

The following was excerpted and adapted by Lauren Spiro from “**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

*Donald M. Berwick may be appointed to head the Centers for Medicare and Medicaid Services, according to Health Affairs Blog <http://healthaffairs.org/blog/2010/03/28/cms-nominee-berwick-on-empowering-patients-and-improving-quality/>*

“...A radical transfer of power and a bolder meaning of “patient-centered care”

When he was denied access to a procedure room to continue to be with a friend who had asked him to accompany her, Dr. Donald M. Berwick wrote that it was an “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 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. . . . I have come to believe that we . . . would all be far better off if we professionals . . . 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. . . .”

“... 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.”

“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.’ ”

**“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 . . .”

“... 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. (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. (8) Patients physically capable of self-care would, in all situations, have the option to do it.”

“**Clinicians’ needs and wants:** . . . 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.”

Under **Health System Design**, Dr. Berwick makes these points, among others:

“**Locus of control** . . . firmly vest in patients and families control over decisions about care in all its aspects. . . .”

“**Individualization and customization** . . . this means creating flexible systems that can adapt, on the spot, to the needs and circumstances of individual patients. . . .”

“**Training** . . . Equip students with confidence in their own emotional intelligence, as well as skills in mindfulness, inquiry, and dialogue. . . .”

“**Toll on clinicians** . . . 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. . . . What chills my bones is indignity. It is the loss of influence on what happens to me. . . . That’s what scares me: to be made helpless before my time . . . to be alone when I need to hold my wife’s hand, to eat what I do not wish to eat . . . to be told when I wish to be asked. . . .”

“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 healers, then I suggest that that is not a route to the point; it is the point.”