

Let's Require Patients to Review a High-quality Decision Aid Before Receiving Important Tests and Treatments

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THE PROBLEM

When providing medical care, choices often must be made among 2 or more medically reasonable options. In the United States, and elsewhere, most of those decisions are made by physicians, with patients being relatively uninformed and uninvolved, sometimes not even knowing more than 1 option existed.¹⁻³ Many prominent groups have called for more shared decision making, asking physicians to make efforts to provide patients faced with a decision with needed information about their options and to encourage patients to participate in making a choice. These groups include The National Quality Forum,⁴ the Patient-Centered Primary Care Collaborative,⁵ the American Medical Association,⁶ the National Learning Consortium,⁷ and the National Academy of Medicine.⁸ The Institute of Medicine made this its first principle of patient-centered care: "Respect for patients' values, preferences and expressed needs: Involve patients in decision making, recognizing they are individuals with their own unique values and preferences. Treat patients with dignity, respect and sensitivity to his/her cultural values and autonomy."⁹ However, so far, not much has changed in day-to-day practice.

In this paper, we argue that the most effective and easiest way to increase patients' knowledge and involvement in decisions about their medical care is have them review high-quality decision aids before getting important tests and treatments. Further, in order to make decision aid delivery happen routinely, we propose that physicians should be paid for providing decision aids to their patients and payers should require that patients review these decision aids as a prerequisite for paying providers when these services are rendered. We will outline the benefits that will accrue from this policy, why we think arguments against routinely providing decision aids are not sound, and the specific steps needed to make this policy change happen.

THE BENEFITS

- (1) One of the key ethical standards for medical care is beneficence, that providers should favor the well-being and interests of the patient in each situation. To personalize care, providers need to understand what is most important to patients and tailor testing and treatment recommendations appropriately. However, studies suggest that patients' preferences rarely drive practice. Exposure to high-quality decision aids clearly helps to better align treatment with preferences.^{10,11}
- (2) In addition, there is a legal requirement for informed consent that ensures patients are able to make an informed and voluntary decision about accepting or declining medical care. Unfortunately, here, too, a preponderance of evidence suggests informed consent as currently practiced does not ensure patients are informed and involved in medical decisions. Routinely viewing decision aids could help elevate the level of informed consent.¹²⁻¹⁴

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- (3) A different issue is that when patients are not well informed, and physicians make decisions for them, medical care is not appropriately distributed. The phenomena of geographic practice variation and health care disparities by sex, race, and ethnicity illustrate this problem.^{15,16} Many studies show that patients often decline offered treatments when they are informed by a decision aid. In the United States, there is probably overuse of tests and treatments on average. In settings with overuse, decision aids can reduce the delivery of unwanted care.^{11,17–19}
- (4) The use of decision aids can not only help address overuse but also underuse of tests and treatments, especially for vulnerable populations. The use of decision aids was associated with a reduction in the rates of knee and hip replacement in one major medical setting.²⁰ More intensive distribution of decision aids to patients considering surgery by health plan health coaches in a randomized trial was associated with less surgery.²¹ However, studies have shown an increased use of some underused treatments when decision aids are used to inform patients, especially those with lower health literacy. For example, Ibrahim and colleagues had his Black patients considering hip or knee replacement review the same decision aid used in the above study. In the Ibrahim study, seeing a decision aid before making a decision led to an increase in the use of knee replacement.²² A Cochrane review of the use of decision aids for testing and treatment showed decision aids can increase use of high value care including colorectal cancer screening, use of medication for heart disease, and actions to prevent diabetes.¹¹ It is likely that if patients were more informed and involved in their treatment decisions, there would be less unwanted practice variation and less overtreatment and undertreatment.
- (5) However, the most salient argument for routine use of decision aids is that decisions are better because patients get the care that is most consistent with their own informed values and preferences. The studies demonstrating that point have shown that decision aids produce patients who have less decision conflict, are more engaged in the decision process, make decisions that are consistent with what they say the value, make decisions they say they would make again, and make decisions that are informed and consistent with what patients say they want.^{8,10,11,23,24}

About the Counter Arguments

When the issue of the routine use of decision aids is brought up, there are 3 basic counter arguments: patients do not want it, doctors should be the ones to inform patients, and doctors do not have time for shared decision making.

- (1) Patients do not want decision aids. There is a widespread perception that many patients want to delegate decisions to their doctors, especially older patients, those with less formal education and those from racial and ethnic minorities. We have asked literally thousands of patients who watched decision aids what they thought, and almost none said they got more information than they wanted or would not recommend that patients get the information they learned. For example, in 1 study, 2900 patients were

given decision aids for a variety of decisions. A third were over 65 and a third had no formal education past high school. When they were asked for their opinions about the use of decision aids, over 80% said it was “extremely” or “very” important for patients to see decision aids when making a decision, and 95% rated the decision aids “excellent,” “very good,” or “good.”²⁵ In another study involving over 2000 patients who had been given decision aids for surgical decisions, 95% or more rated the decision aids “good” or better in helping them understand their conditions and their choices and helping them understand what was important to them.²⁶

Research by Frosch and colleagues provides some insights into where the perception that patients do not want to be informed and involved might be coming from. When they conducted focus groups with patients about their interactions with doctors, they found many patients, particularly older patients, felt intimidated by asking their doctors questions, largely because they did not want to be seen as “problem patients.” This reticence may lead some physicians falsely to conclude patients are not interested in being informed and involved.²⁷ In fact, decision aids have been shown to increase patients’ participation in medical decisions.¹¹ Of course, there are some patients facing some decisions who prefer to heavily weight their doctors’ opinions. However, that is more the exception than the rule. Very few informed patients want to completely delegate decisions to doctors and almost none would prefer to be uninformed about their options.

- (1) Let physicians inform patients. Leaving it to physicians to explain complex information and options to patients in a clear and balanced way does not work as well as using decision aids because:
- Often physicians are not fully versed in the latest clinical science; they do not necessarily have the latest and best information at their fingertips. Moreover, some studies suggest that physicians are frequently confused themselves by quantitative data on risks and benefits of interventions like screening tests for cancer.²⁸ Decision aids can be created by true experts without conflicts of interest and reviewed regularly to make sure they have information that is balanced, accurate, and up to date.
 - It takes a good bit of time to explain the nature of a condition, the options for testing or treatment, and the potential benefits and harms of each option. Having patients review decision aids before seeing the physician can make better use of limited physician time.
 - Particularly if there are quantitative risks and benefits that need to be communicated, there is excellent evidence that appropriate visual presentations are needed to make such evidence clear to most patients. It is particularly important to note that when good methods for risk communication are used, people with less education can become as informed about risks and benefits as highly numerate college students.²⁹ The use of well-developed decision aids can effectively communicate complex information to most patients.

- (d) Decision aids can present options in a balanced and fair way. It is hard to ensure such consistency and balance in an ad hoc presentation. For example, studies have shown that urologic surgeons and radiation oncologists made different recommendations when presented with the same profiles of prostate cancer patients, favoring the treatments they themselves deliver.³⁰ Perhaps a more concerning example is Rothberg findings that patients who underwent percutaneous coronary interventions greatly overestimated the survival benefits of their procedures, although their cardiologists generally understood the outcome data.³¹ Deyo et al³² similarly found that spinal fusions were being done at an ever-increasing rate, despite clear evidence that a less invasive and expensive alternative was just as effective for many patients, and had fewer complications. Definitely one of the great advantages of having patients see a well-designed decision aid is to reduce the degree to which physician biases affect the presentation of the options.
- (2) Using decision aids takes too much time. Physicians have only limited amounts of time to spend with patients. Insurance paperwork, electronic medical record systems, and other nonmedical demands on their scarce time mean that adding another responsibility feels unreasonable. We have often heard doctors express concern that having patients use decision aids will increase the amount of time they have to spend with patients. However, orthopedic surgeons in an experiment using decision aids said that patients who had seen decision aids asked better questions and the surgeons rated the efficiency of visits with patients who had seen decision aids significantly better.³³ Another study found that 87% of orthopedic surgeons who used decision aids rated the visits with patients “normal” or shorter than normal.³⁴ A survey of primary care physicians who used decision aids found 75% saying use of decision aids does not lengthen visits.³⁵ The Cochrane review found that decision making visits after patients saw decision aids took, on average, only 2 minutes more than usual care.¹¹ Overall, the evidence does not support the idea that taking up physician time is a reason not to use decision aids.

A related argument is that the routine use of decision aids would require too much support staff time. We think that concern is primarily a reflection of the fact that informing patients is not a priority.

The Solution

We propose the following steps to make the use of decision aids routine when patients are facing decisions about important tests and treatments:

- (1) As a start, make a list of 15–20 medical situations in which most patients have 2 or more reasonable options about tests, medications, surgery, or other kinds of treatments. The list should be weighted toward decisions that are common and involve significant quality of life or monetary costs for patients.
 - (2) For each decision, identify 1 or more available decision aids. The Ottawa Hospital Research Institute maintains an extensive inventory of decision aids on its Web site.³⁶ Obviously, if there are not good decision aids for a topic, that would be a reason for deferring inclusion of that decision until a good decision aid was created.
 - (3) Set up and fund an independent organization to certify the quality of decision aids. Alternatives for funding include having the certifying organization supported by payers or by the manufacturers of decision aids. The certifying organization itself should not have any relationship to any organization that has a financial interest in particular decisions or medical interventions. The individuals in key positions, particularly those who vet the evidence, need to be conflict free. The National Academy of Medicine provides a model for the criteria for members of committees in order to produce trustworthy clinical practice guidelines.³⁷
 - (4) Make certification that a decision aid meets high standards a requirement for using it to qualify for payment. Certification criteria should include ensuring that the pros and cons of all reasonable options are presented in a balanced way, that it is made clear to patients that there is a decision to be made and their values and concerns have a role to play, that the program uses strategies for conveying risks and benefits that are appropriate for all audiences, that programs have been tested with patients for clarity and balance, and that the evidence is up to date and fairly presents what is known. This evaluation is a very important step. There are hundreds of decision aids that have been created, as the listings on the Ottawa Hospital Research Institute can attest.³⁶ However, they vary widely in quality.³⁸ When Washington State launched a program to encourage the use of decision aids, it also initiated the first decision aid certification program in the country.³⁹ Their criteria are on their Web site.⁴⁰ The National Quality Forum has also published a set of guidelines for evaluating decision aids,⁴¹ using Washington State as a model. Both of those efforts built on the work of the International Patient Decision Aids Standards group.⁴² So the work of establishing quality criteria is well along. The critical needed step is to have an organization that systematically applies them.
 - (1) Set up the decision aids on a Web site. The site should be able to document that a patient went through the decision aid and could ask a few questions at the end to assess whether patients understood the basic content.
 - (2) Health care payers, private insurers, Medicare, and Medicaid should establish a policy that in order to get paid for a test or procedure that is on the list, a provider must first arrange for the patient to view a certified decision aid. Physician practices should also be given a modest payment for providing decision aids to their patients. An additional benefit to physicians of a program like this is that medical liability insurers may offer a discount on premiums to physicians who routinely use decision aids, as one insurer did in Washington State.⁴³
- How this program might affect smaller practices will vary greatly. However, just as small practices have been banding together to make electronic records and other quality improvements

work better, there may be some incentive for small practices to work together to use decision aids more cost effectively.

Why Via the Web?

It is true that some people will have problems accessing decision aids on the web, and allowance will have to be made for them. However, the web is the easiest way to widely deliver audiovisual material to most people. Having the information on the web also provides the opportunity to potentially individualize the information, for example by tailoring risks and benefits to the characteristics of the patients. Finally, it also provides a proven way to easily verify that patients have been through the decision aid. Although not all good decision aids are available for use on the web, we have reviewed the lists of aids on the Washington State site and in the Ottawa Research Institute catalog and found that the clear majority of decision aids are designed for use on the web.^{36,39}

Why Such an Approach?

Because Medicare and the program in Washington State have tried less drastic approaches, and they have not worked. Medicare requires shared decision making and use of decision aids for several procedures such as low-dose computed tomography scans for lung cancer screening and implantable defibrillators. However, they do not have a certification system in place, nor can they verify that decision aids were reviewed. The assessments so far suggest that the CMS approach has not been successful.⁴⁴ Washington State was very advanced in certifying decision aids. However, using decision aids depended on physicians' interest, perhaps in part to take advantage of protections against malpractice suits that were built into the Washington state program. Physicians have not proven to be very interested. To quote the latest assessment from the group overseeing the Washington State effort is: "Unfortunately, involving patients as equal partners in health care decisions that have multiple clinically appropriate options by fully discussing risks and benefits remains limited within clinical practice."⁴³

Requiring patients to use certified decision aids, in a way that can be verified, before paying for a test or treatment seems to us the clear path to finally making the use of decision aids routine.

How Can It Happen?

Although we urge all current payers to adopt this policy, Medicare, given the size of its enrollment and the fact that its members are most likely to face serious health decisions, would be the obvious candidate to take the lead. It would be ideal if Medicare would build on what it started with respect to lung cancer screening and implantable cardiac devices. The 2 key steps would be setting up and funding a certification program and requiring the use of certified aids as a condition for paying for designated interventions. However, it may be that some other payers want to get out front on this. For starters, they could build on the certification work that has been done by Washington State and the evaluations that the Ottawa Hospital Research Institute routinely does on decision aids they list on their Web site.^{36,39}

We realize, of course, that requiring decision aids is not the same as requiring shared decision making. Although decision aids seem to stimulate a more participatory interaction between patients and providers, they do not ensure it. The ideal we aspire to is that patients are informed and have their views fully represented when decisions are made. However, routinely monitoring the quality of patient-physician interaction is not widely feasible at this time. We fully support training physicians in shared decision making and doing whatever can be done to use these skills. Yet, at this time, the routine use of decision aids seems to us the clearest, simplest and most practical approach to having more informed and more involved patients. This proposal is highly consistent with other thinking about how to increase the voice and power of patients in their medical care, such as the highly praised NUKA project: an innovative reorganization of health care delivery in Anchorage, Alaska, through which Alaska Native people are in control as the "customer-owners" of their health care system.^{45,46}

There is a wealth of evidence that when patients review good-quality decision aids, they generally do understand their options and the pluses and negatives of the alternatives and they participate more in making decisions.¹¹ Making decision aids routine will produce more informed and involved patients. If we can achieve that, we will have taken a big step toward improving the match between the medical care that is delivered and patients' goals and preferences. In turn, that step forward will increase the value of the medical care patients receive.

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