Beyond Information: Exploring Patients' Preferences

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mediately. New radiation therapy machines would be required not only to produce the same level of health as the current ones but also to be substantially less expensive.

Showing the private sector that comparative effectiveness funds will be used in this way could change the entire research and development process in the US health care industry. It could also help the current administration achieve its goal of making health care more affordable for all US citizens.

To adopt these 2 criteria for funding comparative effectiveness research, the agencies that release funds must make tough decisions. The agencies will be accused of sponsoring rationing.[5] A strong case can be made that this does not represent rationing but rather uses research dollars to produce therapies that are better and substantially less expensive. After all, when a computer is purchased today at a small percentage of the cost of computers produced years ago, it is not believed that the private sector has rationed computer chips. Instead, the research and development model in the computer industry has been to make better machines and to make them at increasingly lower costs, thereby making computers affordable to many more individuals.

It is time to use public funding and comparative effectiveness research to accomplish the same thing in medicine. If this opportunity is missed, another one is unlikely to come along. Then rationing may actually become the only way by which reductions in health care expenditures can be achieved.

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REFERENCES

1. The American Recovery and Reinvestment Act of 2009. US Government Printing Office Web site. http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=111_cong_bills&docid=f:h1enr.pdf. Accessibility verified June 10, 2009.
2. The White House. Issues: health care. http://www.whitehouse.gov/issues/health_care/. Accessed May 22, 2009.
3. Baucus M. *Call to Action Health Reform 2009.* Washington, DC: Senate Finance Committee; 2008.
4. McGlynn EA, Asch SM, Adams J, et al. The quality of health care delivered to adults in the United States. *N Engl J Med*. 2003;348(26):2635-2645.
5. Kyl J Senate Amendment 793 to Senate Continuing Resolution 13. 2009.

Beyond Information

Exploring Patients' Preferences

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THE INSTITUTE OF MEDICINE CONSIDERS PATIENT-centered care ("care that is respectful of and responsive to individual patient preferences, needs and values"[1(p6)]) to be a foundation of high-quality health care, along with effectiveness, safety, efficiency, timeliness, and equity. Patient-centered care is empirically based and promotes respect and patient autonomy; it is considered an end in itself, not merely a means to achieve other health outcomes.[2]

Two parallel efforts have furthered patient-centered care. Shared decision making promotes defining problems, presenting options, and providing high-quality information so patients can participate more actively in care.[3] Patient-centered communication promotes healing relationships that elicit and consider patients' perspectives and understand patients as persons.[2] Both approaches assume that patients can articulate preferences based on stable guiding principles or values. While this may be true in straightforward situations, in novel, unanticipated, and emotionally charged situations, preferences may not be elicited as much as they are constructed—shaped by how information is presented and by the opinions of family, friends, and the media. This Commentary explores how physicians might reconcile the imperative to provide patient-centered care with the complex ways in which clinicians and patients construct preferences.

Stable and Constructed Preferences

When a patient with an uncomplicated upper respiratory tract infection must choose what to do, the situation is simple, consequences are few, and several options exist; preferences are likely stable.[4] However, preferences are more likely to be unstable in unfamiliar, high-stakes, and uncertain situations, with potential outcomes that have not been considered or cannot be imagined. For example, patients newly diagnosed as having cancer might not have well-articulated preexisting preferences; rather, they construct their preferences by applying more basic values and beliefs.[5] Consider 2 patients with localized prostate cancer. Both are considering radiotherapy, surgery, and watchful waiting in the absence of compelling data favoring one approach. Even though the patients may be well informed, their preferences may be influenced by personal health beliefs—one patient may fear that surgery can spread cancer, whereas the other prefers surgery because he wants all cancer removed; both avoid watchful waiting because doing something is better than doing nothing. The even more unfamiliar and uncertain decisions regarding bone marrow transplantation are rife with choiceless choices and in-

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ability to imagine the treatment ordeal despite being well informed.[6] The values underlying preferences (eg, a meaningful life) also may change as patients get sicker. After facing unimaginable situations (eg, colostomy, quadriplegia), patients sometimes report greater quality of life and meaning than they would have predicted.[7]

Physicians Help Patients Construct Preferences

Cognitive, emotional, and relationship factors affect how preferences are constructed. Cognitive factors (eg, how information is presented) have been studied the most.[5] Physicians subtly influence patients' preferences by framing outcomes in positive (survival) vs negative (mortality) ways or by presenting a favored option first, making it seem like the middle of the road, highlighting its benefits, and even using a different tone of voice. Information, like a drug, must be dispensed in the right dose; information overload can diminish logical consistency and even drive patients away from participating in decisions.[8] Information about the risks and benefits of a treatment is important, but patients may try to reduce cognitive effort by oversimplifying complex situations; eg, not appreciating that both high risk and high benefit coexist. Furthermore, both parties may overestimate patients' comprehension and recall. Clinicians and patients may be unaware of these preference-construction processes, including their inconsistencies.

The Role of Affect

Reason-based choice theories[5] suggest that good decisions require logical consideration of options without interference from emotions. Evidence from neurocognitive research, however, highlights the importance of emotions. Damasio[9] suggests that human thought processes are not ideas (eg, concepts, words); rather, they are images that include sensory (eg, olfactory, visual) and emotional markers. When considering options, impressions are mapped onto a library of past experiences that are colored by emotions and sensations, often outside of everyday awareness. As clinicians, these somatic markers manifest as gut feelings that inform an affective rationality[5] and help experienced physicians identify the sick child or a depressed person. Patients likely engage in similar processes. Choices consistent with patients' goals are most likely to emerge when emotions and logic work in concert—when patients think as well as feel their way through decisions. Without emotional processing, individuals can make disastrous choices.

Gut feelings do not always lead individuals to preferences concordant with their values. Future events (eg, lung cancer) carry less weight than current events. Emotions also alter perceptions of quantity and value.[5] In clinical settings, a more-is-better heuristic might influence seriously ill patients who say "yes" when asked if they "want everything done," even when "everything" might be undesirable. Individuals pay preferential attention to positive images; clever advertisements for a cancer-related medication portray robust-appearing actors with hair, smiling and playing with their children—while reciting potential adverse effects. Importantly, emotions dominate more in patients with lower numeracy or slower cognitive processing, contributing to age-related and social disparities in care.[10]

Patient-Physician Relationships

Most knowledge about preference construction comes from carefully controlled experiments; little is known about it within the complex and powerful relationships formed by patients and physicians. Psychology, ethics, and clinical practice guidelines do not offer sufficient guidance concerning how to respect and respond to patients' preferences: How would a physician know whether a patient's preference is stable, shallow, or incoherent? What does it mean for a physician to help patients construct preferences? To what extent, in what circumstances, and exactly how should the physician insert his or her own perspectives into the construction process? What ways of framing discussions should the physician use, and why? How should physicians provide emotional support during the discussion of preferences? How would a physician know when good vs bad construction has occurred? Neither current models of patient-centered communication nor shared decision making fully address these questions.

"Libertarian paternalism,"[11] currently popular in public policy, suggests that leaders should influence patients' preferences to achieve desired goals while leaving the ultimate choice to the individual. For example, opt-out policies can increase organ donation. Similarly, some argue that making "do not attempt resuscitation" the default option for terminally ill patients could promote humane care.[8] However pragmatic and ethical this may seem in straightforward situations, libertarian paternalism in preference-sensitive situations is problematic, in part because of physicians' own unexamined biases.

Shared Knowledge

Current shared decision-making models acknowledge the need for information.[3] Preferences cannot be accurate if based on misinformation. To the degree possible, clinicians can ascertain whether they and their patients are sufficiently knowledgeable to construct informed preferences. Patients, however, need to go beyond comprehension to a greater depth of knowledge and the ability to apply information meaningfully to a particular situation.[10,12] Shared knowledge also includes the physician's knowledge of the "patient as person"—his or her habits, culture, family, and prior behavior under uncertainty.[2] More than a nicety, this is at the core of understanding whether an expressed preference corresponds with the patient's underlying values and whether those values are consistent and clearly articulated.

Shared Deliberation

Patients sometimes need help in understanding what they believe and want, especially in unfamiliar circumstances. In this situation, physicians must balance sins of commission (unduly influencing patients' decisions) and sins of omission (allowing patients to misunderstand or consider an incomplete option set).[4] However, physicians rarely assess patients' understandings of complex clinical situations,[13] and little research exists to guide how clinicians should engage in shared deliberation to achieve mutual understanding and consensus. Thus, a few suggestions, awaiting empirical validation, could be considered. Clinicians can develop a habit of reflective questioning by asking themselves, "Has the patient demonstrated understanding of the relevant options?" "What do I understand about the patient's values?" "Have I framed the options from more than one perspective?" and "How have my thoughts and feelings informed and/or biased the patient's preferences?" Similarly, physicians can help patients reflect on whether their preferences are stable by suggesting that preferences can change after learning more about the benefits and risks, introducing doubt ("For some people, a 10% risk seems like a lot, but for others, it seems small compared with the benefit."), and uncoupling short-term emotions from long-term utility ("Although you have some pretty negative images of what it would be like to live with a colostomy, you might be surprised that most patients report a high quality of life."). In the process, deliberation may increase or expose decisional conflict. Thus, decisional conflict should not be considered a marker of poor decision making; rather, physicians should help patients deal with transient increases in anxiety that accompany an appreciation of complexity and greater choice.

Shared Mind

Collaborative cognition[14]—working through complex situations conjointly—can result in emergent, collaboratively generated ideas that correct misconceptions and increase options, self-efficacy, and learning. Collaborative cognition depends on the physician being mindful not only of the patient's values, thoughts, and feelings but also his or her own. Research exploring shared deliberation and shared mind must bridge cognitive science, decision research, and communication skills training and evaluate communication processes as well as patients' experience of care.

Future Directions

Respecting and responding to patient preferences—the hallmark of patient-centered care—means eliciting, exploring, and questioning preferences and helping patients construct them. Shared deliberation that goes beyond information provision should be considered an essential skill. A healing patient-physician relationship provides the framework for exploring preferences but is not enough; families and other clinicians also provide essential input. In addition, decision aids, patient videos, and other media can help if they engage affect; are sensitive to default options, framing, and ordering effects; encourage deeper discussions with family members and clinicians; and strengthen healing relationships.

The biases and distortions involved in eliciting and constructing preferences have been known for decades. Current deliberations about preferences should go beyond paternalism (not considering them), naive consumerism (giving patients what they initially ask for), and abandonment dressed as autonomy ("go home, think about it, and let me know"). Rather, clinicians should understand that they are part of preference-construction processes. Fundamental skills to promote shared knowledge, shared deliberation, and shared mind are collaborative patient-centered communication and self-awareness. These skills can be taught, learned, and retained.[15] Through communication, physicians can more effectively engage patients in constructing preferences in the face of uncertainty, informed by understanding how patients and clinicians think in the complex, unforeseen, and terrifying situations when health goes awry.

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REFERENCES

1. Committee on Quality of Health Care in America, Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century.* Washington, DC: National Academy Press; 2001.
2. Duggan PS, Geller G, Cooper LA, Beach MC. The moral nature of patient-centeredness: is it "just the right thing to do"? *Patient Educ Couns*. 2006;62(2):271-276.
3. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Soc Sci Med*. 1999;49(5):651-661.
4. Fischhoff B. Cognitive processes in stated preference methods. In: Maler KG, Vincent JR, eds. *Handbook of Environmental Economics.* Pittsburgh, PA: North Holland; 2005.
5. Lichtenstein S, Slovic P. *The Construction of Preference.* New York, NY: Cambridge University Press; 2006.
6. Little M, Jordens C, McGrath C, Montgomery K, Lipworth W, Kerridge I. Informed consent and medical ordeal: a qualitative study. *Intern Med J*. 2008;38(8):624-628.
7. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: the disability paradox and health care decision making. *Health Psychol*. 2005;24(4)(suppl):S57-S62.
8. McCaul KD, Peters E, Nelson W, Stefanek M. Linking decision-making research and cancer prevention and control: important themes. *Health Psychol*. 2005;24(4)(suppl):S106-S110.
9. Damasio AR. *The Feeling of What Happens: Body and Emotion in the Making of Consciousness.* New York, NY: Harcourt Brace; 1999.
10. Peters E, Hibbard J, Slovic P, Dieckmann N. Numeracy skill and the communication, comprehension, and use of risk-benefit information. *Health Aff (Millwood)*. 2007;26(3):741-748.
11. Thaler RH, Sunstein CR. Libertarian paternalism. *Am Econ Rev*. 2003;93:175-179.
12. Woolf SH, Chan EC, Harris R, et al. Promoting informed choice: transforming health care to dispense knowledge for decision making. *Ann Intern Med*. 2005;143(4):293-300.
13. Silberman J, Tentler A, Ramgopal R, Epstein RM. Recall-promoting physician behaviors in primary care. *J Gen Intern Med*. 2008;23(9):1487-1490.
14. Meegan SP, Berg CA. Contexts, functions, forms, and processes of collaborative everyday problem solving in older adulthood. *Int J Behav Dev*. 2002;26:6-15.
15. Rao JK, Anderson LA, Inui TS, Frankel RM. Communication interventions make a difference in conversations between physicians and patients: a systematic review of the evidence. *Med Care*. 2007;45(4):340-349.