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# Patient-Centered Care, Yes; Patients As Consumers, No

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**ABSTRACT** There are numerous calls for building health care delivery systems that are more patient centered. The focus on patient-centered care has increasingly begun to rely upon, and even merge with, the concept of patients as consumers. Early references to patients as consumers were made by patient advocates who were attempting to challenge professional and corporate dominance in health care. Today, “consumer-driven” health care has become associated with neoliberal efforts to emphasize market factors in health reform and deemphasize government regulation and financing. In our view, a narrow focus on consumerism is conceptually confused and potentially harmful. The consumer metaphor wrongly assumes that health care is a market in the usual understanding of that term, that the high cost of US health care is a function of excessive consumer demand, and that price transparency and competition can deliver on the promise of reducing costs or ensuring quality. Furthermore, a consumer metaphor places disproportionate burdens on patients to reduce health care costs, and it could erode professional obligations to provide appropriate and effective care.

**B**uilding a health care delivery system that is more patient centered has a lengthy history, including powerful grassroots efforts beginning in the 1960s. These initiatives see patient-centered care as an important means of improving health outcomes<sup>1</sup> and a morally worthy good in itself.<sup>2,3</sup> As a means to an end, patient-centered care includes efforts to make the care delivery system more efficient and easier for patients to navigate. Patient engagement—a particular form of patient-centered care—yields better, well-documented outcomes by stimulating patients to take on more active roles in promoting and maintaining their health. As a moral end in itself, patient-centered care emphasizes the importance of honoring patients’ values and preferences, and it is less paternalistic and more respectful. Although there are concerns about how the concept might be misapplied,<sup>3</sup> there is

broad support for it, evidenced by federal investment in studying how best to ensure patient-centered outcomes and patient-centered outcomes research.<sup>4</sup>

Increasingly, however, the focus on patient-centered care has begun to rely upon, and even merge with, the concept of patients as consumers. In this article we call for greater vigilance in distinguishing patient-centered care from the concept of consumer-driven health care. Too often *consumer-driven health care* is used as if it were a synonym for *patient-centered care*. We argue that consumer-driven care is based on critical myths about what creates, and what can rein in, high-cost care. Moreover, the consumer-driven concept can easily place the burden for systemwide cost containment on the shoulders of individual patients. In this article we offer a brief history of the patient-centered care movement, demonstrate how the language of patient-centeredness

is becoming appropriated by those advocating market reforms, and then articulate why the consumer metaphor is misguided and potentially harmful.

## Origins Of The Patient-Centered Care Movement

The term *patient-centered medicine* was introduced by Enid Balint in the late 1960s to contrast with “illness-oriented medicine.”<sup>5</sup> As with the “biopsychosocial” model developed in the 1970s, the intent was to emphasize a holistic approach to patient care that would include attention to more than just the physical markers of illness.<sup>6</sup>

Throughout the 1960s and 1970s a grassroots effort sought the right of patients to informed consent and to have greater say over their care.<sup>7</sup> These included efforts by the women’s health movement,<sup>8</sup> which fought against both sexism and the profit motive in medicine.<sup>9</sup> For example, in 1970 a group of women led by clinical social worker Nancy Miriam Hawley published a booklet titled “Women and Their Bodies,” in which they argued that women should have a greater say in their health care. This was followed in 1973 by the publication of *Our Bodies, Ourselves* by the Boston Women’s Health Book Collective and inspired efforts to challenge the routine use of procedures such as hysterectomies.<sup>10</sup>

In 1986 the patient-centered care movement advanced further when philanthropist Harvey Picker established the Picker Foundation.<sup>11</sup> After witnessing the care his wife received for an incurable infection, Picker decided that he wanted the medical system to treat patients as persons, rather than “imbeciles or inventory.”<sup>12</sup> The Picker Foundation transferred its assets to the Commonwealth Fund, which created the Picker/Commonwealth Patient-Centered Care Program. Among other accomplishments, the program identified sources of distrust between patients and health care providers and helped popularize the term *patient-centered care*. By the end of the program in 1995, it had created the not-for-profit Picker Institute.

In 2001 the Institute of Medicine (IOM) published two reports. The first, *Envisioning the National Health Care Quality Report*, defined *patient-centered care* as “health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients’ wants, needs, and preferences and that patients have the education and support they need to make decisions and participate in their own care.”<sup>13(p7)</sup> In the second, *Crossing the Quality Chasm*,<sup>14</sup> patient-centered care was identified as one of six core elements of high-quality care.

Although there remains considerable debate about the definition of *patient-centered care* and how to measure it,<sup>1</sup> patient engagement has been well researched. There is evidence that patient engagement is effective in achieving health outcomes. One dimension of patient engagement involves patient activation, a construct developed over the past two decades.<sup>15</sup> When patients are helped to take a more active role in maintaining their health, preventing disease, and managing chronic illness, health status improves.<sup>3,16,17</sup>

Another dimension of patient-centered care that can lead to better outcomes is care coordination. Patients often want and need the medical professionals caring for them to speak with each other. When medical professionals fail to communicate, it places additional burdens on patients and can result in poor outcomes, including dangerous overuse of medications, increased use of emergency departments, and inpatient hospitalizations.<sup>18,19</sup>

But what if the preferences of patients are not consistent with what medical professionals view as safe and efficient? What if the demands of patients conflict with what medical professionals believe is reasonable? The tension over how much control patients should have over their care has never been fully resolved. Donald Berwick, the former administrator of the Centers for Medicare and Medicaid Services, argued “for a radical transfer of power and a bolder meaning of ‘patient-centered care,’”<sup>2(p w555)</sup> in which “leaving choice ultimately up to the patient and family means that evidence-based medicine may sometimes take a back seat”<sup>22(p w561)</sup> because empowering patients should be viewed as a good in and of itself, not merely a means of achieving greater safety and efficiency in the health care system.

For all of these reasons, patient-centered care and patient engagement represent worthy goals for a health system intent on improvement. Increasingly, however, the language of patient-centered care is being adopted by advocates of market solutions to health care costs. For example, conservative critics of government health care regulation and financing are using the term *patient-centered care* nearly synonymously with *consumer-driven* or *consumer oriented care*.<sup>20</sup> Former House Speaker Paul Ryan (R-WI) argued that “improving the flexibility of health savings accounts and other consumer-oriented health care options will further enhance individual choice.”<sup>21</sup> This language was echoed by the conservative interest group Americans for Prosperity, founded by David and Charles Koch. Americans for Prosperity referred to Speaker Ryan’s “Better Way” health plan as “patient-centered.”<sup>22</sup> *Patient-centered care* is now a term often used to emphasize neoliberal commit-

ments to using market forces to effectuate health care reform.<sup>23</sup>

Early references to patients as “consumers” were made by patient advocates who were attempting to challenge professional and corporate dominance in health care. In a 1974 report titled *Advancing the Quality of Health Care*, the IOM called for “enlarging consumer influence” so that patients “can be informed of the relative effectiveness of various health providers and make their choices accordingly.”<sup>24(p6)</sup> This was a call for shifting control over decisions from physicians to patients. The first branch of Ralph Nader’s Public Citizen organization—called the Health Research Group—tried to provide consumers with a directory of doctors as well as their fees, hours, and other items, in an effort to provide patients with the information they needed to make informed decisions about their care, instead of relying on physicians to make these decisions on their behalf.<sup>25</sup>

In contrast to the early use of these terms to connote ways of empowering patients, *consumer driven* and *consumerism* are now associated with market-oriented health reforms that place a burden on patients to solve cost and quality problems.<sup>26</sup> These consumer terms function as metaphors that represent conceptual confusion and are potentially harmful. The terms wrongly assume that health care is a competitive market and that the high cost of US health care is a function of excessive consumer demand. Because these requisite assumptions are not met, the metaphor’s remedy—price transparency and competition—cannot deliver on the promise of reducing costs or ensuring quality. Moreover, it is misleading to use *consumer driven*, defined in this narrow sense, as a synonym for *patient centered*. A consumer metaphor could also erode obligations by policy makers and health care systems to build a truly patient-centered care system. We take up each of these problems below.

### Health Care Is Not A Market

Patients can be construed as consumers only if they are operating within a market. But health care is not a market in the usual way that markets are defined, and thus patients do not have the power that consumers have to shape that market.<sup>27</sup> Patients are not as well informed as physicians are about medical care. Often patients do not have well-formed preferences, and they seek care under circumstances in which they do not have the time or emotional stamina to shop around on the basis of quality and price.<sup>28</sup> And if policy makers treat health care like any other market, there will likely be very limited cost savings, if any, and huge inequities will continue

and likely increase. As Nancy Tomes puts it, “this linguistic transformation has come to represent the worst consequences of American medicine’s growing market orientation.”<sup>25(p83)</sup>

### The High Cost Of US Health Care Is Not Due To Excessive Consumer Demand

Policy makers in the US frequently act as if the main problem is excess volume,<sup>29</sup> which in turn arises from excess patient demand. Because most patients in the US have some form of health insurance, they are insulated from the full cost of health care. Some commentators are concerned that there is a potential moral hazard, because insurance provides patients with an incentive to consume health care beyond the point at which marginal benefit equals marginal cost.

More than just a technical term, *moral hazard* is a concept that is normatively loaded. It suggests that health care spending is the result of policies that offer an incentive for bad behavior. As Deborah Stone explains in her critique of this concept, “insurance, by lowering the price of medical care, induces people to get something good for themselves without having to pay its full cost.... When insured people make such decisions, they act selfishly, without regard to the effect of their behavior on others—especially on taxpayers in the case of social insurance. In the moral lingo of today, they fail to take personal responsibility.”<sup>30(p888)</sup>

The claim about moral hazard is partially supported by the findings of the Rand Health Insurance Experiment in the 1970s.<sup>31</sup> Researchers found that higher out-of-pocket obligations, or cost sharing, do lead to lower health care spending. However, critics argue that the experiment also found that cost sharing was equally likely to reduce appropriate health care use, not just wasteful procedures. Greater out-of-pocket spending will also place greater burdens on people with lower incomes.

Moral hazard concerns suggest that the use of expensive hospitalizations, surgeries, and other interventions are shaped primarily by ability to pay. This perspective fails to recognize that most people consume such services only reluctantly.<sup>32</sup> The use of these services is often driven by providers, not by patients. Indeed, academics and policy makers have expressed concern for decades about the reliance of the health insurance system on fee-for-service payments to physicians, hospitals, and other health care providers. Fee-for-service provides an incentive for physicians to deliver additional and more complex services than patients need (or more care than economists would view as efficient) because

# Pursuing the sensible goal of creating a patient-centered health system will be undermined if consumer metaphors prevail.

health care providers receive an additional payment for every additional service—and services that are viewed as more technically complex generate higher fees.<sup>32</sup> In most countries outside the US, however, “provider-driven” demand is not countered by shifting costs to individual patients and asking them to control costs by acting as informed consumers in a marketplace. Instead, most countries rely on a combination of overall budget targets for health care services and systems of all-payer rate regulation in which national health insurance funds negotiate rates for hospital, physician, and other services with representatives from those professions.<sup>33</sup> Because the US does not use the negotiating power of government to confront the power of providers, it pays higher prices for all medical goods and services than other countries do.<sup>34</sup>

Recent studies reinforce the idea that most payers in the US do not have the bargaining power necessary to drive down prices, especially in regions where providers have a strong market position. In areas of the country where hospitals have greater market power, hospital prices are substantially higher.<sup>35</sup> Even after controlling for other factors, Zack Cooper and colleagues found that “hospital prices in monopoly markets are 15.3 percent higher than those in markets with four or more hospitals.”<sup>35</sup> In contrast, the State of Montana was able to drive down prices for its state workers’ health plan because it used its bargaining power with hospitals to set “reference prices,” instead of allowing hospitals to demand prices for their services and negotiating discounts from that starting point.<sup>36</sup> The experience in Montana also bolsters our contention that transparency cannot substitute for price negotiations by institutional payers.

Not only is the use of market competition limited when it comes to asking patients to make efficient decisions about health care services and

providers, but it also does not work well when it comes to making decisions about health insurance plans. Competition among health plans in the Medicare program was promoted as a method for reducing the costs of the program, but Medicare Advantage has not produced the intended savings. In fact, there has been some examination of choices made in Medicare Part D, suggesting that consumers do not necessarily make choices in their own best interests: Beneficiaries fail to select plans that provide better risk protection at lower cost.<sup>37</sup> These findings are consistent with earlier work on choice overload and Medicare beneficiaries’ selection of health plans.<sup>38</sup> The findings led economist Paul Krugman to exclaim that “‘consumer-based’ medicine has been a bust everywhere it has been tried.”<sup>39</sup>

While it is wise to help patients make more informed decisions about the costs of care and to grow in their ability to make quality comparisons across health systems, the main driver of health care costs is not consumer demand, but rather the introduction of new technologies and unwillingness on the part of US political leaders to regulate prices—or at least use government bargaining power as leverage to negotiate lower prices. The US relies on a system of uncoordinated payment by thousands of payers, many of which do not have the bargaining power necessary to drive down prices.<sup>40</sup> This has resulted in high prices for medical services.<sup>41</sup> Technological improvements in health care have driven increases in cost all over the world,<sup>42</sup> but extraordinarily high prices and a refusal by government to regulate them or bargain them lower differentiate the US from other countries.

## Price Transparency Is A Good Goal, But Not A Remedy For Spending Or Quality Problems

Making costs and efficacy transparent to patients as part of the treatment decision-making process makes the US health care system more patient centered. It is helpful for patients to understand the cost implications of treatment alternatives and to discuss these with their providers as part of shared decision making.

Patients do factor in out-of-pocket expenses when thinking about the costs and benefits of treatment alternatives, and many physicians agree that this is a reasonable consideration.<sup>43</sup> Such information should be presented to patients in a way that “combats common biases and misperceptions—for example, explicitly addressing people’s tendency to overweight the probability of low-likelihood, high-cost events.”<sup>44</sup>(p895)



There is little evidence that offering price transparency can reduce spending. Such proposals adopt the assumption that with transparency, patients are consumers who will “shop around” for high-value providers whose use will translate into substantial reductions in health care spending.<sup>45</sup> Price transparency is not a “magic bullet,” and evidence suggests that “consumers do remarkably little comparison shopping in health care,”<sup>46(p786)</sup> while efforts to increase price transparency provide mixed evidence—with most suggesting little or no decrease in costs.<sup>46,47</sup> Price transparency could even act to increase prices when providers sign contracts in which they agree not to charge lower prices to other purchasers.<sup>46</sup>

### The Consumer Metaphor Could Erode Health Care Professionalism

In truly professional settings, physicians are free to refuse to provide treatment that they believe would be ineffective or harmful, even if patients demand such treatment.<sup>48</sup> Medical professionalism requires independent, discretionary judgment. Professionals do not simply do as they are told or requested but must act on the basis of knowledge, skill, and fiduciary obligations to patients’ well-being.

Professional organizations resist the attitude that “the customer is always right.” Such disputes can arise, for example, when terminally ill patients or their families insist on cardiopulmonary resuscitation or other treatments that their physicians believe would be harmful or ineffective.<sup>49</sup> Hospitals must judge each case to find the right balance between patient and family preference and physician integrity. It seems reasonable to anticipate that as the consumer metaphor grows, physicians’ authority in these kinds of cases could erode to the point where

they may become technicians doing what they are asked to do, but doing so against their own consciences.

Professionalism may also erode if physicians are more inclined to offer unproven treatments simply because patients demand them. If the customer is always right, self-restraint on the part of providers could erode. Responding to consumers’ requests for unproven treatments might not even seem like exploitation.

### Conclusion

After four decades of organized patient advocacy, US patients are still struggling to influence the health care decisions and policies that shape their lives. Conflating consumer approaches with authentically patient-centered approaches will exacerbate this gap. In health care delivery and health policy, a patient-centered approach affirms the ethical principles of respect for persons and justice while striving to make the health system more responsive to patients’ values and preferences. There are some patient-centered approaches, such as patient engagement and activation, that yield substantial improvements in health outcomes. Pursuing the sensible goal of creating a patient-centered health system will be undermined if consumer metaphors prevail. It is important for policy makers and health system leaders to be vigilant in distinguishing between these seemingly similar, but different, approaches. Patient-centered approaches aim to ensure clinical care that can meet patients’ preferences and needs. That is different from a consumer orientation calling on patients to be prudent purchasers of medical care services. The former approach empowers patients. The latter expects patients to solve society’s cost-containment challenges. ■

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