

# New Roles and Rules for Patient-Centered Care

Michael L. Millenson, BA<sup>1,2</sup>

<sup>1</sup>Health Quality Advisors LLC, Highland Park, IL, USA; <sup>2</sup>Kellogg School of Management, Northwestern University, Evanston, IL, USA.

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“Patient-centered care” was anointed one of six aims for US health care in a 2001 Institute of Medicine report that simultaneously unfurled a long list of its defining traits. The term encompassed “qualities of compassion, empathy and responsiveness to the needs, values and expressed preferences of the individual patient” while addressing “technical care and interpersonal interactions” within “a healing relationship.”<sup>1</sup>

A dozen years later, a 2013 IOM workshop sounded a strikingly different note. It recommended “strategies and policies at multiple levels to advance patients, in partnership with providers, as leaders and drivers of care delivery improvement through the protected use of clinical data, informed, shared decisions and value improvement.”<sup>2</sup>

Despite the leaden language, this shift signals significant progress. Behaviors formerly presented as ideals are being reframed to include measurable benchmarks such as one might see in a financial plan. The analogy is apt, since patient-centeredness is now deemed essential to transforming the \$2.7 trillion health care system. As the IOM workshop put it: “Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs and better health.”

The ongoing change from aspirational goals to operational ones in patient-centeredness can be seen in the “meaningful use” regulations affecting doctors and hospitals using health information technology obtained with federal grants. Even more significant, the Patient Protection and Affordable Care Act uses “patient-centered” 43 times and includes nine separate provisions requiring “patient-centered” quality measures. There are also references to patient satisfaction, patient experience of care, patient engagement and shared decision-making.

This burst of activity and enthusiasm, while welcome, carries its own dangers. Distinct ethical, economic and clinical concepts have been cobbled together under the “patient-centeredness” banner. These separate ideas are sometimes complementary, but they can also clash. The central importance of a new kind of collaborative relationship between doctor and patient risks being lost in a blizzard of buzzwords.

Certainly, “patient-centered care” was not the goal originally pursued by patients: what they demanded was shared power. The Boston feminists who authored *Our Bodies, Ourselves* were angry about doctors denying them information; that their manifesto quickly morphed from booklet to best-seller showed how widely those feelings were shared. In the courtroom during this same period, patients’ lawsuits forced doctors to explain risks and benefits of proposed treatments in plain English. In the streets, gay men identified themselves as Persons with AIDS (not AIDS “victims”) and insisted that clinicians listen to their voices.<sup>3</sup>

The term “patient-centered care” was popularized in 1987 by a Picker Institute/Commonwealth program of that name. Their definition, later adapted by the IOM, attacked the problem of power sharing through language that relied heavily on precepts of autonomy and individual rights.

In contrast, consumerism springs from different soil, involving purchasing decisions based on the perceived value of what is being sold. To be sure, there is consonance between the two concepts in health care. The availability of same-day appointments, for example, constitutes consumer and clinical responsiveness. Nonetheless, the casual use of “patient” and “consumer” as interchangeable terms is problematic.

For example, when a “consumer” chooses a doctor using price and ratings information, she trusts that *caveat emptor* will not replace *primum non nocere* when she walks into the exam room as a “patient.” Should she, or should marketplace rules prevail? When a doctor recommends an expensive test, how should a “consumer” respond to “drive value improvement,” in the IOM’s phrase? Might that differ from how a sick and vulnerable “patient” would behave? Is consumer satisfaction (“my money’s worth”) really identical to patient satisfaction?

I believe that what distinguishes patient-centered care in its fullest sense from beneficence or better customer service is that it involves actions undertaken in collaboration with patients, not just on their behalf. It requires clinicians to appropriately share power even when that sharing feels uncomfortable.

Consider the doctor who is both a careful listener and parsimonious with his prescription pad, i.e., a paragon of patient-centeredness in its ethical and economic dimensions. He nonetheless may balk at a diabetic patient’s demand that

he download data from her continuous glucose monitor so he can better serve as a “consultant” on treatment. (This is a real example.)

The problem here is not the absence of a “prepared and engaged patient,” as the IOM would have it, but power: who is engaging whom on what terms? Similarly, the right to shared decision-making has historically been bestowed on patients. As clinically relevant data are increasingly generated and controlled by patients, who is sharing decisions with whom?

This disruption goes much deeper than “Dr. Google.” Online information has become abundant, cheap, personally oriented and designed for participation, notes the Pew Research Center. Simple sensors like the Fitbit have attained mass-market status, and biosensing clothing that records respiration and heart rate is not far behind. Individuals can access sophisticated diagnostic algorithms and almost equally sophisticated treatment efficacy data derived from patient-generated reports. In medicine, as in every other field, the information monopoly of the experts has been shattered.

How should internal medicine respond to the challenge of patient-centered care in the information age? I believe the “enhanced autonomy” model developed by clinician-ethicists Timothy Quill and Howard Brody offers one answer.<sup>4</sup> Though their model isn’t new, it has acquired new resonance in the current environment.

The enhanced autonomy model speaks in the language of relationships. It encourages patients and physicians to *actively exchange* ideas, *explicitly negotiate* differences, and *share* influence and power. It establishes an overarching framework—“an *intense collaboration* between patient and physician”—and directly addresses the experience of illness (emphasis added).

Quill and Brody write: “Patients can autonomously make choices that are informed by both the medical facts and the physician’s experience.” With these few words, they implicitly cede claims of unlimited power and agree to accept reliable facts from any source (including the patient’s glucometer). At the same time, they reaffirm that when the fear and uncertainty that can surround illness threaten our sense of self—“the kingdom of the sick,” in Susan Sontag’s memorable phrase—the doctor’s counsel retains its enduring value.

This formulation shares power responsibly. It embraces patients who prefer the old ways, those who wish their doctor to serve mostly as “guide and fellow traveler” and those who vacillate in their preferences. It accommodates the radical patient-centeredness exemplified by OpenNotes, where nearly 2 million patients now have ready access to the same medical record the doctor sees. It responds to rules and regulations while protecting clinicians’ powerful sense of mission from being suffocated by red tape.

At the same time, the model’s prerequisite of intense collaboration and explicit discussion engenders patient responsibilities to go along with patient rights. As a result, conversations about the necessity or price of a particular

treatment take place within a very different context than either the traditional doctor-patient consultation or a seller-buyer discussion.

Enhanced autonomy is no panacea. Success will require support from organizations and institutions whose rules and reimbursement still govern physicians’ lives. Technical challenges, differences among members of the clinical team, legal fears and lingering uncertainties will not disappear. The changed roles, rules and expectations that accompany a paradigm shift are inherently traumatic. Nonetheless, the rich relationship this approach nurtures is crucial to care, cost and caring at a time of dizzying change.

In his landmark book, *The Silent World of Doctor and Patient*, psychiatrist Jay Katz wrote:

I believe that patients can be trusted. If anyone were to contest that belief, I would ask: Can physicians be trusted to make decisions for patients?...[B]oth must be trusted, but...they can only be trusted if they first learn to trust each other.<sup>5</sup>

The IOM erred. “Prepared, engaged patients” are not the fundamental precursor to transforming health care. Patients and providers alike must change. What we need is not better patients, but a framework that enables a far deeper partnership.

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**Corresponding Author:** Michael L. Millenson, BA; Health Quality Advisors LLC, 2735 Fort Sheridan Avenue, Highland Park, IL, USA (e-mail: mm@healthqualityadvisors.com).

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