RIGHTS TALK AND PATIENT SUBJECTIVITY: THE ROLE OF AUTONOMY, EQUALITY, AND PARTICIPATION NORMS

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[I]llness is not merely a state of the organism and/or personality, but comes to be an institutionalized role.[1]

If the government was going to continue to act as if we didn't exist, if the medical establishment was prone to gridlock over funds, if the drug companies were waiting till the curve got high enough for profit, then we would find our own way.[2]

INTRODUCTION

The great majority of individuals have related to the health care system primarily as patients. For most of the history of medicine, the patient has been the embodiment of a diagnosis, the passive target of treatments, the recipient of injections and infusions, and the (hoped for) compliant consumer of medications and follower of orders. No more. Patients themselves have changed the social meaning of "patient" so dramatically that it only thinly resembles its meaning of even a generation ago.

The patient's role today is often that of a partner in managing care. The patient can be a co-creator—sometimes more so, sometimes less so, but almost always potentially—of the medical regimen that she undertakes. And with this increasing autonomy comes increasing accountability for prevention, wellness, and maintenance, as well as various forms of liability—socially if not (yet) legally—if those responsibilities are not fulfilled.

We also understand the patient today to be a consumer of medical services, with a consumer's orientation to questions of price, quality, and value. Yet "consumer" both fails to capture what is

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1. Talcott Parsons, *The Sick Role and the Role of the Physician Reconsidered*, 53 MILBANK MEMORIAL FUND Q. 257, 261 (1975).

2. PAUL MONETTE, BORROWED TIME: AN AIDS MEMOIR 103 (1988).

unique about the experience of health care and also implicitly cabins individual agency and responsibility to market-related interactions.

In short, the role of the patient has become far more complex than it ever has been before. The identity of patient has been de- and reconstructed into ever thicker formulations. The conceptual root of our contemporary understandings of "patient" is an assumption of autonomous subjectivity, i.e., of an individual aware of and capable of acting on her choices for medical care. The Symposium of which this Essay is a part considers the most recent stage in this evolution of meanings: the concept of patient-centeredness, with its implication of provider deference to the patient's perspective.

Throughout this process of an evolving patient identity, law has played a central constitutive role. In the 1960s and 1970s, the law of informed consent brought the concept of patient autonomy into the constellation of metanorms shaping the idealized doctor-patient relationship.[3] From that process, the patient as a rights-bearing subject emerged. In the 1970s and 1980s, women's health advocates and AIDS patients brought a new level of militancy to the patient role, undertaking representation on their own behalf and on behalf of future patients with the same disease. Their efforts produced lasting legal changes in such fundamental medical endeavors as clinical research.[4] In the last two decades, the rise of managed care and the growing shift of financial burdens and risk onto the patient were reflected in the model of patient as consumer, market actor, and self-insurer—a change also inscribed by and into law.[5]

Each of these developments carries a distinct political valence with differing, even contradictory, implications for legal and political frameworks for the health care system. Informed-consent doctrine exemplifies liberal rights discourse, disease activism connotes organized collective action, and the health-consumer identity has facilitated market-oriented health policy. All have become part of the experience of seeking health care, and all share one common theme: they reflect a shift in the cultural meaning of "patient" from a passive figure to that of an agentic actor with multiple dimensions of subjectivity. They provide a starting point for understanding just who the patient at the center is, what her roles will be in the health care system as a whole, and what her reasonable expectations of that system will encompass.

In this Essay, I take patient autonomy as the beginning point, the source of much in modern bioethics and the antecedent of the concept of patient-centeredness. My project is to enrich the values at the core of patient identity, expanding them beyond autonomy and beyond the treatment context and the doctor-patient dyad. I

3. *See* JESSICA W. BERG ET AL., INFORMED CONSENT 21 (2d ed. 2001).
4. *See infra* Part II.
5. *See infra* Part III.

identify three additional dimensions of patient subjectivity that must be accounted for if one is to develop a sound conceptualization of patient-centeredness. In the process, I argue that the basis for a new cultural norm of biocitizenship is emerging.

Part I retells the story of informed consent by surfacing the role of equality norms. The law related to patient autonomy has overlooked the role that the development of equality norms played in the realization of concepts such as informed consent, as individual and collective concerns about unequal treatment provided greater support for the individual's right to decide. In this context, I mean for equality to connote equal dignity, rather than the formal equality of antidiscrimination doctrine. The law's oversight is largely a product of the inadequacy of both antidiscrimination and informed-consent law to capture the full nature of the harm involved. Current trends in informed-consent law are reinforcing the move toward more equality in physician-patient status.

Part II examines the collective dimension of patient participation in medical care. Disease-group activism has become the most vibrant example of patient involvement in care, one that was transformed when people with AIDS began articulating a vision of patient empowerment that extended far beyond what were then its assumed boundaries. This aggressive claim of a right to participation as a group in research, resource allocation, and policy decisions has been taken up by other advocates, most prominently those involved with breast cancer issues. Although particular factors associated with these two diseases suggest that widespread migration of a norm of collective participation is unlikely, and there are reasons as well to believe that it can be counterproductive in certain ways, it nonetheless has become culturally available as a model of doctor-patient relations.

In Part III, I analyze the ways in which the rhetoric of medical consumerism interfaces with norms of autonomy, equality, and participation. Although much in the language of "consumer-directed" health policy is driven by the desire to cut costs rather than to enhance patient selfhood or the quality of care, the promotion of an identity as consumer is a double-edged sword, both altering and reinforcing traditional hierarchies of power in the health care system.

Part IV places these strands in the context of biocitizenship theory. The three qualities discussed in Parts I through III—autonomy, equality, and participation—create a conceptual platform on which it is possible to imagine building an understanding that patients can, at least in some instances, assume the rights and responsibilities that we associate with membership in a political community.

To summarize, patient-centeredness could function as simply the updated, more user-friendly iteration of the autonomy principle, unless autonomy is not only supplanted but expanded in the ways

that I describe. As we apply patient-centeredness to health law, our aspiration should be to keep it both as multidimensional as each patient actually is and as scalable as our massive health care system demands. Recognizing the broader context—with acknowledgment of the importance of the values of equality and participation—and seeing the possibility of further enhancing the individual's role into that of citizen-like engagement will help us achieve this goal.

I. ECHOES OF EQUALITY

I begin with a normative claim and a working definition. The normative claim is that the core of any meaningful idea of patient-centeredness must be a prioritization of patient dignity.[6] My working definition is that patient dignity embodies, at the least, two principles: autonomy and equality—that is, that each patient is presumed to be equally entitled to the respect due a moral agent, and that in the realm of dignity and respect, doctor and patient are peers.[7] The role of equality as central to autonomy may seem self-evident, but it is, at best, underdeveloped in the literature.

The law protecting patient autonomy is grounded most deeply in informed consent. Doctrinally, informed consent is a species of tort, and conceptually, it resonates with contractual notions of "[s]elf-conscious, rational, functionally-specific agreements between independent individuals."[8] The normative trump card is the "value-complex of individualism."[9]

Equality is a much trickier concept; the formal equality standard derived from antidiscrimination law once powerfully applied to and altered health care institutions,[10] but that is much less true today.[11] Moreover, the principle of equal dignity

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6. The Institute of Medicine defines "patient centered" 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." COMM. ON QUALITY OF HEALTH CARE IN AM., INST. OF MED., CROSSING THE QUALITY CHASM: A NEW HEALTH SYSTEM FOR THE 21ST CENTURY 40 (2001).

7. For purposes of this Essay, I wish to simply bracket the cultural contingency of meanings of autonomy and to note that my focus is solely on American culture and law.

8. Renée C. Fox, *The Evolution of American Bioethics: A Sociological Perspective*, *in* SOCIAL SCIENCE PERSPECTIVES ON MEDICAL ETHICS 201, 206 (George Weisz ed., 1990).

9. *Id.*

10. *See* DAVID BARTON SMITH, HEALTH CARE DIVIDED: RACE AND HEALING A NATION 32–63, 96–142 (1999).

11. When the Supreme Court eliminated the possibility of private parties bringing disparate impact challenges under Title VI in *Alexander v. Sandoval*, 532 U.S. 275 (2001), litigation against health care institutions on the ground of race discrimination virtually stopped. *See* Sara Rosenbaum & Joel Teitelbaum, *Civil Rights Enforcement in the Modern Health Care System: Reinvigorating the Role of the Federal Government in the Aftermath of* Alexander v. Sandoval, 3

encompasses something different from—both more and less than—the command that likes should be treated alike. I wish to draw out the *relationship* between the concepts of autonomy and equality in health care and the central role that equality norms have played and continue to play in the construction of patient autonomy and informed consent.

The legal literature on informed consent and the literature on rights-oriented social movements are seldom in conversation.[12] Yet one could not understand patient rights, patient subjectivity, or patient-centeredness without incorporating both autonomy and equality rights. This Part of the Essay initiates that process.[13] I begin by identifying how the cross-cutting nature of these concerns shaped the origins of informed-consent law. I then discuss some of the ways that equality concerns continue to influence that body of law.

A. Revisiting Informed Consent

The patient as rights-bearing subject entered both the law and the medical community through the creation of the requirement of informed consent.[14] Most histories of the law of informed consent attribute its origins to a slow accretion of references in state tort law that expanded a physician's duty not to touch patients without their consent to include a duty to apprise patients of the risk of a procedure.[15] This approach to autonomy draws on its deep moral and philosophical roots.[16]

YALE J. HEALTH POL'Y L. & ETHICS 215, 238–45 (2003).

12. See *infra* note 24 for some exceptions.

13. Two caveats: First, I am not making a simple causal argument, i.e., that certain social reform movements created informed-consent law (however, I am arguing that those movements shaped how and when the doctrine emerged). Second, this Essay does not attempt the kind of extensive historical analysis of this relationship that, in my view, remains to be done. A full history would consider the role of right-to-die campaigns, the disability rights movement, groups organized to demand more control over access to unapproved drugs, and efforts to secure translation services, among others.

14. *See* RUTH FADEN & TOM L. BEAUCHAMP, A HISTORY AND THEORY OF INFORMED CONSENT 86–100 (1986).

15. *See* BERG ET AL., *supra* note 3, at 45–46; FADEN & BEAUCHAMP, *supra* note 14, at 119–40; *cf.* Marjorie Maguire Shultz, *From Informed Consent to Patient Choice: A New Protected Interest*, 95 YALE L.J. 219, 280–81 (1985) (explaining that changing views of professional responsibility increased expectations of doctors' affirmative disclosures of medical procedures). The term "informed consent" was first used in *Salgo v. Leland Stanford Jr. University Board of Trustees*, 317 P.2d 170, 181 (Cal. Dist. Ct. App. 1957). Margaret A. Berger & Aaron D. Twerski, *Uncertainty and Informed Choice: Unmasking* Daubert, 104 MICH. L. REV. 257, 270 n.78 (2005).

16. *See, e.g.*, Alfred I. Tauber, *Historical and Philosophical Reflections on Patient Autonomy*, 9 HEALTH CARE ANALYSIS 299, 304–10 (2001); Bruce J. Winick, *On Autonomy: Legal and Psychological Perspectives*, 37 VILL. L. REV. 1705, 1707–15 (1992).

In their definitive history of informed consent, Professors Ruth Faden and Tom Beauchamp describe the key conceptual innovation as the law's articulation of an affirmative duty by physicians to provide the patient with the "facts which are necessary to form the basis of an intelligent consent."[17] They mark this as the inauguration of the independent importance of the autonomy principle, apart from the instrumental value of patient consent as an enhancement of old-fashioned patient obedience.[18] Similarly, Jaime King and Benjamin Moulton describe patient autonomy as "the most well known principle of medical ethics."[19]

Change in medical consent law was indeed evolutionary during most of the twentieth century.[20] The initial cultural groundwork for informed consent was laid by public revulsion against experiments conducted by Nazi physicians, and its legal codification derived from the Nuremberg Code's prohibition against using human beings as research subjects without their consent.[21] The pace of change vastly accelerated in the early 1970s, however.[22] This occurred not only because of the broader "rights revolution" in American society during the same time, but also specifically because of the politicization of medicine, along with other institutions. Indeed, it is striking how neatly the instantiation of the informed-consent requirement fits the model of a cycle—including a burst of rapid, dramatic change preceded and followed by more dormant periods—that often characterizes social-movement change.[23]

The women's and racial justice movements were especially

17. FADEN & BEAUCHAMP, *supra* note 14, at 125; *see also* Canterbury v. Spence, 464 F.2d 772, 787 (D.C. Cir. 1972); Cobbs v. Grant, 502 P.2d 1, 11 (Cal. 1972) (citing *Canterbury*, 464 F.2d at 786).

18. FADEN & BEAUCHAMP, *supra* note 14, at 125.

19. Jaime Staples King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 AM. J.L. & MED. 429, 435 (2006).

20. *See* FADEN & BEAUCHAMP, *supra* note 14, at 119–40.

21. *See* 2 NUERNBERG MILITARY TRIBUNALS, TRIALS OF WAR CRIMINALS 181 (1949), *available at* http://www.loc.gov/rr/frd/Military_Law/pdf/NT_war-criminals_Vol-II.pdf ("The voluntary consent of the human subject is absolutely essential."); *see also* FADEN & BEAUCHAMP, *supra* note 14, at 153.

22. DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE: A HISTORY OF HOW LAW AND BIOETHICS TRANSFORMED MEDICAL DECISION MAKING 3 (2003) ("Without putting too fine a point on it, the critical period of change was 1966 to 1976."). For other important cases in addition to *Canterbury* and *Cobbs* decided during the 1970s, see *Riedesser v. Nelson*, 534 P.2d 1052 (Ariz. 1975); *Holton v. Pfingst*, 534 S.W.2d 786 (Ky. 1975); *Sard v. Hardy*, 379 A.2d 1014 (Md. 1977); *Llera v. Wisner* 557 P.2d 805 (Mont. 1976); *Gerety v. Demers*, 589 P.2d 180 (N.M. 1978); *Scott v. Bradford*, 606 P.2d 554 (Okla. 1979); *Cooper v. Roberts*, 286 A.2d 647 (Pa. Super. Ct. 1971); *Wilkinson v. Vesey*, 295 A.2d 676 (R.I. 1972); and *Scaria v. St. Paul Fire & Marine Insurance Co.*, 227 N.W.2d 647 (Wis. 1975).

23. *See* John D'Emilio, *Cycles of Change, Questions of Strategy: The Gay and Lesbian Movement After Fifty Years*, *in* THE POLITICS OF GAY RIGHTS 31, 41–42 (Craig A. Rimmerman et al. eds., 2000).

significant in the move toward recognition of patient-autonomy rights.[24] Physician disrespect of patients had long been exacerbated by race and gender, and equality movements of the mid-twentieth century included these issues as part of their agendas.[25] This equality-focused "master frame" of social change,[26] and the new social meanings that resulted from it, shaped the contours, timing, and social meaning of the informed-consent doctrine.

An example is the role of women's health issues in the construction of informed consent. Recent historical research tells us that a case that is often cited as a classic of autonomy principles because of Justice Cardozo's epigrammatic dictum—"Every human being of adult years and sound mind has a right to determine what shall be done with his own body"[27]—could be more properly understood as early evidence for the women's health movement. *Schloendorff v. Society of New York Hospital* arose from the unauthorized performance of a hysterectomy after the physician determined that the patient was "too nervous" for a vaginal examination.[28] Observing the etiquette of a hundred years ago, Justice Cardozo did not mention these details in his opinion. Mary Schloendorff consented to an "ether exam" but not to surgery.[29] The outcome did not vindicate informed consent, however; the New York Court of Appeals affirmed judgment for the hospital on the ground of charitable immunity.[30]

Framed as a women's rights case, *Schloendorff* marks a protofeminist departure point for the resistance of women patients to a broad range of misogynist practices in later decades. Historian David Rothman notes that the women's movement of the 1970s

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24. Dr. Barron Lerner has specifically noted the impact of the women's health movement on the development of informed-consent law. *See* Barron H. Lerner, *Inventing a Curable Disease: Historical Perspectives on Breast Cancer*, *in* BREAST CANCER: SOCIETY SHAPES AN EPIDEMIC 25, 42 (Anne S. Kasper & Susan J. Ferguson eds., 2000); *cf.* Patricia A. King, *Race, Equity, Health Policy and the African American Community*, *in* AFRICAN AMERICAN BIOETHICS 67, 69 (Lawrence J. Prograis Jr. & Edmund D. Pellegrino eds., 2007) (discussing the history of disparity in African-American health care). *See generally* Patricia A. King, *Reflections on Race and Bioethics in the United States*, 14 HEALTH MATRIX 149 (2004).

25. *See* ROTHMAN, *supra* note 22, at 142–44 (describing how feminist movements in the 1960s increased female patient autonomy); SMITH, *supra* note 10, at 40–44, 50–57, 76–79, 91–95.

26. *See* David A. Snow & Robert D. Benford, *Master Frames and Cycles of Protest*, *in* FRONTIERS IN SOCIAL MOVEMENT THEORY 133, 138–44 (Aldon D. Morris & Carol McClurg Mueller eds., 1992) (explaining "master frames" and their relevance to social movements).

27. Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914), *superseded by statute*, N.Y. PUBLIC HEALTH LAW § 2805-d (McKinney 2007).

28. Paul A. Lombardo, *Phantom Tumors and Hysterical Women: Revising Our View of the* Schloendorff *Case*, 33 J.L. MED. & ETHICS 791, 795 (2005).

29. *Schloendorff*, 105 N.E. at 93.

30. *Id.* at 95.

found that "the issue of men dominating women was inseparable from doctors dominating patients."[31] The catalog of deprivations of patient autonomy that motivated feminists included Cesarean sections for physician convenience and sterilization and mastectomy without specific consent.[32]

Informed consent both was and was not a "women's issue." There are many post-*Schloendorff* cases that resonate with heavily gendered forms of paternalism and legal arguments.[33] Needless to say, what was then the professional norm for beneficence, including the failure to tell patients of terminal diagnoses[34] or the taking of liberties during surgery,[35] extended to male patients as well. Yet many of the common practices used with women patients reinforced a broader set of subordinating practices and thereby triggered an explicitly feminist political response.

Despite this connection, there was no sex discrimination legal claim, as such, available. Title VI of the 1964 Civil Rights Act, covering entities such as hospitals that receive federal funds, does not prohibit discrimination based on sex.[36] No portion of the Civil Rights Act prohibits discrimination in the provision of services by private health care providers. And a claim against a public entity grounded in the Equal Protection Clause requires a showing of intentional discrimination, which can be difficult to prove.[37]

Somewhat independently, abortion was also an important issue for both the women's movement and bioethics, and it illustrates the speed of change in the doctor-patient relationship during the same period. Justice Blackmun insisted that his opinion for the Supreme Court in *Roe v. Wade* did not allow "abortion on demand" because of the central role accorded to the physician in decision making.[38] However, in the late 1960s and early 1970s, medical authorities

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31. ROTHMAN, *supra* note 22, at 142–43.

32. *See* Lerner, *supra* note 24, at 40–42; 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, 157–63 (1994); *see also* Lombardo, *supra* note 28, at 796–97 (describing the *Schloendorff* physician performing a hysterectomy without the patient's consent).

33. *See, e.g.*, Hall v. United States, 136 F. Supp. 187, 193 (W.D. La. 1955); Carman v. Dippold, 379 N.E.2d 1365, 1370 (Ill. App. Ct. 1978); Charley v. Cameron, 528 P.2d 1205, 1210 (Kan. 1974); Henry v. Bronx Lebanon Med. Ctr., 385 N.Y.S.2d 772, 775 (App. Div. 1976); Sinclair v. Block, 633 A.2d 1137, 1140–41 (Pa. 1993); *see also* Suzanne K. Ketler, Note, *The Rebirth of Informed Consent: A Cultural Analysis of Informed Consent After* Schreiber v. Physicians Insurance Co. of Wisconsin, 95 NW. U. L. REV. 1029, 1039–45 (2001).

34. *See* JAY KATZ, THE SILENT WORLD OF DOCTOR AND PATIENT 17–25 (1984).

35. *See* Canterbury v. Spence, 464 F.2d 772, 784 (D.C. Cir. 1972).

36. *See* 42 U.S.C. § 2000d (2006).

37. *See* Washington v. Davis, 426 U.S. 229, 238–42 (1976).

38. *See* Roe v. Wade, 410 U.S. 113, 164–65 (1973); Nan D. Hunter, *Justice Blackmun, Abortion, and the Myth of Medical Independence*, 72 BROOK. L. REV. 147, 184–85 (2006).

shifted from seeking liberalization of abortion laws to supporting repeal of any abortion-specific restrictions.[39] As a result, the effect of delegating authority to the treating physician amounted to giving the full right to decide to the woman patient. Later, the Court recognized protection for autonomy in reproductive choice to be a necessary component of women's equality as citizens and references to the physician's role as joint decision maker effectively ended.[40]

Alongside change in the law regarding informed consent in medical care, the question of informed consent for human research subjects was revolutionized when press reports brought public attention to the Tuskegee Syphilis Study.[41] For the previous forty years, many of the almost four hundred African-American men who were subjects in a Public Health Service study of the effects of syphilis had been denied treatment for the disease, including penicillin, which became available roughly midway through the study.[42] Although the necessity of informed-consent principles for research had already become part of the Nuremberg Code[43] and the Helsinki Declaration,[44] Tuskegee—with its implication of profoundly racist medical decision making—led to a literal rewriting of the law. Congressional hearings followed the disclosure in the press,[45] as did the National Research Act,[46] which created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research,[47] which published the *Belmont Report*,[48] which led to the federal regulation now known as the "Common Rule."[49]

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39. *See* Hunter, *supra* note 38, at 192–96; *see also* Doe v. Bolton, 410 U.S. 179, 197–98 (1973) (striking down a law that allowed abortion only if a committee of physicians approved the procedure).

40. *See* Planned Parenthood of Se. Pa. v. Casey, 505 U.S. 833, 852 (1992).

41. *See, e.g.*, Jean Heller, *Syphilis Victims in U.S. Study Went Untreated for 40 Years*, N.Y. TIMES, July 26, 1972, at A1.

42. *See* JAMES H. JONES, BAD BLOOD: THE TUSKEGEE SYPHILIS EXPERIMENT 147, 150, 160–64 (1981); SUSAN M. REVERBY, EXAMINING TUSKEGEE: THE INFAMOUS SYPHILIS STUDY AND ITS LEGACY 63–64, 89–90 (2009).

43. NUERNBERG MILITARY TRIBUNALS, *supra* note 21, at 181–82; *see also* REVERBY, *supra* note 42, at 189.

44. WORLD MED. ASS'N, WORLD MEDICAL ASSOCIATION DECLARATION OF HELSINKI: ETHICAL PRINCIPLES FOR MEDICAL RESEARCH INVOLVING HUMAN SUBJECTS 2–4 (2008), *available at* http://www.wma.net/en/30publications/10policies/b3/17c.pdf; *see also* REVERBY, *supra* note 42, at 189.

45. *See Quality of Health Care—Human Experimentation, 1973: Hearing on S. 974, S. 878, and S.J. Res. 71 Before the Subcomm. on Health of the S. Comm. on Labor and Public Welfare*, 93d Cong. 3–4 (1973); *see also* REVERBY, *supra* note 42, at 100–03.

46. National Research Act, Pub. L. No. 93-348, 88 Stat. 342 (1974).

47. *Id.* § 201, 88 Stat. at 348.

48. Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research, 44 Fed. Reg. 23,192, 23,192–93, 23,195 (Apr. 18, 1979).

49. *See* 45 C.F.R. §§ 46.101–.124 (2009); Fazal Khan, *The Human Factor: Globalizing Ethical Standards in Drug Trials Through Market Exclusion*, 57 DEPAUL L. REV. 877, 887 (2008) ("Pursuant to the National Research Act, [the

The Tuskegee Study survivors themselves received compensation from the settlement of a class action lawsuit filed on their behalf by lawyers working with the NAACP Legal Defense Fund.[50] Ironically, however, this case did not contribute to the development of informed-consent doctrine. In part because of the participation of the historically black Tuskegee Institute and local African-American physicians in the study, the plaintiffs' lawyers faced a difficult proof problem in basing the case on a violation of the Equal Protection Clause.[51] The other major claim—a claim that the study failed to obtain informed consent from the participants—was complicated by a potential sovereign-immunity defense, which plaintiffs sought to avoid by proceeding under the Federal Tort Claims Act ("FTCA"),[52] a strategy that made relief contingent on whether Alabama state law recognized a cause of action for abrogation of informed consent.[53]

The court never reached the merits of the claims, and the settlement was probably a relief to plaintiffs' lawyers.[54] The legal obstacles they encountered illustrate the misfit in law between the principles of equal dignity and the structure of antidiscrimination law. In what today would be recognized as an example of the kind of doctrinal lacunae identified in intersectionality theory,[55] the law simply lacked the conceptual capacity to capture the full nature of the harm done to the men in the study.

The Tuskegee example implicates two forms of compound discrimination:

> '[M]ultiple discrimination' can occur in at least two ways: where the grounds of discrimination are additive in nature, and/or where the discrimination is based on an indivisible combination of two or more social characteristics. The former,

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government] instituted regulations governing human research that became known as the "Common Rule.").

50. *See* Pollard v. United States, 69 F.R.D. 646, 647–49 (M.D. Ala. 1976); Larry I. Palmer, *Paying for Suffering: The Problem of Human Experimentation*, 56 MD. L. REV. 604, 608–10 (1997).

51. *See* FRED D. GRAY, THE TUSKEGEE SYPHILIS STUDY 84–90 (1998). Professor Palmer argues that Attorney Fred Gray's decision to build the case around a theory of racial selection was "unwise" because it ignored the complexities of who was involved. *See* Palmer, *supra* note 50, at 610.

52. 28 U.S.C. § 1346(b) (2006).

53. Under the FTCA, an individual can obtain damages from the government upon showing governmental action resulting in what amounts to a personal injury in the law of the state where the injury occurred. *Id.* § 1346(b)(1).

54. Fred Gray, plaintiffs' lead counsel, had hoped to avoid litigation altogether by obtaining financial relief for his clients after the congressional hearings, but those efforts failed. *See* REVERBY, *supra* note 42, at 101–03.

55. *See* Sarah Hannett, *Equality at the Intersections: The Legislative and Judicial Failure To Tackle Multiple Discrimination*, 23 O.J.L.S. 65, 68 (2003) (Eng).

> 'additive discrimination', describes a situation where an individual 'belongs to two different groups, both of which are affected by [discriminatory] practices.' The latter, commonly referred to as 'intersectional discrimination,' 'arises out of the combination of various oppressions which, together, produce something unique and distinct from any one form of discrimination standing alone.'[56]

The men in the Tuskegee Study were certainly victims of the former and perhaps also of the latter.

Research practices in the 1940s, when the study began, were such that particular forms of oppression were directed toward black research subjects, thus arguably constituting that as a specific identity. The Tuskegee Study was extreme but not aberrational. Professor Smith quotes a New York surgeon in 1926 as saying, "[T]he Negro has always been appropriated as choice 'clinical material' by the medical profession. In the eyes of racists in that profession, the Negro was always next in line beyond the experimental animal."[57] The men in the Tuskegee Study were victimized both because of their race and their status as research subjects, but neither ground alone provided a strong legal basis for recovery. Neither antidiscrimination nor tort law was adequate to address the extent to which dual subordinating discourses had deepened the harm to plaintiffs.

In neither of these examples—the Tuskegee Study nor the women's health movement—can one assume that abstract principles of informed consent or equality, without more, would have offered adequate remedies. One might question, for example, how genuinely autonomous any decisions made by low-income African-Americans in Alabama in the 1940s could have been. Even the strongest informed-consent protocols were not likely to have had much impact in that context.

Yet the dominant lesson that emerges from efforts to eliminate subordinating practices based on race and sex remains that of the mutually reinforcing and constitutive nature of the relationship between equality and autonomy norms. Over time, arguments for one value have strengthened claims for the other.

B. The Micropolitics of Medicine

Doctors' offices and hospitals are highly politicized sites of interaction, in which both the intrastaff work culture and the provider-patient treatment culture produce and enforce a broad range of norms. Clinical medicine is a venue rife with power relations. In this context, where information parity between doctor and patient exists only rarely, the concept of informed consent has

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56. *Id.* at 65, 68 (alteration in original) (citations omitted).
57. SMITH, *supra* note 10, at 24.

allowed development of a medical practice norm in which treatment is a team effort joined by physicians, staff, and patient working as partners, each with differing roles.

In effect, informed-consent doctrine has created a legal platform upon which a partial equalization between doctor and patient can be built into the culture of medical practice. Depending on their level of psychological and physical strength, many patients continue to seek doctors to whom they can entrust decision-making authority. But most patients no longer approach physicians with the "abject dependence"[58] formerly characterized as typical.

This is not to claim that the informed-consent process is a smoothly functioning means of patient empowerment, or that the answer is a simple response of "the more informed consent, the better." Empirical studies have found that both doctor and patient are often unsatisfied with current informed-consent standards, sometimes for conflicting reasons.[59] Both frequently resist wholehearted reliance on patient decision-making,[60] while at the same time patients are also dissatisfied with insufficient levels of participation in decision making.[61] Physicians routinely truncate the process, now referred to as "consenting the patient." Looking toward the future, the economics of medical practice seem increasingly likely to impede the expansion of the informed-consent process as an ingredient in doctor-patient interaction.[62] Its utility as a remedy is questionable because of the difficulty of proving causation and damages.[63]

Yet, despite the gap between informed-consent law as it exists on the books and as it occurs in medical practice on the ground, the ideal of patient autonomy retains its power to shape norms and social understandings.[64] Informed consent has become engrained in

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58. Cobbs v. Grant, 502 P.2d 1, 9–10 (Cal. 1972).

59. *See* Peter Schuck, *Rethinking Informed Consent*, 103 YALE L.J. 899, 932–35 (1994) (discussing various studies).

60. *See* CARL SCHNEIDER, THE PRACTICE OF AUTONOMY 40–46 (1998); Cathy J. Jones, *Autonomy and Informed Consent in Medical Decisionmaking: Toward a New Self-Fulfilling Prophecy*, 47 WASH. & LEE L. REV. 379, 397–427 (1990); King & Moulton, *supra* note 19, at 446–48, 461–62. *See generally* Clarence H. Braddock et al., *Decision Making in Outpatient Practice: Time To Get Back to Basics*, 282 JAMA 2313 (1999); Jay Katz, *Informed Consent—Must It Remain a Fairy Tale?*, 10 J. CONTEMP. HEALTH L. & POL'Y 69 (1993).

61. *See* King & Moulton, *supra* note 19, at 468–73.

62. Joan H. Krause, *Reconceptualizing Informed Consent in an Era of Health Care Cost Containment*, 85 IOWA L. REV. 261, 292–305 (1999). To some extent, this problem may be alleviated through the use of videos and other "decision aids." *See* King & Moulton, *supra* note 19, at 488–90.

63. *See generally* Aaron D. Twerski & Neil B. Cohen, *Informed Decision Making and the Law of Torts: The Myth of Justiciable Causation*, 1988 U. ILL. L. REV. 607 (proposing a shift from focusing on proximate cause to identifying and valuing the patient's decision rights, which, the authors argue, doctors destroy by withholding information).

64. Faden and Beauchamp describe the mixed impact of informed consent

rights talk for patients generally and in various versions of a "patient bill of rights."[65] Moreover, patients are pushing the boundaries of informed consent, albeit with limited success. Patients are using informed-consent arguments to seek information about the physician as well as about the nature of the proposed treatment. The new topics to which courts have, to varying degrees, applied informed-consent principles are provider experience, provider health status, and financial incentives.

Two state supreme courts have ruled that an informed-consent claim may lie depending on the circumstances and degree of falsification if a physician misrepresents her experience or credentials. The Wisconsin Supreme Court ruled that a physician was liable under an informed-consent theory for misleading the patient about how many times he had performed the surgery in question, which was a difficult neurological procedure, and for failing to disclose the comparative risks between having the surgery and not having it.[66] The New Jersey Supreme Court followed Wisconsin in holding:

> [I]f an objectively reasonable person could find that physician experience was material in determining the medical risk of the . . . procedure to which plaintiff consented, and if a reasonably prudent person in plaintiff's position informed of the defendant's misrepresentations about his experience would not have consented, then a claim based on lack of informed consent may be maintained.[67]

However, as the New Jersey court pointed out, generally courts have held that physicians do not have an affirmative duty to disclose information regarding their experience or training.[68]

Courts have also diverged in how they have handled claims that a patient had a right to be notified of other physician characteristics, such as a history of substance abuse or a diagnosis of a communicable disease such as AIDS or HIV. Several courts have expressed fear of a slippery slope of possible required disclosures that extend too far to be justified by public policy, or have deferred

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on medical practice as follows: "At the same time that nothing has changed in medicine, everything has changed." FADEN & BEAUCHAMP, *supra* note 14, at 100.

65. *See, e.g.*, Thomas L. Hafemeister & Richard M. Gulbrandsen, Jr., *The Fiduciary Obligation of Physicians To "Just Say No" if an "Informed" Patient Demands Services that Are Not Medically Indicated*, 39 SETON HALL L. REV. 335, 361 & n.145, 362 (2009).

66. Adler *ex rel.* Johnson v. Kokemoor, 545 N.W.2d 495, 510 (Wis. 1996); *see also* Aaron D. Twerski & Neil B. Cohen, *The Second Revolution in Informed Consent: Comparing Physicians to Each Other*, 94 NW. U. L. REV. 1, 3–8 (1999) (discussing *Johnson*, 545 N.W.2d 495).

67. Howard v. Univ. of Med. & Dentistry of N.J., 800 A.2d 73, 84 (N.J. 2002).

68. *Id.* at 82–83.

to professional organizations to impose discipline in situations of physician substance abuse.[69] Other courts, however, have found a cause of action.[70]

Acceptance of the individual's right to know how her health plan structures financial incentives that might influence a provider's recommendations related to treatment has produced federal[71] and state[72] disclosure requirements.

These new directions in informed-consent law are not about who will make the final decision regarding a course of treatment or even about bargaining power between doctor and patient. If patients are sufficiently annoyed by a paternalistic or uncommunicative doctor, most can switch physicians, at least for outpatient care. Although the doctrinal function of informed consent is to guarantee that a patient is told of all material risks associated with a course of treatment so that she can intelligently decide whether to proceed, the actual function of the doctrine on the ground may do more to shape patient expectations about communication than about decision making per se.

One major rationale for informed consent is to diminish the information asymmetry between professional and layperson.[73] It is also true, however, that information disclosure about the physician—and not merely about the statistical risk associated with a given procedure—functions as a partial equalizer of doctor and patient. Traditionally, the patient's role has been to furnish a detailed medical history while often knowing no more about a physician than her practice areas and what can be gleaned from diplomas on the wall. Asserting a claim to know more signifies an unwillingness to accept the traditional hierarchy, as well as a desire for self-determination.

C. Summary

The ostensible purpose of the informed-consent requirement is

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69. *See, e.g.*, Albany Urology Clinic, P.C. v. Cleveland, 528 S.E.2d 777, 787 (Ga. 2000) (alleged cocaine use); K.A.C. v. Benson, 527 N.W.2d 553, 559–60 (Minn. 1995) (HIV/AIDS); Kaskie v. Wright, 589 A.2d 213, 216–17 (Pa. Super. Ct. 1991) (alleged alcohol abuse).

70. *See, e.g.*, Hidding v. Williams, 578 So. 2d 1192, 1198 (La. Ct. App. 1991) (alleged alcohol abuse); Faya v. Almaraz, 620 A.2d 327, 339 (Md. 1993) (HIV/AIDS).

71. *See* Employee Retirement Income Security Act (ERISA) of 1974, Pub. L. No. 93-406, §§ 404, 502, 88 Stat. 829, 877, 891 (codified as amended at 29 U.S.C. §§ 1104, 1132 (2006)). The disclosure duty is on the health-plan provider, not the medical provider. *See* Tracy E. Miller & William M. Sage, *Disclosing Physician Financial Incentives*, 281 JAMA 1424, 1427 (1999).

72. *See, e.g.*, ARIZ. REV. STAT. ANN. § 20-1076(i)(6) (2010); R.I. GEN. LAWS § 23-17.13-2(b)(8)–(10) (2008); *see also* Krause, *supra* note 62, at 375–85 (discussing state statutes' disclosure requirements); Miller & Sage, *supra* note 71, at 1427, 1430 & n.33.

73. *See* Schuck, *supra* note 59, at 957–58.

to provide the patient with a form of the right to exit, i.e., a right to determine whether to proceed with treatment that the doctor recommends. I suggest that one reason its vitality as an ideal continues, however, is that, although its utility in securing the right to exit may be more aspirational than real, because patients often rely on physicians for the expertise that determines their decisions, it does enable at least some patients to rebalance the doctor-patient power dynamic in communication. In other words, its primary function is less about exit than about voice, and specifically about a more dialogic, mutually respectful voice. This inflection in the social meaning of informed consent grew from the impact on its development of the women's health movement and the civil-rights movement.

It is not difficult to understand why the equality dimension of informed consent has been understated in legal scholarship. The primacy of individualism in health law is overdetermined by the prevailing values in American culture, the individualist norms of bioethics, and the structure of medical practice. In addition, the concept of equality is difficult to define in health care; the standard antidiscrimination approach offers little assistance. And, at least in terms of the doctor-patient dyad, equality in every respect is not even desirable: patients *want* there to be some information asymmetry between themselves and their care providers.

Yet the invisibility of equality norms in this context is unfortunate. An increasing number of patients—either individually or, as I will address in the next Part, collectively—approach health care with at least the hope of a collaborative relationship with their provider. As the financial consequences of both treatment and health status increasingly shift to patients, the trend toward more active patient involvement in such care is only likely to gather steam. In this situation, the technical concept of consent as the assumption of known risk is a desiccated understanding of equal dignity and, therefore, of patient-centeredness.

II. PATIENT ACTIVISM

One of the most profound changes in the role of patients has been the emergence of group-identity movements based on specific diseases. Disease-based advocacy groups have operated in the United States since early in the twentieth century, initially with the goals of informing the public and the medical profession about the particular disease and seeking additional funding for research.[74]

74. Even early public education campaigns could be militant, however. In 1936, the American Cancer Society launched a volunteer effort known as the Women's Field Army, complete with khaki uniforms and the insignia of rank. Women's Field Army members solicited funds and sponsored events that greatly increased popular knowledge of cancer. *See* JAMES T. PATTERSON, THE DREAD DISEASE 71–73, 121–24 (1987).

But the response to HIV/AIDS redrew the boundaries of possibility for health care related activism. The social-movement model that AIDS activists created became the new template for disease-based advocacy, such that within a decade after the HIV/AIDS epidemic began, a rising generation of breast cancer advocates self-consciously adopted and adapted it. In this Part, I analyze these two movements and the role of law in shaping how activism influences individual patient subjectivity.

AIDS activism and breast cancer activism share three important characteristics that are not accounted for in either the autonomy or the civil-rights literature. First, the identity implicated in each movement is two-dimensional, in that it is both specific to a disease and heavily associated with another stigmatized characteristic. Thus, both were able to build on the organizational and other resources already developed by a closely related identity-politics movement. Second, legislation enacting formal equality protections for the group was not the primary focus of either group's campaign, although both sought change that was heavily predicated on equality norms. Thus their agendas differed from those of traditional civil-rights organizations. Third, both movements instead prioritized the appropriation of additional funds to combat the disease with which they were concerned, and the adoption of mechanisms guaranteeing participation by group representatives in decision making concerning research and other scientific questions. Most important, both movements altered the protocols for the governance of scientific and medical institutions, a major step beyond the traditional role of patients.

A. HIV/AIDS Activism

Militant engagement by AIDS patients began in 1983, when a conference of PWAs (persons with AIDS—the very term "patient" sounded too dependent) met in Denver.[75] One of their first acts was to adopt the Denver Principles ("Principles"), which both reaffirmed patient autonomy and powerfully raised the ante.[76] The Principles recognized the rights of PWAs to receive "full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives."[77]

By the late 1980s, the center of AIDS activism was the New York City organization ACT-UP (AIDS Coalition to Unleash

75. William B. Rubenstein, *Law and Empowerment: The Idea of Order in the Time of AIDS*, 98 YALE L.J. 975, 990–91 (1989); Michael Callan & Dan Turner, *A History of the People With AIDS Self-Empowerment Movement*, THE BODY (Dec. 1997), http://www.thebody.com/content/art31074.html.

76. *See* Rubenstein, *supra* note 75, at 990.

77. *Id.* at 991; *see also* Callan & Turner, *supra* note 75.

Power).[78] ACT-UP, composed primarily of gay men, who then constituted the overwhelming majority of AIDS patients,[79] led an extraordinarily successful strategy that changed the terms of clinical trial enrollment, research design, and pharmaceutical approval processes. ACT-UP's modus operandi was a combination of "street theater and intimidation on the one hand, [and] detailed position papers and painstaking negotiation on the other."[80] Although part of the response to AIDS stigma included efforts to enact antidiscrimination and privacy laws, those issues were never the primary focuses for ACT-UP. Instead, driven by the urgency of a fatal disease with no cure and initially no treatment, activists left civil-rights issues to established public-interest law organizations and concentrated their demands on securing access to possible medications and on obtaining larger appropriations for research, treatment, and prevention.[81]

They succeeded repeatedly. In 1987, ACT-UP protested limited enrollment in clinical trials for AZT (zidovudine) and the lengthy Food and Drug Administration ("FDA") process for allowing drugs onto the market.[82] As a direct result, unapproved drugs were made available under a "compassionate use" program, and the FDA revamped its formal approval process.[83] Similar protests led to community-based clinical trials and the growth of "buyers' clubs" that purchased pharmaceuticals from outside the United States.[84] Other accomplishments included enactment of the nation's first disease-specific funding law, the Ryan White CARE Act.[85]

Sociologist Steven Epstein argues that the legacy of AIDS activism is a new kind of patient identity in at least two respects. First, he asserts that "it has rapidly become something of a cliché to say that the doctor-patient relationship will never be the same in the wake of AIDS."[86] Acknowledging that alterations in the paternalism-dependency dynamic had already begun, Epstein contends that "the significant effect of AIDS . . . is that a more cooperative model has become normative (at least in medical

78. *See* Rubenstein, *supra* note 75, at 993–94.

79. *See* PATRICIA D. SIPLON, AIDS AND THE POLICY STRUGGLE IN THE UNITED STATES 4–5 (2002).

80. Robert M. Wachter, *AIDS, Activism, and the Politics of Health*, 326 NEW ENG. J. MED. 128, 128 (1992).

81. *Id.*

82. STEVEN EPSTEIN, IMPURE SCIENCE: AIDS, ACTIVISM, AND THE POLITICS OF KNOWLEDGE 213–14, 222–26 (1996).

83. *See* Elizabeth Weeks Leonard, *The Public's Right to Health: When Patient Rights Threaten the Commons*, 86 WASH. U. L. REV. 1335, 1355–56 (2009); Kent A. Sepkowitz, *AIDS–The First 20 Years*, 344 NEW ENG. J. MED. 1764, 1770 (2001).

84. *See* SIPLON, *supra* note 79, at 26–32.

85. *See id.* at 93–102.

86. EPSTEIN, *supra* note 82, at 346.

rhetoric)."[87] However, it hardly needs stating that it is difficult to imagine that the conduct of these physicians, or the application of this norm, was the same for low-income or minority HIV/AIDS patients as it was for the primarily middle-class white men who dominated ACT-UP. It is more likely that the doctor-patient relationship will never be the same for some patients, but will change much less for others.

In perhaps a more justifiable claim, Epstein argues that AIDS advocacy produced a new conception of scientific knowledge.[88] Some ACT-UP members developed an extraordinarily sophisticated grasp of technical knowledge, enabling them to hold their own in debates with scientists over such rarefied subjects as identification of surrogate markers of the disease.[89] Even more challenging to the scientific establishment, ACT-UP also contended that patients brought new and different kinds of knowledge that should be considered necessary for excellence in medical research.[90] AIDS catalyzed what became the first movement to self-consciously transform patients into "activist-experts."[91]

B. Breast Cancer Activism

The women who took up breast cancer patient advocacy in the 1980s and 1990s continued feminist health political work from the 1970s and added to it the tactics of AIDS activism.[92]

Like the 1970s women's groups, the breast cancer movement rejected medical paternalism in treatment norms. Echoing ACT-UP, organizers also sought to refashion research. The movement directed its primary demands toward the goals of access to new drugs, changing inclusion criteria for clinical trials, and setting new directions for funding and priorities in medical research.[93]

Unlike those in the movement related to HIV/AIDS, advocates for breast cancer patients were dealing with a disease that was neither new nor communicable. As a result, research efforts were more standardized and not susceptible to the lurching, frenzied changes that occurred as scientists desperately pursued more information about AIDS and the causative virus. Moreover, the stigma associated with breast cancer was far less intense than the stigma associated with AIDS, if only because the disease was much less threatening to those who did not have it. Thus in many ways, the breast cancer campaign provided a test, under more normal

87. *Id.*
88. *Id.* at 8–9, 229.
89. *Id.* at 8–9.
90. *Id.*
91. *Id.* at 8.
92. CAROL S. WEISMAN, WOMEN'S HEALTH CARE: ACTIVIST TRADITIONS AND INSTITUTIONAL CHANGE 207 (1998).
93. *See* REBECCA DRESSER, WHEN SCIENCE OFFERS SALVATION 165–67 (2001).

circumstances, of the validity of the HIV/AIDS model for a social movement related to health care.

Much of the "law" generated by breast-cancer patient advocacy, like much of what ACT-UP generated, consisted of appropriations and funding legislation.[94] However, the cancer-patient advocates took the AIDS strategy one step further and more firmly institutionalized its successes in achieving a place for patients inside the major research institutions. The breakthrough came in two budget allocations in the mid-1990s.[95] Congress appropriated ten million dollars to implement the Clinton administration's National Action Plan on Breast Cancer in legislation that included a provision that allowed patient advocates to participate in the review committees for research grant making.[96] Soon after, advocates obtained an equivalent provision in legislation that established breast cancer research in the Department of Defense ("DoD"), a location that insulated it from cuts in domestic funding that customarily exempted DoD.[97] The National Breast Cancer Coalition then established its own training programs to prepare lay advocates to be able to engage effectively with the physicians and scientists with whom they would interact in the grant application review process.[98]

C. Limiting Factors

The kind of mobilization that HIV/AIDS and breast cancer patients organized is still ad hoc and rare. It requires, at a minimum, sufficient material resources and physical ability for extended engagement, in addition to a shared sense of urgency. And although both groups made efforts to encourage more democratic levels of participation among their constituencies, the socioeconomic status of the most active participants was middle class or higher, a status that was atypical of the group as a whole.[99] The same provisos would apply to earlier women's movement activism that insisted on more egalitarian treatment of patients by physicians and that developed alternative or self-help health centers.[100]

What Rebecca Dresser has called the "patient-centered

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94. Carol S. Weisman, *Breast Cancer Policymaking*, *in* BREAST CANCER: SOCIETY SHAPES AN EPIDEMIC, *supra* note 24, at 213, 220–22.

95. *See* WEISMAN, *supra* note 92, at 207–08.

96. *Id.*; Jane Erikson, *Breast Cancer Activists Seek Voice in Research Decisions*, 269 SCIENCE 1508, 1509 (1995).

97. *See* Department of Defense Appropriations Act, Pub. L. No. 102-396, 106 Stat. 1876 (1993); WEISMAN, *supra* note 92, at 208; Erikson, *supra* note 96, at 1508.

98. WEISMAN, *supra* note 92, at 208; Erikson, *supra* note 96, at 1508–09.

99. *See* DRESSER, *supra* note 93, at 166–67; SIPLON, *supra* note 79, at 5–6; Constance A. Nathanson, *A Skeptic's Guide to a Movement for Universal Health Insurance*, 28 J. HEALTH POL. POL'Y & L. 443, 450 (2003).

100. *See* WEISMAN, *supra* note 92, at 73.

approach to study design and evaluation"[101] is here to stay, but it comes with significant shortcomings. In addition to the unrepresentative composition of patient-advocacy groups, the enhanced participation of disease-specific groups in medicine can create new problems, even for advocates of greater autonomy, equality, and participation.

For example, even the most truncated version of modern informed consent is imperiled by advocate-driven misinformation—usually excessively high expectations—about the benefits of clinical trials.[102] The experience associated with high-dose chemotherapy with autologous bone marrow transplants ("ABMT") illustrates the point. Many patients initially demanded access to ABMT, with significant success, which delayed the completion of clinical trials—that in the end found that it was not a useful treatment.[103] Another form of misinformation was the widespread and incorrect belief associated with the breast cancer movement that the risk of that disease to women's health was substantially greater than statistics indicated.[104]

The paradox for equality is that the greater the success of some disease-advocacy organizations, the greater the likelihood that social inequality will be exacerbated rather than mitigated because of the skewed composition of those groups.[105] Moreover, research on diseases that for whatever reason are not represented by active lobbyists may be underfunded, even if they result in greater mortality and morbidity.[106] And a simple interest-group advocacy model is completely unequipped to address more nuanced issues of distributive justice, such as trade-offs in resource allocation between patients most likely to benefit versus those who are worst off.[107]

Lastly, although norms favoring expanded participation would seem the least likely to be undercut by the success of disease-specific advocacy groups, even here the incorporation of patients into policymaking entities is not without cost. Questions arise about the quality and legitimacy of the patient representatives.[108] Intracommunity disputes, such as the debate among AIDS

101. DRESSER, *supra* note 93, at 153.

102. *Id.* at 58–59.

103. *Id.* at 61–62.

104. Weisman, *supra* note 94, at 236.

105. For example, Professor Renée Landers has argued that reducing information asymmetry between patients and physicians may *increase* the gap in the capacity for informed consent between patients who are best situated by education and other skills to use the information, and patients who lack those resources. *See* Renée M. Landers, *Massachusetts Health Insurance Reform Legislation: An Effective Tool for Addressing Racial and Ethnic Disparities in Health Care?*, 29 HAMLINE J. PUB. L. & POL'Y 1, 57 (2007).

106. *See* DRESSER, *supra* note 93, at 83–84.

107. *See id.* at 80–83.

108. *Id.* at 10–11, 35–39.

advocates over how funds should be allocated between research and treatment, can further jeopardize the process.[109]

On balance, however, these are problems produced by the achievements of movements that have called into question what once was understood as a natural and inevitable characteristic of how patients experience the health care system: as individuals disconnected from each other and lacking any sense of group identity. A patient-centered perspective on care must take account of this change and incorporate the possibility of patient-group identity, as well as individual values.

III. BUYING POWER

The last major component of patient identity that I will address is that of "consumer." However distressing it is to ethicists, the American health care system "is being actively reshaped by the expectations of consumers"[110] and "consumer-centric financial incentives."[111] I will not repeat here the catalog of differences between the role of patient and the role of consumer.[112] Regardless of whether medical consumerism is primarily good or bad (for whom? for what end?), the important point about such consumerism for purposes of this Essay is how it aligns with other aspects of the evolution in patient self-understanding.

Medical consumerism itself is most often discussed in one of two ways: either as a watered-down version of patient activism, characterized by the ability of individuals to self-educate largely via the web;[113] or as a mechanism to contain health care costs by enticing patients into plans that shift to them more of the expenses of treatment.[114]

As to the former, David Rothman has described consumerism enabled by the availability of information as the "second stage in the patient autonomy movement."[115] He argues that the driving force is

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109. *See* SIPLON, *supra* note 79, at 93.

110. Kenneth W. Kizer, *Establishing Health Care Performance Standards in an Era of Consumerism*, 286 JAMA 1213, 1213 (2001).

111. James C. Robinson, *Managed Consumerism in Health Care*, 24 HEALTH AFF. 1478, 1479 (2005).

112. *See, e.g.*, GEORGE J. ANNAS, THE RIGHTS OF PATIENTS 3–5, 16–19 (3d ed. 2004); Wendy K. Mariner, *Can Consumer-Choice Plans Satisfy Patients? Problems with Theory and Practice in Health Insurance Contracts*, 69 BROOK. L. REV. 485, 491–95 (2004).

113. *See* David J. Rothman, *The Origins and Consequences of Patient Autonomy: A 25-Year Retrospective*, 9 HEALTH CARE ANALYSIS 255, 259–60 (2001).

114. For an example, see the euphemistic description offered by Aetna. *Consumerism in Health Care*, AETNA, http://www.aetna.com/about/aoti/aetna_perspective/consumerism_healthcare.html (last visited Oct. 29, 2010) ("Consumerism in health care is based on the idea that individuals should have greater control over decisions affecting their health care.").

115. Rothman, *supra* note 113, at 259.

not a sense of rights, but the diffusion of technology: "[T]he balance of power in the examining room has shifted in the 1990s not so much because of lawyers, but because of web masters."[116]

The latter form of consumerism is exemplified by the rhetoric used by various industries to advertise products or by insurers promoting "consumer-directed health care" plans that shift greater financial risk to patients.[117] For example, a firm that offers management consulting services declared on its website that:

> In 2008, the U.S. health care system was and continues to be in the midst of a transformational change that many believe is centered on consumerism—the process of enabling and engaging consumers more directly in selection and purchase decisions regarding health care services. A traditionally one-way conversation is becoming a dialogue as the health care system transitions from patient-oriented to consumer-oriented.[118]

Similarly, pharmaceutical companies argue that direct-to-consumer advertising empowers patients with information and promotes "participatory health care."[119]

The appropriation of empowerment language in such statements—framed in terms of "decisions," "dialogue," and "participation"—illustrates how market discourse can depoliticize the idea of rights. At the same time, however, seeking to encourage a consumer perspective for the patient also creates a paradox: the effort both reduces and reinforces the idea of patient empowerment.

In many respects, the reframing of patient as consumer re-inscribes a hierarchy of subordinating structures along new lines, with patients gaining fool's gold; physicians losing power; and greater control flowing, directly or indirectly, to payors and marketers. Treating the patient as consumer also reflects a commodification of the ethos underlying informed consent. On this understanding, information and choice are simply component parts of the service or product being provided.

On the other hand, while understanding oneself as a medical consumer may not enhance one's actual power or capacity for self-determination, the rhetorical structure used to advance this idea is consistent with norms of autonomy and participation. This superficial meaning accounts for the considerable popular appeal of the consumer identity.

In sum, medical consumerism can be a quasi-bait-and-switch

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116. *Id.* at 260.

117. *See, e.g.*, *Consumerism in Health Care*, *supra* note 114.

118. *Health Care Consumerism: 2008 Findings*, DELOITTE, http://www.deloitte.com/view/en_US/us/Insights/centers/center-for-health-solutions/6ca7f42c8d1fb110VgnVCM100000ba42f00aRCRD.htm (last visited Oct. 29, 2010).

119. Rothman, *supra* note 113, at 261.

technique in which the promotion of certain products or services highlights patient decision making, while the concomitant heightened financial responsibility for these choices is occluded. Lurking in the background is the serious ethical question about whether it is ever legitimate to force individuals with serious medical conditions to take on such responsibility.

A more defensible byproduct of the way that consumer talk is used to backburner rights talk is that it reinforces the separate norm of accountability. Individual accountability in the realm of health care is a controversial principle, because it too can be directed to the goal of cost cutting without regard to improving the quality of care. Yet there are undeniably some contexts in which the individual patient's assumption of responsibility for aspects of her own health is beneficial to her, as well as to others. Accountability has always been the flip side of the autonomy coin in moral philosophy.[120] Increasingly, accountability is yet another dimension that is reshaping how individuals experience the role and identity of patient.

IV. THE FOUNDATION FOR BIOCITIZENSHIP

Citizenship has become a kind of multitasking paradigm, invoked to signify much more than an individual's legal membership in a sovereign state. Legal scholarship routinely uses citizenship as a metaphor, analyzing how individuals understand themselves to be "citizens" in relation to their families, workplaces, and ethnic affinity groups,[121] as well as virtual citizens of more than one nation-state.[122] In its broader sociological sense, citizenship denotes roles and identities as well as rights and obligations. It creates a subject position not only as to nation-states, but also as to a range of much broader systems and discourses.

Especially given this proliferation of citizenship talk, it is notable that the intellectual history of any concept of health care citizenship is sparse, all the more so as it applies to a nation like the United States with largely private sector medical care. The classic formulation of a health-related concept of citizenship is T.H. Marshall's work. Marshall analyzed citizenship as a compound of

120. *See* H. Tristram Engelhardt, Jr., *The Many Faces of Autonomy*, 9 HEALTH CARE ANALYSIS 283, 286–89 (2001).

121. *See, e.g.*, Cynthia L. Estlund, *Working Together: The Workplace, Civil Society, and the Law*, 89 GEO. L.J. 1, 16–17 (2000). *See generally* Jennifer Gordon & R.A. Lenhardt, *Rethinking Work and Citizenship*, 55 UCLA L. REV. 1161 (2008).

122. *See generally* Kim Barry, *Home and Away: The Construction of Citizenship in an Emigration Context*, 81 N.Y.U. L. REV. 11 (2006); Peter J. Spiro, *Dual Nationality and the Meaning of Citizenship*, 46 EMORY L.J. 1411 (1997); Alejandro Portes, *Global Villagers; The Rise of Transnational Communities*, AM. PROSPECT, Mar. 1996, at 77.

rights existing in three domains: legal or civil, political, and social.[123] Marshall's legal or civil element referred to a citizen's right to freedom from oppression, or autonomy.[124] The political domain of citizenship spoke to a right of participation in public decision making.[125] His concept of social citizenship referred to citizens as beneficiaries of public goods and resources.[126] Writing in Britain after World War II, Marshall equated health citizenship with the entitlement to medical care, placing it in the third social domain.[127]

The term "biocitizenship" is an invention of political rather than legal theory, intended to mark the process by which individuals and the state contest power relations as to matters of health and illness. It does not refer to any form of literal citizenship.[128] Rather, it connotes a relationship between the individual and the health care system that has been more central to the interpreters of Foucauldian concepts of biopower than to more traditional political philosophers.[129] British political sociologist Nikolas Rose, for example, proffers a concept of "biological citizenship" that is both historical and contemporary.[130] Rose argues that concepts such as race, blood lines, and eugenics have long been associated with the framing of national citizenship, but that today new kinds of biological citizens are forming around genetic and somatic notions of both individuality and collectivity.[131]

My focus in this Essay has been on the normative values that lie at the heart of patient-centeredness: autonomy, equality, participation, and accountability. These are also characteristics that we associate with participation in a political system. Contemporary patients, like citizens, are agentic actors, even as

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123. T.H. Marshall, *Citizenship and Social Class*, *in* CONTEMPORARY POLITICAL PHILOSOPHY 291, 294 (Robert E. Goodin & Philip Pettit eds., 1997).

124. *Id.*

125. *Id.*

126. *Id.*

127. *See id.* at 308–09.

128. I acknowledge that citizenship, with its intrinsic function of exclusion as well as inclusion, is a particularly fraught concept to invoke in the realm of health care, especially in the United States, where "universal" health-reform legislation barred participation by illegal immigrants in health insurance market exchanges. *See* Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 1312(f)(3), 124 Stat. 119, 184 (2010). Thus I allude to "citizenship" only to point out its synchronicity with the dynamics of patient subjectivity that also function as components of patient-centeredness.

129. "Biopower" is the term Michel Foucault used to describe indirect but highly effective techniques of surveillance and control, through devices necessary to the functioning of a modern state, such as health education, population control, and the compilation of health statistics. *See* Bryan S. Turner, *From Governmentality to Risk: Some Reflections on Foucault's Contribution to Medical Sociology*, *in* FOUCAULT: HEALTH AND MEDICINE, at xi–xiv (Alan Petersen & Robin Bunton eds., 1997).

130. *See* NIKOLAS ROSE, THE POLITICS OF LIFE ITSELF 22–27 (2007).

131. *Id.*

they are simultaneously the subjects of medical or governance practices.

Patients are increasingly engaging in decision making, the formulation and pressing of equality demands, consideration of resource allocation, and responding to "patriotic" calls to assume greater responsibility for their own health. By these very activities, they are being (re)constituted yet again, this time as virtual citizens in a metaphorical polity of health care.

CONCLUSION

In filling out the contours of patient-centered medicine, scholars and policy makers should begin by examining how patients have in fact acted to reconfigure their own experience of the health care system. As patient subjectivity has expanded to encompass the assumption of rights and responsibilities and as norms of autonomy, equality, participation, and accountability have become more embedded as components of the identity of "patient," the idea of citizen-like engagement with the health care system becomes increasingly plausible. The move toward a model of care based on patient-centeredness will only further strengthen this development.