

SHOULD THE PATIENT CONQUER?

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Within the turreted ramparts of London's ancient Tower, long the most famous political prison in the English-speaking world, modern tourists can view hundreds of inscriptions hand scratched on the walls of chambers that were once the habitations of those unfortunate enough to incur the wrath of the Crown.¹ Some are mournful, some are sycophantic, some are bitter, some are philosophical, and some merely record a name or date to preserve the transitory existence of their authors.

In 1596, one Robert Bainbridge carved the following in the Beauchamp Tower: "The patient shall conquer."²

It is highly unlikely that Bainbridge was an early advocate for recipients of medical care, imprisoned perhaps by a cruel sheriff denied his payroll taxes or by a domineering barber refused his fee. But the inscription's unintended meaning would immediately provoke sympathy from many health care reformers.

Like the political prisoner, the medical patient endures suffering and loss of independence that compassionate people may well seek to relieve. Indeed, nearly all progressive impulses among American health lawyers and policy makers over the past half century have sought to liberate and empower the patient. Phrases used to express this desire include "patient autonomy,"³ "patients' rights,"⁴ "patient self-determination,"⁵ "patient preferences,"⁶

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1. The Tower of London, located strategically along the Thames River, today is primarily a magnet for tourists. It began existence in 1066 as a fortified castle for the new Norman rulers of England, and for nearly as long has served as a prison for disgraced noblemen and political prisoners, especially in the sixteenth and seventeenth centuries. *See generally* DANIEL DIEHL & MARK P. DONNELLY, *TALES FROM THE TOWER OF LONDON* (2004).

2. I noticed this carving on a family visit in May 2009. Unfortunately, my handwritten notes, scrawled on a pub napkin, have been lost to posterity.

3. Autonomy denotes the ability to make important decisions for oneself. In medicine, it underlies informed consent both to health care services and to participation in research, and it supports decisions to refuse life-prolonging treatment. *See generally* RUTH R. FADEN & TOM L. BEAUCHAMP, *A HISTORY AND THEORY OF INFORMED CONSENT* (1986); CARL E. SCHNEIDER, *THE PRACTICE OF AUTONOMY* (1998).

4. In the 1970s, concerns arose over the practices to which patients confined in hospitals and other health facilities might be subjected without

“patient protection,”⁷ and, recently, “patient-centeredness”—as in the “patient-centered medical home.”⁸

This orientation is by and large laudable. Our medical-care system spends roughly \$2.5 trillion annually, ostensibly to benefit patients.⁹ If this staggering sum is being diverted to other ends—to serve health care providers, insurers, suppliers, or government—it should be reclaimed. If those appointed and rewarded to care for people afflicted by illness or injury are neglecting the physical, mental, and spiritual well-being of patients, those individuals should be compelled to reengage in those tasks.

As we confront the critical challenges of implementing national health care reform, however, whether the patient should conquer is a legitimate topic for debate. Ever since the first attempts to universalize U.S. health care in the early twentieth century,¹⁰ the

their knowledge and consent. In response to these concerns, “Patients’ Bills of Rights” were passed into law in many states. See, e.g., N.Y. PUB. HEALTH LAW § 2803-c (McKinney 2007) (enumerating patients’ rights and responsibilities and requiring hospitals to post notices explaining those rights and responsibilities).

5. See 42 U.S.C. § 1395cc(f) (2006) (requiring hospitals, skilled nursing facilities, and home health care agencies to provide written information to patients concerning their rights under state law to make decisions about medical care and formulate advance directives). The common name of the statutory scheme from which this provision is drawn is the Patient Self-Determination Act. See *Health Care Advance Directives: What Is the Patient Self-Determination Act?*, A.B.A., http://www.abanet.org/publiced/practical/patient_self_determination_act.html (last visited Oct. 10, 2010).

6. For example, the decision whether or not to screen for prostate cancer depends on how individual men feel about the trade-offs between eradicating any disease that might be found and suffering side effects from surgery. See generally Ann Barry Flood et al., *The Importance of Patient Preference in the Decision To Screen for Prostate Cancer*, 11 J. GEN. INTERNAL MED. 342 (1996).

7. In the 1990s, the backlash against the perceived interference of managed care organizations with physicians’ decisions about clinical care manifested itself in the form of “patient protection acts,” passed under state and federal law. These statutes were enacted largely at the behest of the medical profession, and are sometimes disparaged as “provider protection acts.” See David A. Hyman, *Regulating Managed Care: What’s Wrong with a Patient Bill of Rights*, 73 S. CAL. L. REV. 221, 223 (2000).

8. See Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 3502, 124 Stat. 119, 513–15 (2010) (to be codified at 42 U.S.C. § 256a-1) (establishing community health teams to support patient-centered medical homes); see also COMM. ON QUALITY HEALTH CARE IN AM., INST. OF MED., *CROSSING THE QUALITY CHASM* 39–40, 48–51 (2001) (defining quality care as care that is safe, effective, patient centered, timely, efficient, and equitable, and expounding on each of those characteristics).

9. See Micah Hartman et al., *Health Spending Growth at a Historic Low in 2008*, 29 HEALTH AFF. 147, 147 (2010) (noting that national health spending reached \$2.3 trillion in 2008 and is growing at almost 5% annually).

10. See Randall R. Bovbjerg et al., *U.S. Health Care Coverage and Costs: Historical Development and Choices for the 1990s*, 21 J.L. MED. & ETHICS 141, 141–42 (1993) (describing health care reform efforts in the period before 1929); Paul Starr, *Transformation in Defeat: The Changing Objectives of National*

inexorable rise in health care spending has prompted a series of interpretations that suggest quite different answers to this question over time.

Initially, rising health spending seemed simply to be the price of progress in medical science, which, if rejected, meant needlessly condemning the poorer ill to their fate.¹¹ Then rising health spending seemed a response to emerging social preferences for expensive treatments, which reflected the increased wealth accompanying American power and prosperity.¹² Then rising health spending seemed a threat mainly to public purses and redistributive impulses, positing a tension between tolerating persistent inequality and indignity on one hand or accepting high taxes and bureaucratic waste on the other.¹³ Now, unfortunately, we seem finally to have reached the point at which spending more on health care means denying our other material needs.¹⁴ Stagnant wages for many middle-class Americans, for example, may in part reflect the rising cost of employer-sponsored health coverage crowding out cash raises in workplaces.¹⁵

In pursuit of much-needed economy, we now have two daunting tasks before us. First, because the value we currently receive from the money we pay is so poor, we must dramatically improve the quality and efficiency of our health care delivery system.¹⁶ Second, we must become healthier. Otherwise, the financial burden and

Health Insurance, 1915–1980, 72 AM. J. PUB. HEALTH 78, 79–81 (1982) (describing the early “campaign for health insurance in the United States”).

11. In the mid-1920s, the privately organized Committee on the Costs of Medical Care concluded that the medical needs of the American public were high, and that more money would have to be spent to satisfy them. See PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 261–66 (1982).

12. See SHERRY GLIED, *CHRONIC CONDITION: WHY HEALTH REFORM FAILS* 101–06 (1997).

13. C. Eugene Steuerle & Randall R. Bovbjerg, *Health and Budget Reform as Handmaidens*, 27 HEALTH AFF. 633, 634 (2008).

14. Satisfying our other material needs may also increase our health care costs. The reciprocal relationship between the price of health care and the price of food was seen a decade ago as reassurance that rising medical costs were not impoverishing us. See GLIED, *supra* note 12, at 101–03. In retrospect, however, cheap but unhealthy food may have contributed to epidemic obesity and its attendant adverse health consequences.

15. Other forces also are responsible for wage losses, which tend to afflict less educated, lower-wage workers more than workers who enjoy health care benefits. See GLIED, *supra* note 12, at 104–06. At some point, nonetheless, employers cannot increase total worker compensation beyond what the markets for their output will bear. See MARK V. PAULY, *HEALTH BENEFITS AT WORK* 121–34 (1997).

16. See *Getting Better Value in Health Care: Hearing Before the H. Comm. on the Budget*, 110th Cong. 17 (2008) (statement of Jeanne M. Lambrew, Ph.D., Assoc. Professor, Lyndon B. Johnson Sch. of Pub. Affairs, Univ. of Tex. at Austin); Meredith King Ledford et al., *Introduction*, in *THE HEALTH CARE DELIVERY SYSTEM: A BLUEPRINT FOR REFORM* 1, 1–2 (2008), available at http://www.americanprogress.org/issues/2008/10/pdf/health_delivery_full.pdf.

reduced productivity associated with the chronic diseases we have inflicted on ourselves will be greater than even the most efficient health care system can support.¹⁷

The principal achievements of the recently enacted federal health care law¹⁸ heighten the urgency of our situation. If health insurance will be broadly accessible, the health care system will no longer enjoy the pretense of affordability that has accompanied the ability to exclude the most costly beneficiaries from coverage. 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.

This raises an ethically challenging question: does the patient's conquest risk the collapse of the health care system that he or she would dominate? There are several reasons why it might.¹⁹

Individual experience of illness. First, patient-focused care prioritizes the individual experience of illness, and regards other values—even personal ones—as incommensurable. A seriously ill individual would seem to have no higher use for resources than to obtain care; therefore, personally to forgo it for economic reasons seems a coerced decision—a “highwayman's choice.”²⁰

We often apply similar reasoning when we decide to make social investments in health as opposed to other activities. We tend to resist private-sector models of health care production that free up resources to move elsewhere in the economy as siphoning money away from patient care and into corporate profits.²¹ We have no

17. See Thomas Bodenheimer et al., *Confronting the Growing Burden of Chronic Disease: Can the U.S. Health Care Workforce Do the Job?*, 28 HEALTH AFF. 64, 64 (2009) (“The cost burden of chronic illness—currently 78 percent of total health spending—will increase markedly by 2023 . . .”).

18. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010).

19. For an overview of ways in which individually focused laws may compromise the health care system, see William M. Sage, *Relational Duties, Regulatory Duties, and the Widening Gap Between Individual Health Law and Collective Health Policy*, 96 GEO. L.J. 497 (2008).

20. Compare William M. Sage, Letter to the Editor, *Potential Cost Savings from Legalizing Physician-Assisted Suicide*, 339 NEW ENG. J. MED. 1789, 1789 (1998) (“I do not believe that one can sidestep the issue of cost merely by dismissing the aggregate savings as trivial. Therefore, I hope that future discussions of assisted suicide and cost will focus on individuals, as well as systems, and will explore the moral legitimacy of making a personal physical sacrifice for an equally personal financial benefit.”), with Ezekiel Emanuel, Letter to the Editor: Author Response, *Potential Cost Savings from Legalizing Physician-Assisted Suicide*, 339 NEW ENG. J. MED. 1789, 1790 (1998) (“Your money or your life? This is the macabre question of the highwayman. . . . The highwayman's menacing threat does not constitute a reasonable choice, and it is one that society cannot allow—not in the case of physician-assisted suicide and not in the case of other life-and-death choices.”).

21. For example, the Patient Protection and Affordable Care Act limits “medical loss ratios” for health insurers, reflecting a preference for the pass-through of premium dollars to health care providers over measures to reduce

choice but to grant government the privilege of apportioning public monies between individual health care and other uses, but we often do so grudgingly. For example, we partition investment in care for the individual from investment in public health, and often stuff the former while starving the latter.²²

We emphasize the importance of preventive care for identified patients, but neglect the “pre-patient” whose behavior in the community frequently foreshadows serious illness.²³ We also neglect the community that is often responsible for the unhealthy behavior.²⁴ Consequently, we tend to underestimate the contribution of good health to workplace productivity, as well as the crucial role of education in promoting both health and economic opportunity.

Physician-patient dyad. A second problem with the patient’s conquest is that a physician champion seems necessary to produce a triumphant patient. As a result, we elevate the physician-patient relationship to iconic status, and design our health care system to isolate and support this dyadic image of fiduciary representation in pursuit of health.²⁵

This is problematic on both sides. A single physician struggles to navigate the complexity of modern medicine and tends to ignore critical design elements of the health care system in which his or her practice is embedded. Assertions of undivided loyalty to individual (insured) patients allow physicians to rationalize inattention to alternative sources of care, wasteful clinical decisions, and financial self-interest.

Because we place such high expectations on caregivers, moreover, we overemphasize the role of physicians in the health care workforce. The image of the heroic physician fighting disease leads us to regard medical doctors as uniquely capable and ethical, and discourages teamwork and interdisciplinary practice. Over the

the cost of claims if they increase administrative expenses or profits. See § 1331(b), 124 Stat. at 220.

22. See generally Lawrence O. Gostin et al., *The Future of the Public’s Health: Vision, Values, and Strategies*, 23 HEALTH AFF. 96 (2004).

23. “Metabolic syndrome,” for example, consists of a constellation of attributes—including central obesity—that predispose individuals to diabetes and other serious diseases. Over twenty percent of Americans age twenty and older have metabolic syndrome. See Earl S. Ford et al., *Prevalence of the Metabolic Syndrome Among US Adults: Findings from the Third National Health and Nutrition Examination Survey*, 287 JAMA 356, 356–57 (2002).

24. See generally Marice Ashe et al., *Local Venues for Change: Legal Strategies for Healthy Environments*, 35 J.L. MED. & ETHICS 138 (2007) (acknowledging the challenges associated with America’s obesity problem and suggesting structural solutions at the community level).

25. See, e.g., Jerome P. Kassirer, Editorial, *Managing Care—Should We Adopt a New Ethic?*, 339 NEW ENG. J. MED. 397, 398 (1998) (concluding that physicians should not “capitulate to an ethic of the group rather than the individual”).

longer term, more widely distributed—and likely more effective—models of community-based prevention and care fail to develop.

On the patient side, a dyadic view of care promotes dependency and paternalism. Unsurprisingly, physicians—not patients—exercise most authority in practice, notwithstanding efforts to enforce patient autonomy through ethics and law.²⁶ The apparent need for customized treatment also discourages standardization and therefore efficiency.²⁷ Even strong privacy protections can be used in counterproductive ways, such as to conceal disorganization and to resist accountability.²⁸

Identified lives. A third problem with urging the patient to victory is that political decisions regarding health-system design are dominated by what one might call the myth of the identified life. 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.²⁹ In health policy, moreover, even prospective social choices tend to be guided by a mental image of ourselves or our loved ones facing a dreaded disease.

As a result, our impulse for justice favors assisting the person who is ill over the person who is poor, and we pay insufficient attention to the critical task of preventing people from becoming either poor or sick. Similarly, we regard health insurance as a life raft for those in peril instead of a common-pool resource requiring stewardship. We reach desperately for any new technology that might help defeat death. Any preplanned limit seems like a death panel.³⁰

26. Empirical work suggests, moreover, that many patients prefer physicians to make decisions for them. See SCHNEIDER, *supra* note 3, at 35–46.

27. See Charles E. Dean, *Personalized Medicine: Boon or Budget-Buster?*, 43 ANNALS PHARMACOTHERAPY 958, 958–60 (2009).

28. See STARR, *supra* note 11, at 299–300 (describing the American Medical Association’s first declaration, in 1934, of its core principles for accepting private health insurance).

29. See David C. Hadorn, *Setting Health Care Priorities in Oregon: Cost-Effectiveness Meets the Rule of Rescue*, 265 JAMA 2218, 2218–19 (1991) (explaining how the original methodology of Oregon’s priority-setting list for coverage under its Medicaid program failed to give primacy to life-saving treatment); see also Paul Menzel et al., *Toward a Broader View of Values in Cost-Effectiveness Analysis in Health Care*, HASTINGS CENTER REP. May–June 1999, at 7, 9 (explaining the “rule of rescue”).

30. The new federal health-reform law funds “patient-centered outcomes research,” but eschews any use of that research to dictate health care financing decisions unless narrowly limited to clinical effectiveness. See Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 6301(c), 124 Stat. 119, 740 (2010) (“The Secretary shall not use evidence or findings from comparative clinical effectiveness research conducted under section 1181 in determining coverage, reimbursement, or incentive programs under title XVIII in a manner that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill.”).

Diseases. A fourth problem is that a patient is usually defined by a disease. Constructing a system around each patient therefore implies constructing a system around each disease. In part because communicable diseases were in temporary abeyance during the rapid advance of “patients’ rights” in the 1960s and 1970s, afflictions tend to be seen as separate and personal.³¹ This is a clinical problem because care for millions of patients with multiple chronic diseases remains fragmented and often ineffective. It is also a political problem because individual diseases are supported by strong special interest groups composed of providers, suppliers, and patients that can make excessive claims on shared resources.³² At the same time, no common collective interest in a well-functioning health system has emerged to counter the current, highly partisan macropolitics of ideology or fiscal austerity.³³

The patient should be at the center of medical practice. That is not controversial. But a conquering patient should not be the goal of health care reform. A patient-centered system has benefits, but it also perpetuates and exacerbates gross inefficiencies and inequities in the health care system. Instead, the best response to the challenges of health care reform should be a collective one. This will not be easy. It would have taken a very brave soul locked in the Tower of London to etch “The people will conquer” into those blocks of stone.

31. See Leslie P. Francis et al., *How Infectious Diseases Got Left Out—And What this Omission Might Have Meant for Bioethics*, 19 *BIOETHICS* 307, 307–08 (2005) (suggesting that the lack of collective ethics derived in part from the happenstance of bioethics developing when infectious diseases seemed to have been conquered).

32. The early history of popular mobilization to support the eradication of particular diseases can count among its successes the development of a polio vaccine, the founding of the American Cancer Society, and the establishment of the National Institutes of Health (the plural reflecting Congress’s approval of a “categorical” approach). See DAVID M. OHSKINSKY, *POLIO: AN AMERICAN STORY* 45–46, 48–55, 67–69 (2005); STARR, *supra* note 11, at 342–47.

33. See Lawrence R. Jacobs, *Politics of America’s Supply State: Health Reform and Technology*, *HEALTH AFF.*, Summer 1995, at 143, 146–52 (discussing the highly politicized nature of the modern U.S. health care system); see also William M. Sage, *Why the Affordable Care Act Needs a Better Name: ‘Americare,’* 29 *HEALTH AFF.* 1496, 1496–97 (2010).