Shared Decision Making — The Pinnacle of Patient-Centered Care

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> Nothing about me without me.
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> — Valerie Billingham,
> *Through the Patient's Eyes,*
> Salzburg Seminar
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Caring and compassion were once often the only "treatment" available to clinicians. Over time, advances in medical science have provided new options that, although often improving outcomes, have inadvertently distanced physicians from their patients. The result is a health care environment in which patients and their families are often excluded from important discussions and left feeling in the dark about how their problems are being managed and how to navigate the overwhelming array of diagnostic and treatment options available to them.

An audio interview with Dr. Barry is available at NEJM.org

In 1988, the Picker/Commonwealth Program for Patient-Centered Care (now the Picker Institute) coined the term "patient-centered care" to call attention to the need for clinicians, staff, and health care systems to shift their focus away from diseases and back to the patient and family.[1] The term was meant to stress the importance of better understanding the experience of illness and of addressing patients' needs within an increasingly complex and fragmented health care delivery system.

The Picker Institute, in partnership with patients and families, conducted a multiyear research project and ultimately identified eight characteristics of care as the most important indicators of quality and safety, from the perspective of patients: respect for the patient's values, preferences, and expressed needs; coordinated and integrated care; clear, high-quality information and education for the patient and family; physical comfort, including pain management; emotional support and alleviation of fear and anxiety; involvement of family members and friends, as appropriate; continuity, including through care-site transitions; and access to care.[1] Successfully addressing these dimensions requires enlisting patients and families as allies in designing, implementing, and evaluating care systems.

This concept was introduced in the landmark Institute of Medicine (IOM) report *Crossing the Quality Chasm*[2] as one of the fundamental approaches to improving the quality of U.S. health care. The IOM defined patient-centered care as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions." This definition highlights the importance of clinicians and patients working together to produce the best outcomes possible.

As the definition implies, the most important attribute of patient-centered care is the active engagement of patients when fateful health care decisions must be made — when an individual patient arrives at a crossroads of medical options, where the diverging paths have different and important consequences with lasting implications. Examples include decisions about major surgery, medications that must be taken for the rest of one's life, and screening and diagnostic tests that can trigger cascades of serious and stressful interventions.

For some decisions, there is one clearly superior path, and patient preferences play little or no role — a fractured hip needs repair, acute appendicitis necessitates surgery, and bacterial meningitis requires antibiotics. For most medical decisions, however, more than one reasonable path forward exists (including the option of doing nothing, when appropriate), and different paths entail different combinations of possible therapeutic effects and side effects. Decisions about therapy for early-stage breast cancer or prostate cancer, lipid-lowering medication for the primary prevention of coronary heart disease, and genetic and cancer screening tests are good examples. In such cases, patient involvement in decision making adds substantial value.

In an influential article on clinical practice guidelines, David Eddy argued that an intervention should be considered a "standard" only if there is "virtual unanimity among patients about the overall desirability . . . of the outcomes."[3] For the vast majority of decisions in which there is no intervention that meets this high bar, patients need to be involved in determining the management strategy most consistent with their preferences and values.

The process by which the optimal decision may be reached for a patient at a fateful health crossroads is called shared decision making and involves, at minimum, a clinician and the patient, although other members of the

health care team or friends and family members may be invited to participate. In shared decision making, both parties share information: the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values. Each participant is thus armed with a better understanding of the relevant factors and shares responsibility in the decision about how to proceed.[4]

When more than one viable treatment or screening option exists, clinicians can facilitate shared decision making by encouraging patients to let clinicians know what they care about and by providing decision aids that raise the patient's awareness and understanding of treatment options and possible outcomes. Decision aids, which can be delivered online, on paper, or on video, can efficiently help patients absorb relevant clinical evidence and aid them in developing and communicating informed preferences, particularly for possible outcomes that they have not yet experienced.

Just as there are randomized trials of tests and treatments, there have been randomized trials of shared decision making supported by patient decision aids. According to the latest Cochrane review of 86 trials published through 2009, the use of patient decision aids for a range of preference-sensitive decisions led to increased knowledge, more accurate risk perceptions, a greater number of decisions consistent with patients' values, a reduced level of internal decisional conflict for patients, and fewer patients remaining passive or undecided.[5] The use of decision aids is also associated with patients' choosing prostate-specific–antigen tests for prostate-cancer screening and major elective surgery less often, which suggests that shared decision making could be a tool to help address the problems of overdiagnosis and overtreatment.[5]

Through shared decision making, clinicians can help patients understand the importance of their values and preferences in making the decisions that are best for them. Experience has shown that when patients know they have options for the best treatment, screening test, or diagnostic procedure, most of them will want to participate with their clinicians in making the choice. This interest is shared by patients worldwide, as demonstrated by the recent release of the Salzburg statement endorsing shared decision making, authored by representatives from 18 countries.

Although talk about patient-centered care is ubiquitous in modern health care, one of the greatest challenges of turning the rhetoric into reality continues to be routinely engaging patients in decision making. To successfully address this critical component of quality and safety, we must break down critical barriers between clinicians and patients. Patients should be educated about the essential role they play in decision making and be given effective tools to help them understand their options and the consequences of their decisions. They should also receive the emotional support they need to express their values and preferences and be able to ask questions without censure from their clinicians.

Clinicians, in turn, need to relinquish their role as the single, paternalistic authority and train to become more effective coaches or partners — learning, in other words, how to ask, "What matters to you?" as well as "What is the matter?" In addition, novel patient-centered health information technologies that deliver information in a more timely fashion can help clinicians identify patients who are facing fateful health care decisions and to more efficiently elicit their preferences.

If we can view the health care experience through the patient's eyes, we will become more responsive to patients' needs and, thereby, better clinicians. Recognition of shared decision making as the pinnacle of patient-centered care is overdue. We will have succeeded in building a truly patient-centered health care system when an informed woman can decide whether to have a screening mammogram and an informed man can consider whether to have a screening prostate-specific–antigen test without their clinicians labeling the decision "wrong" on the basis of different values and preferences.

Disclosure forms provided by the authors are available with the full text of this article at NEJM.org.

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