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ANALYSIS & COMMENTARY

# Why The Nation Needs A Policy Push On Patient-Centered Health Care

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ABSTRACT The phrase "patient-centered care" is in vogue, but its meaning is poorly understood. This article describes patient-centered care, why it matters, and how policy makers can advance it in practice. Ultimately, patient-centered care is determined by the quality of interactions between patients and clinicians. The evidence shows that patient-centered care improves disease outcomes and quality of life, and that it is critical to addressing racial, ethnic, and socioeconomic disparities in health care and health outcomes. Policy makers need to look beyond such areas as health information technology to shape a coordinated and focused national policy in support of patient-centered care. This policy should help health professionals acquire and maintain skills related to patientcentered care, and it should encourage organizations to cultivate a culture of patient-centeredness.

lthough the phrase "patientcentered care" was coined several decades ago, it entered the health policy lexicon in 2001, when it was featured as one of the six aims for high-quality health care in the landmark report from the Institute of Medicine (IOM), Crossing the Quality Chasm.1 Recent advocacy for the patient-centered medical home has focused renewed attention on the phrase, 2,3 and organizations such as the Commonwealth Fund have proposed steps to achieve such care. But many in the health policy community do not have a good understanding of what "patient-centered care" means, or why it matters.

This article synthesizes the literature to offer a clear definition of patient-centered care, describing why it is important and how it can be fostered. We set forth the idea that patient-centered care has distinct, identifiable characteristics and has demonstrated cost and quality outcomes of great relevance to policy makers today. 4 Multiple studies show that patient-centered care improves patient satisfaction, quality of care, and health outcomes while reducing health care costs

and disparities in health care.5-14

We further demonstrate that patient-centeredness is not just giving patients what they want, when they want it, regardless of value or cost. Although the use of health information technology and similar infrastructure supports are important enablers of patient-centered care, the concept, at its core, encapsulates healing relationships grounded in strong communication and trust. These relationships can be cultivated and measured.15 We argue that policy makers seeking to advance patient-centered care should focus on these metrics.

We begin with the "what"-describing what patient-centered care is. We then turn to the "why"—summarizing the empirical evidence on outcomes associated with patient-centered care. Finally, we turn to the "how"-detailing steps that policy makers can pursue to advance patient-centered care via organizational supports, such as open-access policies, procedures to support coordination of care, information technology that facilitates effective communication and continuous quality improvement, and communication training for health care teams, Ronald M. Epstein (ronald epstein@urmc.rochester.edu) is a professor of family medicine, psychiatry, and oncology, and is director of the Rochester Center to Improve Communication in Health Care. University of Rochester Medical Center, in New York.

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1489

as well as through efforts to monitor and strengthen the quality of patient-clinician relationships and interactions.

# The What: Defining 'Patient-Centered Care'

Patient-centered care is often defined by what it is not—namely, disease-centered, technology-centered, physician-centered, or hospital-centered care. <sup>16</sup> Patient-centered care, likewise, is not simply capitulating to patients' requests, nor is it throwing information at people and leaving them to sort it out on their own.

The IOM's *Quality Chasm* report defined *patient-centered care* as care that is "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions." These attributes are more than just desirable. They are critical to providing the right care for the right person at the right time—a goal that has important cost and quality implications, as discussed in more detail below.

HEALING RELATIONSHIPS Patient-centered care ultimately derives from the healing relationships between clinicians and patients and, by extension, patients' family members. A patient-centered approach fosters interactions in which clinicians and patients engage in two-way sharing of information; explore patients' values and preferences; help patients and their families make clinical decisions; facilitate access to appropriate care; and enable patients to follow through with often difficult behavioral changes needed to maintain or improve health.

Patient-centered care also aims to improve clinical practice by building caring relationships that bridge demographic, social, and economic differences between clinicians and patients. 14,17-19 Thus, clinicians come to know and respect patients' values, beliefs, hopes, and ways of dealing with adversity, in addition to patients' clinical symptoms and concerns. In this context, clinicians can work to provide personalized care that is attuned to the needs of a particular patient. Clinicians should know the patient's family circumstances and cultural norms well enough to help him or her with decisions about care, adherence to treatment regimens, and self-management to promote healing and prevent illness.

These attributes of personalized care obviously go well beyond knowing the patient's genetic background and its implications for tailored drug therapy.<sup>20</sup> Truly patient-centered care requires knowing the patient as a person and engaging the patient as an active participant in his or her own care. This context also enables clinicians to be directive and to challenge the

patient's beliefs and values when necessary to optimize treatment.

NEED FOR TEAMWORK BY CLINICIANS Achieving these objectives often requires a well-coordinated community of health care professionals working together with these goals in mind.<sup>21</sup> Although the actions of each individual clinician are critically important, it is a tall order for a single clinician to independently meet these expectations for all patients. However, it should be noted that although patient-centered care sounds labor-intensive, it need not require more time. In fact, some studies suggest that when patients arrive for office visits prepared with questions, and when clinicians elicit patients' concerns early in a visit, they actually use less time and achieve equal patient satisfaction.<sup>22,23</sup>

CHALLENGES IN ACHIEVING PATIENT-CENTERED CARE An example can help bring to life the notion of patient-centered care. Consider John Harland (a pseudonym), a patient recently diagnosed with localized prostate cancer, who now faces complex decisions about surgery, radiation, and possible hormonal treatments. A straightforward transaction—a physician visit or interactive multimedia software—can provide him with timely information to help him make those decisions. However, giving the patient information about the disease, such as diagnosis and stage, and learning information about the patient, such as age, sex, and occupation, do not suffice to produce patient-centered care.

To engage in more meaningful interaction over the treatment options, Harland's care team needs to know him as a person; what is important to him in this phase of the life cycle; and how he will interact with the circumstances he encounters. For example, knowing that he tends to be fearful, stoic, or intolerant of side effects may alter the way his physician approaches discussions with him about treatment choices. Furthermore, each patient with the same disease will have different sets of concerns, contexts, and health beliefs, some of which have been shaped by discussions with family or coworkers or by information in the media.<sup>24</sup>

Ultimately, patient-centered interactions strive to achieve a state of shared information, shared deliberation, and shared mind. Again, consider Harland as he chooses among treatments for prostate cancer. Perhaps he has a history of depression that he fears might recur if he receives androgen deprivation therapy. Or he may be surprised that his values have changed—that the preservation of erectile function does not seem as important to him as the possibility of improved survival. He might not have considered these options in advance, and, feeling overwhelmed, he might appear to forfeit his

involvement in the decision by saying, "You're the doctor; you decide." Or, out of fear, he might insist on pursuing a treatment for which there is no clinical evidence of effectiveness.

- ▶ SHARED INFORMATION: Sharing information between clinician and patient means going well beyond providing just facts and figures. Using a patient-centered approach, the clinician frames and tailors information in response to an understanding of a patient's concerns, beliefs, and expectations. The clinician takes into consideration a patient's level of health literacy and ability to understand and apply information to his or her clinical situation. Clinicians who truly share information know that although patients generally indicate that they want to know everything about their health,25 they may quickly become overwhelmed by the sheer volume of information. As a consequence, patients may become more anxious and, ironically, make poorer decisions.26
- ► SHARED DELIBERATION: Shared deliberation refers to the personalized consideration of each patient's needs and preferences, which evolve over time. It may consider previously unimaginable health states, such as a colostomy or even the need to take a pill every day.<sup>27</sup> Shared deliberation helps clinicians and patients question their own assumptions, "gut" feelings, and understanding of the facts—or what they perceive to be the facts—as well as the opinions of family and friends.<sup>28</sup> Shared deliberation might also involve nudging patients toward greater involvement in these discussions even if they express a preference to be passive, because their willingness to engage may change over time.<sup>29</sup>
- ► SHARED MIND: The intent of shared deliberation is to achieve what could be termed "shared mind," or a consensus about an approach to care that goes far beyond simple informed consent to a specific treatment. For example, Harland may consult a radiation oncologist, a urologist, and a medical oncologist, all of whom offer a different view of the problem and suggest different treatments.<sup>24</sup> They may all suggest that he go home and think about his options. He may then encounter a colleague who had complications after surgery, or hear his wife say that she wants "everything done" for him.

Who will help Harland integrate the information and multiple recommendations, based on knowing him as a person? The care he is getting might not be patient-centered, even if the various doctors deliver their opinions with kindness. In fact, we think that it is not, because Harland's interactions with physicians have not yet resulted in his feeling more supported to provide input into decisions about his own care.

In many straightforward medical situations, clarity and consensus may be achieved effort-lessly. In other cases, specialists or emergency physicians have to gain patients' trust and achieve consensus in a single visit. But complex care situations often benefit from the involvement of other professionals and the patient's family, to achieve a sense of shared mind that is both medically sound and concordant with the patient's values. These discussions often occur over time, not in a single visit.

Perhaps Harland has a primary care physician with whom he can build shared mind<sup>30</sup> because the physician knows him, his values, and his social context through prior contacts.

# The Why: Patient-Centered Care Matters

THE RIGHT THING TO DO The case for patientcentered care can be made on both moral or ethical grounds. It is intrinsically a good thing, regardless of whether it achieves other instrumental or pragmatic goals such as improved quality, patient well-being, or just distribution of resources. From the perspective of medical ethics, patient-centered care fulfills health care professionals' obligation to place the interests of the patient above all else and to respect patients' personal autonomy. Autonomy is often enhanced by caring partnerships between physicians and patients that support patients' ability and willingness to consider all reasonable options and to participate in their own care. In the absence of healing relationships, patients may be left to sort things out on their own in a fragmented health care system. Patient-centered care also promotes the absence of abandonment,<sup>31</sup> or the ethical obligation to care for patients regardless of health status and response to treatment.

improved care The case for patient-centered care can also be made on instrumental grounds—it yields demonstrably better care, as measured by a number of important indicators. For instance, patient-centered care has been shown to improve disease-related outcomes and quality of life.<sup>32,33</sup> Research over the past twenty-five years has demonstrated that achieving shared understanding—and enabling patients to participate actively in all aspects of their care, such as choices about treatment and self-management—results in better adherence to medications and improved chronic disease control, without incurring higher costs.<sup>5,32,34,35</sup>

**IMPROVED WELL-BEING** Patient-centered care also improves patients' well-being. It can do so directly through reducing anxiety and depression, and also indirectly by building trust and

social support. These outcomes, in turn, increase patients' ability to cope with adversity, while also promoting access, understanding, and adherence. <sup>36,37</sup> They also promote patient self-efficacy, enabling patients to navigate the health care system more effectively. <sup>38</sup>

addressing disparities Patient-centered care is critical to addressing racial, ethnic, and socioeconomic disparities in care and outcomes. 39,40 Patients who are ill, have low health literacy and numeracy, are members of marginalized groups, and have cognitive deficits tend to ask fewer questions and get less information than their peers without these obstacles. They are also less likely to understand technical and nontechnical language. The practice of patient-centered care helps bridge differences among physicians and patients in health beliefs, race, ethnicity, and culture<sup>41</sup> and mitigates disparities in prevention and treatment. 39

BETTER VALUE Last but not least, patientcentered care leads to better value for the health care dollar. For instance, it has been associated with reduced diagnostic testing costs in primary care settings.9 Primary care physicians and surgeons who demonstrate more patient-centered communication are less likely than others to be sued. 42 Patient-centered care increases value because it produces the kind of healing relationships that patients want, need, and expect.<sup>43</sup> It also contributes to patient safety by ensuring that patients' behaviors, choices, and needs are accurately communicated to clinicians. For example, a patient might not disclose use of an herbal medication to his primary care physician unless the physician made an open-ended inquiry (such as, "What have you tried?") and had established a trusting, respectful relationship.

The How: Criteria For Achieving Patient-Centered Care

Patient-centered care depends on three factors: an informed and involved patient and family; receptive and responsive health professionals who can focus on disease and knowing the patient; and a well-coordinated and well-integrated health care environment that supports the efforts of patients, families, and their clinicians. Policy makers' support for patient-centered care must include all three legs of this stool.

Investments in infrastructure (increasing accessibility, use of nonphysician staff, quality metrics for index conditions, and systems for coordinating care) and information technology (IT) applications (patient registries, performance reporting, tools for organizing clinical data, test and referral tracking, electronic prescribing) are important in fostering environ-

ments that enable accessible, coordinated, and responsive care. Yet policy makers should recognize that the presence of infrastructure and IT alone are not sufficient to produce healing relationships and effective communication. They should be seen as catalysts to improve the quality of interpersonal relationships—the ultimate sign of patient-centered care.

In a recent paper we described how health policy can support improved relationships among health care professionals, patients, and families by promoting the capacity of clinicians to communicate with patients and patients' ability to be actively involved in their care.44 Health policy should also promote programs that encourage patients and families to be more effectively involved in care through information, coaching, navigation of the health care system, and advocacy. Clinicians' focus on patients' wellbeing is energized by clinicians' personal sense that their work has purpose and meaning, as well as by their "adaptive reserve," or ability to face unfamiliar situations with curiosity and resilience. 45 The opposite of curiosity and resilience is burnout, which both is caused by and causes alienation from the meaningful healing relationships that characterize patient-centered care.

**PATIENT-CENTERED INFORMATION TECHNOL- OGY** Health IT should not be viewed as an end in itself. Rather, it should be used to reinforce healing relationships, continuity, and shared mind. Patient-oriented information systems should give the clinician easy access to information about the patient's family and other contextual data; provide space to document the patient's treatment preferences; and not distract the clinician with burdensome documentation for administrative and billing purposes.

Health IT should help patients be more active in clinical encounters by helping them formulate questions. <sup>46</sup> It should also consider the needs of minority populations, as well as those with limited English proficiency and low literacy. These groups may not only have reduced access to the Internet, but they may also need help navigating Web sites and extracting relevant information.

patient-centered organizations So-called high-reliability organizations—such as aircraft carriers or operating rooms—offer insights into how to broaden our conceptualization of what is required to support patient-centered care. These organizations base safety, efficiency, and quality on relationships as well as on processes and products. Effective communication is fundamental to their design and operations.<sup>47</sup>

When functioning well, these organizations are able to adapt to the often unexpected and context-dependent requirements of each situation, rather than just relying on fixed protocols.

3

#### Factors

Patient-centered care depends on:
(1) an informed and involved patient;
(2) receptive and responsive health professionals; and
(3) supportive health care environment.

People in the organizations tend to seek information from multiple sources and have ways of incorporating that information into evolving designs of activity. The leaders of such organizations recognize that policy cannot always come from the top. They understand that there must be mechanisms to give leaders the perspectives of those who actually deliver a service.

These principles suggest that the implementation of patient-centered care should be based on both services and relationships and should strive for trust, a team orientation, consensus, and continuity. Adopting a patient-centered outlook requires resources, thoughtful planning, and informed flexibility. In addition, organizational change leading to patient-centeredness requires an ongoing commitment by leaders and members of health care organizations to support difficult, but necessary, structural and personal transformations.48

CONNECTIONS AMONG CLINICIANS Healing relationships grow in number and complexity when patients face serious or chronic illnesses. Whereas healthy patients often have only one chief point of connection with the health care system, seriously or chronically ill patients and their families have multiple connections with multiple clinicians. Accordingly, health care organizations should not only focus on individual clinician-patient relationships and well-defined medical teams, but they should also support more loosely affiliated "communities of care."21 These communities promote communication among clinicians who may have only intermittent contact and may not know each other personally, but who need to act collaboratively to ensure that patients' needs are met.

Consider again our patient Harland's fragmented health care experience. A "community of care" would provide ways of sharing personal knowledge of Harland as well as information about him. Members of the community would collaborate in recognizing and responding to his informational, relational, and emotional needs during a terrifying experience of illness. Even in our fragmented health care system, communities of care currently exist in a few clinical settings. Health policy makers should work to expand them so that patient-centered care is the norm, not the exception. Interventions that would facilitate communities of care might include providing means for quick, nondisruptive communication among health professionals of different disciplines and specialties; transdisciplinary training for health professionals drawing on a common model of communication skills; and promoting a sense of collective responsibility for patients' well-being, not just for the completion of a procedure or task.

## **Measuring Patient-Centered Care**

Despite its complexity, patient-centered care can be measured, and policy makers can thus monitor progress toward creating a more patient-centered health system. A recent National Cancer Institute monograph outlines six measurable aspects of patient-centered care: fostering healing relationships, exchanging information, responding to emotions, managing uncertainty, making decisions, and enabling self-management.<sup>37</sup> There are robust and validated measures for each of these aspects.

**MULTIPLE MEASURES** Just as no single measure can tell us whether the economy is healthy, no single tool can determine whether a person—or a system—is patient-centered or not. Multiple measures should thus be used in combination. Some measures of patient-centered care assess communication and relationships, whereas others assess technology and the health care environment. In addition, multiple sources need to be tapped to adequately reflect patient-centered care, including a combination of patient surveys, direct observation, and qualitative and quantitative methods.<sup>15</sup>

LIMITATIONS OF PATIENT RATINGS Ultimately, patient-centered care should be judged primarily by the quality of patients' experiences of care and the quality of their relationships with clinicians. Although patient surveys can be helpful in assessing these elements, they need to be paired with other data sources. Patients' ratings may provide false reassurance when patients have never experienced anything but suboptimal care. For example, patients may report that they engaged in shared decision making with clinicians when audio recordings of those sessions reveal no such discussions. 49 Patients with limited education may overestimate their knowledge and skills.<sup>50</sup> The wording of a question may matter for instance, patients may answer differently if asked whether a particular event occurred ("Did you sit down and go over the options?"), or about hypothetical situations ("Would you feel comfortable if ...?") or their level of satisfaction ("Were you satisfied...?"). $^{51,52}$ 

NEED FOR CONSENSUS Importantly, there is a need for greater consensus about a consistent set of measures of patient-centered care that will be used by local health organizations as well as to set national benchmarks.<sup>53</sup> There has been much progress-for example, through the Consumer Assessment of Healthcare Providers and Systems, a public-private initiative that has developed standardized surveys of patients' experiences with ambulatory and facility-level care.54 Yet there is still a need to inform health policy through even more definitive measures of ongoing relationships and communities of care.

#### Measurable Aspects

Patient-centered care has six aspects that can be measured:

- (1) fostering healing
- relationship; (2) exchanging information;
- (3) responding to emotions;
- (4) managing uncertainty;
- (5) making decisions; and
- (6) enabling selfmanagement.

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### Conclusion

As policy makers actively explore methods of achieving improved patient care in ways that attain greater value for the money, the practice of patient-centered care warrants close attention. Although at first blush the concept may sound very subjective, it can be defined and measured.

Policy makers should publicly commit themselves to a coherent and coordinated effort to advance patient-centered care, setting specific performance targets that will allow health system leaders to measure progress toward improvement goals. To this end, policy makers need to acknowledge that patient-centered care is not a mere by-product of infrastructure and technological supports. To truly realize the benefits of patient-centered care, the health care community needs to be focused on achieving important gains in the quality of relationships and interactions between patients and clinicians, as this paper has described.

Leadership on this issue can help inspire action among the multiple players needed to ad-

vance patient-centered care. For instance, educational programs must teach and assess interpersonal skills more frequently and rigorously, and grants should be made available to develop and assess such curricula.55 Consumer advocates need to help encourage patients to be more involved in their own care and support shared decision making. Health care organizations need to foster a culture of patient-centeredness through policies that promote effective communication and minimize disruptions of healing relationships. 56,57

Finally, there should be a coordinated and focused national policy to support patientcentered care. This policy should help health professionals acquire and maintain skills related to patient-centered care. It also should encourage organizations to move toward a culture of patient-centeredness. In turn, these organizations should support patients in self-management and shared decision making. Taken together, these efforts will help the health care system realize the promise of quality and value that the public deserves and wants.

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**HEALTH AFFAIRS**