

PATIENT-CENTERED CARE: A Vision to Guide Health System Reform

Report from the 2008 ABIM Foundation Forum

By Cara Lesser



The 2008 ABIM Foundation Forum convened 150 health leaders, physicians, nurses, researchers, payers and individuals with compelling experiences as patients and family caregivers to discuss a complex and critical issue: how to achieve patient-centered care. Participants grappled with defining patient-centered care – examining barriers and identifying affordable and sustainable strategies to achieve this goal. All Forum participants were invited to share their experiences as patients and caregivers, acknowledging that “we are all, at times, both patients and caregivers.” The Forum conversations bridged the emotional need and the intellectual argument for advancing patient-centered care, bringing what Harvey Fineberg, Institute of Medicine, characterized as new passion and energy to the debate about health system reform.

RECALIBRATING THE PATIENT-PHYSICIAN RELATIONSHIP

“Patient-centered care is care which is perceived as such by the patient. The patient is the only one who can deem it as such,” said Margaret Murphy, WHO World Alliance for Patient Safety, and one of the individuals participating in the Forum as a family caregiver. Murphy began the Forum with the gripping story of her son Kevin’s death at age 21 from hypercalcemia induced by a parathyroid tumor, a relatively common and treatable problem that went misdiagnosed and untreated. She eloquently described how these diagnostic errors were compounded by miscommunication, poor coordination and a system that fails to listen and engage patients and family members.

At its core, patient-centered care is about recalibrating the relationship between physicians and patients in order to give voice to patients and family caregivers in the care delivery process. Notably, two of the opening speakers at the Forum, Kimball Lecturer Don Berwick, Institute for Healthcare Improvement, and Ronald Epstein, University of Rochester Medical School, invoked the metaphor of hospitality – Berwick suggesting that clinicians should behave more like guests in the lives of their patients, and Epstein suggesting that clinicians should also act as hosts for patients encountering a complex health care environment in a time of need.

Don Berwick described a personal experience of attempting to accompany a friend into a cardiac catheterization lab. He met resistance from the cardiologist, who said, “I’m sorry. I’m just not comfortable with that. We don’t do that here. It doesn’t work.” When pressed, the cardiologist persisted, “It’s just not possible,” and ultimately Berwick’s friend was wheeled away, shaking in fear and in tears. Berwick portrayed this experience as a form of assault on the patient, describing this behavior as asking the patient to accommodate the system and increasing, rather than assuaging, fear. Building on this anecdote, Berwick advocated for a radical definition of patient-centered care, one in which “everyone writes their own rules” and clinicians behave as guests in patients’ lives, actively promoting shared decision-making and customizing care at the individual level.

Ronald Epstein offered a variation on this definition: he emphasized that patient-centered care is far from simply taking patient requests at face value or abandoning patients to come to their own conclusions about an appropriate course of treatment, but rather partnering with patients to share in deliberation and decision-making. He called for “a vision of mindful hospitality,” in which “patient-centered care is an interaction between an informed, activated, participating patient and family; an accessible, well-organized health care system; and a patient-centered community of clinicians.” He noted that patient preferences are neither static nor uninformed; rather, they are constructed through interactions with clinicians, family members and the media. In these interactions, he argued, clinicians have an obligation to be self-aware and transparent to patients in such a way that they can interpret information in the context of the clinician’s inherent biases and perspectives.

The ABIM Foundation is launching a website, *Shared Wisdom*, based on a compilation of patient and caregiver stories that was released at the 2008 Forum. The website will be available in January 2009. We invite you to visit the site to read these personal accounts, as well as share your own story and reflections to contribute to a movement focused on enhancing patient-centered care.

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– MARGARET MURPHY
WHO WORLD ALLIANCE
FOR PATIENT SAFETY, AND
A FAMILY CAREGIVER

PATIENTS AND CLINICIANS: A “MEANINGFUL DIALOGUE”

This type of “meaningful dialogue” between patients and clinicians was at the heart of what many participants characterized as patient-centered care. As Susan Edgman-Levitan, Massachusetts General Hospital, put it, “When we talk about patients as the source of control, patients really don’t want to be their own doctors. We want to be able to say, ‘I don’t want to make this decision,’ or ‘I need help with this’ and know that we have a safety net and there’s going to be somebody there to help us sort our way through it.” Margetty Coe, a Philadelphia artist who has been through a maze of physicians and systems as a result of treatment for a pituitary tumor, echoed this sentiment, saying the conversation between the physician and the patient is where patients can sort out their individual wants and needs and make them known to their physicians to promote meaningful, informed decisions about their care.

“I’ve never felt so not listened to in my life,” said Greg Lipski, a first-year medical resident, as he relayed one chapter in his story as a medical student diagnosed with acute lymphoblastic leukemia. His doctors dismissed his suspicions of a lung infection that occurred in the course of his treatment. Yet, they ultimately arrived at the same conclusion a month later.

Don Berwick encouraged the group to acknowledge that patient-centeredness includes understanding how much knowledge and wisdom resides within the patient. He challenged the group to up-end the traditional medical notion of “adherence,” calling for a more collaborative approach to sharing and building knowledge about what works for the individual patient. Dana Safran, Blue Cross Blue Shield of Massachusetts, suggested that patient adherence should evolve from its current status as a “don’t ask, don’t tell” part of the interaction between a clinician and patient to becoming an explicit structured communication that explores the patient’s barriers to a suggested course of action. Mark Smith, California HealthCare Foundation, commented that “the notion that we’re moving patients around like marionettes is our own self-delusion,” and suggested that clinicians be cognizant that each patient has a doctor within – and give that doctor the chance to go to work.

A HALLMARK OF QUALITY OR A LUXURY WE CAN NOT AFFORD?

Many participants argued that patient-centeredness should be as important a measure of quality as any outcome, and that patient-centeredness can contribute to better outcomes. Don Berwick urged the health care community to affirm patient-centeredness and family-centeredness as dimensions of quality in their own right, and not just through their effects on health status and outcomes, technically defined. As he put it, “I suggest that we should, without equivocation, elevate patient-centeredness to the status of a primary quality dimension all its own.”

Dana Safran provided a compelling overview of research linking the quality of clinician-patient interactions to important business outcomes – such as increasing loyalty to a medical practice, reducing malpractice risk and recommending the practice to others – and health outcomes – such as adhering to clinical advice, enhancing symptom resolution and improving clinical status.

Several patient participants reinforced these findings with anecdotes from their personal experiences. After surgery for a pituitary tumor, Margetty Coe met with several endocrinologists who focused on the textbook version of what Coe “should be” experiencing, but was not. Finally, she met one endocrinologist who spent an hour with her and listened to her symptoms. By exploring Coe’s individual experience, the physician helped her achieve better outcomes.

Similarly, Galen Buckwalter, an accomplished psychology researcher who is quadriplegic, reflected on the power of a physician to inspire resilience in a patient. He described a neurologist who, after an incredibly thorough examination, spent an hour asking how Buckwalter managed in his daily life, seeking to learn from him and thereby “nudging” him forward. Buckwalter praised the physician for accepting his role as a healer, which empowered Buckwalter as a patient and inspired a higher degree of engagement that, he believes, helped to reduce the cost of his care. It is in the patient-physician interaction, Buckwalter argued, that patient-centered care is realized.



AN ORGANIZING PRINCIPLE FOR HEALTH REFORM?

Some Forum participants argued for patient-centered care as an organizing principle for health reform. Peter Lee, Pacific Business Group on Health, noted that patient-centered care is not a stand-alone feature purchasers care about, but is a thread that ties together many things they value, such as safety, effectiveness and timeliness. Michael Richardson, Edward Hines, Jr. VA Hospital, provocatively asked the group to consider whether patient-centered care was, in fact, a “MacGuffin” – a narrative device that advances the plot, but the details of which are of little importance. In his view, patient-centeredness is a phrase that motivates the conversation around health reform and moves us closer to core issues we need to address: namely, who is the system being designed for, or, as he put it, “Which patients and whose center?” He suggested that patient-centered care may, in fact, prompt a more critical examination of fundamental health care disparities and how to overcome them.

But concerns were raised that valuing what patients “want and need” could inadvertently exacerbate the unnecessary utilization that already plagues the health care system. Andy Webber, National Business Coalition on Health, cautioned that such an approach risks sanctioning even more pronounced overuse. Troy Brennan, now with CVS Caremark and previously with Aetna, argued, “We want people to get everything they need, but what they need is what the evidence supports.”

A number of participants pushed back on this assertion and contended that incentives for overuse in the current payment system are at the crux of the problem. They suggested that patient-clinician dialogue is an important mediating force in the process of constructing “wants” and “needs” and that by providing patients with information and the opportunity for frank discussion about medical decisions, physicians could engage the public in a discussion about overuse, leading to more appropriate utilization.

FROM HERE TO THERE: THE ROAD TO PATIENT-CENTERED CARE

While participant views of patient-centered care and its impact varied, there was consensus that the current system is far from achieving this goal. Some questioned whether physicians or patients are ready for the challenges posed by patient-centered care, noting that many primary care physicians are overburdened and both physicians and patients need education and training to make care more patient-centered. Wendy Levinson, University of Toronto, echoed these concerns, saying the practice of patient-centered care is hard to teach and involves a sophisticated skill set that needs to be nourished early and continuously in medical school and training.

Others encouraged the physician community to collaborate with the many disciplines involved in the care delivery process. Indeed, some patients may feel more of a personal connection to the medical assistant or nurse on the team, and these relationships should be leveraged to achieve the goals of patient-centeredness. As Pamela Mitchell, University of Washington, reminded the group, “Nurses have been providing patient-centered care for a long time,” and suggested that with a more team-oriented, system-level approach, patient-centered care may be within reach. On this theme, Karen Nelson, UNITE HERE Health Center, and Delfina Ramirez, Clinica Campesina, provided powerful case studies of how organizations can build on teams to make patient-centered care affordable and accessible to diverse populations.

While much can be done in terms of practice redesign and training to promote patient-centered care, participants also acknowledged key barriers in the structure and financing of the system. Darrell Kirch, Association of American Medical Colleges, noted that “we have a payment system that rewards rescue care, diagnostic technology and big interventions, more than prevention. If we hope for patient-centered care in the middle of that system, we are swimming upstream.”

“I SUGGEST THAT WE SHOULD, WITHOUT EQUIVOCATION, ELEVATE PATIENT-CENTEREDNESS TO THE STATUS OF A PRIMARY QUALITY DIMENSION ALL ITS OWN.”

– DON BERWICK, MD
PRESIDENT AND
CHIEF EXECUTIVE OFFICER,
INSTITUTE FOR HEALTHCARE
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MOVING FORWARD: A CALL TO ACTION

Reflecting on the experience of the Forum, several participants remarked on the power of the personal story and the patient/caregiver voice in the dialogue about health reform. Harvey Fineberg, Institute of Medicine, said he was struck by the richness of the conversation in comparison to the “anemic reform debates” in Washington and suggested that “we have to turn to those outside of the profession to help us both to educate the public and to lead the way to reform the system to achieve access, patient-centered care, safety and quality at all levels.”

Mark Smith challenged the group to be bold and forward-looking, warning that there are “changed conditions ahead” that require vision. He suggested that there is much to be learned from other fields to help the health care system develop more scalable, durable models that are responsive to individual consumers’ needs. He also reinforced the need to partner with patients and consumer groups and urged the medical profession to be better participants, in addition to better leaders, to achieve the vision of patient-centered care.

Patient and family caregiver participants offered some specific ideas for action. Karen Tate, a parent who cared for a child with an arteriovenous malformation and who now works at the Children’s Hospital of Philadelphia, advocated bringing patients and families into the process from the very beginning to ensure that their views are incorporated across the range of efforts to reform the health care system. Margetty Coe called for establishing a venue, mediated by a third party, for patients to express concerns about failings in their care in order to press clinicians to acknowledge harm, where appropriate, and to help ensure that other patients won’t suffer similar consequences. Both patients and clinicians noted that this mechanism would encourage reflection and learning from mistakes and drive improvement in the system. This suggestion underscored the sentiment echoed by many patient participants that protection from harm – and clinician commitment to mitigate harm – is a foundational principle of patient-centered care.

Ultimately, the power of the Forum rested in the passionate and thoughtful dialogue that grew out of patient and family caregiver experiences and the recognition of the mistrust that has developed between health care professionals and the individuals they serve. The meeting concluded with a call to bridge this divide at the micro and macro levels of our health care system – both by adopting a more patient-centered approach to care delivery that can foster a therapeutic alliance between clinicians and patients and by exploring ways that patients and health care professionals can join forces to press for needed changes in the organization and financing of care in the policy sphere.

Please visit www.abimfoundation.org/dialogue/forum.shtm to access Forum presentations and supplemental materials.

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