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PARADIGM, NOT PILL: THE NEW ROLE OF PATIENT-CENTERED CARE

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In the years since the Institute of Medicine (IOM) pronounced patient-centered care one of six core aims of a high-value system, its definition has broadened and become more prescriptive. The 2001 IOM report spoke loftily of “providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.”¹ In contrast, a February 2013 IOM workshop called for “strategies and policies for activities to be undertaken at multiple levels to advance patients, in partnership with providers, as leaders and drivers of care delivery improvement through the protected use of clinical data, informed, shared decisions and value improvement.”²

The difference in tone reflects a substantive shift in the role of patient-centeredness in health system reform. What began as an adjuration to physicians about values has progressed to a prescriptive guide incorporating activities and objectives that reverberate well beyond the individual clinical encounter. As the 2013 IOM meeting put it: “Prepared, engaged patients are a fundamental precursor to high-quality care, lower costs and better health.”

In this essay I explore the sometimes conflicting roles that have become part of the real-world definition of patient-centered care, describe evidence of the concept’s economic and clinical impact, and examine the opportunities and barriers involved in making patient-centeredness an integral part of U.S. health care.

EVOLVING AND OVERLAPPING ROLES

While the 2001 IOM definition is oft-quoted, “patient centered” is commonly used today to describe three distinct ideas that can be synergistic but can also clash: patient-centeredness as an ethical responsibility, an economic relationship and a clinical partnership. Though intertwined, each role comes with its own rules and expectations.

Ethical Responsibility. The term patient-centered care originated as an ethical critique, with activists from the civil rights and feminist movements rejecting the idea of patients as passive objects. The IOM built on that foundation by positioning patient autonomy and self-determination as basic human rights.³

Economic Relationship. The economic aspects of patient-centered care play out in marketplaces frequented by consumers. It is consumers, for example, who compare coverage and puzzle out co-payments when buying insurance. However, the role of consumerism in a clinical context is less clear. Though the terms patient and consumer are increasingly used interchangeably, they describe very different relationships that may be complementary or conflict.

The individual in a high-deductible health plan (HDHP) could be motivated to avoid an unneeded test or procedure both as a consumer seeking savings and a patient wanting to ward off unneeded interventions. But HDHP enrollees trying to economize could also eschew necessary care that would prevent greater expense later on (a consumer benefit)

or personal suffering (patient benefit). Or, in another scenario, the consumer “bargain” of a free screening test could lead to false positives that go against the patient’s interest.

Roles and expectations switch back and forth. The consumer may choose a high-value hospital, but it is the patient who waits anxiously for the procedure to begin. The woman who uses a smartphone app to select her doctor assumes the marketplace mantra of *caveat emptor* will not replace the clinical imperative of *primum non nocere* when she walks into the exam room as a patient – but should she? Policy discussions about patient-centeredness and consumerism must directly address these emerging dilemmas.

Clinical Partnership. The third concept embodied in patient-centered care is that of clinical partner. This concept has many labels, including person-centered care, patient activation, shared decision-making and participatory medicine. By whatever name, a partnership between patient and clinical team is the key to improving clinical and economic outcomes. That’s particularly true in an era when chronic disease accounts for three-quarters of costs. While a surgeon can perform a bypass, it may take a clinical partnership to control the hypertension that made the surgery necessary.

EVIDENCE OF IMPACT

Evidence about the impact of patient-centeredness depends upon carefully defining the intervention. Proclaiming patient-centeredness

“the blockbuster drug of the century” is catchy, but the reality is more complex.

Patient-centered communication can lead to improved knowledge, treatment adherence and self-care, all connected to improved outcomes.⁴ Similarly, activated patients appear to have better health behaviors, outcomes and satisfaction,⁵ and also fewer rehospitalizations⁶ and less spending.⁷ In addition, patients allowed to access their doctor’s notes reported a greater sense of control and being more likely to take prescribed medications.⁸

Shared decision-making, meanwhile, has been linked to fewer hospital admissions and surgeries for preference-sensitive conditions.⁹ However, one study of inpatients participating in care decisions found longer stays and higher costs,¹⁰ while a separate evidence review of shared decision-making cautioned that sweeping conclusions about reducing overtreatment and cost are unjustified.¹¹

Consumerism is also no cure-all. Health plan members with a chronic condition were more likely to report delaying or forgoing care because of cost when enrolled in an HDHP than when in traditional health insurance. Skipped services ranged from a sleep study to an MRI for melanoma.¹² Separately, California HDHP enrollees did no better in shopping for care than non-HDHP enrollees, possibly because they lacked needed information.¹³

GROWING POLICY SUPPORT

Efforts to make patient-centeredness more pervasive are proceeding rapidly. That’s due partly to high hopes for clinical and economic benefit, partly to patient activism and partly to the boom in online health information and apps. A greater emphasis on incentives and transparency can be seen in multi-stakeholder collaborations, such as the 2013 IOM effort, and from formal requirements in the public and private sectors.

Accountable care organizations in the Medicare Shared Savings Program, for instance, must demonstrate patient-centeredness in governance (e.g., a patient representative on their board); at the clinical level (e.g., evidence-based medicine with a patient-centric focus); and in the individual patient-clinician interaction (e.g., patients’ active participation in medical decisions). Progress in meeting goals is publically reported. Some private payers have similar requirements.

TURNING INTENT INTO IMPLEMENTATION

Despite the movement toward shared power and responsibility, the gap between intent and implementation remains large. Patient-centered care represents a new paradigm

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more than a new pill. Emerging care delivery models demand that individuals actively manage their health and health care and that providers and purchasers help them do so. Both sides are still adjusting.

The word, “doctor” derives from the Latin “to teach,” and the clinical encounter continues to resemble lecture more than dialogue. Even well-educated individuals “feel compelled to...defer to physicians” rather than risk being labeled a “difficult patient.”¹⁴ Physicians, for their part, fear unreasonable patient demands and unrestrained monologues. Patients and doctors alike are unsure how to discuss economic concerns or how to use health information technology for effective collaboration. One suggestion is distributing formal “rules of engagement” that explicitly set out respective responsibilities.¹⁵

Unsurprisingly, uncertainty reigns. When a health plan gives members electronic tools to manage their health and health care, is it fostering patient-centeredness or meddling in medicine? Is using behavioral economics to promote healthy behaviors or help consumers save money meritorious or manipulative? Whether ostensibly patient-centered activities bring bravos or brew a backlash remains to be seen.

Advances in online health information pose an additional challenge. Individuals can go outside traditional channels for tracking vital signs, sophisticated diagnostic and treatment algorithms, and communities of patients and doctors to help interpret the results. In theory, patient-generated data should interface seamlessly with information from health plans, providers and others. The next round of federal meaningful use regulations for electronic health records is expected to address patient-generated data, but a smooth-functioning electronic partnership remains years away.

True patient-centeredness must go beyond increased empathy, better customer service or hiring a few health coaches. Making patient-centeredness a central element of care demands a cultural shift among payers, providers and patients alike. It means developing new structures and processes, but also new roles, responsibilities and expectations. As with any paradigm shift, difficulties, disruption and discomfort will inevitably ensue.

We are, after all, upsetting deeply established practices that affect patient lives, medical tradition and one-sixth of the U.S. economy. Though there will be criticisms and course changes, the journey to a more patient-centered health care system nonetheless promises extraordinary clinical, economic and ethical gains.

ENDNOTES

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