Quality Matters
Helping Patients Make Better Treatment Choices with Decision Aids

Summary: When patients are given decision aids, such as educational booklets, DVDs, or interactive tools, to help them make treatment choices, they are more knowledgeable and satisfied with their care. But the use of such aids as part of "shared decision making"—a communication approach that seeks to balance clinicians' expertise with patients' preferences—has until recently been limited to research trials. Now some health systems and public policymakers are supporting more widespread use of shared decision making in efforts to promote patient engagement, reduce inappropriate use, and control costs.

By Martha Hostetter and Sarah Klein

In a recent national survey of adults facing a medical decision—to take a new medication, have elective surgery, or undergo a cancer screening—patients overwhelmingly said they wanted to learn about the risks associated with various treatment options and have their providers listen to them. But less than half of patients reported that their provider asked them about their goals and concerns for treatment.

To address this problem, some private payers and public policymakers, as well as some health care systems, are encouraging the practice of shared decision making, which involves not just a physician recommending a course of action, or a patient left on their own to make a choice, but rather both parties working together to balance clinicians' experience and expertise with patients' preferences and values. Decision aids such as educational literature, videos, or Web-based tools are designed to help patients prepare for these conversations by weighing the potential benefits, risks, and uncertainties of a medical procedure.

A literature review of shared decision making trials that involved patient engagement, use of decision aids, and discussion of health problems and potential treatments found that this communication approach is consistently linked to greater satisfaction among patients. And a comprehensive review by the Cochrane Collaboration found the use of decision aids, in particular, improves patients' knowledge of and satisfaction with their care. Patients viewing decision aids also chose to pursue major elective invasive surgery less often—a finding that has caught the attention of those hoping to reduce overuse or misuse: research has shown that as much as 25 percent of elective surgery may be unnecessary or inappropriate. But in spite of the evidence that patients value the tools and learn from them, and in spite of their potential to reduce inappropriate use and control costs, decision aids and shared decision making are not in widespread use. "Given the level of evidence, this may be one of the best-documented but underused intervention in American medicine," says Michael J. Barry, M.D., president of the Informed Medical Decisions Foundation, a nonprofit that develops and disseminates shared decision making tools. (See Q&A with Richard Wexler, director of patient support strategies at the Informed Medical Decisions Foundation.)

Prescribing Shared Decision Making and Decision Aids

Shared decision making is encouraged for patients with "preference-sensitive conditions," for which there is more than one reasonable form of treatment. Unlike situations in which the course is clear—say, operating to remove a burst appendix—there is no clear "best" choice of treatment for others such as early-stage breast cancer. Deciding whether to have mastectomy or lumpectomy, or undergo radiation, may be a function of a patient's preferences and tolerance for risk.

Because decision aids play a vital role in the shared decision making process, a number of research groups, companies, and health systems have been developing them. Some, like those developed by the nonprofit group Healthwise or the private companies Welvie and Health Dialog, come in the form of videos, educational literature, and/or interactive tools that patients typically use on their own time to learn about their treatment options and hear from patients who have undergone them (or have chosen not to). Others, like those developed by the nonprofit group Advance Care Planning Decisions for end-of-life care planning or the Mayo Clinic for chronic care, are designed to be used during office visits, with clinicians working alongside patients. In all cases, they are meant to complement, rather than replace, direct counseling from physicians.

Yet another model is used by Expert Medical Navigation, a company founded by Mass.-based vascular surgeon Ibramin Eid, M.D., after meeting patients who had undergone surgeries without understanding the procedures' limitations. After assessing patients' level of knowledge and providing relevant decision aids, Expert Medical Navigation pairs patients with board-certified specialists who test whether they understand the risks and benefits of different treatments. "[The doctor] is not in your town. He doesn't know your doctor and he doesn't see your records because he's not providing a second opinion," but is rather assessing your ability to make an informed decision. "Our motto is, 'Don't get a second opinion. Get the first one right,’” he says.

Eid says one of the benefits of Expert Medical Navigation's approach, which is only in pilot testing, is that it provides feedback to the original physician about how effective his or her communication on different treatment options has been. "Even in my own practice, we have 20 percent of patients saying they learned things [from the outside physician] we didn't discuss," he says. It can also provide feedback to primary care physicians about the effectiveness of communication by specialists to whom they refer.

Putting Decision Aids Into Practice

Much of the evidence on the effect of decision aids has emerged from research trials, but now several health systems are experimenting with their use as part of routine clinical practice.

Seattle-based Group Health decided to implement decision aids in 2009, after finding evidence of unwarranted variation in elective surgery—even though they are an integrated health system with standard care protocols and salaried surgeons. As reported in a recent...
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Group Health's use of decision aids in one area—orthopedic surgery—led to 26 percent fewer hip replacement surgeries and 38 percent fewer knee replacements over a six-month period.

Initially, the decision aids—DVDs and educational booklets provided by Health Dialog—were distributed to patients by specialists after their initial visit. But Group Health is now encouraging primary care physicians to order the aids at the point of referral under the assumption that having such information would be most useful to patients before their initial contact with surgeons.

To convince physicians of the decision aids' value, Group Health had providers review the aids and shared positive feedback from patients. "We wanted providers to know that this was going to help better educate their patients, not replace their need for the provider's opinion," says David Arterburn, M.D., M.P.H, a general internist and associate investigator at Group Health Research Institute. "That was the approach that worked best for us—not focusing on unwarranted variation, which put surgeons on the defensive—but talking about better educated patients and higher quality of decision making."

An added incentive is greater liability protection: in 2007, Washington became the first state to pass legislation establishing increased legal protection to physicians who clearly document that decision aids were used during the informed consent process.

The Mayo Clinic has been developing and testing its own decision aids since 2005 and distributing them free of charge to other health care providers. Most of Mayo's decision aids are related to chronic disease care and are designed to be used as conversational props during office visits. For example, the Diabetes Medication Choice Decision Aid helps patients and their providers choose among the six medications commonly used to treat type-2 diabetes. Patients choose the options that are most important to them—blood sugar control, method of administration, daily sugar testing required, risk of developing low blood sugar, weight change, side effects, and costs—and then work with their physicians to make side-by-side comparisons among the drugs, based on the chosen criterion. Sometimes a second or third criterion is necessary to make a decision.

"These cards open a space for conversations that just do not happen without them," says Victor Montori, M.D., director of the Health Care Delivery Research Program at Mayo. "We had one patient who said the risk of having low blood sugar was most important to him. This was surprising until we learned he was a surgical orderly—since his job required him to stand and be attentive for long stretches, having a diabetes drug that never led to low blood sugar was a priority."

Mercy Clinics, based in Des Moines, Iowa, is one of 10 demonstration sites funded by the Informed Medical Decisions Foundation to gauge the impact of decision aid use in both primary and specialty care practice. Starting in 2009, eight of its primary care clinics adopted decision aids as part of efforts to engage patients and better coordinate their care under the medical home model. After providers identify patients who may benefit, health coaches distribute the aids, either booklets or DVDs, and then follow up with patients to discuss their treatment options. Thus far, the pilot has shown that more patients who were unsure about their treatment options leaned toward nonsurgical treatments after using the aid.

According to Del Konopka, R.N., M.S., education coordinator for Mercy's accountable care organization, Mercy's pursuit of shared decision making helped to lay the groundwork for its creation of an accountable care organization. (The health system officially launched its accountable care organization on July 1, 2012, under the Medicare Shared Savings Program.) In fact, all health care organizations that are participating in the ACO program are required to demonstrate their use of decision aids and CMS has said it will measure groups' success in doing so.

Medicare is also experimenting with direct support of decision aids. As part of the Health Care Innovation Challenge grants, the Center for Medicare and Medicaid Innovation awarded $6.76 million in June to the St. Louis, Mo.—based company Welvie to demonstrate how its surgery decision support program affects treatment decisions and surgical outcomes among Medicare beneficiaries. In the trial, the program will be offered to 160,000 beneficiaries in Ohio, with 160,000 of the state's beneficiaries serving as a control.

Welvie's online decision support tool uses short video, tutorials, and animation to walk users through the steps of clarifying their diagnosis and exploring their treatment options. For those who choose surgery, it offers advice on what to expect and how they can prepare, for instance by encouraging friends to accompany them to the hospital and ensuring that clinicians mark the incision site and provide appropriate antibiotic to discourage infection.

Barriers to Shared Decision Making

As Barry, president of the Informed Medical Decisions Foundation, points out, despite the enthusiasm of shared decision-making proponents, the approach has not spread widely. Many in the industry say they face an uphill battle in persuading providers of their value, especially when physicians are pressed for time. Those institutions that are most effective tend to have executive support, independent or external sources of financing for implementation, and established processes to review patients' experiences and outcomes.

The experience of another effort supported by the Informed Medical Decisions Foundation, its Breast Cancer Initiative, underscores the challenges of getting practices to adopt decision aids on their own—without the top-down support provided in a health system such as Group Health or Mercy Clinics.

Under the leadership of Karen Sepucha, M.D., director of the Health Decision Sciences Center at Massachusetts General Hospital, some 250 clinics have been sent letters offering them free breast cancer treatment decision aids over the past seven years. Among the 127 sites expressing interest, about half used the decision aids and 37 continue to actively use decision aids in their practices. In surveys, practices list among the main barriers to using decision aids the fact that they didn't have a way to identify patients who would benefit from the decision aids, lack of time to distribute them, too many other educational materials, and lack of clinician support.

"To achieve implementation of decision aids beyond the early adopters, it will take some combination of leadership commitment, financial support, clinician support, and possibly external pressure via performance measurement or legislative mandate," says Sepucha. "I don't think anyone has the answer yet to which lever is best, and [I] imagine that we will need some combination to reach a tipping point. What we did find is that some of the best ways to generate clinician support are to have them watch the programs and to give them positive feedback from their patients who have watched them."

Leaders at Group Health and Mercy Clinics add that implementing decision aids must be part of a larger process involving review of health care outcomes and engagement with providers. "It's not just the aid that's driving lower rates of surgery, lower costs," says Group Health's Arterburn. "It's the entire strategy to raise awareness about surgical care—the fact that we had providers review decision aids, met with them repeatedly, tracked volume of aids delivered, and gave providers feedback on surgery volumes."

http://www.commonwealthfund.org/Newsletters/Quality-Matters/2012/October-November...
It's worth noting that not all patients will want to share in decision making, but instead may prefer to have their physicians make decisions in their best interest. According to the national survey referenced above, a sizable minority of patients (20 percent) did not want to hear the full truth of their diagnoses, and even more (30 percent) did not want to hear about the risks of treatment.

On the other hand, some patients may want to make decisions independently, without hearing their physicians' views. Still others may want to move beyond the use of decision aids to play active roles as fully informed and engaged members of their health care team.

Payment Reform, Culture Change Needed

There is a clear business case for the use of decision aids to promote safe, recommended care and reduce unwarranted variation in health systems that receive global or per capita payments to manage the overall care for a patient population. But it will likely take new incentives to encourage providers working in fee-for-service environments to adopt decision aids. "When doctors are being paid not for episodes of care but quality of care—that's going to make a difference," says Martin Gabica, M.D., chief medical officer at Healthwise, a nonprofit that develops health information and interactive decision tools.

Providers also may need different kinds of training and incentives to engage in open conversations with their patients about treatment options and uncertainties, says Dave deBronkart, one of the founders of the Society for Participatory Medicine and an advocate for patient engagement known widely as e-Patient Dave. "We need a culture of accepting—despite what some doctors were taught in medical school—that it's not necessarily their job to provide certainty to patients. Patients and families, especially those under stress, need to know that there are often hard choices; that it's okay to ask what their options are."

deBronkart believes strongly, too, that health care organizations should be required to proactively disclose their safety records and accident rates as part of any decision on whether or not to treat. "At the best hospital in America, according to CMS Hospital Compare, 5 percent of patients die from preventable complications," he says. "For there to be integrity in the shared decision making process, this kind of information has to be included."

Notes

1 More than 80 percent of patients said they wanted their providers to listen to them; 80 percent wanted to know the full truth of their diagnosis, even though it may be uncomfortable or unpleasant; and 70 percent wanted to understand the risks of treatment. The survey also found a professional bias toward intervening: among providers offering a definitive recommendation (80 percent), patients reported that providers overwhelmingly recommended pursuing surgery, a new medication, or procedure.

2 A May 2012 Cochrane review of 86 randomized trials found that patients who use decision aids improve their knowledge of their treatment options, have more accurate expectations of the potential benefits and risks, reach choices that accord with their values, and more actively participate in decision making. Instead of elective surgery, patients using decision aids opted for "conservative options," including medication, physical therapy, and waiting, more often than those not using decision aids. RAND and others have found that up to 25 percent of elective surgery is unnecessary. Evidence of overuse or misuse in other medical procedures is widespread. For example, recent news stories focused on a federal investigation of thousands of potentially inappropriate angioplasty and other cardiac procedures in the for-profit chain of HCA hospitals.

3 The Washington law also established a shared decision making demonstration project and designated it as one strategy to be used in governor-appointed collaborative aiming to improve quality and outcomes. Two other states, Vermont and Maine, have passed legislation promoting shared decision-making. See A. Shafir and J. Rosenthal, Shared Decision Making: Advancing Patient-Centered Care Through State and Federal Implementation, National Academy for State Health Policy, March 2012.

4 Mayo Clinic recently became a Shared Decision Making National Resource Center. Such centers were created by the Affordable Care Act to develop and assess decision aids and offer technical assistance to providers in implementing them.

5 The Center for Medicare and Medicaid Innovation was created under §3021 of the Affordable Care Act. Other parts of the federal health law reform seek to promote shared decision making, including through a new—and as yet unfunded—program to develop, test, and certify decision aids and research through the Patient Centered Outcomes Research Institute.

6 For its Hospital Safety Score, the Leapfrog Group scored 2,600 general hospitals on the Agency for Healthcare Research and Quality's Patient Safety Indicator 4, Failure to Rescue, used to assess the number of deaths per 1,000 patients who develop specified complications of care during hospitalization. It excludes patients age 75 and older, neonates in MDC 15, patients admitted from long-term care facilities, and patients transferred to or from other acute care facilities. Of the 2,600 hospitals, the best hospital had 48 deaths from preventable complications per 1,000 Medicare discharges, or 5 percent. For more information, see www.HospitalSafetyScore.org.