

## Engaging Health Care Consumers to Improve the Quality of Care

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**BACKGROUND.** Researchers and policy makers have focused on informed choice as the primary role for consumers in improving care. Consumers may play two other roles in improving quality—by being active participants in their care (coproducer role) and by evaluating the care they receive (evaluator role). Enhancing the roles consumers are able to play in the health care system may significantly increase their influence on quality.

**OBJECTIVES.** To examine the evidence available on the contribution of consumers to quality through the coproducer and evaluator roles.

**RESEARCH DESIGN.** Conceptual framework and review of the literature.

**FINDINGS.** Patients who engage in collaborative care, shared decision-making with their providers, and chronic disease self-management have improved health outcomes.

The Strategic Framework Board's charge was to develop guiding principles for a national approach to health care quality measurement and reporting. The goal of such a system would be to improve the quality of care for all. Consumers have a critical role to play in any effort to improve quality of care. This paper examines the potential roles that consumers could play in improving care and examines the evidence for how these roles might contribute to improved care.

There is a growing recognition of the potentially potent force that consumers can represent in bringing about change within the health care sector. Policies aimed at consumers seek to encourage them to use the weight of informed

Training patients with chronic diseases to self-manage their disease increases functioning, reduces pain, and decreases costs. Developing the evaluator role will support and increase the effectiveness of the other two roles—the informed choice role and the coproducer role.

**CONCLUSIONS.** Only the informed choice role is being actively promoted for consumers. Increasing the coproducer role would require system and provider change, as well as an increase in consumers' skills and knowledge and a change in their understanding of their appropriate role. Harnessing the power of consumers to create change will depend on the degree to which all these roles are encouraged and supported.

**Key words:** Coproducer role; evaluator role; informed choice; quality measurement; shared decision-making. (Med Care 2003;41:I-61-I-70)

selection to influence the health care market. Such policies assume that, if consumers use comparative performance information for choice, providers will be motivated to improve the quality of medical care. Current efforts are aimed at producing the necessary comparative information and encouraging consumers to use it for choice.

However, there are at least two other roles that consumers can play which may improve the quality of their care and of care delivered within the system as a whole: coproducer and evaluator. The coproducer role refers to patients helping to "produce" health by acting as effective partners with providers in the care process. The evaluator role refers to consumers providing data on provider

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and system performance and participating in defining the parameters of quality.

The three roles have the potential to directly or indirectly improve care and produce better care and better health outcomes (Fig. 1). All three roles are built on the overarching idea that, to get the best-quality care, consumers must have a significant role in managing, selecting, and evaluating their care. This article examines these three roles and explores how explicit attention to each can contribute to better care.

### The Informed Choice Role

When consumers use quality of care as a key criterion for making provider, plan, and hospital selections, they are engaging in the informed choice role. Those who engage in informed choice are assumed to obtain higher quality care. It is further assumed that, if a sufficient number of consumers exercise informed choice, providers (ie, physicians, hospitals, health plans) will be motivated to improve. This is particularly true if consumer choice means that higher-performing providers are rewarded with greater market share or increased revenues and lower-performing providers penalized with less market share or decreased revenues. There is currently no evidence to support these assumptions about consumer behavior. To date, there is only limited use of comparative information by consumers.<sup>1-5</sup> Perhaps because little evidence exists that consumers are using quality in making choices, the link between consumer choice and quality improvement has also not been observed. This does not mean that these are nonviable assumptions. It may simply mean that we need to find more effective ways of supporting informed choice among consumers.

The use of comparative quality reports is new and, like any new innovation, it may take time for the idea to be adopted. Getting a new idea or behavior adopted in a population, even when it has obvious advantages, is often very difficult and may take many years. A common dilemma is how to speed the rate of adoption. Based on theory and empirical evidence, six factors that affect the rate of adoption have been identified: (1) awareness of the existence of the innovation; (2) whether the innovation is viewed as an improvement over what was done in the past; (3) the complexity of the innovation; (4) the compatibility of the innovation with users' other views, needs, and values;

(5) whether the innovation can be tested on a trial basis; and (6) whether potential adopters can observe others using the innovation.<sup>6</sup> The first four factors are most relevant to the use of comparative performance information and are used here to promote understanding of the barriers to adoption and possible strategies for hastening adoption.

### Awareness

Awareness of performance measurement and exposure to comparative reports is relatively low among consumers. Only 30% of consumers report having seen quality comparisons within the last year.<sup>7</sup> Even among employees who were sent quality reports, only approximately 30% to 50% remember seeing them.<sup>8,9</sup> There is evidence that repeated exposure to quality reports increases awareness and perceived value of the reports,<sup>3</sup> supporting the notion that time and exposure will increase adoption. In any case, efforts are needed to increase awareness among consumers about the availability of and the need to use performance information in choice.

### Perceived Advantage

Among consumers who are aware of comparative reports and have a choice of plans, quality reports typically are viewed as at least moderately useful.<sup>8-10</sup> The public does not understand quality in the same way that it is presented in comparative reports. In a recent survey, consumers named doctor qualifications, doctor-patient relationships, ability to choose, access, cost, and coverage as what they mean by "quality."<sup>7</sup> Consumers lack an understanding of the degree to which technical quality varies and the need to protect oneself from poor care. They do not understand that they could be at risk, or how much better their own care could be. There is little understanding of how consequential making even one provider choice can be.<sup>10</sup>

In theory, comparative performance information is actionable; in reality, it often is not. Plans often share overlapping provider panels in a market and the data often show almost no differences among choices. In addition, approximately 35% of consumers who get their coverage through their employer have no choice at all.<sup>7</sup>

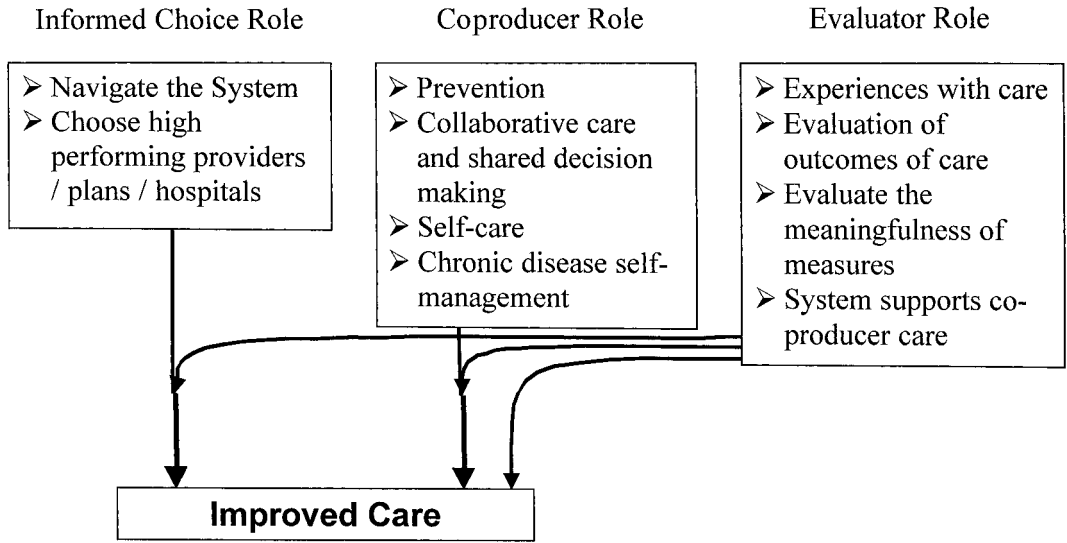


FIG. 1. Three consumer roles that may contribute to the improvement of care.

**Complexity**

The amount of information in most report cards is beyond what humans can effectively process and use.<sup>11</sup> Comparing multiple plans on multiple performance dimensions is a difficult information-processing task. Many report cards list as many as 20 performance indicators and may compare as many as 17 plans. Moreover, consumers have other types of information to factor into their choices: plan type, benefits and coverage levels, provider panel considerations, geographic locations, and costs. Trying to integrate several different types of variables into a decision increases the complexity and the difficulty. Bringing all the disparate parts together and not leaving out important variables is a further challenge. An added level of complexity is present when the decision-makers must make trade-offs.<sup>12,13</sup>

When faced with too much information or decisions that involve burdensome cognitive processes like trade-offs, people tend to take shortcuts that may undermine their own interest. There is evidence that consumers do engage in these “short-cut” strategies to reduce complexity and burden.<sup>14</sup>

There are ways to make the health quality data and information easier to use. One way would be to use computer decision aids designed to reduce cognitive burden. These programs break down decisions into smaller steps and can perform the

difficult cognitive tasks for the user. For example, a computer-assisted decision aid can narrow choices based on the user’s preferences and thereby reduce the amount of information to process. These aids can also make trade-offs, compute user-defined differential weights, and bring all the factors together into a choice.

Another approach presents data so it is easier for consumers to discern which are better and worse options. Such “evaluable” data presentation approaches allow the viewer to quickly and easily see which are high performers and which are low performers. They summarize data for the viewer so that the best options “pop out” at them. Examples of evaluable approaches include ordering by performance or using visual cues or labels that identify high performers.

In recent controlled experiments, it was found that consumers were more likely to use quality data in their choices when the data were presented with evaluable presentation approaches.<sup>14</sup> Therefore, although complexity is high, there are effective strategies available to overcome the complexity.

**Compatibility**

Communication research indicates that people will pay attention to a message that is more consonant with their views than a message that is

not.<sup>15-19</sup> What messages are compatible with how consumers think about health plan choice? Recent surveys report that more than half of consumers are worried that their health plans are more concerned about saving money than providing the best treatment.<sup>7</sup> Similarly, only 44% of consumers in managed care programs were confident that, if they had a serious health problem requiring costly treatment, their plan would pay most of the cost.<sup>20</sup> Therefore, there is evidence that consumers look at their health care choices in a potential loss or risk framework. Yet almost all quality reports to consumers use a message about gain or maximizing quality.

Building on the idea of crafting messages consistent with consumer concerns, Hibbard and colleagues<sup>21</sup> conducted an experiment in which Consumer Assessment of Health Plans Study (CAHPS) data were framed in the usual way with a gain message ("get the best quality"), as opposed to a risk frame ("protect yourself from problems in health plans"). Framing the health plan decision as a possible loss or risk significantly increases how well the comparative information is understood, how much it is valued, and how much weight it receives in decisions.<sup>21</sup>

A message that tells consumers how to protect against problems in health plans is apparently a more salient message than one that focuses on getting better-quality care. At present, there is no "felt need" to maximize quality, but there is a felt need to avoid problems.

There are significant barriers to the use of comparative reports in choice. Lack of awareness of comparative quality reports, poor understanding of the information in the reports, messages that are not compatible with consumer concerns, and the complexity of the task are factors that are working against adoption. Therefore, the current slow rate of diffusion is not too surprising. However, it is equally clear that there is much that can be done to hasten the adoption process.

### Coproducers of Care

Consumers can be, and often are, "coproducers" in the care process. Consumers, who are also referred to herein as patients when acting within the care system, are the ones who make day-to-day decisions about their health and health care. Patients can play an active and indispensable part in diagnosis and treatment. If their part in the

process results in a health gain, it can be said that they helped to produce it. As a coproducer, patients may make decisions about when to seek care, work with providers on managing conditions, engage in self-care, make informed choices among treatment options based in part on their own values and needs, provide vital information about their health and functioning to aid in diagnosis and treatment, make recommended lifestyle changes, follow through on agreed-on treatment regimens, and take preventive actions. Patients as coproducers are an undervalued and underused resource.

New information sources and technologies can better inform consumer actions. In addition, these new information sources may reduce the "knowledge gap" that traditionally has defined the doctor-patient relationship by upgrading the skills and knowledge of the patient and supporting the patient's role as partner in the care process.

There are several concepts defined and assessed in the literature that are relevant to the coproducer role: shared decision-making, collaborative care, and self-management. There is overlap in their conceptualization, but each has distinct elements and emphases.

### Shared Decision-Making

Shared decision-making is a process by which doctor and patient consider available information about the medical problem in question, including treatment options and consequences, and then consider how these fit with the patient's preferences for health states and health outcomes. Shared decision-making is built on the assumption that, for treatment decisions to result in the most desirable outcomes for patients, the active participation and engagement of both patient and physician is required.<sup>22,23</sup>

### Collaborative Care for Chronic Disease

Collaborative care for chronic disease incorporates shared decision-making but goes beyond to include patients in a broader set of activities. Collaborative care acknowledges the centrality of patients as primary caregivers by integrating them as key actors in the care processes. Collaborative management occurs when patients and care providers have shared goals, a sustained working

relationship, mutual understanding of roles and responsibilities, and requisite skills for carrying out their roles.<sup>24,25</sup>

Providers typically define problems in terms of diagnosis, poor compliance with treatment, or failure to change lifestyle. Patients are more likely to define problems in terms of pain, symptoms, problems in functioning, or difficulties in making lifestyle changes. Collaborative care is based on the assumption that patients are more likely to benefit when these two perspectives are blended. Similarly, when patients and providers jointly focus on a specific problem and together set realistic objectives and develop an action plan, the likelihood of making progress toward those goals is enhanced. Assuring that patients have the skills for following through on their part of medical regimens is also part of the collaborative care model, as is follow-up to ensure that progress is being made toward the defined goals.<sup>24</sup>

### Self-Management

Self-management is also concerned with the patient role in management of chronic disease. Assuring that patients have the problem-solving skills, the decision support, and the confidence to take the on day-to-day management of their own care is the focus of self-management interventions.<sup>26</sup> Lorig<sup>26</sup> points out that the three distinguishing features of the self-management model are (1) dealing with the consequences of disease, not the physiologic disease; (2) being concerned with problem solving, decision-making, and patient confidence, rather than prescription and adherence; and (3) placing patients and providers in partnership.<sup>26</sup>

Collaborative care and self-management are conceptually similar; however, the emphasis of the former is on how the delivery system can incorporate patients better into the care process and the latter focuses more on the skills needed for the day-to-day functioning of the individual and less on the delivery system.

The evidence suggests that, when patients engage in collaborative care, shared decision-making, and self-management, they have improved health outcomes.<sup>24,27,28</sup> For example, training patients with chronic diseases to self-manage their disease is effective in increasing functioning, reducing pain, and reducing health care costs.<sup>29</sup> When patients have a greater sense of

self-efficacy and confidence in their knowledge and ability to perform self-care management tasks, they are more likely to engage in these behaviors. Several studies have demonstrated the relationship between self-reported self-care efficacy and health outcomes.<sup>30–35</sup>

Recent work by Lorig et al<sup>27</sup> showed that patients with an array of chronic conditions who were enrolled in a comprehensive self-care management program experienced significant improvements in adherence to medical regimens (eg, medications), health behavior change recommendations (eg, exercise), psychosocial and emotional distress caused by illness, self-reported health status, reduced occurrence of hospitalization, and reduced costs of care. Lorig's work is also noteworthy because it was carried out by volunteers in a community setting, not under the aegis of the delivery system.<sup>27</sup>

Just by exerting more control in the doctor-patient interaction, patients have been shown to have better health outcomes.<sup>35</sup> Coaching patients to be more involved and to have more control in the medical encounter has been shown to produce better health and functioning in patients.<sup>36,37</sup> Although there are apparent advantages to the coproducer role, it must also be recognized that there are also serious barriers. First, many patients do not want to engage in self-management, collaborative care, or shared decision-making. For example, the process of weighing risks and benefits of a medical intervention is new to many patients. Patients may be intimidated by the complexity of medical choices or may have anxiety about making the right choice. These anxieties may lead the patient to want to surrender decision-making to the physician.<sup>38</sup> Research shows that, whereas patients typically express high preferences for information about their illness and its treatment,<sup>39–43</sup> preferences for participation in treatment decisions are mixed.<sup>44,45</sup> Many patients have been socialized to think that the physician knows best, and because they lack the expertise to make the treatment decisions, they prefer to be passive in the choice.<sup>1</sup> It is important to recognize this and respect patient preferences. However, it is equally important that patients have the opportunity, encouragement, and support to participate to the degree that they are able.

Physician behavior is a strong determinant of the degree to which there is a mutual exchange of information in the doctor-patient relationship. Roter and colleagues<sup>46</sup> analyzed audio tapes of



doctor–patient communication and applied an interactional coding system. Their findings indicate that almost two thirds of all visits fall into categories of interaction in which most of the exchange is about biomedical issues, with little focus on psychosocial issues. That is, most visits consist of the physician asking most of the questions and talk is confined to the more technical aspects of care. Patient-initiated talk and psychosocial or social exchange was minimal. In this style of interaction, in which patient values and preferences are not discussed, the physicians' values and judgments tend to determine treatment choices.

The frequency of this style of doctor–patient interaction suggests that the traditional patient role of passivity, trust, and compliance is often reinforced during office visits. That is to say, the delivery system itself is a barrier for patients to take on the coproducer role.

The delivery system changes that are necessary to adequately support the coproducer role are just beginning to be understood. Most of the work in this area is emerging from research on chronic disease care. Von Korff et al<sup>28</sup> identified four key elements of effective collaborative chronic disease care:

- Collaborative definition of problems: patient-defined problems are identified along with medical problems diagnosed by physicians
- Joint goal-setting and planning: patients and providers focus on a specific problem, set realistic objectives, and develop an action plan for reaching those objectives in the context of patient preferences and readiness
- The creation of a range of self-management training and support services: patients have access to services that teach skills needed to carry out medical regimens, guide behavior changes, and provide emotional support
- Active and sustained follow-up that involves regular monitoring and assessment of progress toward goals

Collaborative care implies significant change in how care is delivered and the roles that patients and providers take on. Reaching shared problem definitions and achieving joint goal-setting between providers and patients implies the need for new communication skills and styles on the part of providers and patients. Active and sustained follow-up with regular monitoring and assessment toward goals implies further changes in the

focus of office visits and how visits are planned and initiated. Integrating patients as partners in the care process means minimizing institutional routines that force patients into passive compliance and maximizing opportunities for patients to have more control and a greater role in their care.

Ensuring that patients have access to the required information and the skills training to help them effectively self-manage implies further system change. The practical integration of effective behavioral interventions into the care process has proven difficult to achieve. Although intensive efforts with trained staff have been shown to be effective in supporting patients as self-managers, delivery systems rarely follow through by permanently integrating these programs into the day-to-day processes of care.<sup>27</sup> A major challenge for delivery systems is how to incorporate patients more fully into the care process and how to weave the supports they need for this role into care.

## Evaluators of Care

The evaluator role refers to the inclusion of the patient's perspective in the measurement of the performance of health care. For this role, consumers are a source of information for determining the quality of care. In this role, consumers evaluate the experiences of care, the outcomes of care, and the degree to which they were supported in their coproducer role in the care process.

## Evaluating the Experiences of Care

The degree to which care is patient-centered, or consonant with patient values, preferences, and expressed needs, is one way of evaluating patient experiences of care and the basis for improving care.<sup>47,48</sup> Patient-centered care seeks to understand the care process through the eyes of the patient. The concept of "patient-centeredness" has been used primarily to help practitioners and administrators learn how to improve the care process by creating delivery systems that are responsive to patient preferences and values. Therefore, the evaluator role can have an important and direct impact of the quality of care.

The evaluator role also works hand-in-hand with the informed choice role. The CAHPS is an example: it measures consumers' experiences in getting health care.<sup>49</sup> Part of the CAHPS process is

to report the information back to consumers so it is possible to compare quality (from the consumer's perspective) across different health plans. CAHPS is the most widely used set of products for the collection and reporting of consumers' ratings of health plans. These data collection and dissemination efforts provide information to help consumers make choices and also provide information to health plans, providers, and hospitals so they can improve.

Projects that support the evaluator role let consumers define quality and delineate the areas of performance that are important to them. These efforts allow consumers to take control of the evaluator role and set the measurement agenda. Online companies (eg, [www.doctorquality.com](http://www.doctorquality.com)), have the flexibility to allow the individual user to define quality as they report on their experiences.

Other efforts focus on the evaluator role while at the same time supporting the coproducer role. The Foundation for Accountability (FACCT) is conducting an online study in Maine using its new "Compare Your Care" tools for asthma, diabetes, and general health. These tools combine surveys with personalized feedback designed to encourage consumers to work with their doctor to improve their health care.

### Evaluating the Outcomes of Care

Patients often are the best evaluators of their own health and functioning.<sup>50</sup> FACCT is using patient assessments to assess the outcome of specific types of chronic disease care. Similarly, the Centers for Medicare and Medicaid Services is beginning to use patient reports of health and functioning to compare health plan performance ([www.hcfa.gov/quality](http://www.hcfa.gov/quality)). More tools that would help consumers evaluate the degree to which their care was clinically successful should be developed. To be valid, these tools will have to include adequate methods for risk adjustment, a further methodologic challenge.<sup>51</sup>

### Evaluating Delivery System Support for the Coproducer Role

If the coproducer role is to be supported by the care delivery system, measures should be developed to evaluate how well the provider is performing in terms of supporting and using the patient's

skill in managing his or her condition. This general concept is being applied in the evaluation of the quality of higher education.<sup>52</sup> The traditional way to rank or rate colleges and universities is by reputation, the number of research dollars the institution attracts, and/or the size of the library holdings. A new approach surveys students about the degree to which they are engaged in the learning process, the level of academic challenge on campus, active and collaborative learning, student-faculty interaction, and supportive campus environments.<sup>52</sup> The similarities with health care delivery are obvious. The degree to which patients are collaboratively engaged in their own care, supported in that role, and have a sense of efficacy in carrying out this coproducer role are key areas in which providers could be evaluated.

For example, patients could provide evaluative information on the degree to which they had the opportunity and the information they needed to be involved in decisions about their own care, whether they had the opportunity to gain skills in self-management, whether their sense of control with regard to their care is increasing over time, and whether they are supported and encouraged to be involved in their care. Patients who are less interested or able to be involved in their own care can still be given the encouragement, support, and opportunities appropriate to their current abilities and interest.

A self-assessment tool to help care delivery systems identify areas for improvement in their care for chronic illness has been developed by Bonomi et al.<sup>53</sup> The tool has a section for assessing the degree to which effective self-management support is in place for patients. However, there are no existing tools for patients to evaluate the degree to which the system supports them as partners in the care process. Measurement of provider performance in this area is just beginning to emerge; further development is needed.

Thus, the evaluator role includes consumer assessments of their experiences in getting care, the degree to which the care improved their health and functioning, and the degree to which they were supported as a partner or coproducer of care. Developing all three of these elements of the evaluator role will likely help support the other two roles—the informed choice and coproducer roles—in the following ways:

- Signal to consumers and providers that good care includes a significant coproducer role for patients
- Emphasize that consumers are consequential actors in their own care
- Increase the salience and perceived value of comparative performance measurement
- Make it more likely that reports are attended to and used by consumers
- Encourage delivery systems to compete over how well they support the coproducer role and provide an opportunity to make systems more accountable in these areas

### Conclusions

The three consumer roles described here are linked to improved care and better health outcomes (Fig. 1). Yet, consumers face significant barriers to the assumption of these roles. The evaluator role may boost the probability that the other two roles will be successfully adopted. In addition, the three roles may be mutually reinforcing. All three are built on the overarching idea that, to get the best quality of care, consumers must have a significant role in managing, selecting, and evaluating their care. For example, if patients understand that they get better results when they are coproducers, they may want to select providers that support this coproducer role. That is, when this overarching idea is understood and accepted, consumers may be more open to the adoption of all three roles.

The notion that the evaluator role may have a synergistic effect on the efficacy of the other two roles, or that the roles are mutually reinforcing, is of course, speculative. However, as there are valid and acceptable reasons to support and encourage all three roles, there may be an opportunity to observe whether the development and encouragement of all three would produce greater effects together than if only one or two of the roles were encouraged and developed.

At this point, only the informed choice role is being actively promoted for consumers. Increasing the coproducer role would require system and provider change, an increase in consumers' skills and knowledge, and a change in their understanding of their appropriate role. It is likely that the success of efforts to harness the power of consumer behavior to create change will depend on the degree to which all three of these roles for

consumers are encouraged and supported within the delivery system and the extent to which consumers come to understand that engagement in these roles will reduce their risk of receiving poor-quality care.

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