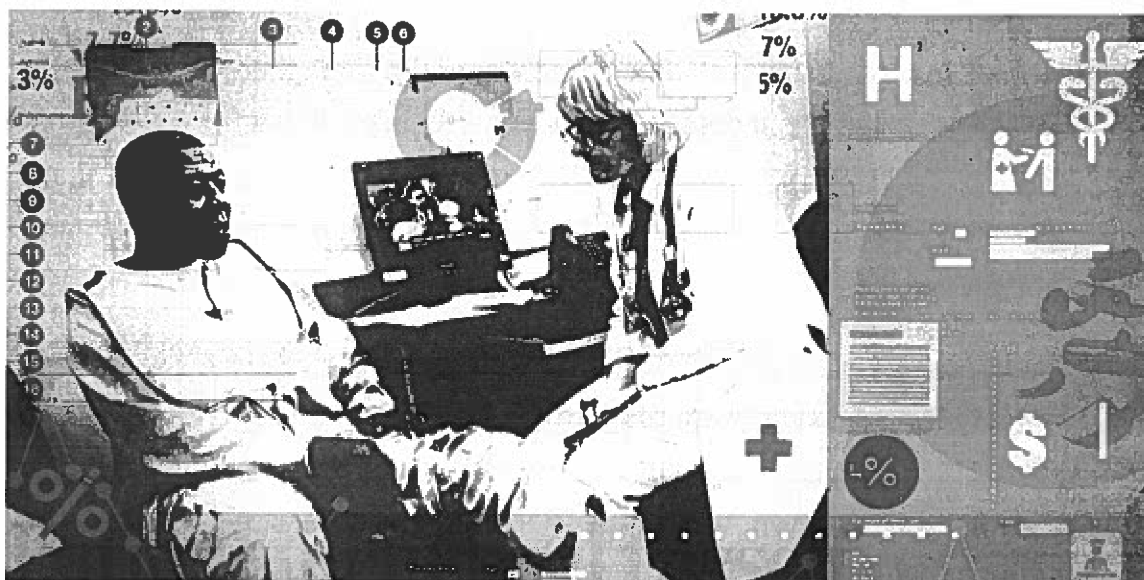
THE MEDICAL ISSUE

# Patient, help heal thyself

## A case for letting patients help pick their treatments.




ALEX WILLIAMSON

**By Dr. Glyn Elwyn and Eric Weinberger** | OCTOBER 13, 2013

THE AFFORDABLE CARE ACT will lead to many administrative changes in how Americans receive and pay for health care, that is clear. But embedded within the vast and complex legislation is also a call for a transformation in how you and your doctors interact: Doctors are now encouraged to talk to you differently, to

fully explain your medical options, and to collaborate when there are difficult decisions to be made about treatment. This process is known by the cumbersome term "shared decision making."

Unless you've attended medical school, this scenario might sound frightening. Patients often want their physicians to understand what matters to them, make good recommendations, but keep decisional responsibility. Most patients probably do not consider themselves health care decision makers — nor do they want to be. They worry about the responsibility the process confers, or anticipate regret if they end up making the "wrong" decision. We know reform is asking us to take a more active role in our health, but for many patients shared decision making is a step too far, as if the professional healer is abrogating her role as expert guide.

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But shared decision making isn't about that, especially when there is one correct treatment. Emergency room doctors aren't about to take a break from what they're doing and ask if you really want them to stop the bleeding. Instead, shared decision making will apply to medicine's gray areas, when there is more than one right option.

Consider the example of breast cancer. Put simply, mortality rates for women with early-stage breast cancer are roughly the same whether they choose lumpectomy (removing just the cancerous tissue) or mastectomy (removing the entire breast). But the procedures differ after surgery: Lumpectomy is usually followed by radiation therapy and comes with a higher risk that the cancer will return; mastectomy is the more disfiguring treatment. Neither treatment is right for everyone. Interviewing patients near Dartmouth College, where we work, we found one woman in her late 50s who wanted the cancer "gone" and said of her breast, "Just take it off." Another patient of the same age told us, "Why would I want any of my healthy breast tissue removed?"

Because the mortality outcomes are so similar when it comes to breast cancer, patients' preferences should matter. But since the imbalance of information between patient and doctor is usually enormous, it doesn't always work that way. Physicians are human beings with their own preferences, developed over years or even decades of schooling and experience.

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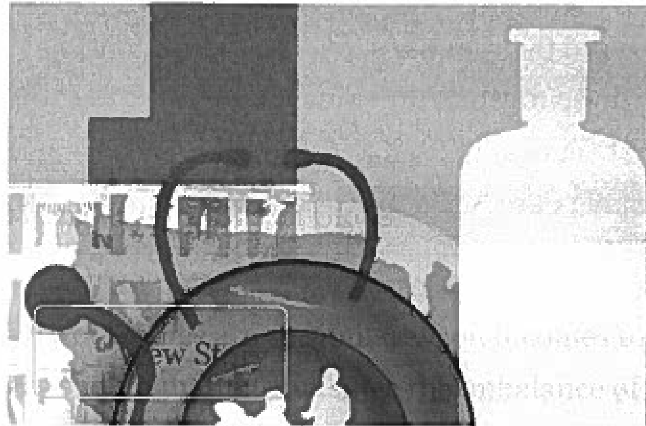

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It is well known among surgeons that some of their colleagues in cancer care are biased toward lumpectomy, preserving as much of the breast tissue as they can. As a result, the consultation between such a doctor and a patient who prefers mastectomy could be, and sometimes is, quite difficult.

Shared decision making is an effort to fix that. Its goal is to improve conversation between informed patient and attentive clinician, leading to a better clinical decision in tune with a patient's preferences as much as with her needs.

This process will certainly involve more work on the part of patients, who will be asked to turn to tools such as booklets, videos, or websites that compare treatment options in neutral, nonjudgmental language. We have five breast cancer DVDs at Dartmouth, along with several dozen other "decision aids" that cover conditions such as knee or hip osteoarthritis and prostate cancer. These tools allow patients and their families to learn more about the variety of treatments, and to do so together, at home if they wish. The problem is that these decision aids are not yet easy to find, and doctors aren't using them enough (one result of the Affordable Care Act is that doctors will have incentives to make them available).

And yet creating a willingness among physicians to participate in shared decision making will also require a cultural change on the other end of the examination table. We might as well face it: Clinicians are accustomed to being regarded as experts and deciders and can be slow to adopt a more egalitarian approach. Most feel that they already share decisions with patients and see no problem that requires federal legislation and incentives to solve. For them, the invitation toward clinical shared decision making can be perceived as either a threat to their status or an insult to the way they have always done things.

Patients don't have to think of themselves as the ultimate decision makers, but they need not accept paternalism, either. It is your doctor's job to make you feel comfortable asking questions, and lots of them. Getting doctors to explain the pros and cons of treatment alternatives in plain English will help them examine their preferences and recommendations.

Among the things you, as a patient, might ask: In this particular situation, are there other options, and, if so, what are they? Is it OK if we do some research on how to compare options? Are there any decison aids to help us figure this out? Is it acceptable to wait — could we possibly do nothing?

Perhaps the reactions to these questions from some physicians will be defensive, even negative. In which case, the solution is simple: Find another doctor. It will be a very arrogant doctor indeed who refuses to work with you to explore your questions. You shouldn't accept refusal or reluctance to pursue answers. During discussions with your doctor, it could be helpful to add that you do not expect those answers immediately; that you know such evidence is hard to obtain and to compare. But also that you are willing to search and read — and listen to tips.

Following this approach, you will be doing every patient an enormous favor: You will be making the medical culture more responsive to all our needs. You will be doing your bit to help doctors realize that they cannot recommend treatments without understanding how they compare, and how what matters most to you must influence the final decision. Yes, you are being asked to share responsibility, but doctors are asked to share what they're thinking, too. Most will admit that the experience is salutary for them as well, making them more thoughtful and purposeful in their recommendations. As a patient, you will be getting much better care, and your doctor will be reminded why he or she got into medicine in the first place.

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