MUSINGS ON PATIENT-CENTERED LAW AND ETHICS

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INTRODUCTION

What exactly might "patient-centered" law or ethics mean? Let's start by reflecting on what it might mean for *any* body of law or kind of ethics to be centered on something, or anything, and why that might matter.

The focal point of law or ethics will influence: (1) which questions are considered important; (2) how they are addressed; and (3) what values are paramount—in other words, the scope, the methods, and the substance of the field. So, this seems like something we should certainly try to get right. And, the focal point of health law is especially problematic because law is decided by judges who face concrete cases, and is practiced by lawyers who serve clients with particular interests. Therefore, law tends to focus on the problems and concerns of the people or institutions with money to hire lawyers and to pursue litigation (or to influence legislators and regulators).

I. A BRIEF INTELLECTUAL HISTORY

This client focus is seen, for instance, in the original law-and-medicine casebook,[1] which was starkly physician centered. It was devoted primarily to forensic medicine and secondarily to public health, regulation of medical practice, and liability.[2] This balance reflected the composition of the turn-of-the-century medical discipline known at the time as "medical jurisprudence," which studied various medical issues relevant to the legal system—such as pathology, cause of injury, toxicology, and determination of

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1. WILLIAM J. CURRAN, LAW AND MEDICINE: TEXT AND SOURCE MATERIALS ON MEDICO-LEGAL PROBLEMS (1960).

2. *See id.* at vii–viii.

insanity—as well as aspects of liability and regulatory law that were relevant to physicians' professional practice, such as malpractice and licensure.[3]

Philosophers and theologians, of course, do not have clients, and no earthly authority adjudicates their issues. Thus, bioethics arose in an entirely different fashion than did health law. Indeed, it arose pretty much in opposition to the professional concerns that shaped medical law and traditional medical ethics.[4] Historically, medical ethics also was very much physician centered,[5] but as such, it also recognized and responded to the unique features of sickness, healing, and medical relationships—albeit in a highly imperfect way. In the 1970s, "[c]oncerns about the special qualities of the doctor-patient relationship became associated with old-guard paternalism and its reactionary resistance to the patient rights movement."[6] So, in the modern era, the relational perspectives from the past fell into disfavor or were reinterpreted in rights-oriented terms.[7]

Rather than focusing on the psychological realities of trust, vulnerability, and illness, bioethics came to view trust skeptically, questioning whether physicians deserved trust. As explained by one physician-ethicist:

> The language of rights and the language of trust move in opposite directions from one another. The scrupulous insistence on observance of one's rights is an admission that one does not trust those at hand to care properly for one's welfare. This point can be seen in the fact that "rights" are a peculiarly modern moral language, developed for and appropriate to the highly impersonal social relationships that characterize our times, times in which the breakdown of trust is endemic.[8]

In the 1990s, threats to the doctor-patient relationship arose from the increasing corporatization of medicine, but ethicists struggled to find the right conceptual framework and empirical data to use in analyzing these issues. Because the traditional rubric of beneficence, autonomy, and justice was felt to be inadequate to the

3. *See generally* JAMES C. MOHR, DOCTORS AND THE LAW: MEDICAL JURISPRUDENCE IN NINETEENTH-CENTURY AMERICA (1993); Emil F. Frey, *Medicolegal History: A Review of Significant Publications and Educational Developments*, 10 L. MED. & HEALTH CARE 56, 56–57 (1982).

4. *See generally* ALBERT R. JONSEN, THE BIRTH OF BIOETHICS (1998).

5. *See* Edmund D. Pellegrino, *Thomas Percival's Ethics: The Ethics Beneath the Etiquette*, *in* MEDICAL ETHICS; OR, A CODE OF PRECEPTS, ADAPTED TO THE PROFESSIONAL CONDUCT OF PHYSICIANS AND SURGEONS 1, 34–37 (1985).

6. Mark A. Hall, *Law, Medicine, and Trust*, 55 STAN. L. REV. 463, 469 (2002); *see also* JONSEN, *supra* note 4, at 336–37.

7. DAVID J. ROTHMAN, STRANGERS AT THE BEDSIDE 107 (1991).

8. Richard Sherlock, *Reasonable Men and Sick Human Beings*, 80 AM. J. MED. 2, 3 (1986).

emerging issues at hand, it came to be denigrated as the "Georgetown mantra,"[9] in recognition of the influence of scholars at that university's Kennedy Institute of Ethics.

Following the lead of bioethics, the modern version of health care law that emerged in the 1990s is decidedly not physician centered. But, owing to the client- and problem-focused nature of law, neither is it primarily patient centered. Instead, it now is more institution focused.[10] As first clearly articulated in the 1987 casebook by Furrow, Johnson, and colleagues, the field's main concerns now are usually grouped and summarized as quality, autonomy, access, and cost—as applied to the primary topics of malpractice liability, bioethics, insurance financing, and corporate regulation.[11] Although this quadrified structure has never assumed the "mantric" status of bioethics' principlism,[12] coalescence around these four themes and four broad topic areas has helped health law to solidify. The field is now regarded as the doctrinal and public policy study of law that emerges from the health care industry's encounters with judicial, legislative, market, and regulatory systems.[13]

Despite law's shift away from physician centrism, the modern focus on industry and public policy concerns has rightly been criticized for neglecting the actual experience of being ill and seeking care.[14] Some have argued, for instance, that health law tends too often to regard people who receive medical treatment more

9. *See generally* Abdallah S. Daar, *Beyond the Georgetown Mantra: Review of Training Manual on Ethical and Human Rights Standards for Health Care Professionals*, 5 HEALTH & HUMAN RIGHTS, no. 1, 2000 at 186 (book review).

10. *See generally* BARRY R. FURROW ET AL., HEALTH LAW: CASES, MATERIALS AND PROBLEMS 321–95 (1st ed. 1987) (examining the law surrounding health care institutions).

11. *See id.* at xxxv–xxxvi.

12. *See generally* TOM L. BEAUCHAMP & JAMES F. CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS 99–331 (6th ed. 2009) (discussing the moral principles of bioethics: respect for autonomy, nonmaleficence, beneficence, justice, and professional-patient relationships).

13. *Accord* James F. Blumstein, *Health Care Law and Policy: Whence and Whither?*, 14 HEALTH MATRIX 35, 35–36 (2004) (stressing the public policy dimension of health law); Barry R. Furrow, *From the Doctor to the System: The New Demands of Health Law*, 14 HEALTH MATRIX 67, 67 (2004) ("Health law is the legal domain that addresses the health care industry in all of its component parts."); Clark C. Havighurst, *Health Care as a Laboratory for the Study of Law and Policy*, 38 J. LEGAL EDUC. 499, 499 (1988) ("[T]he common denominator that best unifies the study of health care law is the health care industry itself.").

14. *See* Raymond Tallis, Commentary, *Leave Well Alone*, 318 BRIT. MED. J. 1757, 1757 (1999) ("Someone who is ill and seeking help—unlike someone who is purchasing a pair of socks or a pound of sausages—is often vulnerable, certainly worried, sometimes uncomfortable, and frequently frightened. [The label of] customer, like the other obvious choices—clients, consumers, and users—erases something that lies at the heart of medicine: compassion and a relationship of trust.").

as consumers than as patients.[15] Medical ethics has always regarded those who receive care much more as patients than as consumers. Nevertheless, "[m]edical law and ethics embraced an implicit consumerist ethos starting in the 1960s, as an aspect of the patients' rights movement that challenged physician paternalism."[16] In the 1980s, this consumerist view gained greater support as a way to cope with public policy's acceptance of market dynamics as a means to control health care costs.[17] For instance, rights as medical consumers were invoked to protect patients from undesirable aspects of managed care stemming from competitive health insurance.[18]

II. ALTERNATIVE VIEWS

Without reinstating old-style paternalism or undoing rights-based reforms, scholars from a range of disciplines and perspectives are attempting to reconcile ethical theory and professional practice with the essential attributes of caregiving medical relationships. In previous work, I have proposed an essentialist approach that asks: what are the essential features of health care delivery that merit special attention in legal analysis and that distinguish health care law from other legal fields?[19] This approach resonates broadly with Professor Lon Fuller's approach to defining law or legality generally. In his jurisprudential debates with the legal positivists a half century ago, he argued for an "inner morality" of law consisting of eight constitutive elements that give law its legitimacy.[20] My proposal is for a similar form of essentialism to explain why health care law is deeper than the simple positivist definition of all law that happens to apply to the health care industry. In my view, the core of what makes health law a distinctive intellectual field can be found in the phenomenology of what it is to be ill and to be a healer of illness.

A similar "internal morality" framework has also been applied

15. *See, e.g.*, George J. Annas, *A National Bill of Patients' Rights*, 338 NEW ENG. J. MED. 695, 696 (1998) ("Attempts to transform the physician-patient relationship into a business transaction fundamentally threaten not just physicians as professionals but people as patients.").

16. Mark A. Hall, *The Legal and Historical Foundations of Patients as Medical Consumers*, 96 GEO. L.J. 583, 586 (2008); *see also* GEORGE J. ANNAS, THE RIGHTS OF PATIENTS 1–16 (2d ed. 1992) (explaining the patient rights movement).

17. Hall, *supra* note 16, at 586.

18. *Id. See generally* Marc A. Rodwin, *Consumer Voice and Representation in Managed Healthcare*, 34 J. HEALTH L. 223 (2001).

19. Mark A. Hall, *The History and Future of Health Care Law: An Essentialist View*, 41 WAKE FOREST L. REV. 347, 358 (2006). For an instructive application of this approach, see Andrew Fichter, *The Law of Doctoring: A Study of the Codification of Medical Professionalism*, 19 HEALTH MATRIX 317 (2009).

20. LON L. FULLER, THE MORALITY OF LAW 41–42 (rev. ed. 1969).

to medical ethics.[21] In the words of Professor Edmund Pellegrino, this approach bases clinical ethics on "the universal realities of the clinical encounter, i.e., healing, helping, caring, health,"[22] rather than on more generic, ad hoc, or socially contingent ethical principles. As I have previously observed:

> Under this essentialist approach, when ethics or law regards patients, it tends to regard them as patients, rather than as people who happen to be patients. And the same is true for people who are physicians and for services that are medical care. Sometimes, it matters fundamentally, even profoundly, that a legal [or ethical] matter involves physicians caring for patients, rather than providers servicing generic consumers. When this is so, general law [or professional ethics] becomes health care law [or medical ethics].[23]

Of course, any applied body of law should take some stock of its particular subject matter. Banking law is about financial institutions, and transportation law is about trains, planes, and automobiles. But, this need to contextualize is much more compelling in health care law than in many or most other economic and social arenas. This is why health care law should be "radical[ly] particular[ized]," to use sociologist Carol Heimer's phrase, meaning that it should draw deeply from the particular embedded attributes of medicine and treatment relationships.[24]

I am especially intrigued by the possibility that a broader patient-centered perspective might reconcile many of the tensions between a strong patient-rights orientation and a more enlightened version of professionalism. Likewise, participants in this Symposium and others have advanced patient-centered versions of law and ethics as antidotes to basing professional responsibilities and regulation on individual rights or undiluted market theory.[25]

III. THERAPEUTIC JURISPRUDENCE

"Therapeutic jurisprudence" may be one path that legal analysis

21. *See generally* Howard Brody & Franklin G. Miller, *The Internal Morality of Medicine: Explication and Application to Managed Care*, 23 J. MED. & PHIL. 384 (1998); *cf.* ERIC J. CASSELL, THE NATURE OF SUFFERING AND THE GOALS OF MEDICINE 62–75 (2d ed. 2004) (analyzing the doctor-patient relationship).

22. Edmund D. Pellegrino, *Praxis as a Keystone for the Philosophy and Professional Ethics of Medicine: The Need for an Arch-Support: Commentary on Toulmin and Wartofsky*, *in* PHILOSOPHY OF MEDICINE AND BIOETHICS 69, 76 (Ronald A. Carson & Chester R. Burns eds., 1997).

23. Hall, *supra* note 19, at 361.

24. Carol A. Heimer, *Responsibility in Health Care: Spanning the Boundary Between Law and Medicine*, 41 WAKE FOREST L. REV. 465, 504 (2006).

25. Such others include Gregg Bloche, Roger Dworkin, Marsha Garrison, Robert Gatter, Peter Jacobson, and Wendy Mariner. For a recent example of this brand of scholarship, see Fichter, *supra* note 19.

could follow toward greater patient-centeredness. First developed by Professor David Wexler and Bruce Winick in the field of mental-health law, therapeutic jurisprudence asks what legal principles are most beneficial to patient welfare and consistent with the actual experience of being sick.[26] This phenomenological legal perspective contrasts with other organizing principles that have a more formalistic orientation. Like therapeutic jurisprudence, a patient-centered perspective invites us to think instrumentally and empirically about the law, rather than in terms of intrinsic rights or a priori principles. But unlike other behavioral, economic, or social science perspectives, which consider multiple versions of social welfare or individual utility, therapeutic jurisprudence examines how law affects only the therapeutic goals of a treatment relationship.[27]

This approach is behaviorally, socially, and empirically complex and sophisticated, but it is also normatively presumptive—asserting that law has a consequentialist agenda and that health or healing is its proper telos.[28] Agnosticism about the ends of law may be appropriate in other areas, such as criminal or family law, which are driven by different sets of concerns. But therapeutic goals should be primary considerations in a body of law that arises from and governs a common enterprise whose central objective is individual health and well-being. Certainly, the same point might be made about any field of law defined by a common enterprise, such as banking law or education law, but the point has even greater force in light of the intrinsic and universal importance of health.

It is obvious that law has consequences for patients meriting study when, for instance, it affects the behavior of physicians or the availability of treatment. Beyond these fairly prosaic applications, the notion of patient-centeredness can advance the understanding of how law might affect the more subtle and subjective aspects of medical care that are revealed, for example, in the powerful placebo effect or the growing popularity of alternative medicine. Applied in a more thoroughgoing fashion, patient-centeredness analyzes law from a phenomenological perspective, focusing on patients' actual experiences in their relationships with physicians, hospitals and

26. *See generally* DAVID B. WEXLER, THERAPEUTIC JURISPRUDENCE (1990) (advocating a therapeutic jurisprudence approach to mental-health law); DAVID B. WEXLER & BRUCE J. WINICK, ESSAYS IN THERAPEUTIC JURISPRUDENCE (1991) (same); David B. Wexler, *Reflections on the Scope of Therapeutic Jurisprudence*, 1 PSYCHOL. PUB. POL'Y & L. 220 (1995) [hereinafter Wexler, *Reflections*]; Bruce J. Winick, *The Jurisprudence of Therapeutic Jurisprudence*, *in* LAW IN A THERAPEUTIC KEY 645 (David B. Wexler & Bruce J. Winick eds., 1996) [hereinafter Winick, *Jurisprudence*].

27. *See* Wexler, *Reflections*, *supra* note 26, at 226–29; Winick, *Jurisprudence*, *supra* note 26, at 647–52.

28. Winick, *Jurisprudence*, *supra* note 26, at 649–50; *see also* Hall, *supra* note 6, at 468.

other facilities, insurers and health plans, and various government agencies. Relationships among and within these components of the health care delivery system (doctor to hospital, hospital to insurer, government to profession, etc.) also can be viewed from patients' perspectives by considering how these internal or overarching relationships affect patients' experiences in the delivery of care.

The effects of law on health care delivery can be studied in both an immediate mechanistic fashion and in a more psychosocially complex way. The straightforward applications of patient-centeredness ask whether regulatory, market, or liability rules embody scientifically accurate or socially optimal medical practices, and examine various observable aspects of treatment—such as length or number of visits, adherence to physicians' recommendations, or the effectiveness of treatment measured through quantifiable and observable outcomes.[29] The more complex analyses "ask how law shapes behaviors and affects outcomes through less obvious or more subjective mechanisms. For instance, . . . how law influences the social and psychological dimensions of personal relationships and institutional structures in medicine."[30]

Both of these approaches are in line with the burgeoning academic interest in expressive theories of the law, the interaction of law and social norms, and the "New Chicago school" of sociobehavioral law and economics.[31] These various analytic perspectives recognize that law, both through direct regulation and through its invocation and promotion of social and professional norms, can (and does) enforce patients' expectations, punish violations of trust, and facilitate effective treatment relationships.

These patient-centered legal attitudes sometimes come into conflict because enforcing patients' expectations can also weaken the interpersonal foundations of treatment relationships. Therefore, striking the best compromise among competing legal stances toward patients is often an arduous endeavor that requires nuanced use of law's instrumentalities, based on detailed but inevitably incomplete empirical information. That task is complex and uncertain, and thus bound to generate ample disagreement and debate. Nevertheless, each of us who contributed to this Symposium, in his or her own distinctive voice, agrees that generic legal doctrine does not adequately take account of certain essential features of

29. *See, e.g.*, Kevin Fiscella et al., *Patient Trust: Is It Related to Patient-Centered Behavior of Primary Care Physicians?,* 42 MED. CARE 1049 (2004).

30. Hall, *supra* note 6, at 468.

31. On the expressive function of the law, see generally Matthew D. Adler, *Expressive Theories of Law: A Skeptical Overview*, 148 U. PA. L. REV. 1363 (2000). On norms and the law, see generally Richard H. McAdams, *The Origin, Development, and Regulation of Norms*, 96 MICH. L. REV. 338 (1997). On the "New Chicago school" of behavioral law and economics, see generally Lawrence Lessig, *The New Chicago School*, 27 J. LEGAL STUD. 661 (1998).

medicine. Patient-centeredness is one motif that I hope will give voice to this goal of striving for something more apt.