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DIFFERENT WAYS TO UNDERSTAND PATIENT-CENTERED HEALTH LAW

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INTRODUCTION

Patient-centeredness cannot be all things to all people. The law, by its nature, decides between competing conceptions of what is right and what is just, and establishes these choices with the weight of law. At the outset of a project aimed at exploring whether health law might become more patient centered, it is tempting to seek consensus or to try to find broad agreement. But we may find that in law, in policy, and in practice, a narrowing of the definition of patient-centeredness might prove more useful and durable. Lines must be drawn, choices made, and terms defined. Too big a tent may prove too thin to cover anything of use. Patient-centeredness could migrate into something as vague as “caring” or as distant as an academic curiosity if it lacks the precision and coherence required for guiding actual decisions.

I offer here a set of choices to consider.

I. PATIENT VERSUS CLIENT OR CONSUMER

The term “patient” in “patient-centered health law” may simply be the easiest and most common way of identifying a focus on the individual receiving medical care rather than on others (such as doctors, insurance companies, etc.). Or it could mean more. If the unique experience of being a patient were not critical to the concept of patient-centered health law, we could instead choose to talk about client-centered or consumer-centered health law. There are certainly proponents of calling the recipients of medical care “clients”¹ or understanding them as “consumers.”² What does it

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1. See Michael J. Ramdass et al., *Question of ‘Patients’ Versus ‘Clients,’* 21 J. QUALITY CLINICAL PRAC. 14, 14 (2001) (reporting the institutional adoption of the term “client” and survey results of people’s preferences regarding the use of

mean to choose instead the term “patient”? It suggests that patients’ experiences *as patients* are important and should be taken into account, and that the law should recognize the vulnerability and suffering that illness can create and the dependency of the patient on others for knowledge, skill, or care. This in turn suggests that greater attention should be paid to the needs of the patient (beneficence) instead of merely the values of the patient (autonomy). But I have been disappointed to find that much of the medical literature about patient-centered care heavily emphasizes patient *autonomy* and pays comparatively little attention to “the phenomenology of what it is to be ill and to be a healer of illness.”³ That is not to say that patient-centered health law would follow the same path, but without explicit recognition that something other than a heralding of patient autonomy is intended, it could easily do so.

II. PATIENT-CENTERED VERSUS FAMILY-CENTERED HEALTH LAW

As part of the movement toward more patient-centered *medical care*, we have seen advocacy for and adoption by some practitioners of a heightened understanding of the patient as embedded within a family.⁴ According to this view, the centrality of the family to the patient’s experience is so critical that the term “family-centered” medicine is preferred over “patient-centered” medicine. Under this approach, the family (which may be defined by the patient) is also to be considered and cared for, and comprises individuals to whom duties are owed by health care professionals as they are affected by or participate in the medical care of the patient.⁵ When the term

this term).

2. See Janet L. Dolgin, *The Evolution of the “Patient”: Shifts in Attitudes About Consent, Genetic Information, and Commercialization in Health Care*, 34 HOFSTRA L. REV. 137, 175–79 (2005) (discussing the consumer development of in vitro fertilization); Kristen Madison, *Patients as “Regulators”?: Patients’ Evolving Influence over Health Care Delivery*, 31 J. LEGAL MED. 9, 15–21 (2010); Marc A. Rodwin, *Patient Accountability and Quality of Care: Lessons from Medical Consumerism and the Patients’ Rights, Women’s Health and Disability Rights Movements*, 20 AM. J.L. & MED. 147, 153–57 (1994). See generally Mark A. Hall, *The Legal and Historical Foundations of Patients as Medical Consumers*, 96 GEO. L.J. 583, 587 (2008) (cataloguing various public and private initiatives that “are meant to turn patients into consumers by placing them, rather than physicians, insurers, or the government, in the driver’s seat for making medical spending decisions”).

3. Mark A. Hall, *Rethinking Health Law: The History and Future of Health Care Law: An Essentialist View*, 41 WAKE FOREST L. REV. 347, 359 (2006).

4. See, e.g., Helen Harrison, *The Principles for Family-Centered Neonatal Care*, 92 PEDIATRICS 643, 644–47 (1993); see also *Family-Centered Care*, CINCINNATI CHILDREN’S HOSP. MED. CTR., <http://www.cincinnatichildrens.org/about/fcc/> (last visited Oct. 20, 2010) (stating that it “incorporates the family-centered care philosophy into every aspect of its clinical and research practice”).

5. See Harrison, *supra* note 4, at 644–47.

“patient-centered” health law is used, does this reflect a decision to reject a more family-centered approach, or is family-centered health law instead a *subpart* or *tenet* of patient-centered health law? How do we prioritize?

III. THIS PATIENT VERSUS THE REASONABLE PATIENT (SUBJECTIVE VERSUS OBJECTIVE)

Putting aside the question of what we mean by “centering” health law on the patient (see Part VII below), and assuming it is a proper goal, do we structure the law’s centered response in a way that is individual to every patient’s needs and values or to the reasonable patient’s needs and values? The obvious place this dilemma arises is in informed-consent law: must the physician disclose what this particular patient would find material in making his or her decision or what a reasonable patient would find material?⁶ But this dilemma also appears in less obvious places. When the law explicitly permits surrogates to withdraw life-sustaining treatment in some situations but not others, or offers living-will forms that include some conditions but not others, certain defaults are established that presume some choices are reasonable and others are less so.⁷ How tailored must the law’s treatment be to a *particular* patient in order for it to be patient centered?

IV. THIS PATIENT VERSUS ALL PATIENTS

A court ruling or regulatory rule centered on an individual patient may not serve patients generally, or vice versa. For example, a requirement that medical care be provided to those who appear to be in need in the emergency room may arguably be “patient centered” as judged by its attentiveness to the needs of the particular patient. But it may not achieve a patient-centered result if instead we judge patient-centeredness by how patients will generally be affected by such a requirement, and it turns out that the requirement would lead to a reduction in the number of emergency rooms available to accommodate patients.⁸ When trade-

6. See *Canterbury v. Spence*, 464 F.2d 772, 786–87 (D.C. Cir. 1972) (requiring physicians to disclose information that a reasonable person would consider material in making a decision about treatment).

7. See, e.g., FLA. STAT. § 765.303 (2010) (suggesting a standard form for living wills); *id.* § 765.305 (stating that, in the absence of a written advance directive, a surrogate may only exercise an incompetent patient’s right to forgo treatment when “[t]he patient has an end-stage condition, the patient is in a persistent vegetative state, or the patient’s physical condition is terminal”); see also LOIS SHEPHERD, *IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO* 30, 107–09, 180–86 (2009) (discussing the law’s treatment of the minimally conscious patient).

8. The Emergency Medical Treatment and Active Labor Act, enacted in 1986, requires hospitals, as a condition of participation in the Federal Medicare program, to provide emergency screening and stabilizing treatment to

offs are made between the particular patient and other unidentified or future patients, which way does patient-centeredness swing?

V. PATIENTS VERSUS WOULD-BE PATIENTS

Patient-centered health law might refer to the law's approach to people who are patients already, or it might be understood more broadly to include consideration of those who should or would be patients if given the appropriate resources, education, accommodations, and so on. This again is an area in which the movement toward patient-centered *medical care* might contrast with a movement toward patient-centered *health law*, as the former generally focuses on those who are already patients. This leaves out a lot of people for whom some changes in current health law might be beneficial—or who might be disadvantaged by current policies that favor existing patients. The question of “who is the patient” on whom health law should be centered (also implicated in the choice identified in Part IV above) is an important one. It will determine in part the *scope* or *ambition* of a patient-centered health law movement or project. But it is also critical in evaluating a claim that a particular policy choice or law is patient centered. If we were to claim that a particular initiative that focused only on existing patients is patient centered, we should be asked, “Why have you chosen to ignore these others?,” and we should have an answer.

VI. PATIENT-DOCTOR RELATIONSHIPS VERSUS PATIENT-SYSTEM OR PATIENT-SOCIETY RELATIONSHIPS

How far does the concept of patient-centeredness reach? In “centering” health law on the patient, is the focus on doctor-patient relationships or on all relationships in which the status of the individual as a patient, or the status of groups of people as patients, is important? Under a narrower concept, centering on the patient would mean simply that the focus in the physician-patient relationship is less on the desires, traditions, and prerogatives of the *physician* (as in old-style paternalism) and more on the needs and values of the *patient*.⁹ This seems to be a common meaning of patient-centered care in the medical literature, which often focuses on the clinical encounter.¹⁰ Patient-centeredness is defined in the

emergency-room visitors. 42 U.S.C. § 1395dd (2006). For arguments that the imposition of these obligations on hospitals would, or have, caused emergency rooms to close, see RICHARD A. EPSTEIN, MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE? 91–105 (1997), and David A. Hyman, *Patient Dumping and EMTALA: Past Imperfect / Future Shock*, 8 HEALTH MATRIX 29, 53, 55 (1998).

9. See INST. OF MED., CROSSING THE QUALITY CHASM: A NEW HEALTH SYSTEM FOR THE 21ST CENTURY 48–49 (2001).

10. See, e.g., Austin S. Baldwin et al., Preferences for a Patient-Centered Role Orientation: Association with Patient-Information-Seeking Behavior and Clinical Markers of Health, 35 ANNALS BEHAV. MED. 80, 80–81 (2008) (studying

2001 Institute of Medicine (“IOM”) report on quality as “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”¹¹ A more ambitious project for patient-centered medical care (and by extension, patient-centered health law) would be a patient focus within health care financing and delivery systems and liability regimes; that is, even when the patient’s relationships with others (hospitals, insurance companies, and so on) are considered, the patient would have primacy of some sort or another.

VII. GREATER ATTENTION TO THE NEEDS AND VALUES OF PATIENTS VERSUS THE BENEFIT TO PATIENTS (OR AT LEAST DOING NO HARM)

What does “centering” mean? What does it mean for law to be “centered” around or on the patient? Patient-centered health law may simply mean that the unique experience of being a patient, when relevant, should be considered in the resolution of a dispute or the crafting of a ruling or statute. While less ambitious than pursuing benefits for the patient, this more modest approach could nevertheless help us to understand the effects of various laws on patients. The idea would simply be to have more complete knowledge about how laws affect patients, even to insist that they be considered, rather than to have a pro-patient bias. Alternatively, patient-centeredness might mean that patients should actually benefit from laws relating to medical care and health.¹² Benefit to the patient would not be the only goal of health law; there would also be questions of justice, questions of process, and so on, but it would be an important goal. Sometimes perhaps the most that might be achieved would be a standard that the rules of health law should not harm patients, such as by creating incentives to provide poor care or to ignore patient wishes.

It is my hope that we will begin to assemble a framework for answering questions like those posed above, and that particular

patient preferences for patient-centered care using a questionnaire that assessed only the patient-physician relationship in the clinical encounter); Klea D. Bertakis et al., Patient-Centered Communication in Primary Care: Physician and Patient Gender and Gender Concordance, 18 *J. WOMEN’S HEALTH* 539, 539–40 (2009) (stating that the main methodologies for measuring patient-centeredness are “self-reported assessments . . . of the medical encounter and direct observation of the clinical encounter”).

11. *INST. OF MED.*, *supra* note 9, at 6.

12. See Joan H. Krause, *A Patient-Centered Approach to Health Care Fraud Recovery*, 96 *J. CRIM. L. & CRIMINOLOGY* 579, 579–81 (2006) (arguing that health care fraud recovery is not patient centered because the individual patients harmed do not benefit from the compensation scheme established under the law); Joan H. Krause, *Can Health Law Truly Become Patient Centered?* 45 *WAKE FOREST L. REV.*, 1489, 1495 (2010) (softening the author’s earlier view and shifting the emphasis to honesty and transparency in health care fraud recovery).

applications of patient-centeredness in health law can ultimately be guided by the establishment of firmer principles.