

issue brief

The Current and Future Role of Consumers in Making Treatment Decisions

In February 2007, AcademyHealth conducted a meeting on behalf of the Robert Wood Johnson Foundation to examine the role of consumer engagement in improving the quality of health care. In preparation for this meeting, five papers were commissioned on the following subjects: consumer activation, consumer choice of health plan and provider, consumer choice of treatment, patient navigation, and the appropriate role for consumers. This issue brief is based on the paper exploring the evidence for and use of patient decision aids, which was authored by Karen Sepucha, Ph.D. and Albert G. Mulley Jr., M.D., M.P.P.

Making Treatment Decisions: Why Is It So Hard?

Life is full of decisions, but few are as consequential as those we make about our health and health care. Depending on the underlying condition, a lot can be at stake. Unfortunately, evidence suggests that most people have to make these decisions without complete information, under stress, and without the level of engagement and communication they might prefer to have with their health care providers.

Of course, not all choices are equally important or involve the same decision-making processes. A patient's choice of whether or not to undergo chemotherapy is very different from the choice of whether to

have cosmetic surgery. Some choices must be made within a discrete time frame and lead patients down a defined path; others are small decisions repeated over time that may—in total—affect an individual's overall health in the context of a chronic condition. In both cases, it's often hard for people to know which steps will lead to better health. Even the little choices are very challenging for most people—real behavior change is not easy—and the major ones, including significant treatment decisions, are all the more complex because there is so much at stake. Ultimately, it's hard to make good health care decisions alone.

When making treatment decisions, most patients rely on advice, support and information from their friends, family members and health care providers. Of course, the relative dependence on each of these sources varies from one patient to the next. And, in part, this depends on the individual patient's comfort level with taking a meaningful role in the decision-making process. Many patients solicit input from multiple sources, but most tend to follow their doctors' advice and recommendations. Delegating such decisions, however, is not necessarily a good idea. Several studies have found that physicians tend to make treatment decisions fairly quickly, without considering the meaning of the illness and treatment implications for the particular patient at hand. There are many



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possible explanations for this, including a lack of time, a lack of relevant information at the right time and place, and the absence of an incentive structure in the U.S. health care delivery market.

Patients, too, often fail to make rational health care decisions, in part because their choices are forced by frightening circumstances such as the diagnosis of cancer or heart disease. Several researchers have observed that patients faced with emotionally laden treatment decisions experience significant distress, anxiety and loss of control, all of which can impair their capacity to absorb information, ability to communicate effectively with their health care providers and desire to engage in the decision-making process. Furthermore, a common sense of urgency to “do something” when faced with a new diagnosis often affects the amount and quality of attention that both patients and providers bring to the decision-making process.

To confuse matters, there is some controversy as to the appropriate role for patients in the decision-making process, and patients themselves may have varying levels of interest in and capacity for meaningful participation. What is clear, however, is that patients are often not involved in ways they would like to be. A number of studies have documented discrepancies between the amount of information actually given to patients versus what was desired, as well as the level of collaboration permitted versus the patient’s preferred role. And while there is some variation across patient characteristics, such as age, ethnicity and insurance status, patients consistently report a desire for more information and greater involvement in their health care decisions.

In this context, it is not surprising that both patients and their health care providers often fail to make quality treatment choices. In fact, several studies have revealed that in the absence of sound evidence about treatment effectiveness, different doctors make different assumptions and fail to adequately inform patients about their options and the implications of various treatment alternatives. Evidence of this challenge is apparent in descriptive studies, which have documented poor communication, persistent knowledge gaps, and little or no consideration of patient preferences. There is also

epidemiological evidence that points out tremendous variation in clinical practice, and not the kind that can be explained by clinical differences among patients. Rather, these differences are more often attributed to local health care capacities (e.g., the availability of technology), professional tendencies (e.g., habit) or conventional wisdom. Furthermore, we know that these practice variations cannot be solely attributed to patient preferences. For example, patients with a history of cardiovascular disease diverge very little in their desire to avoid another heart attack or death, yet there is wide variation in the use of beta blockers, which have been shown to significantly reduce the rate of repeat myocardial infarction and cardiovascular deaths.

Making Better Treatment Decisions: What’s Involved and What’s At Stake

Clearly, patients and their health care providers need assistance in order to start along a path of improved, shared decision making. On the provider side, greater access to relevant clinical evidence, as well as the time and will to interpret and appropriately apply that evidence in the context of particular patients’ circumstances and preferences, will be critical. Patients, too, will need to engage further, overcome emotional hurdles to rational decision making and ask more questions of their health care providers. In an attempt to support these improvements, more than 400 different tools and methods have been developed over the course of the last two decades. They are available in different formats (e.g., brochures, audiotapes, videotapes, interactive computer programs) and involve varying levels of direct provider/patient interaction. Increasingly, such decision aides are Internet-based, and all attempt to support providers and patients as they work together to make treatment decisions.

One of the first so-called shared decision-making programs, or decision aids, was developed by Wennberg and colleagues in 1987 for patients with benign prostatic hyperplasia (BPH). Through a customized and interactive video, patients could learn about BPH, the relative effectiveness of various treatment options, the likelihood of symptom relief and side effects associated with each one. Patient and provider reactions to the aid were generally positive, and participating patients demonstrated a sig-

nificant increase in knowledge, even reaching a level equivalent to a urologic nurse. But patient knowledge was not the only metric evaluated. In a randomized trial of men using the BPH decision-making tool, higher levels of general health and physical functioning were reported, regardless of treatment choice. This means that the time invested up front to educate patients had a lasting and meaningful clinical impact.

Since that time, stimulated by the evident utility of the BPH tool, many other programs have been developed. In the 1990s, the Foundation for Informed Medical Decision Making developed programs for back pain, coronary artery disease, hormone replacement therapy and numerous other conditions. Researchers at the Ottawa Health Sciences Research Institute also built decision aids, drawing from the fields of psychology, social psychology, decision analysis, decisional conflict, social support and economics. These tools engaged patients through a booklet and audiotape medium and included a worksheet that was designed to facilitate better communications between the patient and provider in the decision-making process. Another computer-based tool called CHES (Comprehensive Health Enhancement Support System) was designed to help individuals cope with medical concerns by providing them with social support and problem-solving tools to encourage behavior change.

While all of these tools appeared to provide both near and long-term benefits to patients, it wasn’t until 1998 that their effectiveness was formally and systematically reviewed by an external party—the Cochrane Collaborative. Starting with an initial evaluation on 17 randomized controlled studies, the Cochrane report found that decision aids increased patient knowledge and participation in decision making and reduced decisional conflict but had no impact on anxiety or satisfaction with decisions. A 2003 update of the report—this time reviewing 34 randomized controlled studies—generally confirmed the earlier findings. It also identified a 20 percent to 30 percent reduction in patient selection of aggressive treatments, which suggests that patients are generally more conservative than their health care providers.

Unfortunately, the majority of these studies looked at the impact of decision aids among predominantly white and well-educated patients, leaving open the question of whether decision aids need to be customized to patient subgroups in order to be effective. Only with some of the tools has there been even limited research to suggest that rates of use and improvement were comparable across patient groups—regardless of age, race, education or computer literacy. Given that some patients exposed to the decision aids started with a lower baseline level of knowledge, the tools were found to provide more benefit among those with minimal education and little or no insurance. Save for cases where there is a language barrier, the evidence thus far suggests that separate decision aids are not necessary for different underserved groups.

While the target populations tested in these studies have not routinely varied, the tools do differ substantially in terms of the amount of information presented, the format of that information and the medium of delivery. This variety, as well as the explosion in the use of the Internet in the last decade, has led to a call for some standardization around what constitutes an appropriate patient decision aid. In 1998, a panel convened by the U.S. Department of Health and Human Services defined a broad set of “Interactive Health Communication Applications.” Tools could only qualify as such if they combined online health information with decision support, social support or behavior change support. More recently, an international consensus process to develop some standards and guidelines has resulted in the publication of 78 consensus criteria within 12 broad domains.

Not all decision tools are purely information focused, nor do they all target patients. Some efforts have concentrated on improving the communication skills of health care providers as they strive to deliver more patient-centered care. Though few studies have evaluated the health outcomes associated with these interventions, a growing body of research suggests that some of these interventions may improve the consultation process between patients and their health care providers, expand patient knowledge, and enhance patient

satisfaction. And unlike the evidence base thus far for patient decision aids, there is some proof that provider communications skills training can decrease patient anxiety in the decision-making process.

With All of These Tools, Why Can't We Do Better?

Despite the fact that more than 400 decision tools now exist and that there is strong evidence to suggest that many of them improve knowledge, communications and outcomes, they are not widely used. Several intuitive reasons for this have been cited, often by the provider community. They include:

- The view that there is not enough time to administer decision aids and then engage in the ensuing discussions with patients
- Inadequate physical space in the clinic setting
- The belief that decision aids are not necessary to achieve informed, shared decision making
- The conviction that patients are not interested in participating or could not cope well with the information or responsibility
- General concerns about upsetting the current doctor-patient relationship

These factors are significant, but more subtle issues—including role confusion and autonomy conflicts—may also limit the diffusion of patient decision aids. If the point of decision aids is to more fully and meaningfully engage patients in their own health care, then all parties need to be prepared for what that means. Specifically, more informed patients may increasingly come to conclusions or select treatment options that differ from those recommended by their health care providers. Sometimes this may simply reflect a difference in perspectives or values, but it's also possible that the patient may be making a logical error based on a misunderstanding or misinterpretation of clinical information. In these cases, it is the responsibility of the provider to help the patient understand the error rather than simply leave patient autonomy unchallenged.

There is also concern about the extent to which autonomous patient preferences might affect society's ability to pay for health care. Would informed patients always choose the most expensive treatment option or use the most care? Based on the evidence thus far, it appears that the opposite is true. When fully informed about risks and benefits, patients tend to choose less intensive interventions than those recommended by their physicians.

Despite these concerns and the general reliance on traditional modes of medical decision making, there are some encouraging models for integrating patient decision aids into medical practice. For example, more than 20 community cancer centers currently deploy breast cancer decision aids to newly diagnosed and metastatic disease patients, and a large hospital in Massachusetts has launched an “ePrescribe” effort, which enables providers to prescribe the use of patient decision aids through their electronic medical records system. In addition, there are some commercial models that leverage call centers and/or the Internet to deliver decision aids directly to consumers. However, these efforts are relatively few and far between and differ in terms of support timing, location, medium and sequence relative to other steps in the decision-making process.

Ideas for Where We Go From Here

Some researchers believe that moving the patient decision aid notion forward requires measuring the status quo and progress toward improvement, since organizational change in health care is rarely achieved without it. Sepucha, Fowler and Mulley (2004) argue that “rigorous and practical measures of decision quality, if used on a widespread basis, would in fact help stimulate positive changes.” In other words, until we start documenting gaps in patient understanding and implementing policies that reward solutions for closing those gaps, we won't get the kind of quality decision making that's desired—and sorely needed.

Fostering competition between provider institutions with respect to how well they inform patients and pay attention to their preferences represents one path forward for quality improvement and an opportunity for further research. Similarly, reward-

ing providers for appropriately informing patients and making measurable improvements in decision quality through pay-for-performance mechanisms is another area for exploration. In order to get to this point, however, several research questions should be studied:

1. How are treatment decisions made in real clinical situations?

2. How do information and preferences influence each other and treatment choices?

3. What are the most effective means of engaging patients in decisions about their care?

With greater input on these important questions, policy-makers, providers, payers

and patients will be in a better position to advocate for appropriate and relevant decision tools.

About the author

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