What 'Patient-Centered' Should Mean: Confessions Of An Extremist

A seasoned clinician and expert fears the loss of his humanity if he should become a patient.

by Donald M. Berwick

ABSTRACT: "Patient-centeredness" is a dimension of health care quality in its own right, not just because of its connection with other desired aims, like safety and effectiveness. Its proper incorporation into new health care designs will involve some radical, unfamiliar, and disruptive shifts in control and power, out of the hands of those who give care and into the hands of those who receive it. Such a consumerist view of the quality of care, itself, has important differences from the more classical, professionally dominated definitions of "quality." New designs, like the so-called medical home, should incorporate that change. [*Health Affairs* 28, no. 4 (2009): w555–w565 (published online 19 May 2009; 10.1377/hlthaff .28.4.w555)]

THE CONCEPT OF THE MEDICAL HOME (a practice team that coordinates a person's care across episodes and specialties) is now reaching center stage in proposals for redesign of the U.S. health care system.[1] The major primary care societies—the American College of Physicians, the American Academy of Family Physicians, the American Academy of Pediatrics, and the American Osteopathic Association—are united in their advocacy for it. This is welcome, of course, for those who hope for a shift of investment into primary care, integrated care, and prevention.[2] The question remains open, however, about the degree to which medical homes will shift power and control into the hands of patients, families, and communities. In this paper I argue for a radical transfer of power and a bolder meaning of "patient-centered care," whether in a medical home or in the current cathedral of care: the hospital.

Three years ago, a close friend began having chest pains. She headed for a cardiac catheterization, and, frightened, she asked me to go with her. As I stood next to her gurney in the pre-procedure room, she said, "I would feel so much better if you were with me in the cath lab." I agreed immediately to go with her.

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The nurse didn't agree. "Do you want to be there as a friend or as a doctor?" she asked.

"I guess both," I replied. "I am both."

"It's not possible. We have a policy against that," she said.

The young procedural cardiologist appeared shortly afterward. "I understand you want to have your friend in the procedure room," she said. "Why?"

"Because I'd feel so much more comfortable, and, later on, he can explain things to me if I have questions," said my friend.

"I'm sorry," said the cardiologist, "I am just not comfortable with that. We don't do that here. It doesn't work."

"Have you ever tried it?" I asked.

"No," she said.

"Then how do you know it doesn't work?" I asked.

"It's just not possible," she answered. "I am sorry if that upsets you."

Moments later, my friend was wheeled away, shaking in fear and sobbing.

What's wrong with that picture?

Most doctors and nurses, I fear, would answer that what is wrong with that picture is the unreasonableness of my friend's demand and mine, our expecting special treatment, our failure to understand standard procedures and wise restrictions, and our unwillingness to defer to the judgment of skilled professionals.

I disagree. I find a lot wrong with that picture, but none of it is related to unreasonable expectations, special pleading, or disrespect of professionals. What is wrong is that the system exerted its power over reason, respect, and even logic in order to serve its own needs, not the patient's. What is wrong was the exercise of a form of violence and tolerance for untruth, and—worse for a profession dedicated to healing—needless harm.

The violence lies in the forced separation of an adult from a loved companion. The untruth lies in the appeal to nonexistent rules, the statement of opinion as fact, and the false claim of professional helplessness: "impossibility." The harm lies in increasing fear when fear could have been assuaged with a single word: "Yes."

The IOM Committee

In 1998 the Institute of Medicine (IOM) established a major program on Quality of Health Care in America. I served on the first major IOM committee on that topic, the Committee on Quality of Health Care in America, and I chaired one of its two subcommittees: the one called informally the "chassis subcommittee," because our job was to suggest new designs for care—a better "chassis." That term dated to several years earlier, to the predecessor IOM activity, the National Roundtable on Health Care Quality. One of its members, David Lawrence, famously said, "The problem is that the chassis is broken." He called into question the fundamental design of U.S. health care as standing between the quality of care we have and the quality we could have.

In 1998 the roundtable published a landmark article in the *Journal of the American Medical Association* laying out the basic framework that would guide the subsequent committee.[3] It labeled quality problems as a trio—"overuse, underuse, and misuse"—and it embraced this definition of *quality*: "The degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."

With that as background, the IOM Committee on Quality of Health Care in America set out to reconsider aims for improvement. The group considered "overuse, underuse, and misuse" to be a good start, but somehow incomplete—too technical. In the summer of 2000 we developed a new draft of aims: "safety, effectiveness, patient control, timeliness, efficiency, and equity."

The sticking point in the committee's deliberations was the third item on the list: "patient control." Members sorted themselves into camps along a line that ran, more or less, from radical consumerism (as in, "The customer is always right") to a classic professionalism (as in, "Patients make decisions that are not in their best interests," and "Does that mean that anyone who asks for a CT scan gets one?"). Compromise words surfaced: "partnership," "sharing," "respect for patients," and more. We settled on the term "patient-centeredness" as the aim.

The disagreement surfaced again in the committee's struggle to write what became the "ten simple rules" for redesign—the guiding principles of how the health care system should operate to achieve the six aims for improvement. Rule 3, drafted by the radicals, started out as, "Patients have all the control." Some argued that patients' demands would be unreasonable. Others imagined patients who would not want such control. Rule 3 ended up as, "The patient is the source of control." The third of the six aims, "patient-centeredness," and the third of the ten rules for redesign, "The patient is the source of control," found themselves in those forms in the committee's chartering document, *Crossing the Quality Chasm.*[4]

I find an important, and usually underestimated, difference between the 1997 roundtable's focus on "overuse, underuse, and misuse" as bounding the problem of health care quality and the six aims and ten rules of the *Quality Chasm* report. The difference centers on the third aim and the third rule, which, taken as strongly as I would have them taken, are potentially revolutionary. They can and, in my opinion, should redefine professionalism itself.

■ **"Professionalism" versus "consumerism."** The sociologist Eliot Freidson, in his classic study of health care, *Profession of Medicine*, defines a profession as a work group that reserves to itself the authority to judge the quality of its own work.[5] Freidson posits that society cedes this authority to a profession because of three beliefs: (1) altruism—that professionals will work in the best interests of those they serve, rather than their own interests; (2) expertise—that professionals are in command of a special body of technical knowledge not readily accessible to nonprofessionals, and (3) self-regulation—that professionals will police each other.

Freidson's definition of a profession contradicts the usual assumption of con-

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sumer-oriented production, in which the customer, not the producer, has the "authority," exercised by marketplace choices, to judge quality. In Freidson's world of professions, excellence is in the eye of the professional. In the more normal world of products and services, excellence is in the eye of the customer.

The latter is not a moral position; it is a pragmatic one. The business theory underlying modern quality strategies is that producers that meet consumers' needs, as judged by consumers, will thrive, and those that do not will wither.

The IOM committee found itself uncomfortably torn between Freidson's form of professionalism—"Trust us; we know best what will help you"—and the consumerist view of quality—"Let us know what you need and want, and that is what we will offer." The words "patient-centeredness" and "the patient is the source of control" are verbal analgesics, but they mask real pain.

If the roundtable's technocratic definition of *quality* holds, then only two of the six IOM aims are primary, and "patient-centeredness" is not one of them. The only two that stand on their own are "safety" ("avoiding misuse"—that is, not doing harm from care) and "effectiveness" ("avoiding overuse and underuse"—that is, grounding care in evidence). The importance of the other four aims—patient-centeredness, timeliness, efficiency, and equity—depends only on the extent to which they help determine safety and effectiveness. Of course, we can define *health* to include emotional well-being, which may give more traction to the four lesser aims, but, in the end, "timeliness" and "patient-centeredness" are on the defensive as aims unless evidence shows that they affect health.

A consumerist view of quality differs; it takes each of the six aims on its own merits, just as in judging the "quality" of an automobile, we can independently assess safety, comfort, reliability, gas mileage, beauty, and driving fun as separate characteristics. Although they might be unequal in importance, the merit of each does not depend on its influence on another.

Notice that in the consumerist view, the current IOM definition of *quality* is defective. It is a professionally dominated view of excellence—one that Freidson would immediately recognize. It subordinates by implication the four lesser IOM aims to the technical triad of "overuse, underuse, and misuse."

■ **Defining the ideal practice.** Ten years ago, to help with the Institute for Healthcare Improvement's (IHI's) project on the Idealized Design of the Clinical Office Practice, I suggested as an overarching aim for an ideal practice that its patients would say of it, "They give me exactly the help I need and want exactly when I need and want it." Dartmouth's John Wasson incorporated that question in an improved form in his "How's Your Health" questionnaire: "They give me exactly the help I need and want exactly when and how I need and want it," to emphasize the increasingly

wide range of ways to extend care to patients.

Note that the IHI question explicitly and uncomfortably stresses the view of care through the patient's eyes, especially with the words "need and want," rather than "need" only. The word "want" remains the focal point of ongoing debate and controversy, for the same reasons that the IOM committee argued about Rule 3.

In the territory between the professionally dominant view of quality of health care and the consumerist view, my views are far from Freidson's definition. I think it wrong for the profession of medicine—or any other health care profession, for that matter—to "reserve to itself the authority to judge the quality of its work." I eschew compromise words like "partnership." For better or worse, I have come to believe that we—patients, families, clinicians, and the health care system as a whole—would all be far better off if we professionals recalibrated our work such that we behaved with patients and families not as hosts in the care system, but as guests in their lives. I suggest that we should without equivocation make patient-centeredness a primary quality dimension all its own, even when it does not contribute to the technical safety and effectiveness of care.

Pedigree Of Patient-Centeredness

The idea of "patient-centeredness" did not, of course, spring to life first with the IOM committee; it has a long intellectual pedigree. A complete review is impossible here, but a few pioneers include the following. (1) Barbara Korsch of the University of California, Los Angeles (UCLA), for decades explored skills, attitudes, and knowledge to underpin the listening skills of physicians in training.[6] (2) John Ware and colleagues in the RAND Health Insurance Experiment uncovered and clarified components and drivers of "patient satisfaction."[7] (3) Debra Roter and Judith Hall explored the properties of doctor-patient communication, revealing its dysfunctions and ways to improve it.[8] (4) Howard Waitzkin and John Stoeckle articulated the nature and value of patients' own attributions of their symptoms to causal factors and showed how tapping their views and knowledge could lead to more satisfactory interviews and relationships.[9] (5) Michael Barry, Jack Fowler, Al Mulley, Joseph Henderson, and Jack Wennberg developed theory and technology for shared decision making and showed improvements in outcomes and efficiency as patients become more active participants in the decisions that affect them.[10] (6) Judith Hibbard has investigated the "receiver" end of transparency, deepening our understanding of what patients want to know and how to help them know it.[11]

Although I believe that "patient-centeredness" ought to have stature as a dimension of quality in its own right, it is also true that most researchers who have studied it systematically have found that it does often have a positive relationship to classical health status outcomes.[12] This is in part because patients and families can bring useful knowledge to care if they are invited to do so. Beatrice Golomb and colleagues, for example, found that patients on statin drugs were far more

likely than doctors to initiate discussions of symptoms possibly related to the drugs ($p < 10^8$).[13] Annette O'Connor and colleagues' masterful systematic review of the effects of shared decision-making technologies found a 23 percent reduction in surgical interventions among patients using them, with better functional status and satisfaction.[14] Patient education can help make technical health care interventions more effective, largely through better compliance.

■ **Three maxims.** Others have struggled to find a proper definition of *patient-centeredness.* Three useful maxims that I have encountered are these: (1) "The needs of the patient come first." (2) "Nothing about me without me." (3) "Every patient is the only patient."

"The needs of the patient come first" is a pervasive slogan at Mayo Clinic. In his detailed study of Mayo Clinic, Leonard Berry, a leading scholar of service industries, emphasizes Mayo's teamwork and brand clarity as advantages, but he traces these strengths to the continual and conscious reinforcement of the rule of William J. Mayo: "The best interest of the patient is the only interest to be considered."[15] This perspective is still formally technocratic; Dr. Mayo did not choose to say, "The needs and wants of the patient…," and one wonders how he would have greeted the consumerist assertion that patients know their "best interest" better than physicians do. Nonetheless, the idea that designs of habit or convenience are subordinate to designs that serve the patient is fully modern.

I heard "Nothing about me without me" from Diane Plamping, a U.K. health care organizational sociologist.[16] It calls for levels of transparency and participation uncharacteristic of most health care systems.

I first saw "Every patient is the only patient" at the entryway to the Harvard Community Health Plan Hospital at Parker Hill in Boston, placed there by its chief executive officer, Arthur Berarducci.[17] It connotes to me the attitude of "guest" in the patient's life, and it also expresses confidence in the feasibility and desirability of customization of care to the level of the individual.

As I stood in the pre-catheterization room, watching my friend be rolled away, crying, on her gurney, none of these three design ideas was in evidence. The needs of the patient did not come first—the habits and rules of the doctors and nurses did. Many things were going on about her without her; the alleged rules were neither negotiated in advance nor open for discussion. And she was not "the only patient"; she was anonymous, a member of a class, and her unique needs, wants, and reasons had no voice at all in the face of blunt, deaf standard practices.

■ **A new definition.** My proposed definition of "patient-centered care" is this:

> The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one's person, circumstances, and relationships in health care.

In most circumstances, people would, and should be able to, amend the subject—"patient-centered care"—to include the experience of family and loved ones of

their choosing: "patient- and family-centered care." In this view, a patient- and family-centered health care system would be radically and uncomfortably different from most today. Let me suggest a few examples.

(1) Hospitals would have no restrictions on visiting—no restrictions of place or time or person, except restrictions chosen by and under the control of each individual patient. (2) Patients would determine what food they eat and what clothes they wear in hospitals (to the extent that health status allows). (3) Patients and family members would participate in rounds. (4) Patients and families would participate in the design of health care processes and services.[18] (5) Medical records would belong to patients. Clinicians, rather than patients, would need to have permission to gain access to them. (6) Shared decision-making technologies would be used universally. (7) Operating room schedules would conform to ideal queuing theory designs aimed at minimizing waiting time, rather than to the convenience of clinicians.[19] (8) Patients physically capable of self-care would, in all situations, have the option to do it.

Professionals' Objections

In this form of truly patient-centered design, many, if not most, classically trained health care professionals will find cause for alarm. Let me anticipate three objections.

■ **Evidence-based medicine sometimes must take a back seat.** First, leaving choice ultimately up to the patient and family means that evidence-based medicine may sometimes take a back seat. One e-mail correspondent asked me, "Should patient 'wants' override professional judgment about whether an MRI is needed?" My answer is, basically, "Yes." On the whole, I prefer that we take the risk of overuse along with the burden of giving real meaning to the phrase "a fully informed patient." I contemplate in this a mature dialogue, in which an informed professional engages in a full conversation about why he or she—the professional—disagrees with a patient's choice. If, over time, a pattern emerges of scientifically unwise or unsubstantiated choices—like lots and lots of patients' choosing scientifically needless MRIs—then we should seek to improve our messages, instructions, educational processes, and dialogue to understand and seek to remedy the mismatch. For the same reason, I wish we would abandon the word "noncompliance." In failing to abide by our advice or the technical evidence, the patient is telling us something that we need to hear and learn from. Honestly, how many of us have ever faithfully taken a full ten-day course of a prescribed antibiotic or never consciously skipped a statin dose? Are we fools who did that? Or did we choose that because of some sensible, local considerations of balance, convenience, or even symptom information that the doctor never had?

I can imagine just as easily as my critics can a crazy patient request—one so clearly unreasonable that it is time to say, "No." A purely foolish, crazy, or venal patient "want" should be declined. But my wife, a lawyer, told me long ago the apho-

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rism in her field: "Hard cases make bad law." So it is in medicine: "Exceptional cases make bad rules." You do not successfully rebut my plea for extreme patient-centeredness by telling me that, on rare occasions, we ought to say, "No." I say, "Your 'rare occasions' make for very bad rules for the usual occasions."

■ **Physician as steward of social resources.** A second objection emphasizes the duty of the professional as steward of social resources. Is patient-centeredness of the type I envision socially responsible? No one can yet know the answer to that question. Pandora's box may be empty. O'Connor and colleagues' summary of shared decision making for surgery cuts the other way: more sharing, less invasive care; and the work of Wennberg and Elliott Fisher suggests that supply drives demand, not the other way around.[20] At a minimum, I suggest that becoming responsive to individual needs and wants can give us the information we need for informed social choices to be made where they mostly belong: at the level of public policy.

■ **Clinicians' needs and wants.** A third objection concerns the needs and wants not just of the patient, but of the clinician, too. Does patient-centeredness require of the doctor self-denial and martyrdom? Will it exhaust us? I think not. I believe, rather, that the moats we dig between patients and clinicians can drain spirit from both. When in a caring relationship we deny to the other what we could with free hearts give, we both suffer from the denial; one loses the help, the other loses the joy of helping. Among the most destructive forms of denial is the message: "You should not want that." Even more destructive, in my opinion, is the training and institutional habit of phrasing our choices as lies, in the form, "We cannot do that," when we darn well could.

In a remarkable essay, "A New Professional: The Aims of Education Revisited," Parker Palmer argues against definitions of *professionalism* that separate human beings from their own feelings and hearts. He writes, in part:

> The education of the new professional will reverse the academic notion that we must suppress our emotions in order to become technicians.... We will not teach future professionals emotional distancing as a strategy for personal survival. We will teach them instead how to stay close to emotions that can generate energy for institutional change, which might help everyone survive.[21]

Ask patients today what they dislike about health care, and they will mention distance, helplessness, discontinuity, a feeling of anonymity—too frequently properties of the fragmented institutions in which modern professionals work and train. Palmer is arguing for a reconnection of the feelings of health care professionals with their work, and he believes that violence is done when that connection is sundered by institutional norms and training. I claim that threats to the health of the professions come far more from denying our basic instincts to help

than from embracing them. What undergirds authentic patient-centeredness are the very same words we use when we first came to the patient's side: "How can I help you?" Helping, not the enforcing of restriction, is tonic for our souls.

Issues Related To Health System Design

Let me suggest a few design constraints on the health care system that we need and want, and let me urge the leadership of the professions, those to whom has been reserved the right to judge the quality of their own work, to abdicate that monopoly and instead to bring a never-ending inquiry to those we serve: "What do you want and need?" "What is your way?" "How am I doing at meeting your needs?" "How could I do that better?" "How can I help you?"

The pursuit of truly patient-centered care of this sort can be designed into the medical home, if we wish to do so, just as well as into the design and conduct of a hospital. Here is how.

■ **Patient-centered care as a quality dimension.** First, affirm patient- and family-centered care as a dimension of quality in its own right, and not just through its effect on health status and outcomes, technically defined. A simple way to begin in a proper medical home is to ask the following question at the end of most interactions: "Is there anything at all that could have gone better today from your point of view in the care you experienced?" And then, listen and learn. For quantitative ratings, ask patients to rate on a 1–5 scale disagreement to agreement with the assertion: "They gave me all the care I needed and wanted exactly when and how I needed and wanted it." Seek 5s and study the low raters.

■ **Locus of control.** Second, firmly vest in patients and families control over decisions about care in all its aspects. Take over control only rarely and with permission freely granted.

■ **Transparency.** Third, extend transparency to all aspects of care, including science, costs, outcomes, processes, and errors. Apologize when things go wrong.

■ **Individualization and customization.** Fourth, learn and use individualization and customization as design targets. This means creating flexible systems that can adapt, on the spot, to the needs and circumstances of individual patients.

■ **Training.** Fifth, train all young professionals in these as norms of professionalism. Equip students with confidence in their own emotional intelligence, as well as skills in mindfulness, inquiry, and dialogue.

■ **Toll on clinicians.** Clinicians may fear that extreme patient-centeredness will demand their time and energy with little or no reimbursement. This threat may lessen if and when health care evolves more toward episode-based or population-based payment and as information systems modernize. Visit rates declined at Kaiser Permanente when e-mail care—a major step toward patient-centered design—was widely adopted.[22] I suspect that clinicians expend enormous energy when they enforce restrictive rules and otherwise lose touch with patients' underlying needs, and they will experience patient-centered designs not as burdens, but as reliefs.

An Extreme View

I freely admit to extremism in my opinion of what patient-centered care ought to mean. I find the extremism in a specific location: my own heart. I fear to become a patient. Partly, that fear comes from what I know about technical hazards and lack of reliability in care. But errors and unreliability are not the main reasons that I fear that inevitable day on which I will become a patient. For, in fighting them, I am aligned with the good hearts and fine skills of my technical caregivers, and I can use my own wit to stand guard against them.

What chills my bones is indignity. It is the loss of influence on what happens to me. It is the image of myself in a hospital gown, homogenized, anonymous, power-less, no longer myself. It is the sound of a young nurse calling me, "Donald," which is a name I never use—it's "Don," or, for him or her, "Dr. Berwick." It is the voice of the doctor saying, "We think...," instead of, "I think...," and thereby placing that small verbal wedge between himself as a person and myself as a person. It is the clerk who tells my wife to leave my room, or me to leave hers, without asking if we want to be apart. Last month, a close friend called a clinic for her mammogram re-port and was told, "You have to come here; we don't give that information out on the telephone." She said, "It's OK, you can tell me." They said, "No, we can't do that." Of course, they "can" do that. They choose not to, and their choice trumps hers: period. That's what scares me: to be made helpless before my time, to be made ignorant when I want to know, to be made to sit when I wish to stand, to be alone when I need to hold my wife's hand, to eat what I do not wish to eat, to be named what I do not wish to be named, to be told when I wish to be asked, to be awoken when I wish to sleep.

Call it patient-centeredness, but, I suggest, this is the core: it is that property of care that welcomes me to assert my humanity and my individuality. If we be heal-ers, then I suggest that that is not a route to the point; it is the point.

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