

# FIVE THREATS TO PATIENT-CENTERED CARE: WITH QUESTIONS FOR HEALTH LAW

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*Patients cannot see outside their pain; we cannot see in.  
Relationship is the bridge between.*

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*The “business” of the clinic is to foster and protect  
relationships.<sup>1</sup>*

—David Loxterkamp, MD

## THREAT 1: CONSUMERIST THINKING

Donald M. Berwick’s 2009 *Health Affairs* article on patient-centered care begins with the following scenario:

Three years ago, a close friend began having chest pains. She headed for a cardiac catheterization, and, frightened, she asked me to go with her. As I stood next to her gurney in the

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1. DAVID LOXTERKAMP, *WHAT MATTERS IN MEDICINE: LESSONS FROM A LIFE IN PRIMARY CARE* 116g, 157 (2013).

pre-procedure room, she said, “I would feel so much better if you were with me in the cath lab.” I agreed immediately to go with her.

The nurse didn’t agree. “Do you want to be there as a friend or as a doctor?” she asked.

“I guess both,” I replied. “I am both.”

“It’s not possible. We have a policy against that,” she said.

The young procedural cardiologist appeared shortly afterward. “I understand you want to have your friend in the procedure room,” she said. “Why?”

“Because I’d feel so much more comfortable, and, later on, he can explain things to me if I have questions,” said my friend.

“I’m sorry,” said the cardiologist, “I am just not comfortable with that. We don’t do that here. It doesn’t work.”

“Have you ever tried it?” I asked.

“No,” she said.

“Then how do you know it doesn’t work?” I asked.

“It’s just not possible,” she answered. “I am sorry if that upsets you.”

Moments later, my friend was wheeled away, shaking in fear and sobbing.<sup>2</sup>

Berwick ends this scenario with a question: “What’s wrong with that picture?”<sup>3</sup>—perhaps thinking the answer will be obvious. As a corrective, he offers a definition of “patient-centered care” that reads: “The experience (to the extent the informed, individual patient desires it) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.”<sup>4</sup> We contend that Berwick’s corrective definition misses the most important moral features of this scenario. A major claim in *What Patients Teach: The Everyday Ethics of Health Care* (“*What Patients Teach*”) is that the experience of illness and seeking care—becoming a patient—is emblematic of what it means to be a human being.<sup>5</sup> The idea that the experiences of being a patient are an aberration in a long, normative history of robust well-being, with only occasional brief eruptions of sickness, weakness, or need, is a good example of

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2. Donald M. Berwick, *What “Patient-Centered” Should Mean: Confessions of an Extremist*, 28 HEALTH AFF. w555, w555–56 (2009), available at <http://content.healthaffairs.org/content/28/4/w555.full.pdf+html>.

3. *Id.* at w556.

4. *Id.* at w560.

5. LARRY R. CHURCHILL, JOSEPH B. FANNING & DAVID SCHENCK, *WHAT PATIENTS TEACH: THE EVERYDAY ETHICS OF HEALTH CARE* 1 (2013).

what William James called being “moonstruck with optimism.”<sup>6</sup> Vigorous, independent wellness may be what we all hope for, but it is not the only state—not the customary state for many of us—and valorizing it makes it hard to recognize some of the key moral dimensions of our humanity.

It is Berwick’s implicit embrace of wellness—and the active consumer demeanor that accompanies wellness—that shapes his definition of patient-centered care.<sup>7</sup> The most striking feature of his definition is that it makes no concessions to physical and psychological vulnerability and the subsequent need for trust, which are so evident in the interviews in *What Patients Teach*. It is precisely this vulnerability—and a failure to establish trust—that is *most vividly* on display in Berwick’s scenario. One of our medical students described this well after witnessing a consent process that, regrettably, began only immediately prior to a surgical procedure: “It’s damn hard to ask questions when you’re naked and about to be put to sleep and cut open.”

*Question: In what ways does health law follow consumer paradigms, and to what extent does it deviate from these paradigms to account for the fundamental vulnerability and trust elements that are needed for clinical interactions?*

#### THREAT 2: MODELS FOR CHANGE THAT DISPLACE THE PATIENT FROM THE CENTER OF CARE

Einstein said that we live in an age of “[p]erfections of means and confusion of goals.”<sup>8</sup> “Relationship-centered care”<sup>9</sup> is a phrase that, despite its wide usage, insight, and good intentions, is one such example. This phrase fails precisely because it seeks to perfect the means (the relationship), but results in confusing the means and goals (the good of the patient). This relational means to a beneficent end, we have argued, has its own structure and dynamic, its own benefits, and often contributes to the end sought.<sup>10</sup> The clinician-patient relationship is not just a means—something of only

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6. WILLIAM JAMES, *The Religion of Healthy Mindedness*, in *THE VARIETIES OF RELIGIOUS EXPERIENCE: A STUDY IN HUMAN NATURE* 90, 109 (Random House 1994) (1902).

7. Berwick, *supra* note 2, at w557–60 (explaining that the relationship between patients and health care professionals should mirror the relationship between consumers and professionals in other consumer-oriented productions: the consumer, not the professional, judges quality and controls his choices in the marketplace).

8. ALBERT EINSTEIN, *OUT OF MY LATER YEARS* 113 (1950).

9. CAROL P. TRESOLINI & THE PEW-FETZER TASK FORCE, *HEALTH PROFESSIONS EDUCATION AND RELATIONSHIP-CENTERED CARE* 24–37 (1994), available at <http://www.rccswmi.org/uploads/PewFetzerRCCreport.pdf>.

10. See DAVID SCHENCK & LARRY R. CHURCHILL, *HEALERS: EXTRAORDINARY CLINICIANS AT WORK*, at xiii–xvi (2012).

instrumental value. It can, and often does, have intrinsic worth. But the therapeutic potential for the relationship begins when the focus is unambiguously on the patient and the patient's well-being. In the current climate, in which efficiency and outcomes are the overriding metrics, a focus on the relationship can translate easily into a fixation on "patient satisfaction" in its superficial form, which could elevate consumer happiness to a superordinate position in measures of quality. It is worth remembering that the relationship between doctors and patients differs from other kinds of relationships, in which the *relationship itself* is the end sought, even when it has ancillary benefits. Good examples of this relationship include: marriages; long-term, cohabiting partnerships; and lasting friendships—in which *being in* the positive relationship is, in fact, the chief end, despite the other good things that accrue from just having the relationship.

*Question: Can health law help prevent the displacement of the patient from the center of health care?*

### THREAT 3: NARCISSISM IN MEDICAL CODES

The preamble to the American Medical Association ("AMA") Code begins: "The medical profession has long subscribed to a body of ethical statements developed primarily for the benefit of the patient."<sup>11</sup> Appreciating the ethical dimensions of patient-centered care means moving beyond this sort of self-serving piety. This preamble is a bald, if residual, form of beneficent paternalism. In *What Patients Teach*, we argue that medical codes are narcissistic—not in a psychiatric sense, but simply following the Greek myth in the sense that these medical codes bespeak an unfulfilled love affair with a reflected best image of one's professional self.<sup>12</sup> Narcissus is drawn by Nemesis to a pool where he falls in love with his own reflection.<sup>13</sup> Taking this reflection for reality, Narcissus is thereby doomed to unwitting and unrequited self-love<sup>14</sup>—the absence of a concrete other on whom to bestow, and from whom to receive, affection. In medicine, that concrete other is, of course, the patient. Being patient centered in a professional code would mean working collaboratively with patients to decide what the ethical self-image should be, and specifically, what moral elements belong in the code. A developmentally mature medical oath would mean taking the patient's perspective on *his* needs and values seriously as a basic

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11. *Principles of Medical Ethics: Preamble*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/principles-medical-ethics.page> (last revised June 2001).

12. CHURCHILL, FANNING & SCHENCK, *supra* note 5, at 146–49.

13. MICHAEL GRANT & JOHN HAZEL, WHO'S WHO IN CLASSICAL MYTHOLOGY 357 (2002); *see also* CHURCHILL, FANNING & SCHENCK, *supra* note 5, at 147.

14. *See* sources cited *supra* note 13.

datum for establishing the norms that will guide physician behavior—not simply assuming we already know, or that the tradition of codes already contains what is needed. Narcissus assumed that what he saw in his reflection was reality. He pursued this fantasy relationship relentlessly, and in the end, he drowned in pursuit of it.<sup>15</sup> A medical ethics code that so passionately embraces its own self-image could suffer a similar death of patient trust and public confidence.

A new version of medical ethics is required, one that can replace the old paternalism with something ethically more robust than a consumer-protection model. Although we did make some suggestions about this in *What Patients Teach*,<sup>16</sup> what we offered there is just a beginning. Consistent and systematic patient input is the essential ingredient currently missing.

*Question: Can health law help provide an alternative to current medical codes and their professional narcissism?*

#### THREAT 4: EDUCATIONAL PRIORITIES THAT PRIVILEGE “KNOWING THAT” OVER “KNOWING HOW”<sup>17</sup>

If a core activity of doctoring is forming a therapeutic alliance with patients, and if this depends in a fundamental way on building trust through responsiveness to patient vulnerabilities, then it is imperative to provide occasions to consistently teach, practice, assess, and reinforce the skill set essential to this core activity. Our insistence on calling these responsive demeanors “skills,” as opposed to something vague such as the “art” of medicine, is to underline the idea that these moral skills can be learned. We devote a large section of the last chapter of *Healers: Extraordinary Clinicians at Work* (“Healers”) to an analysis of skills for just this reason.<sup>18</sup>

Medical schools do a poor job of teaching these skills or assessing them as an entrustable professional activity. This is because these skills are undervalued and because there is no widely-accepted taxonomy of the essential skill set. The agenda of *Healers* is to make some headway on the question of just what skill set is important, and the agenda of *What Patients Teach* is to show how very important these features of health care are to patients. Arthur

15. GRANT & HAZEL, *supra* note 13; LUKE ROMAN & MONICA ROMAN, ENCYCLOPEDIA OF GREEK AND ROMAN MYTHOLOGY 337 (2010).

16. See CHURCHILL, FANNING & SCHENCK, *supra* note 5, at 150–56 (advocating a new ethics code for health care).

17. See generally FRANCISCO J. VARELA, ETHICAL KNOW-HOW: ACTION, WISDOM, AND COGNITION (Bd. of Trs. of the Leland Stanford Junior Univ. trans., Stanford Univ. Press 1999) (1992) (discussing the role of unconsciously executed actions in the realm of ethics).

18. See SCHENCK & CHURCHILL, *supra* note 10, at 212–23 (discussing the importance of ethics skills to the practice of medicine).

Frank is surely right when he says that if we foregrounded the relational aspects of health care, medicine would be taught and practiced very differently.<sup>19</sup> A patient-centered educational process would ensure that doctors possess healing skills, not only for the benefit of patients, but also—importantly—for the well-being of doctors themselves.

*Question: Can health law protect and reinforce the “knowing how” of relational care in assessments of professional competence?*

#### THREAT 5: A TRUNCATED PARADIGM FOR BIOETHICS THEORY AND PRACTICE

If both medicine's traditional and modern ethical standards are flawed and fragmentary, where can an adequate replacement be found? Might bioethics provide a remedy? Only in part, we argue, since the story of bioethics, as it has influenced medical ethics, is one of both assets and liabilities. The asset is the recognition that medicine's traditional, paternalistic norms are no longer adequate. But in offering an alternative, bioethics is too often driven by models far removed from clinical practice. The result has been an importation of principles and norms from other spheres of life into the clinical arena. In other words, the liability of bioethics is the belief that the replacement medical ethic needs to be an applied version of a liberal social-contract ethic; or a religious covenantal ethic; or a libertarian, or utilitarian, or Kantian duty ethic; or a feminist care ethic; and so forth. Bioethics scholars often write about the relative merits of applying one or more of these theories, but with little attention as to how any of these approaches would enable and sustain physicians and patients who routinely work together.<sup>20</sup> This is an intellectualist error—a *problem of thinking that the basic task is getting the decisional model right rather than providing practical guidance* that is alert to the tone and spirit needed for therapeutic relationships to succeed. And it is worth adding that this intellectualist bias also favors general theories and formal processes over particular ones.

Whatever medical ethics is, it is not simply an instance of using norms that are serviceable in other realms of life and bringing their insights to medicine. In this sense, each profession has to stand on

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19. See Arthur W. Frank, *First-Person Microethics: Deriving Principles from Below*, 28 HASTINGS CENTER REP. 37, 41–42 (1998).

20. See David M. Smolin, *Does Bioethics Provide Answers?: Secular and Religious Bioethics and Our Procreative Future*, 35 CUMB. L. REV. 473, 478–80 (2005) (advocating the inclusion of religion in bioethics); Deleso Alford Washington, *Critical Race Feminist Bioethics: Telling Stories in Law School and Medical School in Pursuit of “Cultural Competency,”* 72 ALB. L. REV. 961, 965–66 (2009) (advocating a feminist approach to bioethics).

its own moral legs, and if one wants to understand a professional ethic for what it is, it is essential to talk to the people whose lives are shaped by the practical demands inherent in the activity. It is not that each sphere of professional moral activity is unique; it is rather that each sphere is likely to have distinctive features that make analogizing across these forms of moral life hazardous—to be undertaken with great care. A Wittgensteinian admonition may be useful here: “[D]on’t think, but look!”<sup>21</sup> William James provides similar advice: “A large acquaintance with particulars often makes us wiser than the possession of abstract formulas.”<sup>22</sup> More precisely, our claim is that thinking of the moral aspects of medical practice as conflicts to be resolved by principled thinking is of limited help and is often misleading. The customary triumvirate—respect for autonomy, beneficence, and justice<sup>23</sup>—does not describe the everyday moral activity in medicine, nor should these principles hold a preeminent position in bioethics generally. Rather, these important principles are best seen as presumptive boundary markers, not usually important to clinical encounters simply because in most situations they must be assumed to be present for anything else to happen. These principles have a largely tacit status, and if they need to be made explicit, then it is typically a sign that something untoward is happening or that the relationship is not working well.<sup>24</sup>

Principles, of course, are important expressions of ethical insight, but so, too, are virtues. Yet the best vehicles for both expressing and critically probing one’s moral sensibility are often neither principles nor virtues, but stories, parables, riddles, aphorisms, skeptical questions, little maxims remembered from one’s parents or friends, dribs and drabs of religious texts (often taken out of context), and many others. Charles Taylor has put it with characteristic clarity in saying that “the ethical is not a homogeneous domain.”<sup>25</sup> Donald Pfaff, in a far-reaching remark summing up the consensus among neuroscientists, put it this way: “[T]he brain does not have a signaling circuit dedicated to ethics.”<sup>26</sup> Both these remarks suggest that the human capacity for ethics is

21. LUDWIG WITTGENSTEIN, *PHILOSOPHICAL INVESTIGATIONS* 31e (G. E. M. Anscombe trans., 1953).

22. WILLIAM JAMES, *Preface, in THE VARIETIES OF RELIGIOUS EXPERIENCE: A STUDY IN HUMAN NATURE*, *supra* note 6, at xiii.

23. Jennifer L. Rosato, *Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?*, 73 *TEMP. L. REV.* 1, 3–4 (2000).

24. See CHURCHILL, FANNING & SCHENCK, *supra* note 5, at 136–46.

25. 2 CHARLES TAYLOR, *PHILOSOPHY AND THE HUMAN SCIENCES: PHILOSOPHICAL PAPERS* 244 (1985).

26. DONALD W. PFAFF, *THE NEUROSCIENCE OF FAIR PLAY: WHY WE (USUALLY) FOLLOW THE GOLDEN RULE* 19 (2007).

neither singular nor innate, but rather is distributed across several functions, capacities, and skills.

Our experience as ethics consultants and as teachers of ethics confirms this plurality. The effort to reduce moral experiences to formulation in principles is often a way of *misunderstanding* them because it is so often reductive and homogenizing. Conversely, it is also true that principles cannot be reduced to stories, aphorisms, or parables. Each of these tools and processes in ethics has its own useful sphere of application.

In brief, the right use of bioethics must include a certain skepticism—a suspicion of theories that claim more than provisional status, judgments that see themselves as universal, or norms that claim to be definitive. Every time we get this universalizing urge, we are distracted from attending carefully to what others are saying and from what we ourselves are thinking and feeling as others engage us.

But here is the hopeful part: knowledge of what moral features are needed for patient-centered care is an everyday matter, very close at hand, not esoteric or distant, not the province of experts, and not a theoretical product. All of us are patients. All of us are, or eventually will be, either professional or familial caregivers. Careful attention to the moral features of these roles, and the modes of being human they entail, will tell us what we need to know.

*Questions: Does our low-altitude, theory-modest, and pluralistic model of bioethics have a counterpart in health law? What can bioethics and health law teach each other about embracing this deeper understanding of human values?*