PATIENT-CENTERED HEALTH LAW AND ETHICS

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INTRODUCTION

When Eric Cassell's grandmother saw a specialist in New York City in the 1930s about a melanoma on her face, she asked the physician a question during her visit. The physician slapped her face and said, "I ask the questions here. I'll do the talking!"[1] Cassell, relating the story in 1985, wrote, "Can you imagine such an event occurring today? Melanomas may not have changed much in the last fifty years, but the profession of medicine has."[2]

In the early 1990s, Annemarie Mol, thirty-six years old and pregnant, was following national medical guidelines in the Netherlands by undergoing an amniocentesis to determine if her fetus had Down syndrome.[3] As the nurse prepared the long needle to be inserted in her womb, Mol, aware of the risk of spontaneous abortion posed by the procedure, said, "I hope it all goes okay." The nurse snapped back, "Well, it is your own choice."[4]

Are these our only options? On one side, the physician-dominated medical culture of the past—which in its more pleasant guises takes the form of benevolent paternalism rather than the iron fist that opened to strike Cassell's grandmother—or on the other side, the isolationist and consumerist delivery of medical services we get when patient autonomy crowds out all other values. In the Mol story, explains Art Frank, "The nurse uses a vocabulary that is ostensibly patient centered: the language of *choice*. But she uses it against the patient, not for the patient."[5]

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1. This story, as originally told by Eric Cassell, can be found in 1 ERIC J. CASSELL, TALKING WITH PATIENTS: THE THEORY OF DOCTOR-PATIENT COMMUNICATION 1 (1985) (internal quotations omitted).

2. *Id.*

3. ANNEMARIE MOL, THE LOGIC OF CARE: HEALTH AND THE PROBLEM OF PATIENT CHOICE, at xi (2008).

4. *Id.*

5. Arthur W. Frank, *Patient-Centered Care as a Response to* Medification, 45 WAKE FOREST L. REV. 1453, 1456 (2010). Mol herself writes, "[T]he logic of

In April 2010, a group of ethicists and legal scholars gathered to consider what a more patient-centered approach to health law and ethics would mean.[6] We began with the stories above, related respectively by keynote speakers Professor Howard Brody and Professor Art Frank. Discussion on the first day of the Symposium explored what a rich understanding of patient-centered medical ethics would look like—an understanding that was not focused exclusively on patient autonomy, or at least not one that understood patients as mere consumers or, even worse, as interchangeable "stick figures," to use Professor Carl Schneider's term.[7] This discussion took place among invited scholars and audience participants with training and experience in ethics, philosophy, religious studies, medicine, nursing, health administration, sociology, and law—not to mention the authority that we all have to speak from the point of view of having been a patient. But the Symposium was ultimately aimed at answering an even more layered and tangled question, which was the focus of the second day's workshop session: what would a patient-centered *health law* look like and how might it be pursued?

The birth of both health law and bioethics as academic fields dates to roughly 1960.[8] But the two fields have sharply contrasting

choice . . . can shift the weight of everything that goes wrong onto the shoulders of the patient-chooser." MOL, *supra* note 3, at xi.

6. The Symposium was organized by Mark A. Hall and Lois Shepherd. Nancy King, Christine Coughlin, and Elizabeth Motsinger, all affiliated with Wake Forest University, also participated in organizing the Symposium and helped facilitate discussion in various ways. The Symposium was sponsored by the Wake Forest University Center for Bioethics, Health, and Society and was made possible by a generous gift from David Zacks (BA '64, JD '67), a partner at Kilpatrick Stockton, LLP, in Atlanta. Featured speakers at the Symposium included Howard Brody, University of Texas Institute for the Medical Humanities; Larry Churchill, Vanderbilt University Center for Biomedical Ethics and Society; Arthur Frank, University of Calgary, Department of Sociology; Nan Hunter, Georgetown University O'Neill Institute for Global and National Health Law; Sandra Johnson, St. Louis University School of Law, Tenet Endowed Chair in Health Law and Ethics; Joan Krause, University of North Carolina Schools of Law, Medicine, and Public Health; Carolyn McLeod, University of Western Ontario, Department of Philosophy; Ted Ruger, University of Pennsylvania Law School; William Sage, University of Texas School of Law, Vice Provost for Health Affairs; Carl Schneider, University of Michigan Law School and former member of the President's Council on Bioethics; and John Scott, Robert Wood Johnson Medical School.

7. Mark A. Hall & Carl E. Schneider, *Where Is the "There" in Health Law? Can It Become a Coherent Field?*, 14 HEALTH MATRIX 101, 103 (2004).

8. That decade saw the publication of the first law school casebook on health law, William J. Curran's *Law and Medicine: Text and Source Materials on Medico-Legal Problems*, in 1960. Mark A. Hall, *The History and Future of Health Care Law: An Essentialist View*, 41 WAKE FOREST L. REV. 347, 348 (2006). The decade also saw the emergence of social and medical developments that led to the first academic bioethics institutions, the Hastings Center (founded in 1969) and the Kennedy Institute of Ethics (founded in 1971). *See*

intellectual histories—especially regarding their principal foci. Health law began as a physician-centered enterprise, focusing on the issues and perspectives that practicing doctors faced when they encountered the legal system.[9] Only in the 1980s did health law shift to a broader public policy orientation, but even then it adopted an industry-centered focus that attended mainly to issues of importance to hospitals, insurers, and governments.[10]

Bioethics, in contrast, began in very much a patient-centered mode. Its animating purpose was to shift the focus of medical ethics away from physicians' concerns embodied in professional codes of conduct and business affairs and instead to advance an agenda of patients' rights.[11] But the traditional approach to patient-centeredness in bioethics has been criticized as unduly preoccupied with patient autonomy, to the neglect of other patient-centered values and concerns such as suffering, relationships, or trust.[12]

Emphasizing the patient's centrality forces law and ethics to

Daniel Callahan, *The Hastings Center and the Early Years of Bioethics*, 9 KENNEDY INST. ETHICS J. 53, 53–54 (1999) (discussing the founding of the Hastings Center for the study of ethical issues in medicine and biology); *History of the Institute*, KENNEDY INST. ETHICS, http://kennedyinstitute.georgetown.edu/about/history.cfm (last visited Nov. 7, 2010) (explaining that the Kennedy Institute was founded with the goal of establishing the first comprehensive information center for bioethics).

9. Hall, *supra* note 8, at 349–50.

10. *See id.* at 350. In health law, growing dissatisfaction with previous intellectual paradigms led to a group of leading health law scholars convening four years ago to "Rethink Health Law." That group spent two days discussing: "Does health law have a core set of concerns? What new paradigms can best help us reconceive health law? How can health law accommodate the special psychological, emotional, and moral aspects of its subject?" The Symposium prospectus we (along with co-organizer Carl Schneider) sent to participants at that time proposed a patient-centered focus to health law and suggested three underdeveloped approaches that contributors might pursue: patient-centered professionalism, patient-centered empiricism, and a relational perspective that places the patient at the center of a web of relationships. *See* Mark A. Hall, Carl E. Schneider & Lois Shepherd, *Rethinking Health Law: Introduction*, 41 WAKE FOREST L. REV. 341 (2006). The essays produced and the workshop discussions that took place among participants offered promising insights into the emerging concept of a patient-centered health law. *See generally* Symposium, *Rethinking Health Law*, 41 WAKE FOREST L. REV. 341 (2006). This most recent Symposium built on that initial effort with the aim of thinking more systematically and comprehensively about what patient-centeredness might mean and the different approaches it might engender, both in health law and in bioethics.

11. Mark A. Hall, *Rationing Health Care at the Bedside*, 69 N.Y.U. L. REV. 693, 728 (1994).

12. *See, e.g.*, Edmund D. Pellegrino, *The Healing Relationship: The Architectonics of Clinical Medicine*, *in* THE CLINICAL ENCOUNTER: THE MORAL FABRIC OF THE PATIENT-PHYSICIAN RELATIONSHIP 153, 155–56 (Earl E. Shelp ed., 1983); Edmund D. Pellegrino, *Toward a Reconstruction of Medical Morality: The Primacy of the Act of Profession and the Fact of Illness*, 4 J. MED. & PHIL. 32, 53 (1979).

acknowledge and accommodate crucial features of the medical arena that differentiate it fundamentally from other social and economic arenas. Health care law and bioethics address the delivery of an extremely important, very expensive, and highly specialized professional service rendered in situations of tremendous personal vulnerability. These high stakes are what makes health care so expensive and its dilemmas so compelling. They counsel us to attend more closely to the psychological realities of treatment encounters and to the essential ingredients of medical practice and professionalism. As one of us has written, "Sometimes, it matters fundamentally, even profoundly, that a legal matter involves physicians caring for patients, rather than providers servicing generic consumers."[13]

One of the difficulties of envisioning and then bringing about a more patient-centered health law is the fact that the patient is often absent as an active participant in the shaping of law. Much of what we know as health law is common law, shaped by the aims and arguments of litigants and the understanding of judges, and by precedent that was in turn shaped by the aims and arguments of past litigants and the understanding of past judges. Because law is decided by judges who face concrete cases and is practiced by lawyers who serve clients with particular interests, it is fragmented and piecemeal. It tends to focus on the problems and concerns of the people or institutions with the money to hire lawyers and to pursue litigation or influence legislators and regulators. The litigant in health law (other than in malpractice cases) is rarely the patient; the client represented by the lobbyist weighing in on health care legislation is also rarely the patient. Rather, the litigant or the lobbyist's client is typically the physician, the government, the hospital, or the insurance company. And when the litigant *is* the patient, often he or she is a patient no longer—the plaintiff's interest is now malpractice compensation rather than an improved patient experience.

Within academic health law, it has become commonplace to consider health law as involving four principal concerns: "quality, autonomy, access, and cost."[14] Ideally, we want high quality, supreme respect for autonomy, wide access, and low cost. A focus on the experience of patients being ill and seeking care is neither mandatory nor assumed, nor is it embedded in the study of health law as now generally conceived, which tends to focus on industry and public policy concerns.[15] Shifting the focus to the patient in the study of health law opens up greater possibilities for the practice of health law to be more attentive and responsive to patient experiences.

13. Hall, *supra* note 8, at 361.
14. *Id.* at 353.
15. *Id.* at 353–54.

To be clear, this is a project. It is not a description of what is, but a conversation about what could be. We are talking here about an orientation, perhaps as grand as a movement; for those preferring more modest aims, a directional push; for the even more cautious, merely an awareness of how laws affect patients. That, ultimately, is the impulse animating this project: to advance the notion that law that affects patients should better take into account what it means to be a patient. This Symposium was about exploring and developing that impulse, and critiquing and questioning it. And, as to be expected—and invited—there were detractors and caution-bearers.

This Essay identifies the areas in which participating scholars appeared to reach some consensus on this subject over the course of the Symposium, as well as issues about which there was disagreement, uncertainty, or hesitation, and questions for future debate. Also included with this Symposium report are separate short essays in which scholars participating in the Symposium share their individual insights on these and related topics.

I. WHAT WE MEAN BY PATIENT-CENTERED HEALTH LAW AND WHAT IT WOULD LOOK LIKE. WILL WE KNOW IT WHEN WE SEE IT?

While the "slap" and "choice" stories provided examples of medical care that was not patient centered, no story emerged during the two-day Symposium to provide such an example of an ideal patient-centered medical care culture. (Professor John Scott did show us a picture symbolizing what a patient-centered medical home should look like—the modest brick ranch of his childhood, settled into a neighborhood with mature trees and shrubs. He showed another illustrating what it should not be like—a new subdivision carved out of a pasture by a developer who has three models and three paint colors from which to choose.) Perhaps the reason we had no patient-centered story is because it is easier to identify what is wrong than what is right. In one session, we watched film clips from *The Doctor*, *Money-Driven Medicine*, and *Patch Adams*.[16] It was not difficult to criticize William Hurt as the technically proficient but cold and distant surgeon;[17] to empathize with the wife of a burn victim who suffered poor treatment by disintegrated, silent, and "money-driven" care systems;[18] to wryly smile when a faculty member announced to first-year medical students, "It is our mission here to rigorously and ruthlessly train the humanity out of you and make you into something better—we're

16. Christine Coughlin, Director, Legal Analysis, Research, and Writing Program, Wake Forest School of Law, chose the film clips and led the discussion in this session.

17. THE DOCTOR (Silver Screen Partners IV 1991).

18. MONEY-DRIVEN MEDICINE (Jigsaw Productions 2009).

going to make doctors out of you."[19] Medical ethicist Larry Churchill, in *Money-Driven Medicine*, provided this summary of the present state of affairs:

> The current medical care system is not designed to meet the health needs of the population. It is designed to protect the interests of insurance companies, pharmaceutical firms, and to a certain extent organized medicine. It is designed to turn a profit. It is designed to meet the needs of the people in power.[20]

When we came to discussions of law, it was the same—easier to identify where current health law is *not* patient-centered than where it *is*. The classic 1901 case of *Hurley v. Eddingfield* provides a clear example.[21] In that case, a doctor was found to owe no duty to treat a dangerously ill individual even if, as alleged, the doctor had been the patient's family physician, the doctor's fee was tendered, no other physician was procurable in time, and the patient relied on the doctor's services.[22] That patient died.[23] But the physician's right to decide whether he will practice at all and on what terms survived and continues to survive today. *Hurley v. Eddingfield* is presumably still good law.[24]

Even with informed consent—which is the most easily identified aspect of health law that is aimed at promoting patient interests—there are clear, familiar, well-documented weaknesses that cause the doctrine to fall short of being robustly patient centered.[25] There is too little understanding on the part of patients and too much reliance by physicians on getting patients to sign consent forms. Legal standards require aggrieved patients to prove that a "reasonable" patient would have forgone the procedure in question,

19. PATCH ADAMS (Blue Wolf et al. 1998).

20. MONEY-DRIVEN MEDICINE, *supra* note 18.

21. Hurley v. Eddingfield, 59 N.E. 1058 (Ind. 1901); *accord* Walker v. Pierce, 560 F.2d 609, 611, 613 (4th Cir. 1977) (upholding the policy of a physician to deny medical services to a woman on public assistance, who was pregnant with her fourth child, unless she agreed to be sterilized following delivery).

22. *Hurley*, 59 N.E. at 1058.

23. *Id.*

24. *See, e.g.*, Broderson v. Sioux Valley Mem'l Hosp., 902 F. Supp. 931, 940 n.10 (N.D. Iowa 1995) (citing *Hurley* for the proposition that at common law a doctor has no duty to treat a patient); L.S. Ayres & Co. v. Hicks, 40 N.E.2d 334, 337 (Ind. 1942) (citing *Hurley* for the general principle that there is no duty to rescue); Velazquez *ex rel.* Velazquez v. Jiminez, 798 A.2d 51, 56 (N.J. 2002) (citing *Hurley* in a discussion of Good Samaritan statutes); Rice v. Rinaldo, 119 N.E.2d 657, 659 (Ohio Ct. App. 1951) (citing *Hurley* with approval in finding that dentists also had no duty to treat and thus that their offices were not places of public accommodation).

25. *See* Nan D. Hunter, *Rights Talk and Patient Subjectivity: The Role of Autonomy, Equality, and Participation Norms*, 45 WAKE FOREST L. REV. 1525, 1535 (2010).

rather than that they themselves would have done so.[26] State statutes often create presumptions of informed consent when the patient has signed a form[27] though it is likely the patient either did not read the form or, if she did read it, did not understand it.

What we might consider to be patient-centered health law is not as readily identifiable as is its opposite, and the lack of exemplars makes it difficult to define. Moreover, because the task is less one of naming something that is than of describing something that should be, it became clear during the Symposium that one's views about the proper aims of law, and health law in particular, would be wrapped up in the definition selected. So too would one's views about what is possible to achieve with law. Even where there appears to have been movement in the direction of law that is more patient centered, medical culture may be so entrenched that the law would appear to have little effect. For example, according to Professor Sandra Johnson, while some of the legal norms and processes that have been blamed in the past for discouraging physicians from prescribing adequate pain medication have been reformed (triplicate prescription monitoring systems, for example, have been eliminated), physicians still undertreat patients in pain and still blame the law for their actions.[28]

II. HOW WE VIEW PATIENT-CENTEREDNESS IN RELATION TO PUBLIC HEALTH CONCERNS

Despite the lack of obvious exemplars, as well as participants' different and sometimes contrasting views about the role and function of law, discussion at the Symposium did lead to some specification about what patient-centeredness in health law might mean.

Taking a page from the patient-centered movement in medical care, Symposium participants fairly quickly concluded that issues of public health comprise a distinctly different topic. Patient-centered medical care, as currently theorized, does not appear to be aimed at improving the experiences of the entire population vis-à-vis its health.[29] At the center of ideal patient-centered medical care is the actual patient in the hospital, coming to the clinic, receiving home health services, or making an appointment for a follow-up visit. The focus is not on community or public health, not on clean water, the availability of parks, or tobacco regulation. Neither, it seems, should patient-centered health law embrace public health; rather, it

26. *See* Canterbury v. Spence, 464 F.2d 772, 787 (D.C. Cir. 1972).

27. *See, e.g.*, FLA. STAT. § 766.103 (2005) (creating a rebuttable presumption of valid consent if a signed form contains certain requirements).

28. Sandra H. Johnson, *Test-Driving "Patient-Centered Health Law*,*"* 45 WAKE FOREST L. REV. 1475, 1481–82 (2010).

29. *See* Ronald M. Epstein et al., *Why the Nation Needs a Policy Push on Patient-Centered Health Care*, 29 HEALTH AFF. 1489, 1490 (2010).

is a separate subject deserving its own special attention. That appeared to be the consensus of Symposium participants. There are at least two reasons for this.

First, as described above, the impetus to consider whether health law should be more patient centered comes from a sense, shared by many but to widely varying degrees, that while much of health law concerns and affects patients, the experience of *being a patient* is largely absent from consideration.[30] What makes the relationships that are the subject of much health law—the physician-patient relationship, the insurer-patient relationship, the researcher-patient/subject relationship, and the hospital-patient relationship—uniquely problematic and more problematic than other relationships is the dynamic of illness and treatment. Public health concerns are not, at heart, about the experience of being ill or being a patient.

Second is the problem of conflict between the policies and principles that benefit the collective and those that benefit the individual. The term "patient-centered" suggests concern for the individual patient's experience rather than for the health of populations.[31] (If the health of populations were instead the focus of concern, we might instead choose to talk about "health-centered" health law.) The demands of good public health law may conflict with some of the aims of patient-centered care and the law that would support it. For example, public health initiatives to contain the spread of infectious disease may compromise individual patient confidentiality through reporting requirements to public health authorities and contact tracing,[32] efforts to isolate and quarantine would impinge on the liberty of individual patients in order to advance the public good, and so on.

Because the aims of public health and medical care are distinct, it makes sense to think of the legal principles that support them as also distinct. If all the considerations of population health were folded into the concept of patient-centered health law, then we would need to fashion subcategories to organize principles that are more clearly population focused rather than patient focused in order to consider how to balance, trade off, accommodate, or choose between them. We cannot avoid the problem of the tension between public health aims and patient-centered medical care by folding the two together.[33]

30. *See, e.g.*, Lois Shepherd, *Different Ways To Understand Patient-Centered Health Law*, 45 WAKE FOREST L. REV. 1469, 1470 (2010).

31. *See* Epstein et al., *supra* note 29, at 1490.

32. *See, e.g.*, Lawrence O. Gostin & James G. Hodge, Jr., *The "Names Debate": The Case for National HIV Reporting in the United States*, 61 ALB. L. REV. 679, 718–20 (1998) (discussing the potential negative impact of HIV reporting on individual patients).

33. In order to make the distinction from public health clearer, it may be better to use the term "patient-centered health *care* law" rather than "patient-

Is there a risk, though, that a new emphasis on patient-centered law and ethics would have the unintended consequence of diminishing emphasis on public health needs and goals? This concern was expressed by several Symposium participants and cannot be easily dismissed. The recent national health care reform,[34] while generally lauded by Symposium participants, is a recent and stunning example of how attention and resources can be channeled toward medical care for people in need of medical services when more people's health might be better improved by public health initiatives—or even by improvements in the environment, education, or jobs. Professor Bill Sage, in particular, voiced this concern:

> The "rule of rescue" posits that humans will make much larger sacrifices to save those already in trouble than to reduce the statistical risk of future peril. . . . [O]ur impulse for justice favors assisting the person who is ill over the person who is poor, and we ignore the critical task of preventing people from being either poor or sick.[35]

The aim of a patient-centered health law project would not be to champion medical care for existing patients over environmental or educational or other socially worthy goals, whether health enhancing or otherwise. It would, instead, be to address those situations in which patients' lives are affected by medical care practices and medical care delivery systems about which law has or should have something to say.

III. HOW INDIVIDUALIZED PATIENT-CENTERED HEALTH LAW MUST BE

While we may fairly easily justify separating out people who are not patients for separate consideration under public health law and ethics, it is not as clear whether patient-centered health law and ethics should be concerned primarily with existing, individual patients or whether future patients should be considered equally. In

centered health law." This issue was not really discussed at the Symposium, but has been anticipated by earlier writings associated with this project. *See* Hall, *supra* note 8, at 358, 362 (proposing an "essentialist" definition of health law, or "health care law" that does not extend to mental health law, public health law, or environmental health law). *But see* Lois Shepherd, *Assuming Responsibility*, 41 WAKE FOREST L. REV. 445, 459 (2006) (arguing that health law should focus on responsibility for the relief of suffering, which would cause "[t]he lines separating bioethics, health law, and public health [to] become blurred and perhaps disappear altogether").

34. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), *amended by* Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010).

35. William M. Sage, *Should the Patient Conquer?*, 45 WAKE FOREST L. REV.1505, 1510 (2010).

Professor Joan Krause's criticism that fraud and abuse law is not patient centered (despite claims to the contrary by government officials), her assumption is that to be patient centered, recovery of funds through fraud and abuse lawsuits should at least partially go to, or otherwise benefit, those patients harmed by the illegal practice.[36] One could argue instead that because those funds are returned to the federal fisc and therefore assist the continuation of Medicare coverage for beneficiaries—that is, other future patients—that it actually is patient centered.[37]

The question may actually come up often. For example, how would a patient-centered approach analyze recent requirements that Medicare beneficiaries, as a condition of Medicare coverage for certain new treatments, enroll in randomized clinical-trials research?[38] On the one hand, existing patients' autonomy rights are arguably compromised—their consent to participate in research seems less than entirely voluntary. On the other hand, the purpose of the policy is to develop more evidence-based medicine to benefit future patients. So which is it? Is the Medicare requirement patient centered or not? Similarly, some have argued that the Emergency Medical Treatment and Active Labor Act ("EMTALA") requirement that hospital emergency rooms provide medical treatment to all comers, regardless of insurance status or ability to pay, substantially contributed to the reduction or elimination of some emergency-room services, thereby harming patients as a whole.[39] Is EMTALA patient centered because it addresses the

36. Joan H. Krause, *A Patient-Centered Approach to Health Care Fraud Recovery*, 96 J. CRIM. L. & CRIMINOLOGY 579, 579–81 (2006). In this earlier article, Professor Krause wrote:

> While focusing enforcement efforts on returning funds to the Federal Treasury clearly helps to assure that the federal health care programs remain solvent and continue to provide care to beneficiaries in the aggregate, it offers little solace to injured individuals.
>
> This approach stands in marked contrast to efforts to make the United States health care system more "patient-centered."

Id. at 579.

37. Professor Bill Sage made this point in Symposium discussion. Professor Krause explores this issue further in her contribution to this Symposium, concluding that resolving the question of whether, to be considered truly "patient centered," health care fraud recoveries should be used to benefit individual patients harmed by fraud or instead to provide a population-based benefit, is ultimately less important than transparency and honesty about such claims. Joan H. Krause, *Can Health Law Truly Become Patient Centered?*, 45 WAKE FOREST L. REV. 107 (2010).

38. *See generally* Lars Noah, *Coerced Participation in Clinical Trials: Conscripting Human Research Subjects*, 62 ADMIN. L. REV. AM. U. 329 (2010) (critiquing the U.S. Centers for Medicare & Medicaid Services' recent initiative called "coverage with evidence development"). *But see generally* David Orentlicher, *Making Research a Requirement of Treatment: Why We Should Sometimes Let Doctors Pressure Patients To Participate in Research*, HASTINGS CENTER REP., Sept.–Oct. 2005, at 20 (defending this approach).

39. EMTALA, enacted in 1986, requires hospitals, as a condition of

needs of the individual who arrives in the emergency room in distress, or is it not patient centered because it creates incentives to make that emergency room disappear?

These are versions of the ex ante versus ex post dilemma that recurs throughout legal policy analysis, captured in the contrasting perspectives of courts adjudicating disputes to do justice versus legislatures regulating behavior to maximize welfare. Often there is no clean resolution and sometimes trade-offs are unavoidable. The question here is whether the trade has to be made at the outset when we define what patient-centered health law means. In order to have a workable understanding of patient-centeredness, do we need to choose on whom we wish to focus—those patients currently seeking care or claiming rights to care, or the people who will be affected by the policies and precedents established in answering those claims?

Some would say no such choice is necessary. Patient-centered health law can be a concept that covers all existing and future patients and that looks to them both as individuals and in the aggregate.[40] Professor Sandra Johnson, for example, argues that it is equally plausible to view the autonomy-based reforms of the 1970s—which were centered on the individual—as patient centered as it is to view the market reforms of the 1980s that were designed to improve quality and access and to reduce costs for patients as a group.[41] The important shift taking place through these reforms is toward patients (of any kind) and away from physicians, organized medicine, or industry.[42] Along the same lines, Professor Joan Krause suggested at the Symposium that perhaps the most that can or should be said as a definitional matter concerning the patient in patient-centered health law—whether the present or future patient, the individual or reasonable patient, the singular or aggregate

participation in the federal Medicare program, to provide emergency screening and stabilizing treatment to emergency-room visitors. 42 U.S.C. § 1395dd(a)–(b) (2006). Congress passed EMTALA in response to patient "dumping" in the early 1980s, when uninsured individuals in critical need of emergency treatment were transferred to public hospitals or denied treatment by private hospitals because the patient was unable to pay for care. RICHARD A. EPSTEIN, MORTAL PERIL: OUR INALIENABLE RIGHT TO HEALTH CARE? 91–105 (1997) (discussing EMTALA and the duties it imposed on hospitals); *see also* David A. Hyman, *Patient Dumping and EMTALA: Past Imperfect/Future Shock*, 8 HEALTH MATRIX 29, 53–54 (1998) (concluding that "[e]xcept in the (exceedingly) short-run, EMTALA can not increase [emergency room] capacity—and it has a distinct tendency to destroy it," and criticizing Congress's reliance on anecdotal evidence in passing EMTALA).

40. *See* Johnson, *supra* note 28, at 1475–76 (reasoning that both health law reform centered on individual patients and reform addressed to broader populations can be considered patient centered).

41. *See id.* at 1475.

42. *See id.* (defining the development of "patient-centered" care as a movement "away from the dominant paradigm of professionalism and toward the well-being of patients").

patient—is that if the law under consideration does not benefit (or at least pay serious attention to its effect on) the patient, as understood in at least one of these ways, then it is *not* patient centered.[43]

But to others, it was not clear that the question could be avoided. And perhaps this was especially so because the Symposium took place during the year of the national health care reform amid dawning ideas and realities of health care citizenship.[44] Patients in the United States like to insist that nothing should stand between them and their doctors when making treatment decisions.[45] But as Professor Nan Hunter points out, the term "patient" does not speak to the political and policy aspects of the health care system in the way that "citizen" does.[46] Within a health care system, citizenship entails a web of interconnected, interwoven rights and obligations.[47] For years, health law and policy scholars have only reluctantly used the term "system" to describe our current fragmented means of delivering health care—what one scholar has called "a hodgepodge of historic legacies, philosophical conflicts, and competing economic schemes."[48] But a true, or at least truer, "health care system" may be on the way to development with the recently passed Patient Protection and Affordable Care Act.[49] The health care delivery system of the future, in which our interconnectedness will be more evident than ever, may well clash with an entrenched cultural expectation that health care decisions will be the exclusive domain of individual patients and their physicians.[50]

Traditionally, medical care in the United States has been constituted and delivered by a highly diffuse medical authority, which has resulted in highly individualized practices.[51] This is

43. *See generally* Krause, *supra* note 37 (discussing the difficulties health law faces in defining the "patient" and in becoming patient centered).

44. *See, e.g.*, Hunter, *supra* note 25, at 1526 (expanding the concept of "the values at the core of patient identity" to include autonomy, equality, participation, and accountability, which together form a basis for "biocitizenship").

45. *See, e.g.*, Theodore W. Ruger, *Can a Patient-Centered Ethos Be Other-Regarding? Ought It Be?*, 45 WAKE FOREST L. REV. 1513, 1519 (2010).

46. *See* Hunter, *supra* note 25, at 1546–47.

47. *Id.* at 1547; *see also* Sage, *supra* note 35, at 1507–08 ("If health care will be an attribute of citizenship, we can no longer deny that the proper design and operation of that entitlement are collective responsibilities.").

48. J.D. KLEINKE, OXYMORONS: THE MYTH OF A U.S. HEALTH CARE SYSTEM 1 (2001). Kleinke continues, "A group of highly imaginative, energetic people armed with the world's largest Mark-n-Wipe board could not purposefully design a more complex, dysfunctional system if they tried." *Id.* at 2.

49. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010), *amended by* Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029 (2010).

50. *See* Ruger, supra note 45, at 1519–20

51. *See id*. at 1514.

evidenced in the well-known *Dartmouth Atlas* studies, which, along with other research, show wide variation in utilization patterns and costs.[52] As Professor Ted Ruger explains, many of the core doctrinal principles of health law over the years have supported this "therapeutic individualization."[53] For example, traditional medical liability rules have permitted the standard of care to vary by locality and practice setting.[54] Other legal structures—such as state rather than national authority to license practitioners and the prohibition against the "corporate" practice of medicine—have further ensured diffused medical authority.[55] While many of these legal doctrines have been abandoned or weakened, patients in the United States have an expectation (whether entirely realistic or not, considering insurance coverage and other limitations) of highly individualized treatment decisions that lie within their control and that of their physician of choice.[56] In the future, however, even if explicit forms of rationing are off the table, highly individualized treatment decisions may have to give way to more objective measures in the form of practice guidelines connected to comparative-effectiveness research and to coverage decisions.

The recent debate over the age at which women should begin to routinely undergo mammography screening illustrates this tension. In the midst of intense national debate over health care reform in 2009–10, the U.S. Preventive Services Task Force, an independent panel of scientists and physicians appointed by the previous administration, recommended an increase in the age at which women should undergo routine mammography screening from age forty to fifty.[57] The Task Force's recommendation was based on the risks and benefits of screening to women and did not consider the financial costs of screening.[58] Nor did the recommendation directly relate to public or private insurance coverage of the screening.[59]

52. *See generally* Elliott S. Fisher et al., *The Implications of Regional Variations in Medicare Spending. Part 2: Health Outcomes and Satisfaction with Care*, 138 ANNALS INTERNAL MED. 288 (2003) (reporting on the relationship between increased spending and health outcomes).

53. Ruger, *supra* note 45, at 1515.

54. *Compare* ALA. CODE § 6-5-542 (2005) (setting the standard of care as "such reasonable care, skill, and diligence as other similarly situated health care providers in the same general line of practice, ordinarily have and exercise in like cases"), *with* ARIZ. REV. STAT. ANN. § 12-563 (2003) (setting the standard of care as "that degree of care, skill and learning expected of a reasonable, prudent health care provider in the profession or class to which he belongs within the state acting in the same or similar circumstances").

55. *See* Ruger, *supra* note 45, at 1516.

56. *See id.*

57. U.S. Preventive Servs. Task Force, *Screening for Breast Cancer: U.S. Preventive Services Task Force Recommendation Statement*, 151 ANNALS INTERNAL MED. 716, 716 (2009).

58. *See generally id.* (finding a net moderate benefit of screening for women fifty and over and a small net benefit of screening for women under fifty).

59. *See generally id.* (focusing on the accuracy of screening, the

Nevertheless, an immediate public outcry flared against the recommendation, criticizing it as a cost-saving measure and a harbinger of future rationing and government control of treatment decisions.[60]

Damage-control efforts began immediately. Although the Task Force's own report stated that it "recommends against routine screening mammography in women aged 40 to 49 years,"[61] one of the physician members of the panel told Good Morning America, "This is not a recommendation to not screen. It's a recommendation to provide women with the facts. . . . Our recommendations support an individualized decision-making process with the women so that they have knowledge about the risks and benefits associated with mammography screening."[62] The federal government also quickly distanced itself from the Task Force's recommendation, with Department of Health and Human Services Secretary Kathleen Sebelius reassuring the public that each individual woman should, with her doctor, determine what was right for her.[63] Later, the Task Force itself would revise its report to omit the recommendation against routine screening for women under age fifty, and simply include a statement that the decision to start screening before age fifty was "an individual one" in which "the patient's values regarding specific benefits and harms" should be taken into account.[64]

The rhetoric of individual choice and control that resounded so strongly during the mammography screening uproar and other aspects of health care reform (such as the ludicrous charge that Medicare reimbursement for advance care planning conversations between physicians and patients would create "death panels"[65]) belies the fact that a substantial portion of current health law relies on the objective patient, rather than the individual, subjective

effectiveness of early detection, and the potential harms of screening).

60. *See, e.g.*, Dennis Byrne, Op-Ed., *Ouch! When the Feds Manage Health Care*, CHI. TRIB., Nov. 24, 2009, §1, at 19; Dan Eggen & Rob Stein, *Mammograms and Politics: Task Force Stirs Up a Tempest*, WASH. POST, Nov. 18, 2009, at A1; Kevin Sack, *Culture Clash in Medicine*, N.Y. TIMES, Nov. 20, 2009, at A1.

61. U.S. Preventive Servs. Task Force, *supra* note 57, at 716.

62. *See* Lee Ferran et al., *Task Force Responds to Mammogram Controversy*, ABCNEWS.COM (Nov. 19, 2009), http://abcnews.go.com/GMA/HealthyLiving/us-preventative-services-task-force-member-timothy-wilt/story?id=9124113 (comments of Dr. Timothy Wilt).

63. *See* Rob Stein & Dan Eggen, *White House Backs Off Cancer Test Guidelines*, WASH. POST, Nov. 19, 2009, at A1.

64. *Addendum and Correction: Screening for Breast Cancer: U.S. Preventive Services Task Force Recommendation Statement*, 152 ANNALS INTERNAL MED. 688, 688 (2010).

65. *See, e.g.*, Kevin B. O'Reilly, *End-of-Life Care Provision Stirs Angst in Health Reform Debate*, AM. MED. NEWS (Aug. 24, 2009), http://www.ama-assn.org/amednews/2009/08/24/prsa0824.htm (quoting Sarah Palin).

patient, in setting standards, and does so with a rather heavy hand. The prime example here is in the law of informed consent, which requires a successful plaintiff-patient to prove that a reasonable patient would have declined the procedure about which she was inadequately informed and which caused her harm.[66] Other examples are default rules in living-will forms (for example, identifying the permanent vegetative state but not the minimally conscious state or other conditions of severe disability as a condition in which a person might wish to forgo life-sustaining treatment);[67] monitoring of outside-the-norm dosages of pain medications;[68] and the inability to recover money damages as tort compensation for purely dignitary harms.[69] As Professor Carl Schneider pointed out at the Symposium, the individual, subjective patient-research subject is also displaced when institutional review boards reject certain clinical research protocols on the basis of unacceptable risk/benefit ratios. Even if patients would agree to enroll in research, they are often not allowed to.

There are risks and limitations to each approach, to be sure. Focusing on the objective patient may give inadequate attention to important differences among patients. At the same time, the institutional demands of law, such as those discussed by Professor Joan Krause,[70] place limits on the extent to which others can be expected to respond to all of the unique aspects of each individual patient. And, in the policy arena, allowing the individual patient to "conquer," to use Professor Bill Sage's phrase,[71] may mean unwise and ultimately unjust allocations of our limited, collective resources.

At the Symposium, there seemed to be no certain consensus on whether or not it was critical to determine how *patient-individualized* an approach to health law would have to be in order to be considered *patient centered*. The risks and limits to each approach—subjective vs. objective, individual vs. aggregate—may be exactly the sort of conversation that a patient-centered focus in health law could encourage and bring into sharper focus. And in some instances, what may matter more in terms of patient-centeredness is not a particular outcome favorable to one or another understanding of the patient, but instead a process that includes patient participation. In discussions about the mammogram screening controversy, Sandra Johnson wondered how the Task Force's recommendations would have differed had breast cancer

66. *See* Canterbury v. Spence, 464 F.2d 772, 790–91 (D.C. Cir. 1972).

67. *See generally* LOIS SHEPHERD, IF THAT EVER HAPPENS TO ME: MAKING LIFE AND DEATH DECISIONS AFTER TERRI SCHIAVO 30–31, 107–08, 180–86 (2009) (discussing the law's treatment of the minimally conscious patient).

68. *See* Johnson, *supra* note 28, at 1482.

69. Caroline Forell & Anna Sortun, *The Tort of Betrayal of Trust*, 42 U. MICH. J.L. REFORM 557, 559–61 (2009).

70. *See* Krause, *supra* note 37, at 1490–91.

71. Sage, *supra* note 35, at 1506.

patients been included in the panel's membership. Providing an impetus and a venue for asking such questions of both substance and process would itself be a signal that patients matter in health law.

IV. HOW WE VIEW THE PERSON IN PATIENT-CENTERED HEALTH LAW AND ETHICS: VULNERABLE PATIENTS VERSUS ACTIVE CONSUMERS

There was another issue about the patient in patient-centered health law that drew substantial debate at the Symposium. This has to do, as Professor Carolyn McLeod expressed it, with considering what theory of personhood should inform patient-centeredness, as a matter of both health care and health care law. Who are we picturing when we think of the patient? What does this patient look like? Sound like? Smell like? Do we see Curtis Lindell, the temporarily disfigured burn patient in Money-Driven Medicine, covered in an octopus of tubes?[72] Or the hairless child with cancer in Patch Adams?[73] Do we see people who cannot make their own decisions? Or do we see Eric Cassell's grandmother or Annemarie Mol, individuals who appear perfectly capable of asking questions and making decisions?[74] Does illness or fear of undesired test results matter? Or do we also see, as we imagine the patient, the healthy child brought by the caring parent to the pediatrician's office for a check-up?[75]

All of them are patients, as commonly understood. But, we would submit, they have more in common than simply being consumers of medical services, or people who are in a relationship with a health care provider, or individuals seeking services from medical care providers to meet their health goals, or other ways that patients are commonly identified. For some purposes, these characterizations of the patient may be adequate, but an essential part of what appears to be valuable about this project is the concern that the patient's experience of being ill and dependent on others for care is inadequately accounted for in much of bioethics and nearly all of the law. In other words, it matters that the burn patient and the child with cancer are seriously ill, and that Eric Cassell's grandmother and Annemarie Mol sought care in situations when the stakes were high—and that while they were capable of asking questions and making decisions, they nevertheless were disappointed and isolated and flummoxed by medical care relationships. Even the healthy child brought to the pediatrician's

72. MONEY DRIVEN MEDICINE, *supra* note 18.

73. PATCH ADAMS, *supra* note 19.

74. *See supra* notes 1–4 and accompanying text.

75. This suggestion was made by Kathi Kemper, M.D., an audience participant at the Symposium, who offered the definition of a patient as an individual seeking services from medical care providers to meet their health goals.

office for a check-up is brought by a parent who has in the back of her mind both the hope that everything is fine and the fear, "What if something is not right that I cannot yet see?"

Many of the essential features of health care delivery that make health law distinct from other legal fields are the same features that make many patients vulnerable: illness and suffering or fear of these; treatment relationships in which the patient is often dependent, must cede authority to others, and places his or her trust in strangers; the "existential stakes of medical care [such as] death, disability, and the essence of being human"; the uncertainty, complexity, and technology of medical practice; and the high cost of care and the patient's dependence on a faceless government or corporate entities to cover that cost.[76] Despite the law's shift away from physician-centrism, the modern focus on industry and public policy concerns has rightly been criticized for neglecting the actual experience of being ill and seeking care. Some have argued, for instance, that health law tends too often to assume that patients are prototypically healthy and competent adults engaged in fairly generic commercial transactions or social relationships—in short, regarding people who receive medical treatment more as consumers than as patients.[77] Consumer status signifies an individual assessing the generic contractual aspects of a standardized professional service (much like someone who is deciding about automobile repairs), whereas patients, typically and quintessentially, are "sick, sometimes desperate, sometimes dying, seeking care, comfort, direction, and (sometimes life-saving) aid from others with the resources, special skills and knowledge to help."[78] These opposing characterizations make fundamentally different assumptions about people's capacities when they are deciding on or receiving medical treatment.

Among Symposium participants, the extent to which the vulnerability of patients or patients' families should factor into a patient-centered orientation received a mixed reception. There seemed to be clear dissatisfaction with understanding patients as mere consumers. But beyond that there was considerable variation. Professor Art Frank was more willing than others were to say that patients are not actively making choices, that that notion is itself a bit of a fiction. He used the word "panicked" to describe many patients confronting medical treatment decisions.

Others expressed concern that recognizing the vulnerability of the patient could suggest a retreat from the hard-won gains of

76. Hall, *supra* note 8, at 358 (listing these attributes as essential features of health care delivery that distinguish its legal issues from those of other related fields).

77. Mark A. Hall & Carl E. Schneider, *Patients as Consumers: Courts, Contracts, and the New Medical Marketplace*, 106 MICH. L. REV. 643, 688 (2008).

78. Shepherd, *supra* note 33, at 450.

recognition of patient autonomy achieved in the 1960s and 1970s.[79] In his keynote remarks, Professor Howard Brody pointed out that since the 1990s, much of the work done in bioethics has been directed at trying to redress the imbalance between autonomy and other values. But he was also insistent—and Symposium participants appeared to agree with this assessment—that while gaining recognition for the principle of respect for autonomy was a limited victory, it was a victory nonetheless. These gains could be lost by a project that could stereotype or "essentialize" patients as being so overwhelmed by illness or the complexities of medical treatment that they are incapable of making and exercising choices.

That outcome, however, is not a necessary or inevitable consequence of greater awareness of patient vulnerability. Recognizing that patients need and deserve care does not have to replace the idea that patients need and deserve choice. As Professor Carolyn McLeod pointed out, vulnerability does not have to equate to incapacity to make decisions. We all have to make choices within social relationships that influence our values and perceptions, choices that may make us appear to lack some of the basic conditions for autonomous decision making assumed by some standard models of bioethics.[80] But the fact that patients may often feel powerless does not mean that the law or ethical norms should give that power back to physicians or to anyone else. It is possible to appreciate that illness, frailty, disability, or dying can place patients in positions of vulnerability within medical care systems, and still maintain the structures, practices, and attitudes that place a high value on respecting patients' values and preferences.

The tension over this issue was not entirely resolved, nor should we expect it to be, as it ultimately relates to profound philosophical debates over such essential matters as what it means to be human and in relationships with other human beings; these are matters about which classical, religious, feminist, critical, and other conceptions diverge and connect, revise and reconnect, diverge again, and continue to evolve. But at the end of the Symposium this tension did not appear to be an insurmountable obstacle to a more patient-centered health law and ethics that recognized patient vulnerabilities, although the calls for caution were certainly expressed and heard.

V. HOW WE THINK OF SHARED VULNERABILITIES AND RELATIONSHIPS OF MUTUAL ENGAGEMENT

A related concern expressed by Symposium participants was that focusing too much on the vulnerability of the patient could

79. *See* Hunter, *supra* note 25, at 1526.

80. *See* CAROLYN MCLEOD, SELF-TRUST AND REPRODUCTIVE AUTONOMY 106–13 (2002) (critiquing presumptions about autonomy and power relations that underlie standard theories of bioethics).

simply set us up at a different place on a continuum between extreme paternalism (illustrated by the "slap" story) and isolated patient choice (illustrated by the prenatal "choice" story), when what actually needs to happen, as expressed by Professor Sandra Johnson, is to "get off the continuum." Thinking exclusively along the continuum suggests a tug-of-war in which any gain by the physician (or other provider) is a loss by the patient and vice versa, rather than allowing us to envision a mutual engagement in decision-making processes from which both parties benefit.

Within medical treatment relationships, Johnson pointed out, it is not just the patient who is vulnerable. The high stakes involved in medical care cause a shared vulnerability. Physicians have superior knowledge only in some instances, and inferior knowledge in others. They may have a thorough understanding of medicine; they will never have a thorough understanding of the patient. And of course medical knowledge is always incomplete and medical practice filled with uncertainty. Physicians have many fears—fears of being lied to by their patients, fears of failing, fears of being blamed, and fears of being sued.[81]

Rather than describing the parties involved as "the vulnerable patient" or the "physician with superior knowledge," or even the "vulnerable physician," Johnson suggested that a patient-centered health law project would work on describing the relationships that should be created and maintained in the context of medical care. What do we want those relationships to look like? At the top of that list would be mutual trust and respect. But it may also include, as Professors Nan Hunter and Bill Sage emphasized, greater notions of responsibility within a concept of health care citizenship.[82] One of us has in fact argued for understanding our relationships with one another in health care matters as "relationships of responsibility."[83]

There was some agreement, then, that one mark of a more patient-centered health law and ethics would be an appreciation of the *relationships* involved in medical care delivery. Professor John Scott, in sharing his thoughts on patient-centered medicine and the medical home, began from the premise that the principal goal of medicine is healing, and that healing is created through

81. *See* Sandra H. Johnson, *Regulating Physician Behavior: Taking Doctors' "Bad Law" Claims Seriously*, 53 ST. LOUIS U. L.J. 973, 1019–20, 1024 (2009).

82. Hunter, *supra* note 25, at 1547–48; Sage, *supra* note 35, at 1506.

83. *See* Shepherd, *supra* note 33, at 450–51; *see also* Carol A. Heimer, *Responsibility in Health Care: Spanning the Boundary Between Law and Medicine*, 41 WAKE FOREST L. REV. 465, 466, 498–99 (2006) (asking how the law—viewed broadly to include institutional guidelines and "other kinds of 'rules' that form the penumbra of law"—can produce "responsible and responsive health care," a goal that requires both that professionals be morally competent and that social incentives encourage them to assume responsibility for patients' welfare).

relationships.[84] Professor Larry Churchill took a similar approach, as described more fully below.[85]

But participants also expressed caution about an overemphasis on relationships for a new patient-centered health law approach. Focusing too much on relationships—for example, going so far as to think in terms of "relationship-centered health law"—may suggest the idea of the inherent importance of the relationships themselves rather than the idea that these relationships are important because they affect the well-being of the patient.

Moreover, relationships tend to be thought of as dyadic; in health law and ethics the traditional dyad is "patient-physician." This emphasis on single patients and physicians in isolation is now clearly not adequate when health care delivery, and even decision making, is handled through systems, or at least by many different persons (only some of whom are professionals), institutions, and government agencies, all of which are affected not just by the patient's relationship to them, but by their relationships to each other (e.g., institution to institution).[86] There are just too many players involved in modern medical care—insurers, regulators, family caregivers, and surrogates, to name a few—to think in terms of a physician-patient dyad anymore. And, as noted above, for some, health law already emphasizes too much the relational obligations that others have with and to the patient and fails to consider the effects that practices attentive to the individual patient's demands have on the collective.[87]

On the one hand, there is a strongly felt need in medicine and health policy to focus more on how patients experience the complex health care delivery system. Seen in various guises such as patient navigators and medical homes, these patient-centered care initiatives seek in general to simplify and streamline patients' encounters with the health care institution or system.[88] On the other hand, we simultaneously are moving toward a more collective and interconnected health system. Therefore, perhaps it would be an appropriate time to determine and articulate which aspects of health law and ethics that currently do focus on the individual patient should be retained or improved.

84. *See* John G. Scott et al., *Understanding Healing Relationships in Primary Care*, 6 ANNALS FAM. MED. 315, 315–16 (2008).

85. *See infra* notes 93–94 and accompanying text.

86. *See* Dennis Brodeur, *Ethics and Health Care Reform: Institutional Contributions*, 39 ST. LOUIS U. L.J. 65, 66–67 (1994) (describing the increasing importance of relationships between institutional health care providers and other participants in the health care system and in health care ethics).

87. *See* discussion *supra* pp. 108–09; *see also* William M. Sage, *Relational Duties, Regulatory Duties, and the Widening Gap Between Individual Health Law and Collective Health Policy*, 96 GEO. L.J. 497, 499–500 (2008).

88. *See* Epstein et al., *supra* note 29, at 1492.

VI. WHAT WE MEAN BY "CENTERING" AND OTHER QUESTIONS OF SCOPE

The term "centering," like the term "patient," can mean many things, and its usefulness in defining an approach to health law may require that choices are made about what is and is not meant. Because the term "patient-centered" care is now used to signify a certain approach in medicine, one might wonder, again, how these two concepts are related—patient-centered medical care and patient-centered health law.

As noted above, the first day of the two-day Symposium was focused on discussing what is meant by patient-centered medical ethics. Professor Larry Churchill reported on the results of fifty interviews that he and a colleague conducted with exemplar physicians who were considered to have good healing relationships.[89] He asked them what they did to promote healing relationships. From these interviews, he discerned the following eight fundamental themes uniting the concrete things that these physicians do:

(1) Do the little things ("small courtesies and congenial manners");

(2) Take time and listen;

(3) Be open to patient vulnerability;

(4) Find something to like, to love;

(5) Remove barriers to genuine encounters;

(6) Let the patient explain;

(7) Share authority; and

(8) Be committed and trustworthy.[90]

After reporting these results to the Symposium participants and audience, Churchill asked, can health law promote, support, and enhance opportunities for these?

This could be one way of defining what is meant by "centering" the patient in health law. It could mean that health law should promote healing relationships. This would have both a strong normative slant—the aim is to benefit the patient through the existence of healing relationships—and a narrow focus—it would not

89. *See generally* Larry R. Churchill & David Schenck, *Healing Skills for Medical Practice*, 149 ANNALS INTERNAL MED. 720 (2008) (discussing the results of the fifty physician interviews).

90. *Id.*

seem to offer much guidance on health law in situations in which the patient him or herself is not in a relationship with someone. It is true, it seems, that this approach would not necessarily have to be limited to physician-patient relationships, but could embrace relationships between patients and institutions as well. Some of the items Churchill addressed might be encouraged by institutional policies—for example, when hospitals commit to do small things to make patients feel welcome or insurance companies adopt policies to respond quickly to coverage requests. But it is not clear whether an emphasis on healing relationships could offer much with respect to health law issues involving relationships among institutions (e.g., antitrust) or between institutions and providers (e.g., staff privileges) or between institutions and government (e.g., obligations to provide indigent care when enjoying nonprofit status) that may have an effect in some way on patient well-being. And maybe it should not. If—returning to the issue of who is the patient—the focus is to be on the individual patient and, in particular, the patient's *experience* as a patient, then this narrower understanding of centering may make sense.

Because much of the discussion at the Symposium focused on identifying the patient and salient patient characteristics, the question of what was meant by "centering" received less attention than perhaps was merited. Some other ideas mentioned—more in passing than as the subject of specific discussion—were that a patient-centered health law would, in decreasing order of normative force, (a) benefit the patient, (b) do no harm to the patient, or (c) pay attention to the effect that the law would have on patients as patients.

Because health law was the primary topic under consideration, rather than medical practice or even medical culture, a strong imperative that patient-centered health law should "benefit" the patient appeared to receive little support. Law, especially in the realm of litigation, involves questions of justice. It can be no more pro-patient than it can be pro-plaintiff or pro-defendant. But if we return to the idea of patients generally—rather than the specific patient—being benefited or at least not harmed by a particular ruling, or to the idea of law that supports healing relationships, then an explicit normative stance in favor of patients does not seem quite so out of keeping with more general notions of legal justice.[91]

Clearly, there is more work to be done on determining what is, could be, or should be meant by "centering" health law on the patient.

VII. CAUTIONS AND LIMITATIONS

Some of the cautions expressed at the Symposium about

91. *See* Krause, *supra* note 37, at 1490–92.

developing a more patient-centered health law have been noted above. To summarize, extended conversation about "who is the patient" in patient-centered law and ethics highlighted the concerns that *individual* patient medical care might be given primacy over the medical care needs of *all patients*; or that *individual health* might be given primacy over the *health of the population*; that *medical care* might, as a policy and funding matter, be given greater weight over *other means of improving health*; or that *concern over health* as even more broadly understood might be given greater weight over *other things of value* to human beings, such as hedonism or spirituality. There was also some concern that greater, explicit appreciation for patient vulnerability could morph into a renewal of physician paternalism or paternalism from other sources. And there was further concern that focusing on the relational aspects of patient experiences could narrowly emphasize patient-physician relationships when modern medical care, and the ethics and law relating to it, involves so much more.

Another cautionary note, expressed most prominently by Professor Carl Schneider, but shared by some others as well, was that we should not assume that certain consequences will follow from adopting this rule or that rule, but rather should find out through empirical analysis.[92] Grand schemes can fail grandly and do more harm than good. Professor Schneider also repeated the admonishment for which he is well known—we ought to find out what people want rather than assuming that we know.[93] Professor Howard Brody, in his opening remarks, suggested something similar—preferring the "bottom-up" approach (paying attention to concrete, existing particulars and listening to what patients want) rather than a "top-down" approach (applying abstract principles) to discovering how to make medical ethics and law more patient-centered.[94]

Finally, we perhaps overestimate how much the law matters and can matter in effectuating changes in care and care relationships. Professor Sandra Johnson has found this to be the case in her study of the claims that doctors make about what law requires them do with respect to pain management, restraints in nursing homes, and other practices—the law often does not require what they imagine at all.[95] She reminded us that though the law often fails to effect desired changes in medical practice, we do know

92. This theme is further explored in Schneider's book, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions* (1998).

93. *See* Carl E. Schneider, *Hard Cases and the Politics of Righteousness*, HASTINGS CENTER REP., May–June 2005, at 24, 25–26 (explaining that in order to effectively empathize with another person's position on a difficult subject, it is necessary to understand what he or she knows rather than to assume that you know all of the facts).

94. *Accord* HOWARD BRODY, THE FUTURE OF BIOETHICS 49–61 (2009).

95. *See* Johnson, *supra* note 81, at 994–95.

one thing that works to stimulate change: payment.

VIII. CONCLUSION: WHERE WE GO FROM HERE

What a greater focus on the patient might ultimately mean for a comprehensive reorientation of health law or changes to more discrete aspects of health law is still largely unexplored. It became apparent from Symposium discussion that more attention needs to be paid to definitional matters and goals, to the challenges to making health law and ethics more patient centered, and to the counterbalancing concerns that caution against a robust patient-centered approach. It seems to be a particularly ripe time to consider what specific areas of health law and ethics appear to be more patient centered and why, and which areas could be most improved by a patient-centered focus. For example, consideration might be given to what a patient-centered medical malpractice system or a patient-centered regulatory regime in human-subject research might look like.

Do we need a conceptual whole to develop a more patient-centered approach to health law and ethics? Professor Carolyn McLeod said at the Symposium, in another context, that wholeness is overrated. That sentiment may apply here as well. It may be possible to move forward by digging into a number of particular topic areas and then, after substantive and diverse work has been completed, step back and analyze what was discovered or decided along the way. It may be possible, after such work, to see more clearly the overall contours of a patient-centered health law approach and its value for the future of health law.