REPORT

Medical Discussion Guides: Less Confusion, Better Decisions for Patients

By Dave Kendall and Beth Quill

> A doctor's words, "you have cancer," flood a patient with anxiety and fear. As much as a doctor may want to help a patient, that moment is not the right time for a patient to make a major decision about a course of medical treatment. That is why doctors at the Dartmouth Hitchcock Medical Center give patients with breast cancer and other dreaded diseases a "pre-visit" medical discussion guide to review before they meet with a surgeon about treatment options.[1] The guide includes a DVD that shows how women with breast cancer have faced the disease and how they determined the best treatment option for them.

The guide, which draws on scientific evidence to avoid any biases, explains the difference between a mastectomy and a lumpectomy, which have similar success rates in beating cancer. It allows women to consider this tough choice at a time of their choosing. When given the opportunity to make an informed decision, women generally chose the more conservative lumpectomy. Afterwards, patient surveys show they also feel the care they received was better compared to those who did not use the discussion guides. If doctors and patients widely used medical discussion guides for common but complicated health problems, patients would be more satisfied with their care. They would also save money—trimming $11.4 billion from Medicare over ten years for four common ailments.

This idea brief is one of a series of Third Way proposals to cut waste in health care without cutting benefits or hurting care. For patients, less waste means a more streamlined, less complicated health care experience. For policymakers, less waste means more funding for quality care and other national priorities. All of our briefs use ideas pioneered by leading health care organizations and piloted in states throughout the country.

What are Patients Experiencing?

In a word: confusion.

With a major disease or injury, people sometimes feel they do not get a clear explanation of the

problem or the options to treat it. In fact, many health problems do not have one obvious course of treatment but, instead, several options with various possible outcomes. Patients facing chronic back pain or deciding on screening for early-stage breast or prostate cancer have options ranging from supportive care with no active treatment to intensive treatment interventions.[2] Patients and doctors need to communicate clearly so patients get the care that is right for them.

When facing numerous treatment options to consider, patients can be under-informed, overwhelmed, or misinformed in ways that add to their confusion and lead to a bad choice for care.

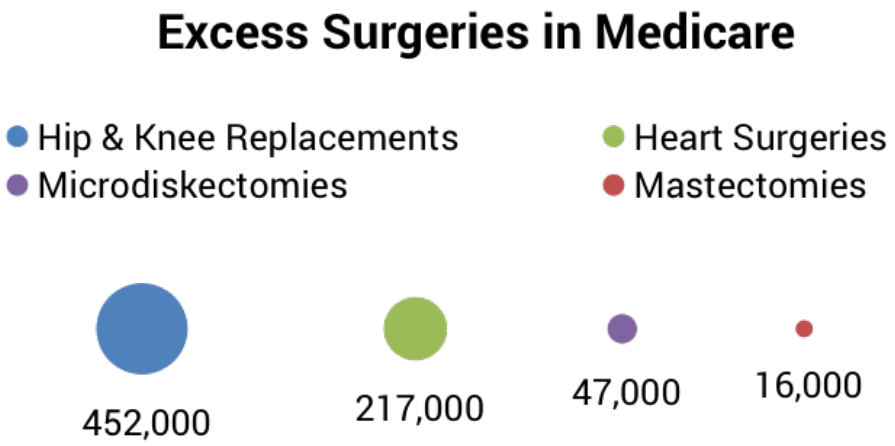
***Under-informed patients*:** Physicians often do not have time to provide all of the information necessary, in a structured and consistent format, for patients to make an informed decision about their care. With much medical care, patients do fine deferring choices to their physician because of their doctor's expertise. But it doesn't work well for situations where the evidence is mixed or where patient's preferences could change the course of treatment. For instance, sometimes physicians don't provide patients with breast cancer with a comparison of how patients fare from mastectomies vs. lumpectomies. One study showed that under-informed breast cancer patients were more likely to choose a double mastectomy over a lumpectomy.[3]

***Overwhelmed patients*:** Further, even when physicians present patients with accurate information regarding their treatment choices, it can be difficult to comprehend and process.[4] For example, it becomes extremely challenging for patients presented with stressful news about their health to make optimal decisions for themselves. People who are in this elevated "hot state" are less likely to process information in a systematic way, which can lead to decisions that are not aligned with their values and preferences. They are also more likely to defer the decision to a trusted physician. Hot state decision-making refers to cognitive biases people experience when they have to make decisions under extreme stress or elevated emotions.[5] For example, breast cancer patients have to make a choice about their care when the scientific evidence is not sufficient to determine the best treatment. They can't make the best decision when they are in a "hot state."

Further, the amount of information provided to patients when making important health care decisions can also easily overwhelm the patient when physicians provide too much or too little information and patients have additional questions requiring clarification. This leads to information overload, the over-abundance of information that can make it difficult to make a decision and can result in decision paralysis.

***Misinformed*:** In a small, but not insignificant, number of situations, providers guide patients to treatment options that are expensive and not in the interests of the patient. Physicians may not be deliberately misleading patients, but the current incentives in fee-for-service medicine encourage some doctors to use many more of these more expensive procedures. For example, the rates of mastectomies for breast cancer treatment vary widely by region, even for the same type of patient.[6]

What happens when patients are under-informed, overwhelmed, or misinformed about their treatment choices? They often end up getting a more expensive treatment, which they do not need or truly want. Patients with breast cancer have a mastectomy instead of lumpectomy. Patients with coronary heart disease, which is blockage or narrowing of the arteries, get heart surgery instead of treating it with medication. Patients with osteoarthritis get hip and knee replacements instead of physical therapy. And patients with lower back pain have a microdiskectomy, which is a disk removal that does not involve any other part of the spine, rather than physical therapy and related medication. The numbers of excess surgeries add up as shown in the chart below, which is based on 2012 data.[7]



Source: Avalere, 2014

Where are Innovations Happening?

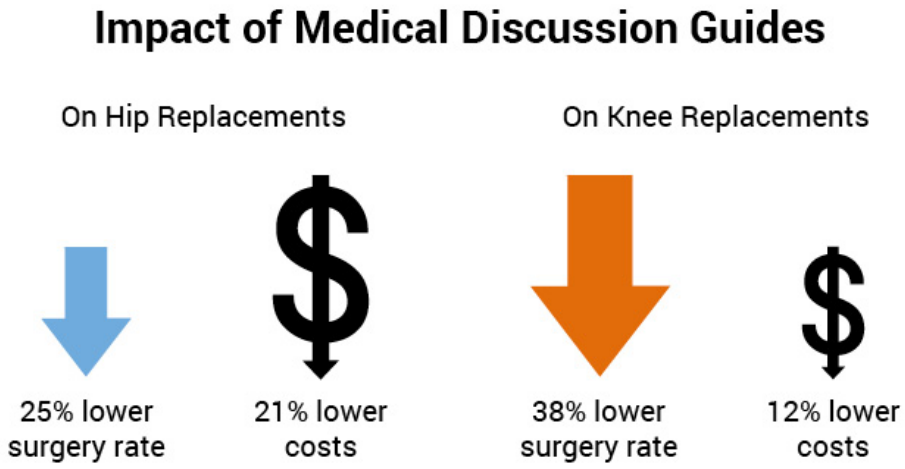
Innovative efforts across the United States are helping patients make the good health care decisions. [Add US Map image and link to local examples backgrounder.] These initiatives all use simple, informative, and objective "discussion guides" that allow patients and doctors to have a productive conversation about medical options. Also known as decision aids, medical discussion guides prompt an important conversation between patients and physicians that may not happen without them.

> Discussion guides are tools that patients can utilize to educate themselves about options for their care and likely outcomes. Patients can navigate through a range of modalities, including online, on paper, using a telephone, or watching a DVD. Health care professionals use the information from the discussion supplement information they give to patients and the guides also give patients the chance to take an active role in decisions about their care where their preferences matter.

Discussion guides are part of a larger process called shared decision-making between patients and health professionals. Shared decision-making is a structured way for both to discuss medical decisions based on evidence-based information about potential courses of treatment and outcomes.[8] Patients who use discussion guides also report greater satisfaction with their care and their decisions.[9]

In 2007, the Washington State legislature passed a law expanding legal protection from malpractice lawsuits for health professionals who use shared decision-making and discussion guides.[10] The law allows health professional to use a state-certified discussion guide as evidence of shared decision-making.[11] Group Health Cooperative, a health system that covers residents in Washington State and Northern Idaho, incorporated 12 discussion guides involving six specialties including orthopedics, gynecology, and general surgery.[12] All patients undergoing the relevant health concerns had access to these discussion guides.

A study of the Group Health results focused on patients with knee and hip arthritis. A year and a half after introducing the discussion guides, Group Health found that the surgery rates for hip and knee replacements fell, along with total cost of care.[13] Patients were also happier with their outcomes and fewer expressed regret about their choices.[14]



Many other efforts to enhance and increase the use of shared decision-making and discussion guides are underway throughout the country. [Link to local examples backgrounder.] In that same year, the Maine legislature authorized the Maine Quality Forum to begin an advisory group in order to study shared decision-making and make recommendations on how to implement discussion guides in the state.[15] The advisory group recommended implementing a Maine shared decision-making demonstration test in order to advance shared decision-making within the state.[16] MaineHealth now uses medical discussion guides as routine care in several practice areas including patients considering knee and hip replacements.[17]

How Can We Bring Solutions to Scale?

These successful state experiments are ready to be scaled up as a nationwide program to better align care with patient needs and wishes. Public policy should ensure that a discussion guide, when available, is utilized before a major course of care begins for common ailments.

> Should men get a test to check for prostate cancer? The U.S. Preventive Services Task Force (USPSTF) currently recommends against testing healthy men of all ages because it concluded that the harm likely outweighs the benefits.[18] The test, called a Prostate-Specific Antigen test, does not indicate cancer directly; it only indicates the possibility of cancer. False-positive results from the tests are common. Only one in four men with positive tests have prostate cancer.[19] However, many physicians believe that the tests are the best way to detect prostate cancer in the early stages.[20] A discussion guide on prostate cancer testing outlines the pros and cons of undergoing the test. Such discussion guides have significantly reduced the number of PSA tests.[21]

What makes a good discussion guide?

A discussion guide succeeds when a patient identifies what is important to them when choosing a course of care and applies this knowledge to the decisions about the care. Discussion guides should frame the decision and outline all the information necessary to make the decision in an unbiased way and in terms the patient will understand. This information includes all of the courses of treatment, likely outcomes, and also former patients reflecting on their experiences with the treatments or options they chose.[22]

Discussion guides should be crafted to present the options in a way that does not overwhelm the patient. For example, one discussion guide that uses a web-based browser asks patients to choose between two treatment scenarios. The next slides continue to narrow down the options by helping the patient to focus on several small decisions at a time.[23] Physicians give patients an overview of their options with the benefits and risks of each treatment option and can use this overview to discuss their options and follow up questions.

What are some barriers within the health care system?

Most physicians don't use formal discussion guides with their patients, and there are a number of reasons for the limited adoption. One study distributed large numbers of discussion guides to physicians and found that, although the majority of physicians said they would like to use discussion guides, few actually did.[24] Another study found physicians underestimated how many patients were interested in shared decision-making. Instead, they assumed that many of those

patients wanted to delegate the decision-making to them.[25]

Another obstacle is that the existing fee-for-service payment system does not reimburse physicians for practicing shared decision-making. The information presented in a discussion guide would take a doctor a considerable amount of time to discuss with each patient which puts an additional burden on doctors.

To be sure, physicians want to understand and act on patient preferences. When they learn how shared decision-making increases patient satisfaction and as up to date discussion guides become available and a system put in place that integrates them into clinical care, physicians are much more likely to adopt it.

What needs to be done?

The use of discussion guides should be standard medical practice. This can be accomplished in five ways:

1. Create a verification process where health plans report on whether patients were offered discussion guides in their decision-making process. Congress should require that performance measures for physicians and health plans include how well they make use of discussion guides. For example, one of the leading sets of performance measures used by 90% of health plans in the U.S., the Healthcare Effectiveness Data and Information Set (HEDIS) from the National Committee for Quality Assurance (NCQA),[26] measures shared decision-making tools.

The final regulations for Accountable Care Organizations (ACOs) from the Centers for Medicare and Medicaid Services (CMS) included shared decision-making measures.[27] Shared decision-making is now a quality measure for ACOs in the Medicare Shared Savings Program.[28] In order to be eligible for the Shared Savings Program, ACOs must report on numerous efforts to incorporate and increase patient engagement. Shared decision-making is also a criteria listed by NCQA for medical home recognition.[29] However, physicians' time and understanding of shared decision-making as well as the availability of updated discussion guides for use at the point of care has limited the adoption of discussion guides.[30]

2. Establish standards for discussion guides. Discussion guides must be balanced, evidence-based and easily understandable to patients with low health literacy.[31] But neither professional organizations nor government agencies have set minimum standards for discussion guides. As a result, the quality of currently available discussion guides varies widely. The Affordable Care Act includes a section meant to facilitate shared decision-making by developing quality measures for the use of discussion guides.[32] It also calls for standards for discussion guides and outlines a certification process for these tools.[33] The problem is that Congress has not appropriated funding for the implementation of this section of the ACA.[34] But using state innovation grant funding, the

Centers for Medicaid and Medicare Services has sponsored efforts in the state of Washington to create standards and a certification process for discussion guides.

3. Provide incentives for health professionals to offer discussion guides to patients as a routine step in receiving Medicare payment. In addition to providing funding for the Administration to implement current law, Congress should allow the Secretary of Health and Human Services to ensure the routine use of a standardized discussion guides among patients and shared decision making between the physician and patient in the case of tests or medical procedures where patients' preferences vary significantly. Physicians who use discussion guides generally find them helpful for having more productive conversations with patients and will not need further incentive to use them. But physicians who do not use them regularly (as indicated by the verification process described above) would simply show that a patient was offered a discussion guide in order to receive payment for services covered by a discussion guide. This process for spreading the use of discussion guides would start with a small list of common procedures where discussion guides have met federally-set standards. Over time, it would encompass all major types of preference-sensitive care. Physicians demonstrating regular and consistent use of discussion guides would not face any requirement to seek preauthorization based on the use of discussion guides.

4. Engage health professionals in the shared decision-making process and use of discussion guides through continuing medical education and medical school curriculum. Teaching health professionals about shared decision-making in continuing medical education sessions or as part of medical school curriculum is essential if we are to adopt widespread acceptance of shared decision-making and discussion guides.

5. Reform state informed consent laws to enable and encourage physicians to use medical discussion guides. Where providers are using discussion guides, it is important to find a way to ensure that these tools are being used and not just being marked off on a checklist.[35] This requires states to take two steps.

The first step is for states to reform informed consent laws. States should incorporate shared medical discussion guides and shared decision-making into the requirements for informed consent. The law should say that a patient who has participated in that process automatically satisfies the requirement for informed consent.[36]

The second step involves the states that are still using physician-based informed consent standards changing to patient-based informed consent. Half of the states use a physician-based informed consent standard that requires physicians to decide what information to share with patients based on what a reasonable physician would share in that situation. This standard has blocked doctors from using discussion guides and shared decision making because these are not yet part of routine medical practice.[37] Those states should mimic what Washington State has done with its informed consent law. There, physicians can follow informed consent requirements in the

standard way, but if they use a certified patient decision aid as part of the informed consent process, the physician will receive a higher degree of legal protection from lawsuits. The use of the decision aid establishes a rebuttable presumption, which means that informed consent will be assumed in a lawsuit unless a plaintiff proves otherwise. This measure will encourage physicians to incorporate shared decision making and medical discussion guides into their practice.[38]

Potential Savings

The federal budgetary savings from this proposal is $11.3 billion dollars over ten years as shown in the chart below.[39] Total savings to national health care spending as a whole is $18.3 billion over ten years. Those savings result from the use of medical discussion guides for four conditions with proven savings potential: hip and knee osteoarthritis, coronary heart disease, lower back pain, and breast cancer. The estimates come from randomized controlled trials of discussion guides for each of the treatment decisions. They include the cost of alternative treatments, which offsets a portion of the savings from patients choosing less aggressive care when using medical discussion guides. The chart below shows the year-by year savings by the major sources of coverage.

Savings from Medical Discussion Guides

(in $billions)	2015	2016	2017	2018	2019	2020	2021	2022	2023	2024	10 years
Medicare	0.9	0.9	0.9	0.9	0.9	0.9	0.9	1.0	1.0	1.0	9.3
Medicaid-federal	0.2	0.2	0.2	0.2	0.2	0.2	0.2	0.2	0.2	0.2	2.0
Total federal	**1.1**	**1.1**	**1.1**	**1.1**	**1.1**	**1.1**	**1.1**	**1.2**	**1.2**	**1.2**	**11.3**
Medicaid-state	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	1.4
Private health insurance	0.4	0.4	0.4	0.4	0.4	0.4	0.4	0.4	0.4	0.4	4.3
Out of pocket spending	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	0.1	1.4
Total-all sources	**1.8**	**1.8**	**1.8**	**1.8**	**1.8**	**1.8**	**1.8**	**1.9**	**1.9**	**1.9**	**18.3**

Endnotes

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