The Patient As Agent of Health and Health Care

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Book Abstract: In the 21st century, the primary challenge for health care is chronic illness. To meet this challenge, we need to think anew about the role of the patient in health and health care. There have been widespread calls for patient-centered care, but this model of care does not question deeply enough the goals of health care, the nature of the clinical problem, and the definition of health itself. We must instead pursue patient-centered health, which is a health perceived and produced by patients. We should not only respect, but promote patient autonomy as an essential component of this health. Objective health measures cannot capture the burden of chronic illness, so we need to draw on the patient’s perspective to help define the clinical problem. We require a new definition of health as the capacity for meaningful action. It is recognized that patients play a central role in chronic illness care, but the concept of health behavior retards innovation. We seek not just an activated patient, but an autonomous patient who sets and pursues her own vital goals. To fully enlist patients, we must bridge the gap between impersonal disease processes and personal processes. This requires understanding how the roots of patient autonomy lie in the biological autonomy that allows organisms to carve their biological niche. It is time for us to recognize the patient as the primary customer for health care and the primary producer of health. Patient agency is both the primary means and primary end of health care.

Keywords: Agency, autonomy, engagement, empowerment, activation, chronic disease, illness, competence, patient-centered, capability

1. Patient-Centered Medicine: Who, What, and How?

We don’t have a clear idea where health comes from. Our efforts to reform health care to make it more patient-centered and more responsive to the challenges of chronic illness have been too superficial. Three lessons for chronic illness care are derived: 1) we cannot assume that death and disease are the most important targets for health care, 2) we must draw on the patient’s perspective to define the nature of the clinical problem and the criteria of success for our clinical interventions, and 3) we must always aim toward increasing the patient’s capacity for self-care. The patient-centered care of chronic disease requires that we recognize the patient as the primary perceiver and producer of health. We must move not only from the passive patient to the informed and activated patient, but to the autonomous patient. Patient agency is both the primary means and primary end of health care.

Keywords: Patient-centered care, patient-centered medicine, autonomy, agency, chronic care model, epidemiologic transition

2. Patient-Centered Care or Patient-Centered Health?

The history of proposals for patient-centered medicine begins with Michael Balint’s proposal for patient-centered medicine as an alternative to illness-centered medicine. This has been weakened in more recent calls for patient-centered care from clinicians, foundations, and professional organizations. It is argued that patient-centeredness consists of both taking the patient’s perspective and activating the patient. Taking the patient’s perspective involves communication skills and may involve developing a “shared mind” with the patient. Two programs for activating patients are contrasted, 1) the Expert Patient program based on the Chronic Disease Self-Management Program of Lorig and Holman and 2) the Patient-Centered Medical Home based on the Chronic Care Model developed by Wagner and colleagues. Patient empowerment involves activating patients on their own behalf and in service of their own goals. A truly patient-centered chronic care model aims not only for patient empowerment, but also for patient capability to pursue health and other vital goals.

Keywords: Patient-centered care, patient-centered medical home (PCMH), Michael Balint, Ian McWhinney, Kate Lorig, self-management, self-transformation, empowerment, capability, Amartya Sen

3. Respecting and Promoting Autonomy in Research, End-of-Life Care, and Chronic Illness Care

Bioethics teaches us to respect patients as persons by respecting their decisional autonomy. We respect patient autonomy by seeking patients’ informed consent, a policy was first developed for clinical research, where it has worked reasonably well. In other areas, most notably end-of-life care, it has not worked as well. Respecting patient autonomy is not adequate respect for them as ill persons. Rather than opposing physician beneficence and patient autonomy, as is customary in bioethics, we should consider the promotion of patient autonomy as a part of physician beneficence. This recasts the conflict between beneficence and autonomy as the conflict between respecting and promoting patient autonomy. This autonomy needs to be understood not just as the ability to make decisions but also as the general ability to do and be things of value (i.e. agency). This autonomy is not just a value that qualifies care, but is a goal of care.

Keywords: Patient autonomy, beneficence, SUPPORT study, Edmund Pellegrino, Albert Jonsen, Thomas Beauchamp, James Childress, informed consent, Tristram Engelhardt, Carl Schneider

4. Escaping the Autonomy Versus Objectivity Trap by Repersonalizing the Clinical Problem

Respect for patient autonomy has been sought as the antidote to the depersonalization that ails modern medicine. It serves as a challenge to the dominance of impersonal disease diagnosis in treatment choice. We now repersonalize treatment at a late stage through the informed consent process. If we are to find another way to repersonalize health care, we need to understand the historical roots of the patient autonomy versus objective disease dynamic in which we are trapped. The same disengaged self that sees ethics in terms of autonomy also sees disease as an observable tissue lesion within the body at autopsy. Clinico-pathological correlation offers a gold standard for clinical diagnosis and a completely objective access to disease. This ability to diagnose objective disease is the source of physician paternalism. It can be countered by incorporating the patient’s view of the clinical problem back into the diagnostic process.

Keywords: Clinic-pathological, Michel Foucault, Rene Descartes, John Locke, Charles Taylor, subjective/objective, Lorraine Daston, Peter Gallison, narrative medicine, palliative care

5. Health-Related Quality of Life as a Goal for Clinical Care

The importance of chronic illness has brought a new focus on patient-reported outcomes of clinical care. Health-Related Qualify of Life (HRQL) is a new goal for clinical care that combines a physician’s view of health as an objective biological fact and the patient’s view of health as a subjective experiential state. The diagnosis of an impersonal and objective disease separable from the patient arose after the French Revolution and helped to delimit the new right to health care. But objective mortality and morbidity metrics are not adequate for capturing the burden of chronic illness. HRQL was invented to capture the burden of chronic illness, but has not been successfully incorporated into clinical trials or clinical care. Chronic low back pain is presented as an example where both objective and subjective metrics of treatment success have failed. We need an openly patient-centered definition of health that is not just a supplement to objective disease diagnosis.

Keywords: Health-Related Quality of Life, patient-reported outcomes, symptoms, function, well-being, utility, cost-effectiveness, mortality, morbidity, burden of illness, chronic disease

6. Health as the Capacity for Action

Objective definitions of health and disease are favored because they promise a value-free measure of health problems and health care needs. But objective health does not simply cause the subjective experience of health. Self-rated health predicts mortality, disability, and hospitalizations for up to a decade after controlling for objective measures of health. Objective tissue abnormalities cannot be discovered to be pathological without reference to the experiences of patients acting in their natural environment. Patients adapt to chronic illness and its functional deficits over time with real improvements in their quality of life. Problems like pain and depression do not distort quality of life assessments, but are at their core. Since neither objective nor subjective models of health are valid, we must derive a different model: health as capacity for action. Any adequate approach to health must foster the patient’s sense of agency, her capacity to achieve her vital goals.

Keywords: Self-rated health, capability, Amartya Sen, Georges Canguilhem, response shift, pain, depression, health-related quality of life, HRQL, action

7. On the Role of Health Behavior in 21st-Century Health

Patient health behavior is crucially important in the care of chronic disease. Medication adherence and lifestyle health behaviors both make major contributions to individual and population health. Clinical interventions to improve adherence and lifestyle are contrasted with their natural determinants. The Chronic Care Model shifts our attention from promoting patient obedience to developing skills for self-management of chronic illness. We need to ask whether treatment of chronic illness, like diabetes, should be accomplished *through* or *around* patient. Two recent diabetes treatment trials, ACCORD and TEAMCARE, provide contrasting approaches to the nature of therapeutic action. The Diabetes Prevention Project demonstrated that it is possible to prevent the development of diabetes through exercise and diet or medication. Adherence to treatment appears to improve health outcomes, even if the treatment is inactive, through the “healthy adherer effect.” This suggests that an active approach to health may have intrinsic benefits.

Keywords: Adherence, compliance, self-management, lifestyle, Chronic Care Model, ACCORD, TEAMCARE, Diabetes Prevention Project

8. Advancing from Activated Patient to Autonomous Patient

Patient action in chronic disease care may not be best understood as “behavior.” Healthy patients do not just emit healthy behaviors but act as agents in their own lives. Bandura revolutionized health psychology through his “agentic” approach that emphasized patient confidence or self-efficacy. Now, the personal importance of behavior change is elicited using techniques like motivational interviewing. These and other approaches that include personal goals and identity shift our focus from behavior to action. Health action includes not just management of a disease separate from the self, but self-transformation. Achieving lasting change in health actions requires attention to the autonomous quality of patient motivation. Self-determination theory offers a useful theory of intrinsic motivation and an understanding of the process of internalization of motivation. This helps us understand the promise of shared decision-making and its difference from informed consent. Ultimately, patient empowerment must be understood as fostering patient autonomy.

Keywords: Albert Bandura, self-efficacy, motivational interviewing, self-determination theory, Edward Deci, Richard Ryan, autonomy, self-transformation, empowerment, shared decision-making

9. Finding Health Between Personal and Disease Processes

Patient autonomy on a personal level is ultimately rooted in biological autonomy on a subpersonal level. Patient decisional autonomy concerns the conscious choices patients make concerning treatments and lifestyle, whereas biological autonomy concerns the ability of patients to shape their environment. To understand the roots of health in this biological autonomy, we must bridge the chasm characteristic of modern natural science between personal meaning and impersonal mechanism. We will find that “health” and “action” represent blind spots for medical and biological theory, respectively. Modern medicine strongly distinguishes the impersonal disease from the patient who has the disease. Four disciplines at the margin of biomedicine are reviewed that challenge this separation: psychosomatics, placebo, alternative medicine, and geriatrics. Attention to personal goals during diagnosis and treatment is one way to bridge the gap between impersonal disease and the patient as person. But, ultimately, the impersonal biomedical disease model needs to be challenged.

Keywords: Psychosomatic medicine, placebo effect, alternative medicine, CAM, geriatrics, frailty, successful aging, Linda Fried, Mary Tinetti, Eric Cassell

10. Seeking the Roots of Health and Action in Biological Autonomy

The roots of biological autonomy and health are the same. Goals make biology distinct as a science, for without goals, we cannot understand why a biological trait exists. Organisms are autonomous biological entities because they define what is inside and what is outside themselves. This boundary between inner and outer gives the organism a self-referential purpose. Claude Bernard made experimental physiology possible with his concept of the internal environment, but he was unable to explain how the organism established the boundary between itself and its environment. Hence, homeostasis portrays the organism as reactive not active. Autopoiesis is an alternative defining characteristic of living beings. It generates biological autonomy through additional biological constraint on chemical processes, not through a special vital force. Healthy organisms can construct their own environmental niche. For humans, this niche is social and is constructed with a social physiology. Both exercise and education increase health by increasing capacity for niche construction.

Keywords: Claude Bernard, internal environment, Alva Noe, Francisco Varela, homeostasis, autopoiesis, capability, eusociality, mirror neurons, Paolo Friere

11. Make the Patient into the True Customer for Health Care

Despite accelerating expenditures on health care, the United States is falling behind peer countries in population health. The mismatch between dollars spent on health care and health achieved raises the question of the *value* of health services. How should we value these? The Affordable Care act expands access to care but does not question expert valuation of health states and health services. Rather than beginning with health insurance, a more productive path for our thinking proceeds from the nature of health to the nature of health care to the nature of health insurance. If we are to keep health care costs from rising no faster than GDP, we must make the patient the true customer for health care. Health policy should not aim to minimize objective disease or maximize subjective well-being, but to foster health capability. This encompasses the ability to enjoy health and to pursue it.

Keywords: Affordable Care Act, Accountable Care Organizations, David Goldhill, health policy, Ezekiel Emanuel, medical necessity, essential health benefits, overdiagnosis, overtreatment

12. Patient-Centered Health Is Produced by Patients

More fundamental than the patient’s capacity to perceive and value health is the capacity of the patient to produce health. Population and individual health do not originate from health care. Health care is not just inefficient at producing health; it can produce significant iatrogenic harm in clinical, social, and cultural ways. Patients may be overtreated. Non-patients may be overdiagnosed. Our culture is seduced into the belief that all death and disease can be controlled. Iatrogenesis transforms into expropriation as we become confused and forgetful about the sources of health itself. We have gradually strengthened our clinical safety net and weakened our social safety net. Yet, international studies suggest social spending improves population health more than clinical spending. The right to health is usually approximated as the right to health care. But this is inadequate and counterproductive. A better policy is a right to health capability.

Keywords: Ivan Illich, Amartya Sen, Jennifer Prah Ruger, health capability, iatrogenesis, population health, health agency, Arthur Barsky