Power to the Patient:

The Importance of Shared Decision-Making

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The Challenge: Patients Don't Know What They Don't Know

Patients make a surprisingly large number of medical decisions each year: 82% of adults over the age of 40 have made a decision about having a surgery or screening test or taking a new medication in the past two years. Fifty-four percent of these adults have faced two or more of these types of medical decisions. These numbers represent 21.6 million people who have discussed a surgery, 97 million who have discussed a screening test, and 75 million who made a decision about a medication in the past two years.[1]

Roughly one-third of medical decisions are about surgeries, tests, treatments, and procedures that have two or more treatment options.[2] These options often have very different trade-offs in terms of likely benefits and risks; these medical decisions are not always easy or straightforward. Because the patient making the choice is the only one who can experience these risks and benefits, there is no universally 'right' course of action.

We call these types of decisions "preference-sensitive" – that is, the preferences of the patient should be the sole driver of the decision. For example, early-stage prostate cancer can be treated through watchful waiting, radiation, or surgery. While survival rates associated with each of these treatments are similar, on average, the risks and types of complication vary. Patients must take an active role in making preference-sensitive decisions to ensure that their personal values and preferences are reflected in the ultimate treatment choice. The provider's role is as a trusted partner who assists by providing information and helping the patient with clarification of preferences and values – this constitutes the shared decision-making process between patient and provider.

Did you know?
Screening tests for colon cancer – stool test, sigmoidoscopy, colonoscopy, and imaging tests – are similarly effective; the choice should simply be based on individual preference.

Unfortunately, the patient-provider relationship has not always focused on patient involvement in decision-making. Until recently, this relationship was based on a paternalistic model of care. The provider evaluated the treatment options and prescribed what (s)he thought was the best course of action. Patients generally played a passive role and rarely participated in making treatment decisions. Over time, there has been a shift from a paternalistic model to a more collaborative one that emphasizes patient-provider partnership and joint negotiations in the decision-making process.[3] However, much of the paternalistic mindset still remains among patients. According to Karen Sepucha, PhD, of Massachusetts General Hospital, on average 70% of uninformed patients felt doing what the doctor thinks is best was a top priority across 6 different medical conditions. When asked the same question, only 20% of healthcare providers felt it was a top priority.[4]

It is clear that many patients do not see themselves as an integral part of the potentially life-altering medical decision-making process. This raises two significant concerns:

1) The lack of patient involvement is problematic from an ethical perspective. Advances in medical science and technology have introduced a growing number of treatment options - many involving considerable tradeoffs affecting the patient's quality or length of life. It is a patient's fundamental right to be fully informed of all options, risks, and benefits and to actively participate in decisions that affect his/her health and well-being.

2) When patients are uninvolved in their own treatment decisions, doctors often decide for them. Unfortunately, physicians are not very good at 'diagnosing' patient preferences. This results in care that is often not aligned with a patient's preferences and values.

Physician decision-making varies by geographic region, a phenomenon known as unwarranted practice pattern variation. Unwarranted variation has been documented for over 30 years by researchers at Dartmouth and can be described as unexplained patterns in healthcare service delivery across the United States. While some differences in treatment patterns are related to real differences in patient needs, a considerable portion cannot be explained by illness, medical need, or the dictates of evidence-based medicine – these differences are *unwarranted*.

Researchers at Dartmouth have produced seminal research papers that document remarkable differences in surgical rates for preference-sensitive conditions. They looked at conditions such as early stage breast cancer, herniated disc, and knee pain, for which surgery is only one of several evidence-based treatment options. The Dartmouth researchers found that the use of surgery to treat preference-sensitive conditions can vary two to fivefold in different regions of the country.[5] Their research suggested that if unwarranted variation in the Medicare system could be eliminated, the quality of care for Medicare participants would be dramatically improved and Medicare costs would be substantially lower.[6,7] The unwarranted variation research brings to light the critical role that patient choice has in reducing unwanted preference-sensitive care.

The Solution At-a-Glance: Shared Decision-Making

Shared decision-making is a process that aims to give patients the care they want and nothing more. The process involves patient use of shared-decision making aids with constructive discussion between patient and a healthcare provider.

A **shared decision aid** (e.g., booklet, video) is a standardized, evidence-based tool that prepares people to participate in medical decision-making. It provides balanced information about options and outcomes from the patient's point of view and helps the patient clarify their own personal values. *Patient decision aids are designed to complement, rather than replace, counseling from a healthcare professional.*[8]

Shared decision-making aids should be coupled with a **discussion between the patient and a healthcare professional** regarding the risks, benefits, and outcomes of the possible treatment options in relation to a patient's circumstances, preferences, and values. The healthcare professional could be a physician, nurse, or health coach. The discussion could take place in person or on the telephone.

The desired outcome of the shared decision-making process is a treatment decision that most closely reflects a fully-informed patient's own values and preferences.

Did you know?

There are almost twice as many hip replacements per capita in Palo Alto as there are in San Francisco, just 35 miles away.

The Landscape

The impact of shared decision-making on patient decision quality is increasingly recognized in healthcare. Washington State passed legislation in 2007 to support the use of shared decision-making. The law recognizes that if a competent patient signs an acknowledgement of having participated in a shared decision-making process, this constitutes evidence that the patient has given informed consent. In addition, the legislation calls for demonstration projects to assess feasibility, as well as cost and quality impacts of shared decision-making in provider practices. This legislation was the first of its kind to acknowledge the value of shared decision-making; other states, including Vermont, Maine, Connecticut, Minnesota, and California have drafted and/or introduced shared decision-making bills in 2009.

The word about the importance of patient involvement in decision-making is also getting out through the media. In the past few months, articles such as "How to Help Patients Make Wiser Health Choices" (*Associated press, Feb 2009)* and "Doctors Often Take the Decider Role, to Patients' Detriment" (*USA Today, Feb 2009)* have raised public awareness about this issue and advised patients to start playing a more active role. In March 2009, the same media outlets published pieces about the value of prostate cancer tests. Additionally, in *Reader's Digest's* April 2009 issue, award-winning healthcare journalist Shannon Brownlee asked if cancer screening is actually doing more harm than good. Whether shared decision-making is disseminated via state governments, health plans, or some other vehicle, its value is being recognized broadly as a critical component of patient rights. Finally, the American Medical Association endorsed shared decision-making as a critical pillar of medical care.

The Solution Up Close

A shared decision-making discussion is a two-way flow of information between a patient and provider that helps a patient "make informed, value-based choices among two or more medically reasonable alternatives".[9] It is a collaborative effort based on mutual respect and trust. In the shared decision-making process, both the provider and the patient have important contributions to the dialogue. The provider contributes expert medical knowledge of available treatment options and the risks, benefits, and areas of scientific uncertainty associated with each. The patient contributes personal expertise of his/her tolerance for risk, lifestyle, and values.[10] The end result is a mutually agreeable course of action for treatment.

Patient decision aids, such as pamphlets and videos, are used to facilitate the shared decision-making process. In general, the goals of patient decision aids are threefold. They are designed to:

1) Provide evidence-based information, including the risks and benefits of potential treatment options and limits of scientific knowledge about outcomes

2) Help the patient clarify his/her own values and preferences

3) Provide guidance and coaching about how to approach the decision making process.[11]

Decision aids go beyond conventional patient education materials by presenting personalized, detailed information about treatment options in a way that helps a patient arrive at a decision.

This contrasts with broader educational materials that describe the diagnosis and available treatments only in general terms and do not help a patient explore his/her values and preferences in relation to the options presented.

The Impact: More Patient Involvement Yields More Appropriate Care

The shared decision-making process improves patient decision quality, which both enhances people's quality of life and has the potential to reduce costs associated with unwarranted practice pattern variation. For preference-sensitive care, decision quality can be measured in terms of how closely a decision reflects a patient's own values. The use of decision aids has been widely studied to determine if they lead to well-informed, values-based decisions. The Cochrane Collaboration systematically reviewed over 50 randomized controlled trials (RCT) to determine the efficacy of patient decision aids for preference-sensitive treatment or screening choices.[12] The trials compared decision aids to no intervention, usual care, alternative interventions, or a combination. The review confirmed that the use of shared decision-making aids increases patient involvement in decision making and led to informed values-based choices. In particular, the use of decision aids leads to:

1) Increased knowledge

2) Accurate perception of treatment benefits and harms

3) Less uncertainty about the decision related to feeling uninformed

4) Less uncertainty about the decision related to feeling unclear about personal values and preferences

5) Reduced numbers of people who remained passive during the decision-making process

6) Reduced numbers of people who remained undecided after counseling.[13]

It is clear from the research that the use of decision aids improves decision quality. The findings also confirm the potential impact that decision aids can have on reducing unwarranted practice pattern variation. Evidence shows that informed patients tend to choose less invasive and less expensive treatment options.[14] In fact, the Cochrane Collaboration's review indicates that, on average, the use of a shared decision-making process involving these aids is associated with a 25% reduction in preference-sensitive surgical treatments.[15]

Even though there is clear evidence of benefits, there has not yet been widespread adoption of the shared decision-making process. However, there has been encouraging support from the provider community. A 2009 survey conducted by Lake Research Partners found conceptual agreement with the shared decision-making process ideology among healthcare providers. In fact, 93% thought that the principle of shared decision-making sounded positive, with 52% saying that it sounded like a "very" positive process.[16] However, the same providers

Did you know?
If an x-ray or MRI shows a back problem, such as a bulging disc, it doesn't mean that the disc is the cause of pain. Imaging tests find abnormalities in over 10% of people not in pain.

also recognized that there are still barriers that currently prevent the full adoption of shared decision-making. The biggest barrier noted by providers is lack of time in a typical office visit to provide patients with detailed options.

Overcoming the Barriers

Health Dialog's care management model integrates the shared decision-making process directly into our member analytic, outreach and health coaching strategy. Our innovative analytics enable us to directly target individuals who are in a decision window for making a preference-sensitive medical decision. Once members are identified, Health Dialog reaches out to encourage them to participate in a shared decision-making process, supported by our award-winning shared decision-making aids and specially trained Health Coaches. Health Dialog's decision aids are developed in collaboration with the Foundation for Informed Medical Decision Making (FIMDM). Our shared decision-making aids include videos, booklets, and online modules that provide evidence-based, unbiased information about treatment options and condition management. They are designed to support a more informed dialogue between individuals and their providers. All Health Dialog decision aids are based on medical evidence researched and evaluated by FIMDM, and are regularly reviewed and updated to ensure the most current and accurate information. These decision aids are trusted in the industry and well respected by the provider community.

Did you know?
After two years, people who had surgery for a herniated disc are only slightly more satisfied with their symptoms than people who didn't have surgery.

Health Dialog's health coaching promotes shared decision-making to help individuals make the treatment decisions that are right for them. Health coaches help the patient to have the confidence to participate in decision-making, the understanding of the critical information required to make the decision, a clear understanding of his/her values, and the most realistic expectations of the treatment benefits, harms, and outcomes; then our coaches help motivate the patient to act according to their preferences and values. We believe that the shared decision-making process offers the best possible chance to improve patient decision quality and therefore impact both patient well-being and healthcare costs.

Conclusion

The shared decision-making process can help patients understand the risks, benefits, and outcomes of treatment options, clarify their own values and preferences for treatment, prepare for discussions with their physicians and follow through with their decisions. Multiple academic and peer-reviewed sources attest to these facts, including the Cochrane Collaboration, *Health Affairs*, Ottawa Hospital Research Institute, the Foundation for Informed Medical Decision Making, and Dartmouth.

At Health Dialog we actively support shared decision-making and incorporate this process into our heath coaching and patient education services. Shared decision-making is the right thing to do for patients and can impact costs associated with unwarranted variation by assuring that patients get the care they want and nothing more, need and nothing less.

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