

BEHAVIOR MATTERS

15 Years of Health Behavior Advocacy

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BEHAVIOR MATTERS: 15 Years of Health Behavior Advocacy
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CHAPTER 4

Are We Really “Consumers” of Health Information and Health Care?

“Consumer” is a word we use with abandon in our market-driven society. In many transactions, it refers to the person who pays for the product or service *and* ultimately uses it. In the medical arena, though, three different parties—one selects the service, another receives it and a third pays the bills—are involved. Often the person consuming the service doesn’t know its price when it is delivered.

It is important to note that the definition of *consumer* varies according to the speaker’s position in the health care sector. Thus:

Health care purchasers typically use the term *consumer* to distinguish their own role from that played by individuals who choose among the options—such as health insurance products, delivery systems or providers—that the purchaser makes available. More recently, private sector purchasers have begun promoting the notion of consumer-driven health plans (CDHPs) in which their employees have substantial freedom of choice among types and qualities of benefits but take on greater financial risk. Purchasers assume that if employees face increased risk, they will begin to make more responsible choices in both their use of health care services and in their personal health behaviors. CDHPs promise that they will provide information and support to help enrollees make the “right” choices.

Insurers, including managed care plans, also use *consumer* to describe a subsidiary purchaser in the marketplace. (For example, the Health Partners Consumer Choice System provides members with access to data about their benefits and services, comparative clinical data and access to their medical records.) For these

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stakeholders, consumers are viewed largely as economic actors making choices in a marketplace.

In contrast, *advocacy organizations*, including groups such as AARP, the Consumer Coalition for Quality Health Care, the National Health Law Program and local groups such as the Medicare Rights Center and the Center for Health Care Rights, use *consumer* to describe a political constituency whose interests they hope to protect and enhance. Some use *patient*, but others are uncomfortable that the term seems to imply a power disparity relative to professionals in determining the desired outcomes of interventions and the choice of interventions. Public policy-makers in both the legislative and executive branches use the term in a similar manner, and often interchangeably with such terms as *citizen* or *the public*.

Health care practitioners—doctors, nurses, and occupational, physical and respiratory therapists—often resist the term *consumer* and prefer *patient* or *client* as more consistent with their own self-identity. Nor do researchers and practitioners working on health behavior change use this term often. They typically view individuals as the “audiences,” “high-risk groups” or “target populations” whose behavior they want to affect with behavior-change interventions or as people who will search out and act on information about disease prevention and self-care.

Two significant underlying themes emerge from this range of definitions. First is the variation in perspective between those who view consumers as marketplace actors and those who see them as a political constituency. This divergence creates confusion, in particular, in discussions about the choices individuals make about health and health care. Those using the term in its economic sense assume consumers can and will make rational choices among available options, while those using the term in its political sense believe consumers should have excellent and affordable choices available and also should be protected either from having no choices at all or from circumstances which lead them to make bad choices.

The second theme is whether individuals are viewed as passive recipients of information and services or as active participants in maintaining and improving their own health. This distinction—or perhaps more accurately, continuum—is critical in designing efforts to support healthy behavior. Here, perspective translates into diverging approaches. It’s the difference between informing people both about the consequences of poor behavioral choices and how to make better ones—or creating laws that either forbid or discourage unhealthy behavioral choices or provide greater access to positive behavioral choices. Specific examples include tobacco use (media campaigns against teen smoking versus strict enforcement of minor access laws) and diet (widespread accurate food labeling versus removing school cafeteria vending machines that offer only sugar- and caffeine-filled drinks.) While these strategies do not have to be mutually exclusive, they often are. For example, there are those who view the accurate labeling of food products as sufficient warning and advice: Individuals will make their own choices and bear the consequences, an echo of typical market-oriented caveat emptor.

Assumptions about the appropriate and feasible roles of individuals as consumers with regard to their health and health care will ultimately have major consequences

on how information and services are organized and delivered. If we expect people to respond positively to the demands placed on them by innovations in health insurance, we must understand the full range of abilities and needs that individuals bring to the task of staying healthy and managing illness.

Assumptions about “consumers”

The term *consumer*, as used by different health stakeholders, rests on a diverse collection of overlapping assumptions, some which are confirmed experientially and empirically, but others which are not. Those who talk about consumers of health information and services make a number of assumptions about human attributes that merit critical attention. Chief among these assumptions are

- Almost all people can and will participate positively in maintaining and improving their health and the health of their immediate family; those who cannot almost always have someone to serve as a trusted proxy for them.
- Individuals have choices about their health care.
- Individuals have rational control over their behavior.
- Providing access to the right information will lead to changes in behaviors and choices.
- Emerging communication technologies will provide needed information to virtually everyone.
- Individuals need and want to be able to make wise behavioral and treatment choices.
- Effective strategies are available to guide the transformation of evidence into information; there is adequate knowledge of how to present and disseminate this information effectively to all individuals in a given subgroup to ensure optimal comprehension and use.
- Individuals will be more likely to acquire this information and use it to make rational decisions if they perceive themselves to be at greater financial and health risk than usual.
- Clinicians are willing and able both to provide this information and to encourage their patients to seek and use such information.

Closer scrutiny of the assumptions

The evidence supporting these assumptions is limited at best; there is considerable evidence that contradicts them.

People’s interest in becoming actively engaged on behalf of their own or their family’s health, especially in terms of taking steps to maintain positive health and prevent ill health, varies. Variations occur in the overall priority people assign to health, in people’s sense that their decisions or behavior will actually make a difference and in their willingness to pay the opportunity costs involved. Many people prefer to depend on family members and designated experts like their doctors to make choices for them. The fact that individual behavior can make a difference in improving health prospects does not guarantee that people will necessarily change

long-held habits. Individuals' abilities to discern and make choices about health care quality and value vary even when adequate information is available.

Many Americans have no one they can trust to help them make health-related decisions. This group includes many older people without family or close friends, as well as people with mental conditions whose behavior has alienated their families. In other words, those with the biggest problems have the most limited resources when it comes to finding their own solutions.

Assumptions about the availability of choices are also not supportable. With regard to medical care (1) lack of insurance, (2) lack of insurance choices, and (3) limitations or lack of providers are all experienced differently by different groups. With regard to health behavior, the basic feasibility of making certain choices can be constrained by a variety of factors. Pressures from family members (e.g., about dietary choices) and friends (e.g., about whether and how much to drink alcohol, smoke or use illegal drugs); pressures from the work environment (e.g., limiting time needed to exercise regularly, limiting food options); and barriers in the neighborhood environment (e.g., healthy food is unavailable or available only at unaffordable prices, lack of safe places to exercise out-of-doors) can all affect the ability to make choices.

Decades of research demonstrate that information alone is rarely enough to lead to behavior change. The gathering and disseminating of information has been enhanced by new technologies, but the transfer of this technology across socioeconomic, race/ethnicity and age divides remains uneven. It is possible that these disparities will gradually narrow if not disappear, but this has not yet occurred. It is necessary for people to have literacy skills to navigate the Internet, not just have Internet access. Downloading music and using e-mail require different skills than seeking health plan quality ratings or finding reliable nutrition information; acquiring them can be daunting to a novice. And while there is clearly potential for these new technologies to become available in multiple languages to mirror the diversity of 21st century America, many people lack basic literacy in any language, not to mention health literacy, to take advantage of these new, primarily text-based opportunities.

Technology is not the central question. Nor is it the answer. Someone unable to digest and respond to a magazine article won't become any more comfortable or competent when the same information is posted on the Internet.

There is some high-quality evidence available to guide people in making personal decisions about health-related behaviors such as smoking, using seat belts and placing infants in the proper position when putting them in a crib. However, there are far fewer effective, widely available interventions that help people adopt healthy behaviors and maintain them over time. Furthermore, in some areas, the evidence about the "right" behavior changes unpredictably as new studies emerge. Here are some examples of areas in which new evidence is emerging:

- Should women under 50 with no special risk factors get screening mammograms, and if so, how often?
- Who should, and who should not, use hormone replacement therapy?

IS “OUR PEOPLE” HEALTHY?

Millions of young people will graduate from high school this year, too many of them unable to balance a checkbook, figure out the true interest rate on a car loan or find Iraq on a map.

Sadly, many of these new graduates also will be unsure how to comply with a medical prescription, how to comprehend the health risks they so often take and how to interpret something as simple as a blood pressure reading.

This is not a jeremiad about the state of education, because it isn't only schools that are at fault for a health illiteracy problem that threatens to retard half a century of biomedical progress. When it comes to understanding our own health, more than 40 percent of adults are left behind.

Reports from the Institute of Medicine and the Agency for Healthcare Research and Quality find that the disconnect between the language of doctors and the comprehension of even educated adults is costing the nation billions of dollars in unnecessary health expenditures. When it comes to illness, people who don't get it, get it.

Recognizing this disconnect is vitally important because people are increasingly expected to make decisions about health and health care on their own. They will have to be able to understand comparable risks; choose among drugs, tests and health plans that differ in price, effectiveness and quality; sign complicated consent forms and make sense of a blizzard of drug company pitches to make you virile, hairy or continent.

The problem is not limited to poorly educated Americans, the elderly or non-English speakers. Health illiteracy is a complex challenge because it also has to do with people's attitudes and fears. For example, a nationwide Gallup survey found that half of those surveyed believe a colonoscopy should be done every year after age 50, instead of every decade. That striking piece of misinformation may contribute to the fear that causes only half of the respondents at risk to have the screening test.

While 75 percent of women understand the purpose of mammograms, only 48 percent know that a Pap test screens for cervical cancer. Thirteen percent of all adult women think the test screens for sexually transmitted disease, ovarian cancer or uterine cancer.

Our nation's investment in biomedical research and our current annual investment in health care delivery fall short because the vital link between what we know and improved health outcomes depends on the ability of people to understand and act on health information.

There is much to do: Use communications research to package and target information to patient groups with different needs and skills; enrich K-12 health education nationwide; persuade doctors to drop their jargon.

These things are not just nice touches to make health care more patient-friendly. They are necessary. The federal government spends \$28 billion a year on research to find cures for illnesses that cost us \$1.5 trillion to diagnose, treat and manage. We cannot afford to shortchange this staggering investment in health just because we can't decipher the prescription.

- Should men over 75 get PSA tests?
- To lose weight, do we need to consume less fat, fewer carbohydrates or just eat less food?

Current evidence on all these questions is equivocal. To be accurately informed, people will need to sift through mixed evidence and weigh person-specific risks and probabilities. These are all complex cognitive tasks requiring time, experience and education.

When evidence is available, research and experience provide can help (1) transform the evidence into “consumer-friendly” information, (2) make it accessible to a particular audience through media channels the audience trusts, and (3) make it easy for them to understand and apply the information to their own circumstances. Much has been learned about how to do this through decades of large- and small-scale social marketing efforts aimed at changing behavior and norms and through more recent efforts to provide quality information to individuals. There is, however, a good deal more to learn and lags in the application of what is known—by information packaging vendors, the government, health plans and practitioners—are considerable.

Another assumption is that people will be more likely to seek and use information in a rational manner in the face of increased risks, a notion that has been the topic of some interest in this time of concern about bioterrorism. Research indicates that people with a particular diagnosis will pay more attention to information that is specific to that diagnosis. However, heightened risk is typically accompanied by heightened anxiety and other strong emotions, and a growing body of evidence suggests that increased risk does not consistently lead to more adept information-seeking and more rational applications of the information to one’s own circumstances. For some people, their ability to process important information actually declines as their need for it grows.

It is also far from clear that health practitioners will typically invest the time and resources required to provide the information people need to participate fully in health decisions and to support patients who are independent information seekers. Clinicians face other constraints in offering information to support self-care and behavioral change such as diabetes management and weight control. These barriers include time considerations and varied quality of counseling skills, not to mention access to appropriate information to which they can refer patients. Some clinicians continue to balk at dealing with independent patients who show up in the examining room with dozens of pages of health information they have downloaded from the Internet.

Aligning the Term *Consumer* with the Evidence

When used as a catch-all term to designate the public at large (i.e., those who have no professional role in health and health care), the term *consumer* can be problematic. It often carries assumptions, expectations and implications for institutional policies and programs that are inconsistent with what is known about human cognition,

motivation and behavior and incongruent with available evidence and technological capacity.

Currently, these mistaken assumptions about so-called consumers are being used to justify policies that expect individuals to take actions that they are sometimes incapable of and to assume responsibility for evaluating and acting on complex information they don't fully understand. To the extent that consumers are expected to take on these roles without support, there is a risk of abrogating the social contract between physicians and patients, between all health professionals and the people whose health they seek to improve, and more broadly, between the health care sector and the society it is supposed to serve.

It is critical to avoid situations in which powerful health stakeholders use virtuous language connoting egalitarianism and individual autonomy to obscure the fact that they are placing the responsibility for technical decisions—and the related financial risk—on those who are most vulnerable.

While it is unrealistic to expect that *consumer* will cease to be used for individuals in the context of health decisions, it is possible to seek some course correction—to encourage careful use of the term based on principles that inform a productive and feasible role for individuals with respect to their health and health care. The principles are as follows:

Recognize diversity in willingness and ability to engage in health concerns. No matter what definition is used, consumers vary widely in their willingness and ability to use information as the basis of health-related action. Some people will want to take a very active role in shaping their health and health care. Others will want to become active at critical points—when they or a loved family member or friend becomes ill; or when they go through a significant life transition, such as retirement, marriage or losing a job—but at most times will want to be more recipients of care than questioners and initiators. Still others will be fundamentally unwilling or unable to act in their own behalf. They do not believe that they are capable of maintaining the necessary vigilance, particularly when ill, and will want to put as many decisions as possible into the hands of physicians and other professionals. Some people are also unwilling to burden their family members and friends with this responsibility. Policy-makers, clinicians and health educators must not abandon these people, who are likely to be vulnerable in terms of their health and functioning. While they should be encouraged to do what they can for themselves, even the most dependent or isolated individuals retain the right to expect that those with a moral obligation to care for patients will do so, rather than punishing people who face real limitations.

Expect and accommodate changes over time and circumstance. This refers to the willingness and ability to actively engage in health and health care changes over time and in response to events. Individuals' needs and preferences must be periodically checked on, especially during illness and other major life events. Formal and systematic methods for inquiring about individuals' wishes about participating either in health behavior or health-promotion decisions are currently not available, although

one measure of “patient activation” is currently being tested. These methods must be developed and incorporated into practice.

Provide support to help people seek and use accurate and useful information. Information is necessary, though not sufficient in itself, to spark sustained action. More must be learned about how to (1) help people overcome the natural barriers to making complex behavior changes, (2) provide technical information in a user-friendly manner, (3) help people apply this information to their own circumstances, and (4) encourage people to make use of the available information and support. The need to customize these approaches to various subgroups—whether defined by language and culture, socioeconomic status, social norms or health status or a combination of these factors—is clear.

Recognize the limits of individual action, and supplement it with action at the societal level. It is important to protect individuals who are either unwilling or unable to take advantage of available information or supports. The nation cannot justify a “caveat emptor” approach to health by simply saying that people have been provided with information and it is up to them to use it or face the consequences of anything from high-tar cigarettes to high-cholesterol school lunches to poor-quality liver transplants to fraudulent infertility clinics.

Implications of this Vision

Those who seek to promote and improve health must carefully consider the diversity in abilities and preferences in any group of consumers targeted for attention, and balance societal level interventions with those directed to individuals. To do so, health-promotion researchers and professionals can move forward in these ways:

They can take what works and put resources into translation, dissemination and provision of needed technical assistance and training to get these interventions implemented “at scale.” Behavior change research has focused primarily on testing the efficacy of interventions rather than exploring the dimensions and determinants of effectiveness in natural rather than “controlled trial” settings. While this may be a function of the past interests of research funders, there is growing awareness among them and the health care establishment in general of the importance of knowledge about health behavior and effective health-promotion interventions. Resources must be invested in completing the “production arc” from laboratory to living room, including effectiveness research, demonstration projects, formal evidence reviews, packaging of interventions and dissemination. There are also implications for training health behavior change professionals, since we will need people who can and will conduct such research and who can routinely deliver evidence-based interventions.

Researchers and implementers must work together to identify knowledge gaps which, if filled, would increase effectiveness of health promotion. Behavior change researchers typically do not work on the front lines of organizing, implementing and delivering the interventions they develop. As a result, research findings are frequently of little practical use to clinicians and other practitioners. Close collaboration by

researchers with those who *are* on the front lines would cause critical research questions to surface. Answers to these questions could significantly raise the relevance and effectiveness of efforts to change behavior to improve health.

They must identify the key dimensions for customization. Researchers with backgrounds in population health and the behavioral and social sciences have the training and perspective to identify the crucial factors that must be considered in tailoring and targeting interventions for different groups to produce optimal outcomes. This knowledge should be shared widely throughout health plans and should also inform health communications and health promotion efforts nationally.

They must improve alignment among individual, family, community and societal level interventions. Health behavior change professionals seem attracted to one of two perspectives: The best advances in health will come from a retail focus (i.e., intervening with high-risk individuals) OR wholesale (i.e., population-based) approaches will yield more significant health improvement. In all likelihood, the greatest advantage will come from well-designed and thoroughly tested interventions that take strategic advantage of the opportunities at all levels while providing consistent messages. Professional flexibility, increased communication and recognition of the size and scope of the task are critical to ensuring success.

The impulse prompting use of the term *consumer* is based on recognition of the potential for people to make wise, value-driven choices about health and health care, but it ignores the variation in the population of the skills, motivations and abilities required to do so. Individuals can indeed play more meaningful roles in promoting their own health, preventing their own diseases and those of their families, and in participating positively in the treatment of their illnesses. But more must be learned—and applied—to maximize the contributions of individuals without leaving them vulnerable to avoidable exposures to low-quality information, health-promotion interventions and medical care. Only on these terms can people who have not made a professional commitment to health or health care be expected to take on the new and significant responsibilities to make choices that will allow them to live for as long and as well as they are able.

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