

Shared Decision-making: The Case for Letting Patients Decide Which Choice Is Best

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The decisions physicians make every day—which tests to order, which treatments to prescribe—involve objective and subjective elements. The objective element consists of weighing the potential outcomes, the benefits and harms, of the various options and determining how likely each is to occur. Doing so requires training in medical science to understand the options and a command of current data on the magnitude or probability of potential benefits and harms. It is a task best performed by clinicians and scientists and not by patients.

Once the likely outcomes are known, however, the next step (determining which option is best) is often subjective. Whether a drug that reduces the risk of death from myocardial infarction by 5% is worth a 1% increase in the risk of stroke cannot be answered by facts alone. It depends on the relative importance assigned to the outcomes, a matter of personal opinion. For patients with strong aversions to dying from a fatal heart attack, the drug may be a good choice. But patients who would rather die than live as a stroke victim might choose otherwise. The personal preferences of doctors are, in themselves, immaterial in this subjective arena. Medical school gives the physician no inherent superiority over the patient in deciding whether shortness of breath, back pain, or incontinence is “important” or “trivial.” It is the patient who must live with the consequences, and it is his or her right to decide.

Unfortunately, medicine’s long tradition of paternalism gives patients little opportunity to “weigh in.” Physicians feel that they should decide what is best for patients. Indeed, many patients want them to do so. But does “telling patients what to do” produce the best results?

Consider a complex clinical decision for which value judgments about the best option differ from

person to person. Suppose that a doctor, convinced that his favored approach is superior, prescribes that option for all his patients without stopping to consider their individual preferences. It follows that some, if not most, of his patients will receive treatments other than the ones they would prefer (if properly informed of the benefits and harms of each). Physicians might respond that they know what their patients want, but studies suggest otherwise.^{1,2} Physicians tend to recommend what they themselves would prefer, in effect projecting their own preferences onto the patient. The resulting choice may be good for the doctor but not for the patient.

Consider the screening tests for colorectal cancer. The options include fecal occult blood testing (FOBT), sigmoidoscopy, barium enema, and colonoscopy. Which is best? The science behind each test is uneven: clinical trials show that FOBT reduces mortality,^{3,5} sigmoidoscopy is supported by a weaker class of evidence (case-control studies),⁶ and no study has shown that barium enema or colonoscopy screening improves outcomes. The strong science behind FOBT is offset by evidence of its high false-positive rate. Data suggest that sigmoidoscopy of the left colon lowers mortality, but common sense suggests that inspecting the entire bowel with colonoscopy or barium enema would save even more lives. The tradeoff for doing so is higher complication rates, discomfort, and cost. Thus, there is no clear winner. Which test is “best” depends on how much importance one assigns to hard evidence, “common sense,” complications, and costs. A doctor who advocates only one screening test for colorectal cancer assumes, in effect, that all patients would come down on the same side regarding each of these variables.

A study in this issue of the *Journal* suggests otherwise. Leard and co-workers⁷ gave 100 patients a 10-minute, scripted oral presentation about the benefits and risks of the four screening tests for colorectal cancer. When asked, based on this information, which test they would prefer, 38 patients chose colonoscopy, 31 chose FOBT, 14 selected barium enema, and 13 chose sigmoidoscopy.

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Suppose the same 100 patients had not received this information and were instead cared for by a physician who routinely performs flexible sigmoidoscopy because he considers it the best test. According to these data, fully 87% of the patients would undergo a procedure other than the one they would prefer if properly informed.

The implication of this finding is not that we must pursue shared decision-making in every clinical decision. We need not ask a patient with a gunshot wound to the aorta whether the benefits of surgery outweigh the harms. Physicians, not patients, must decide which blood tests to order in a diagnostic workup. But in the special circumstance when the tradeoff between benefits and harms is a subjective "close call," when selecting the best choice turns on *utilities* (the relative importance one assigns to potential outcomes), a case can be made for seeking the patient's perspective rather than deciding for him or her.⁸ The intent is not to force patients to make decisions—they are free to decline the offer and defer to the clinician—but to give them the opportunity. Nor is this the same as informed consent, the encyclopedic tabulation of potential complications that we recite before procedures. Shared decision-making seeks to educate patients about likely outcomes and the supporting evidence and to engage them in deciding which choice is best, not to provide medicolegal safeguards for the doctor.

Shared decision-making has been advocated increasingly in practice guidelines, where we have seen the growing reluctance of professional bodies to make blanket recommendations on issues involving close tradeoffs. Finding inadequate data to justify a single best choice, guidelines from specialty societies and government panels on such topics as estrogen replacement therapy,⁹ benign prostatic hyperplasia,¹⁰ screening¹¹ and treatment¹² for prostate cancer, and vaginal birth after cesarean section¹³ have instead concluded that patients should be given information about their options and allowed to make a choice based on personal preferences. This approach was recently advocated for colorectal cancer screening in guidelines from the American Gastroenterological Association,¹⁴ endorsed by the American Cancer Society and other groups, and in those from the American Academy of Family Physicians.¹⁵

The principal benefit to considering patients'

preferences is obvious: it helps ensure that patients actually want the tests and treatments we administer. But there are other, perhaps more important, benefits. Giving patients information about their options improves satisfaction.¹⁶ They appreciate the opportunity, when offered, to take a more active role in their care.¹⁷ Studies suggest that empowering patients to make more informed health care choices improves clinical outcomes.^{18,19} And ensuring that patients actually want the treatments they receive promotes more rational use of costly technologies. How many health care dollars are spent on procedures that patients would decline if properly informed about their limitations? Recent studies report that providing structured information about benefits and risks leads to dramatic reductions in requests for prostate-specific antigen screening^{20,21} and in surgery for benign prostatic hyperplasia.²²

But there are problems with shared decision-making. Chief among these is that many patients do not want to make decisions about their care.²³ They prefer a more passive role (because they are ill, question their abilities, or fear the consequences of making the wrong choice) and ask the doctor to recommend what is best. Even for those patients who do want to decide, it is difficult to ensure that they understand the tradeoffs, probabilities, and technical issues well enough to make a good decision. Some patients have a distorted sense of the probability or implications of certain procedures, perhaps as dramatized on television, creating misconceptions that cannot be overcome by a few minutes of counseling. In these cases physicians may have a better sense of priorities and make better decisions.

Busy physicians have their own problems with shared decision-making. They have little time for long talks. Few can replicate the methods used by Leard et al,⁷ in which a trained interviewer spent 10 minutes with each patient in a private room, reviewing the data with pie charts and tables. Such counseling is rarely reimbursed under fee-for-service plans, and capitation contracts under managed care present a disincentive for lengthy visits. Many clinicians lack aptitude for shared decision-making, being unfamiliar with the data and thus unable to present the facts, lacking communication skills to make the options clear, or inadvertently introducing biases that sway patients' choices. Some physicians, especially those wedded to

paternalism, are uncomfortable with the very notion of letting patients decide what is best. Others see it as an obstacle to quality improvement, recognizing that office tools for implementing guidelines (eg, flow sheets, standing orders, reminder systems) work best with simple, consistent protocols and not a multiplicity of options.

Solutions for many of these problems are on the way. Researchers have developed validated tools (eg, brochures, balance sheets, decision boards, videotapes, interactive videodiscs) that give patients factual information about their options.²⁴⁻²⁷ Busy clinicians who lack the time for lengthy discussions can send patients home with these materials or can delegate some of the counseling steps to other colleagues in the office or through referral. Family physicians and others with continuity practices can extend the discussion over multiple visits, giving patients time to review the educational materials at leisure and discuss their preferences at future appointments.

But the problems with shared decision-making go beyond patients and providers. Health care systems and payers may not be supportive. Although, as noted, early evidence suggests that giving patients control over decisions reduces prostate testing and treatment,²⁰⁻²² the reverse may be true in other areas, potentially driving up demand for expensive interventions. Managed care organizations and other payers may be unwilling to expand coverage for services simply because patients want them.

Finally, society may dislike shared decision-making. Consider the reaction earlier this year to the conclusions of the National Institutes of Health consensus conference on mammography screening for women aged 40 to 49 years.²⁸ The panel reasoned that whether such screening is appropriate is a subjective judgment (whether a 0.04% to 0.07% reduction in the risk of dying from breast cancer within 10 years is worth the 8% to 20% risk of biopsy or surgery) and that this judgment should be made not by government but by individual women, in consultation with their doctor. Advocates of screening lashed out at the panel for its ambiguity, calling its report a "death sentence to thousands of women."²⁹ The news media, health professionals, and the public said that it increased confusion. If experts cannot decide what is best, they argued, how can the layperson? Everyone, it seemed, wanted the panel to take a firm position, to tell

women what to do.

But studies such as that by Leard and associates⁷ compel us to examine the ethics of this sentiment, to ask ourselves whether we truly help people by promoting uniform practice policies. When health care preferences vary dramatically, when judgments about the best choice vary from person to person, is it ethical to promote only one option and not to tell patients about the alternatives? Is it defensible to let patients undergo treatments they would decline if properly informed about the benefits and limitations, because we want to offer easy-to-understand, consistent advice and not "confuse" them? That it is difficult to present the details and for patients to understand them, that some patients ignore the information and defer to the doctor, bears little on the duty to provide it. Clearly, further research and debate are needed to clarify the proper methods and indications for shared decision-making. But to take the easier path and rely instead on our own preferences ignores our duty to ensure that the tests and treatments we administer, which put patients at risk and consume limited resources, are what our patients truly want.

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