

PATIENT-CENTERED CARE AS A RESPONSE TO *MEDIFICATION*

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Two points strike me as foundational for making sense of patient-centered care (“PCC”). First, PCC stands for something everyone wants; like Santa Claus or democracy, PCC is a promise of good things. Second, what any particular person, group, or institution wants under the rubric of PCC varies enormously. There are certainly common themes among different versions of PCC—one would be increased patient input in treatment decisions; another would be physicians taking a more holistic attitude toward patients, as opposed to medicine reducing the patient to a site of pathology. But as I read the PCC literature and listen to various groups formulate their version of practicing PCC, variation impresses me more than commonalities. Thus, any attempt to *define* PCC risks obscuring what is most interesting about it, which is how PCC *works* as a signifier—a linguistic sign—onto which an extraordinary range of personal and institutional hopes and fears can be projected, or may be dumped. The question of PCC is what work this sign will do for whom: whose interests will be advanced by PCC, and which interests may end up being subordinated?

These questions rest, in turn, on a prior question, which is why it became necessary to have a phrase like PCC. How did the relations of medical treatment and care get to the point at which such a phrase attracts so much and such varied investment? If we play the anthropologist-from-Mars game for a moment—and as a social scientist, I think that game is always worth a moment—such a visitor might inquire what else medicine could be centered on, if not on patients. Isn’t PCC a redundant phrase? To this question, we Earthlings could only reply, somewhat nervously, “Yes, PCC probably should be redundant, but . . .” And then we would try to explain why calling for care to become centered on patients is anything but redundant. Most of that explanation is neglected in journal articles that want to move as quickly as possible toward advocating particular changes in institutionalized practice, or better yet, toward measuring changes that have apparently already been undertaken.¹

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1. See, e.g., Timothy Stoltzfus Jost, *Oversight of the Quality of Medical*

So why PCC now—*now* being when searching Google Scholar for PCC shows 339,000 documents, a tenfold increase over the last two years? A sociological explanation for PCC's sudden popularity goes back to the seminal work of Max Weber in the early twentieth century, and what he called *routinization*.² Weber was describing the inexorable tendency of legal-bureaucratic organizations to reduce work processes to routines—predictable sequences of action governed by institutional rules—so that workers have increasingly little discretion in how they do their work.³ Jumping forward to the end of the twentieth century, the philosopher Jürgen Habermas updated Weber's work to describe how institutional systems have become increasingly detached from the lifeworlds in which real people have communicative relationships with one another.⁴

As an example of this process of decoupling lifeworlds from systems, Habermas coined the term *juridification* to describe how law has become an increasingly self-enclosed system, responding to its own conventions and institutional practices and becoming increasingly separated from everyday, common-sense notions of justice.⁵ More simply, juridification marks the increasing distance between law and people's sense of the right thing to do. Habermas is well-aware that most people's idea of *right* is fuzzy and open to disagreement, which is why law develops formalized, institutional practices, undertaken by experts with specialized training.⁶ Habermas's argument is that if law departs too far from what people expect as *justice*, then it loses legitimacy.⁷ Routinization is a tendency not only of legal-bureaucratic systems, but also of expert and professional systems generally.

Just as we have juridification of the legal system, so we also have what I will call *medification*. Medification is not to be confused with *medicalization*, which refers to physicians becoming the privileged decision makers on issues that were previously decided on other grounds, including legal or moral grounds.⁸ Bringing psychiatric defenses into law is an example of medicalization.⁹

By *medification*, I mean the increasing extent to which practices

Care: Regulation, Management, or the Market?, 37 ARIZ. L. REV. 825, 835–38 (1995).

2. See MAX WEBER, THE THEORY OF SOCIAL AND ECONOMIC ORGANIZATION 363–73 (Talcott Parsons ed., A.M. Henderson & Talcott Parsons trans., 1947).

3. H.H. Gerth & C. Wright Mills, *Introduction: The Man and His Work*, in FROM MAX WEBER: ESSAYS IN SOCIOLOGY 3, 52–54 (H.H. Gerth & C. Wright Mills eds. & trans., 1946).

4. See JÜRGEN HABERMAS, 2 THE THEORY OF COMMUNICATIVE ACTION 316–17 (Thomas McCarthy trans., 1987).

5. *Id.* at 356–57.

6. *See id.* at 364–67.

7. *See generally id.* at 356–73.

8. *See* Peter Conrad, *Medicalization and Social Control*, 18 ANN. REV. SOC. 209, 209–11 (1992).

9. *Id.* at 226.

of treatment and care of illness, injury, and disability are responsive first to perpetuating expert and corporate systems. Medication privileges the advance of medical science and the reproduction of expertise on the one hand, and the needs of the medical-industrial-political complex on the other. Medical workers are increasingly accountable for meeting administrative demands for efficiency.¹⁰ Patients become units of *throughput*, a phrase used without irony by hospital planners in Calgary and elsewhere.¹¹ *Care* is redefined as protocols that maximize throughput; that is, treating the greatest number of patients as quickly as possible at the lowest cost. This institutional behavior is hardly malignant. On the contrary, in Canada it attempts to provide equitable health care at the lowest cost to taxpayers, within a publicly funded system—or in the United States, managed care initiatives seek to conserve Medicare funds or keep insurance premiums as low as possible. The problem is that administratively *efficient* care is planned at some distance from real patients and their individual needs. By medication, I mark the point at which patients and front-line medical workers experience the subordination of patients' needs to the needs of professional, corporate, and governmental organizations.

PCC is both a reaction against medication and an Orwellian marketing language in which treatment that is centered on efficiency can claim to be centered on patients. Clarity concerning how it could possibly sound like news to say that medicine should be centered on patients is the best safeguard against the risk that PCC will succumb to becoming part of the routinization of medicine, rather than a countermovement to medication. That risk is real and can be illustrated by two stories, each showing how PCC can be co-opted to serve interests other than those of patients. These stories suggest why I find myself so uneasy, after two decades of attempting to center medical attention on the experiences of patients,¹² when I hear institutional talk or read professional journal articles about PCC. Why isn't PCC just what I hoped my work would contribute to bringing about?

My first story is about clinical care. The narrator is my Dutch friend and colleague, Annemarie Mol, who is a medically trained researcher who writes elegantly conceptualized and finely detailed studies of science and technology. Mol begins her recent book, *The Logic of Care: Health and the Problem of Patient Choice*, with

10. For a general argument with numerous examples from the world of health care, see JANICE GROSS STEIN, *THE CULT OF EFFICIENCY* (2002). For a detailed ethnography of nursing work as oriented to efficiency, see JANET M. RANKIN & MARIE L. CAMPBELL, *MANAGING TO NURSE* (2006).

11. See D. Scott Jones & Maria S. Spencer, *Can Registered Nurse Staffing Affect Quality and Compliance?*, *J. HEALTH CARE COMPLIANCE*, May–June 2009, at 49, 50.

12. See, e.g., ARTHUR W. FRANK, *AT THE WILL OF THE BODY* (First Mariner Books 2002) (1991).

several stories, including the following one:

I am pregnant and 36. A national committee of experts in the Netherlands where I live has looked at the statistics and suggested that pregnant women over 35 should have an amniocentesis and thus the option of abortion should their foetus have Down's Syndrome. Given where I am (I have a healthy child and work that fascinates me and it is difficult enough to juggle between them) I follow the advice. I take a day off and go to the hospital where I also happen to be doing the field work for the book that I am working on at the time. It is slightly strange to shift from the role of observer to that of patient. But I lie down on the examination table and feel the ultrasound probe moving over my belly. Still in my field-work habits, or just to break the silence, I say to the nurse who is preparing the long needle that will be inserted into my womb: "I hope it all goes okay." We both know that a small percentage of women have a spontaneous abortion as a result of the procedure. The nurse snaps back: "Well, it is your own choice."¹³

This story is richly provocative for reflecting on multiple issues in medicine, but my present interest is in the nurse's construction of *choice* as a disclaimer and even a form of accusation. The nurse uses a vocabulary that is ostensibly patient centered: the language of *choice*. But she uses it against the patient, not for the patient.

A complementary story suggests the misuse of PCC at the institutional level. Here we see unanticipated consequences of holding hospitals accountable to specific measures of patient-centered practice. The inclination of governments is to reduce relational concepts like patient-centeredness to unidimensional measures, or metrics, and then to require institutions to meet specific benchmarks.¹⁴ The metrics are taken to be reliable—or at least accountable—indicators of what is valued, being patient centered. Here is one response to proposed legislation regarding metrics:

Mary Jo Haddad, chief executive officer of Toronto's Hospital for Sick Children, says she fears unintended consequences if performance metrics aren't carefully crafted by the province.

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

14. See Louise G. Trubek & Maya Das, *Achieving Equality: Healthcare Governance in Transition*, 7 DEPAUL J. HEALTH CARE L. 245, 277 (2004) (noting that government's role in health care involves "providing funding, creating standards for performance and monitoring and publicizing the results of benchmarking"). See generally Margaret Cyr-Provost, *Aetna v. Davila: From Patient-Centered Care to Plan-Centered Care, A Signpost or the End of the Road?*, 6 HOUS. J. HEALTH L. & POL'Y 171 (2005) (discussing the erosion of PCC).

She could virtually eliminate emergency waiting times if she had to, she says, simply by allocating many of her doctors from other departments. But all other services would suffer, and it would mean patients would wait longer for other care.¹⁵

The familiar problem here is that institutions are capable of meeting specific performance standards of patient-centeredness, but the greater the stakes on meeting those standards—for example, funding incentives or disincentives—the greater the probability of negative consequences as a result of institutions reallocating resources to optimize performance on the specific metric.¹⁶ Those negative consequences are unanticipated in terms of what their specific form will be, but the occurrence of some such consequences can be fully anticipated. To paraphrase one of Michel Foucault's famous aphoristic lines, metrics are not inherently bad, but they are dangerous.¹⁷

The danger results from believing that legislating a benchmark can be sufficient by itself, without far more extensive changes to assist in reaching that benchmark in ways that do not cannibalize other parts of the health care system. The point of both stories, one interpersonal and the other institutional, is that it is superficial at best—and detrimental at worst—to impose either a language or benchmarks of patient-centeredness without making fundamental changes to the culture (including the sense of mission), the work flows, and the resource allocations of health care systems.

Having made this argument, I need to reaffirm my belief in the ideals of PCC. Most significant for me, medical workers need to take seriously what they look like and sound like to their patients. It is with good reason that the top hits for “patient-centered care” on Google Scholar are works advocating that medical workers see their practice through the eyes of the patient.¹⁸

I also believe in the seriousness of the problems that I am calling medication, which is both caused by and results in the self-enclosure of professional, administrative, and corporate-financial systems. Some of the most disturbing arguments against recent health care reform in the United States showed the delegitimization of professional medicine that Habermas would predict when expert-administrative systems become decoupled from everyday

15. Janet McFarland, *Provinces Seek Cure to Swelling Pay Packages in Public Service*, GLOBE & MAIL (Can.), Apr. 10, 2010, at A1.

16. See Nathan A. Bostick et al., *Report of the Council on Ethical and Judicial Affairs: Physician Pay-for-Performance Programs*, 3 IND. HEALTH L. REV. 429, 431 (2006).

17. “My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad.” MICHEL FOUCAULT, *On the Genealogy of Ethics: Overview of Work in Progress*, in ETHICS 253, 256 (Paul Rabinow ed., Robert Hurley et al. trans., 1997).

18. See, e.g., THROUGH THE PATIENT'S EYES (Margaret Gerteis et al. eds., 2002).

lifeworlds.¹⁹

My point is that if patient-centeredness implies making changes to how medical practice is institutionalized, those changes need to be extensive, indeed, massive. Here is a final story that suggests the scope of what I think is required. In the “Narrative Matters” section of the journal *Health Affairs*, an Illinois family physician named Tony Miksanek writes about three “difficult” patients—he places the “difficult” in scare quotes, indicating awareness of all the potential biases of that term.²⁰ Doctor Miksanek makes a compelling case that his conditions of practice—especially the amount of time insurance companies are willing to reimburse for a single visit with a patient—produce situations in which, as he concludes, “[d]ifficult patients and their frustrated physicians fail each other.”²¹

One of those difficult patients is Mrs. Thomasina, whom Dr. Miksanek describes as “lonely” and suffering from “testophilia”—an unnatural affection for medical testing.²² She wears down Dr. Miksanek’s resistance to ordering any and every test she has heard of; her refrain is: “I think I’m worth it.”²³ In the couple of years since the article appeared, I have thought of that phrase whenever I read the escalating public rhetoric about the uncontrollable rise in the costs of health care. I ask myself, “What does Mrs. Thomasina really want from all these tests?” Just as she tells us, she wants tangible evidence that she is *worth it*. And in the systems she moves through, her best place for getting that evidence is in her doctor’s office, and the best evidence she can imagine getting from her doctor is an array of expensive tests.

The sociologist Charles Bosk, in his ethnography of a genetic counseling service, quotes a physician referring to her bioethics work as “mop-up” services.²⁴ In attempting to serve Mrs. Thomasina, medicine may be functioning as society’s mop-up service. The serious disconnection is that the more Mrs. Thomasina, and patients like her, press the medical system for evidence of caring, the more they generate medication, now taking the form of institutional strategies for meeting increased demand by routinizing

19. See Anna Deavere Smith, *Obama’s Audience Speaks First*, N.Y. TIMES, Sept. 9, 2009, at A29 (collecting and reporting various individuals’ feelings about the health care system). The voices Smith collects are in no sense a representative sample, but they are nonetheless provocative. The issue is complex, because these voices also reflect a recognition supported by social scientists—that health care is only one determinant of health, and by no means the most significant among determinants.

20. Tony Miksanek, *On Caring for ‘Difficult’ Patients*, 27 HEALTH AFF. 1422, 1422 (2008).

21. *Id.* at 1428.

22. *Id.* at 1424.

23. *Id.* at 1425.

24. CHARLES L. BOSK, ALL GOD’S MISTAKES 34 (1992).

treatment to the exclusion of personalized care.²⁵ Medication then leaves patients wondering what they are worth to this institution that is supposed to be caring for them. Patients like Mrs. Thomasina escalate their demands as a way of getting that evidence.

To conclude—or on the contrary, to open the conversation—my fear is that PCC can too easily become a signifier onto which too vast a variety of hopes and fears are displaced. PCC is most dangerous when used to support the idea that fixes can be local, individually focused, and legislated. If patient-centeredness is simply grafted onto existing medical systems, it will be a marketing slogan at best, and at worst will risk precipitating detrimental reallocations of resources.

For medicine to become truly patient centered, medical workers like the nurse *treating* Annemarie Mol—but emphatically not *caring* for her—need to be supported in changing who they believe they are and how they see themselves in relation to their patients. Even more difficult a change to bring about, patients like Mrs. Thomasina need to be shown that medicine does believe she is “worth it,” but without that worth having to be expressed in the currency of expensive and clinically counterproductive testing.

We should remember that we would not be speaking of PCC at all—instead patient-centeredness would be self-evident—if there were not deep professional and institutional reasons for being centered on concerns other than patients.

25. The other end of medicine’s mop-up work can be represented by the addicted, undernourished, pregnant patient who lacks housing. As physicians struggle to achieve, as close as possible, a full term, healthy birth, medicine is mopping up multiple nonmedical social problems. For an example of a description of such work, see David Price, Letter to the Editor, *Stopping Infant Mortality*, GLOBE & MAIL (Can.), May 24, 2010, at A10.