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Evidence That Consumers Are Skeptical About Evidence-Based Health Care

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ABSTRACT We undertook focus groups, interviews, and an online survey with health care consumers as part of a recent project to assist purchasers in communicating more effectively about health care evidence and quality. Most of the consumers were ages 18–64; had health insurance through a current employer; and had taken part in making decisions about health insurance coverage for themselves, their spouse, or someone else. We found many of these consumers’ beliefs, values, and knowledge to be at odds with what policy makers prescribe as evidence-based health care. Few consumers understood terms such as “medical evidence” or “quality guidelines.” Most believed that more care meant higher-quality, better care. The gaps in knowledge and misconceptions point to serious challenges in engaging consumers in evidence-based decision making.

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Many studies have shown that some health care provided in the United States is inappropriate, inefficient, and unsafe.^{1–5} Moreover, as the rise in health care costs continues to outstrip wages and growth in other sectors of the economy,⁶ it is critically important to increase the quality and value of health care.^{7,8} Passage of the Patient Protection and Affordable Care Act of 2010 has now laid the groundwork for major reforms, including greater use of evidence-based medicine, shared decision making, comparative effectiveness research, evidence-based benefit design, and transparency of cost and quality information. We refer to these diverse efforts as evidence-based health care.

Although much attention has been focused on the roles of governments, employers, insurers, and providers in evidence-based health care, less attention has been paid to the critical role of consumers. Their attitudes and beliefs about evidence-based health care, and their understanding and acceptance of it, will help determine its success or failure. If consumers don’t under-

stand it or reject it, or if they see it as an invalid basis for making decisions about providers and treatments, the most ambitious goals of this movement may fail.

Increasingly, consumers are being asked to use evidence to manage chronic conditions, choose between treatment regimens, and select providers and health plans. In some respects, consumers are rising to the challenge. Research shows that decision aids, which provide information about options and outcomes, can help increase consumers’ confidence with decision making and improve their understanding and knowledge of treatment options.⁹ If consumers are more involved in decision making generally and self-management of health conditions, the results can be improved adherence to treatment,¹⁰ increased use of screening,¹¹ increased patient satisfaction,¹² better health outcomes,^{12–14} and lower health care costs.¹⁴

At the same time, many consumers’ values, beliefs, and behaviors remain rooted in traditional expectations about the doctor-patient relationship and the medical care system.¹⁵ The dominant role of physicians in determining

patient care has been a fact of medical care delivery for many decades.¹⁶⁻¹⁸ Therefore, many consumers may find it difficult to move into a more active and accountable role in which they are expected to understand and weigh multiple pieces of complex and potentially conflicting evidence.

The purpose of this study was to determine how the concept of making health care decisions based on evidence of effectiveness could be translated into language that consumers would understand and embrace. We conducted this research as part of the development of a “communication toolkit” to help employers communicate more effectively about evidence-based health care. In conducting this research, we identified a number of specific values, beliefs, and misconceptions among consumers that present major challenges to efforts to engage them in evidence-based health care decision making.

Study Data And Methods

We used qualitative research methods including focus groups, in-depth interviews with stakeholders, and cognitive interviews with employees. Cognitive interviews are individual interviews that explore how well consumers understood the materials and what aspects of the materials needed improvement. The project also used quantitative, online survey research methods to assess consumers’ values, beliefs, and experiences with evidence-based health care. Details are available in an online Appendix.¹⁹

How consumers understand and react to evidence-based health care is not well known. Thus, a review of the literature and qualitative methods were most appropriate at the beginning of our research. We used quantitative methods to assess specific topics that our qualitative research showed would be helpful to employers.

LITERATURE REVIEW AND QUALITATIVE METHODS Our research included reviewing published literature and other material such as technical reports and white papers; collecting and reviewing materials from organizations that communicate with consumers about health care; and interviewing forty employer intermediaries such as human resources staff, stakeholders, and experts. In addition, we conducted four focus groups with a total of thirty-four consumers in August and September 2006 to explore their understanding of the components of evidence-based health care and health care decision making, and to obtain their reactions to different ways of conveying information about evidence-based health care.

Between March and December 2007, we conducted one-on-one, two-hour, in-person cogni-

tive interviews with fifty-seven employees to explore how well consumers understood the concepts of evidence-based health care, the consumers’ reactions to the use of evidence of effectiveness in decision making, and their preferred sources of health care information.

The focus-group and interview participants were people ages 18–64 who had health insurance through a current employer and who had taken part in making decisions about coverage for themselves, their spouse, or someone else. We audiotaped all focus groups and interviews. We transcribed the focus-group tapes and generated extensive notes for the interviews, analyzing these to identify key themes.

We employed a variety of well-established techniques to draw conclusions from the data, such as identifying patterns, assessing the plausibility of findings, and noting relationships between patterns. We tested and confirmed our findings by looking for exceptions and alternative explanations.^{20,21}

ONLINE SURVEY AND ANALYSIS In a related effort, the National Business Group on Health commissioned an online survey in September 2007 of 1,558 employees. This survey used the Greenfield Online panel, a convenience sample recruited primarily from the Internet. Findings from our project’s qualitative research were used to ask additional questions about attitudes and behaviors regarding health care, health information needs, preferred sources of information, and health care decisions.²²

Respondents were ages 22–69, employed at least part time by a firm with at least 2,000 employees, insured through an employer- or union-sponsored health plan, and functioned as a key health care decision maker for their household. All panel members who met the selection criteria were eligible to respond to the survey. The survey was discontinued after we reached a sample size of approximately 1,500.

Unless otherwise noted, the findings presented here are consistent within the qualitative methods and between the qualitative and quantitative methods. The findings express recurring issues and themes stated by consumers across the range of methods used (Exhibit 1).

STUDY LIMITATIONS Overall, because of recruitment methods and selection criteria, the project findings overrepresent people who were employed, particularly by large firms; who were insured; and who identified themselves as responsible for health care decision making. As a result, we would expect that our study population is consistently biased toward a “best case” scenario: that individuals understand and value evidence-based health care. Thus, our findings may reflect a more optimistic assessment of

EXHIBIT 1**Consumers' Knowledge, Beliefs, and Attitudes Toward Evidence-Based Health Care Principles**

Features of evidence-based health care	Themes from focus groups and interviews
Using medical evidence and quality standards to make decisions	Unfamiliar with and sometimes confused by the terms “medical evidence,” “quality guidelines,” and “quality standards” Believe that all medical care meets minimum quality standards Think that medical guidelines represent an inflexible, bargain-basement approach to treating unique individuals
Reducing the underuse, misuse, and overuse of treatments and health care resources	Believe that more care is better (higher-quality) care, newer care is better Believe that more costly care is better care
Encouraging consumers to be actively involved in their health care	Workers have limited experience with engagement behaviors

SOURCE Authors' analysis of focus groups, interviews, and online survey.

consumer engagement than would be found in the broader U.S. population.

Study Findings

The key finding from focus groups, interviews, and the online survey is that there is a fundamental disconnect between the central tenets of evidence-based health care and the knowledge, values, and beliefs held by many consumers. For health care experts, variation—in quality among health care providers, the evidence base regarding therapies, and the effectiveness and cost-effectiveness of treatment options—is a well-established fact of the health care delivery system, documented extensively in the published literature and well understood after years of careful study.¹⁻⁵ Yet such concepts are unfamiliar to many Americans and may even seem threatening, to the extent that they raise unwelcome questions about the quality of medical care that people receive.

This study identified gaps in knowledge, specific values and beliefs, and behaviors that will challenge ongoing efforts to ensure patients' acceptance of decision making in evidence-based health care (Exhibit 1).

MISCONCEPTIONS Participants had crucial misconceptions about the underlying concepts of evidence-based health care. They found terms such as “medical evidence,” “quality guidelines,” and “quality standards” unfamiliar and confusing. This lack of familiarity with key concepts was consistent with a finding from our national online survey that only half of the respondents had read or heard about “medical research studies [that] help doctors know what works best for patient care.”

Additionally, only 34 percent of participants ever recalled having a physician discuss what scientific research had shown about the best way to manage their care. Many participants as-

sumed that their health care providers always based decisions on medical evidence, which to them consists just of “things like my test results and medical history.”

BELIEFS AND VALUES Study participants consistently voiced a number of values and beliefs that were at odds with evidence-based approaches.

► **ALL CARE MEETS MINIMUM QUALITY STANDARDS:** Although focus-group participants could envision a health care provider's making an occasional mistake, they found it hard to believe that providers could deliver truly substandard care—and certainly not their own providers. When focus-group participants were told that providing beta-blockers for heart attack patients represents the accepted standard of care, but 25 percent of patients do not receive them,²³ participants immediately offered justifications for the lack of treatment: the patient was “allergic,” the hospital was “too poor” to provide the drugs, or the doctor knew that the patient needed a different medication.

► **MEDICAL GUIDELINES ARE INFLEXIBLE:** Although policy experts define guidelines as best clinical practices based on a large body of medical evidence, focus-group participants perceived them as rigid rules that interfere with providers' ability to draw upon their medical training and experience to tailor their care to the characteristics of individual patients. As one participant said, “Using medical guidelines sounds like... your doctor can't give you other treatment without approval. It's taking your choice away and putting the decision in somebody else's hands.”

Participants were more inclined to trust their own and their physicians' judgments of quality, instead of relying on guidelines that might “discriminate against doctors who give you better care” and “cripple medical advantage. It's thinking outside the box that helps you find a

treatment that works. It's not always rule of thumb."

Some also worried that doctors could use guidelines to protect themselves from potential lawsuits by invoking them to deny care, especially new or innovative care that patients consider necessary. One participant said, "This is just a way for doctors to say, 'I'm following the national guidelines, so you can't sue me if something goes wrong.'"

► **MORE CARE, AND NEWER CARE, IS BETTER:** The idea that getting high-quality care or the "right" care could mean getting less care was counterintuitive. As one interview participant said, "I don't see how extra care can be harmful to your health. Care would only benefit you."

Participants also believed that any new treatment is improved treatment. This attitude may help explain the survey finding that only 47 percent of respondents agreed that it is reasonable to pay less out of pocket for the most effective treatments and drugs. Linking cost sharing to clinical effectiveness may be perceived as restricting treatment options, particularly for unproven therapies (Exhibit 2).

► **MORE COSTLY CARE IS BETTER:** A substantial portion of focus-group and interview participants expressed the view that "you get what you pay for." A third (33 percent) of our survey respondents agreed or strongly agreed with the statement that "medical treatments that work the best usually cost more than treatments that don't work as well." Although 27 percent disagreed or strongly disagreed, 40 percent reported that they were not sure about this (Exhibit 2).

Given the widespread view that lower-cost care is clinically inferior, it is perhaps not surprising that focus-group participants found it inappropriate to discuss with their physician the costs of different treatments, believing that decisions about medical treatments should be based on individual needs alone. A number of participants reacted negatively to the term "good value for the money," equating it with bargain-basement pricing and low quality.

BEHAVIORS IN THE MEDICAL ENCOUNTER Our survey results indicate that many consumers do not engage in behaviors that could be beneficial to them during medical encounters. More than half of the respondents had never taken notes during a medical appointment (55 percent) or brought online information to discuss with their doctor (60 percent). Almost half had never brought someone to provide support or advocacy (44 percent). In addition, 28 percent of the respondents had never brought questions to ask their doctor (Exhibit 3).

Patients often rely heavily on their doctors for information, interpretation, and guidance on treatment options. Thus, they may be reluctant to question or challenge what the doctor advises. In our survey, 41 percent of respondents reported that they had not asked questions or told their doctor about medical problems, because the doctor seemed rushed or they were unsure about how to talk to him or her (Exhibit 3).

Interview participants said that they were reluctant or too timid to raise concerns about unnecessary care. They believed that determining what constituted necessary care was mainly their provider's job: "You are not an expert. The

EXHIBIT 2

Consumers' Views On The Quality, Effectiveness, And Cost Of Health Care, As Related To Consumer Behavior

Variable	Scale (%)		
	Strongly disagree/ disagree	Neither agree nor disagree	Strongly agree/ agree
Medical treatments that work the best usually cost more than treatments that don't work as well	27	40	33
If employees use doctors who have scored high on quality ratings, it is appropriate to have those employees pay less for their health insurance benefits and medical care	16	43	41
If employees use the particular treatments and drugs that research has shown work best for their condition, it is appropriate to have those employees pay less for their health insurance benefits and medical care	15	38	47
If employees have healthy lifestyles or participate in programs sponsored by employers that could help them improve their health (such as programs to quit smoking or lose weight), it is appropriate to have those employees pay less for their health insurance benefits and medical care	10	24	66

SOURCE National Business Group on Health Online Survey, September 2007. **NOTES** Respondents were asked to rate how strongly they agreed or disagreed with each statement. N = 1,558.

EXHIBIT 3

Consumers' Engagement With Their Care, And Communication With Physicians

	Never	Yes, once	Yes, more than once
ENGAGEMENT BEHAVIORS			
These questions ask about things you might have done before or during a medical visit. Have you ever...			
Brought information you found on an Internet Web site to a medical visit and talked about it with your doctor?	60%	20%	20%
Taken notes during a medical visit to help you remember what the doctor or nurse said?	55	16	29
Brought along a friend or family member to your medical visit as your advocate or to give you support?	44	21	35
Brought a list of questions to ask during a medical visit?	28	23	49
PHYSICIAN COMMUNICATION			
During a medical visit, have you ever held back on asking questions or telling the doctor about your medical problems because...			
You were unsure how to talk about your medical problems or how to ask your questions?	59	19	22
The doctor seemed rushed?	59	16	25

SOURCE National Business Group on Health Online Survey, September 2007. **NOTE** N = 1,558.

doctor is supposed to be the expert—you [the system] need to hold the doctor accountable.” Similarly, participants expressed concern about assuming the burden of avoiding medical errors instead of relying on doctors and other providers. Finally, some participants explicitly asked whether their providers knew they (consumers) were being told to raise these issues and wanted reassurances that their providers knew and would welcome their expressions of concern.

Implications

For consumers to truly engage in using evidence for decision making, they have to be informed about the relevant choices for their own situation; value the use of evidence in making those decisions, even if it contradicts conventional wisdom; and accept their role in this process and feel capable and ready to assume it. This is no small challenge, given the continued dominance of paternalistic models of physician decision making, relatively low levels of health and scientific literacy in the general public,²⁴ and the increasing complexity of the choices that patients are asked to make.

Our findings indicate some cause for optimism: A minority—small, but nontrivial—of the public accepts the underlying concepts of evidence-based health care and wants to assume a more informed and active role in their health care and decision making. These individuals are in all likelihood “early adopters,” who, as potential opinion leaders, can help influence later adopters. They represent a foundation on which to build greater acceptance of evidence-based

health care, and they may be a useful resource in stimulating change.

At the same time, our findings illuminate real and significant challenges to the pursuit of broader acceptance of evidence-based health care among consumers. The beliefs underlying the themes that surfaced in both the qualitative research and the survey—more is better, newer is better, you get what you pay for, guidelines limit my doctor’s ability to provide me with the care I need and deserve—are deeply rooted and widespread. Our findings, although preliminary, have implications for several public and private efforts. These efforts intend to foster—and to some degree depend on—consumer engagement, or at least on the absence of overt consumer resistance.

COMPARATIVE EFFECTIVENESS RESEARCH The Institute of Medicine defines *comparative effectiveness research* as “the generation and synthesis of evidence that compares the benefits and harms of alternative methods to prevent, diagnose, treat and monitor a clinical condition, or to improve the delivery of care.”²⁵

To the extent that consumers perceive that the application of comparative effectiveness research to decision making could limit their choice of providers, inappropriately interfere with physicians’ recommendations for treatment, or appear to “ration” care based on cost, these efforts will encounter consumer resistance and could lead to a broad consumer backlash. In fact, news articles and commentaries by critics of the \$1.1 billion for comparative effectiveness research included in the American Recovery and Reinvestment Act of 2009 (ARRA) cited these

arguments to discourage government funding of this work.²⁶⁻²⁹

Now, under the Patient Protection and Affordable Care Act, comparative effectiveness research will be carried forward under the aegis of the planned Patient Outcomes Research Institute. But the act explicitly prohibits the research from being used as the basis of coverage or reimbursement decisions for either public or private payers—which illustrates how much the public worries about rationing health care.

EVIDENCE-BASED BENEFIT DESIGN Whether the effort is called “quality-based benefit design” or “value-based health insurance,” the objective is to use insurance benefit design such as copayments, prior authorization, formularies, and provider network design to encourage effective, high-value care and to discourage ineffective, low-value care. Our findings suggest that this approach, although perfectly logical from the perspective of health policy experts, might not resonate with consumers.

For those who believe that all medical care meets minimum standards and that more care is better, differentiating among physicians, hospitals, or other providers based on quality and efficiency profiles is likely to meet with resistance. Findings from our national online survey are consistent with this notion. Only 41 percent of survey respondents agreed that it is appropriate for employees to pay less for their health insurance or medical care if they use doctors who score high on quality ratings, and 47 percent agreed that employees should pay less for treatments that research has shown to work best (Exhibit 2).

TRANSPARENCY OF COST AND QUALITY INFORMATION Efforts during the past decade to make information available about the quality of care have assumed that if patients are given information about cost and quality, they will be able to make informed and appropriate decisions about plans, providers, and treatment options. However, consumers’ views that high-quality care might cost more and that clinical guidelines represent a minimum standard of care undercut this assumption. The consistent finding that consumers prefer subjective information from friends and family about selecting doctors and hospitals to objective information about performance and outcomes shows how difficult it is to shift toward an evidence-based approach to making health care choices.³⁰

Next Steps

Our findings show that consumers’ current knowledge, beliefs, attitudes, and experiences

Consumers will revolt if evidence-based efforts are perceived as a way to deny them needed treatment.

related to health care are often incompatible with evidence-based approaches. In addition, consumers have deep concerns about how physicians and other providers will respond to questions about the appropriateness of treatments, the basis for referrals to specialists and hospitals, or the cost of treatment.

Effective communication with and support of consumers is essential to improving the quality of health care and containing health care costs. Clearly, consumers will revolt if evidence-based efforts are perceived as rationing or as a way to deny them needed treatment. Policy makers, employers, health plans, providers, and researchers will thus need to translate evidence-based health care into accessible concepts and concrete activities that support and motivate consumers. A necessary condition for effective communication, after all, is to start where your audience is—even if that is not where you hoped or expected it to be.

On the basis of the research we have described, we developed a “communication toolkit.”³¹ It is designed to enable employers and unions to communicate with consumers about evidence-based health care and help them become active participants in their care through customizable materials that translate these concepts into clear, simple, and relevant language. The response from employers and other health care purchasers, health plans, and provider organizations has been enthusiastic, judging by the number of downloads and Web-site hits to the toolkit Web site housed at the National Business Group on Health, feedback at meetings and presentations of the toolkit, and active use of the materials by organizations. We are currently conducting implementation case studies as employers and unions begin to use the toolkit, and we hope that these may provide further guidance on bridging the gap between the need for evidence-based health care and the consumers’ current perceptions of it. ■

Portions of the findings from the research conducted to develop the communication toolkit were presented in different venues, including research,

advocacy, and substantive conferences focused on evidence-based health care. The toolkit and this article were created with funding from the California

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