Consumers in a Complex *and* Dynamic Health Care Environment

Judith H. Hibbard
University of Oregon

NEAHIN
NATIONAL EDUCATION ASSOCIATION
HEALTH INFORMATION NETWORK

Current health policy directions place high expectations on consumers, pressing them to change their behaviors and take on more responsibility. The price of failing to meet these expectations will be high for the individual, for the care delivery system, and for our society as a whole. Three key trends in the health care environment are shaping expectations for consumer behavior: a greater share of the costs are being borne by the individual consumer; more information available to inform choices and more responsibility for choices; and the increased complexity of the health care options and the tasks involved in managing personal health and health care.

Despite the many different approaches to cost control, health care costs have continued to rise, and to rise well above the general inflation rate. Over the last several years U.S. health care expenditures have grown 2.8 percent per annum faster, on average, than the rest of the economy (Reinhardt et al., 2004). These increases are unsustainable, and consumers are no longer as well insulated from the cost of their care as they once were. Individual consumers are now paying a greater share their own health care costs. Fifty-five percent of workers reported an increase in their health care costs in the last year (Employee Benefits Research Institute, 2008). In recent years most insured consumers have experienced escalations in monthly premiums, greater co-payments, and larger deductibles. At the same time, the expectations for consumers to take a greater role in managing their personal health is also increasing. Some employers and health plans are financially penalizing consumers when they fail to change poor health habits or to exhibit healthy biometrics such as recommended BMI or blood pressure levels. Other employers are simply responding to the burden of health care costs by dropping insurance coverage for their employees. That these cost trends are placing a significant burden on consumers is evidenced by the continued expansion of the uninsured population, growing personal medical debt and medical debt-related bankruptcies.

At the same time, consumers also have more information available to them to help make sound health care choices. Some of this new information is based on a growing understanding for the need for more accountability and transparency in health care. For example, recent research indicates widespread quality deficiencies in the care delivered in this country, with patients getting only about half of the recommended care for their conditions, and evidence that medical errors in hospitals kill around 100,000 patients a year (McGlynn et al., 2005; Institute of Medicine 1998). These revelations mean that patients must choose doctors, hospitals, and other health care facilities carefully; their very life may depend upon it. Report cards that compare the quality of care provided by different doctors, health plans, hospitals, and nursing homes are becoming widely available. These reports are intended to help consumers make more informed choices about their care. There is an expectation that if consumers use these reports to choose high quality providers, this will stimulate providers to improve the quality of care they provide. The assumption is that providers will be motivated to improve because they want to either protect their reputations or to protect their market share. Unfortunately, there are few policy levers available to improve the quality of care, as providers are typically paid the same whether they deliver high quality care or not-so-high quality care. Thus, the hope is that consumers, through their informed choices, will be a stimulus for improvements. In other words, policy makers are looking to consumers to help solve deficiencies in the quality of health care.

Patients also may need to protect themselves from poor quality care when they make treatment decisions. Evidence suggests that the services people receive are too often unnecessary or not right for them. For example, studies show that there are far too many unnecessary surgeries, particularly surgeries where there is limited evidence for their efficacy, such as back surgeries, hysterectomies, and coronary bypass surgeries (IOM, 2008). This is not just an issue of waste, but also of potential harm.

By making information about treatment options and the risks, benefits, and costs of options available to patients, the hope is that patients will make choices that not only protect them from waste and potential harm, but also they will make choices that improve their health and ones that reflect their own priorities and preferences. That information on treatment options, which was previously available only to clinicians, is now accessible to anyone with an Internet connection. This means that the knowledge gap between physicians and patients may be reduced and ultimately may allow patients to more fully participate in their own care. These new sources of information represent both an opportunity and a burden. It can be burdensome to have responsibility for choices where the information is unfamiliar and complex and when the consequences of choice are so great. For example, using evidence about treatments may mean that patients have to choose among treatment approaches that produce similar outcomes but risk different side effects. The choice among treatments for

prostate cancer is a prime example, where at least in the short term, there is little difference in efficacy, but the treatments have different rates of frightening and potentially life changing side effects, including impotency, incontinence, and/or bowel disorders. Weighing the risks and benefits here are not about clinical judgment, but about personal decisions reflecting individual values and priorities.

The point is that the choices that consumers must make, along with the information to support those choices, have significantly grown in both volume and complexity.

In addition, consumers also are being pressed to take on a greater role in managing their health. Evidence suggests that what people do in their everyday life, what they eat, how physically active they are, and whether they adhere to treatment regimens will largely determine their health outcomes. For example, it is estimated that people with diabetes who are able through managing their diet, exercise and medications to maintain near normal A1c levels will gain an average extra five years of life, eight years of sight, and six years free from kidney disease (American Diabetes Association, 2004). Taking action to prevent illness is of course the preferred strategy. Individual behavior as it relates to smoking, physical activity, and diet have become the concern of health plans, employers and the payers of health care. Besides exhorting consumers to change, using financial incentives and disincentives to shape individual behavior have become common.

Many of the behaviors required of consumers necessitate the acquisition of new knowledge and skills. For example, with new pharmaceutical approaches to treat diabetes, asthma, cancer, heart disease and HIV/AIDS, patients now must manage complex drug regimens themselves. Similarly, with today's shorter hospital stays, patients often return home sicker and must manage post-hospital drug, feeding, and wound-care regimens on their own. Finally, without interconnected electronic medical records, individual patients find that they must manage the communications among their complex array of doctors, hospitals, diagnostic and laboratory services, and health plans. This is often a huge burden for sick patients and their families. However, to fail to take on this task leaves them even more vulnerable to medication errors, duplicate tests, and gaps in their care.

Compounding the complexity is the fact that the world of health care is about to experience dramatic new insights on the genetic variation in individual response to different diagnostic and treatment interventions (Institute of Medicine, 2008). Thus, the promise of personalized medicine is within reach. However, the new insights will only be realized if the information is accessed and used in clinical choices. As existing evidence is too often ignored in clinical choices now, the inclusion of new emerging evidence into treatment options may require the active intervention of informed patients. All of this adds up to a great deal of responsibility on the patients.

These three trends, taken together, mean that consumers will have increasing responsibilities when it comes to making health care choices and in managing their health. It further means that the impact of their choices will become more consequential for their personal finances and for their health and ability to function. That is to say, the stakes have been raised for consumers. Those who are able to meet these new challenges, likely the more educated and advantaged segments of the population, will obtain higher quality health care and experience better health outcomes. At the same time, those who are less advantaged and those who have fewer literacy and numeracy skills will be further disadvantaged in the current health care environment.

What does it mean to be an active and informed health care consumer in the current health care context?

It is becoming clear that patients must be part of any meaningful solution to the challenges facing health care. Having more knowledgeable, engaged patients making informed decisions about their care and managing their health would improve both the quality of care and health outcomes. It would mean that individuals would fare better and the system would function better.

Specifically, being an engaged and "activated" consumer means that the individual understands that they must take an active approach to their health and can take on the role of being an informed advocate for oneself and one's family. It means understanding the need for a proactive approach in maintaining health and in preventing disease, in managing illness, and in working collaboratively with their providers. It means knowing how one's own behaviors can affect short and long term health. Activated consumers are cognizant of what high quality care entails, and they seek it out. They work with their physicians to make informed choices, and they arm themselves with information. They understand the health care delivery system and how to navigate it.

Being an activated consumer is not just about knowledge. In order to manage one's health, one also must pos-

sess a wide range of skills. It takes problem-solving skills to manage a chronic condition, including how to manage symptoms and how to cope. For example, a patient with a new chronic condition may have to manage complex treatment regimens, learn how to monitor symptoms, learn to emotionally cope with new limits on their life, and change many aspects of their life style. It takes literacy skills to find and use credible information. Numeracy skills are required to understand and use data about risks and benefits of clinical options. It takes decision-making skills to actually weigh those risks, benefits, and costs into a treatment choice. Further, it takes skills to change behaviors, including such skills as learning new ways of shopping and cooking or incorporating physical activity into daily living. Finally, it takes skill and self-confidence to be prepared and assertive in a medical encounter.

This will not be easily accomplished. Many of the behaviors patients are being encouraged to take on run counter to how people have been socialized to behave with regard to using health care. The traditional patient role is to be compliant, passive, and trusting. Some of the behaviors expected of consumers are antithetical to this traditional role, requiring consumers to question or challenge medical authority. For example, bringing a quality report card into a dialog about a referral to a specialist or hospital may be a threatening situation for both the patient and the physician. Even asking for a more thorough explanation during a doctor office visit or just an explanation that is understandable takes an unusually assertive patient. Changing health-related behaviors, which are often lifelong habits embedded in the social, physical, and cultural context in which people live their lives, is not easily done. We actually know quite a lot about identifying and supporting activation or engagement. Having a validated measure, the Patient Activation Measure (PAM), has provided the opportunity to gain insights into how and when activation occurs, what seems to facilitate or inhibit it, and clues as to how to go about explicitly supporting activation (Hibbard et al 2004; Hibbard et al 2005). Using the PAM and studying people's health behaviors, we have observed that those who are highly activated are overall more pro-active about their health, they are more likely to seek out and use information to inform their decisions and to engage in more healthy behaviors (Mosen et al., 2007; Hibbard et al., 2007). The highly activated are also more likely to seek a partnership with their providers and to be persistent in seeking answers when they do not understand something about their care (Hibbard et al., 2004; 2005; Becker & Roblin, 2008).

Those who are less activated (who score lower on the PAM) are much less likely to adhere to prescribed drug regimens and are more likely to have unmet health care needs (Hibbard & Cunningham, 2008). That is, they are more likely to indicate that they did not get care when they thought it was needed, and this is true even when differences in education, income and insurance status are removed (Hibbard & Cunningham, 2008). That is to say, those who are less activated are more vulnerable to barriers, they are less able to problem-solve and less able to cope with stress. Those who have a chronic illness, such as asthma or diabetes and who are less activated are also more likely to go to the emergency room and to be admitted to the hospital than those who have the same condition but are more activated (Mosen et al., 2007).

Thus the PAM, which assesses an individual's knowledge, skill and confidence for self-managing health, provides a great many insights into what it means to be an engaged and activated consumer. More importantly, research indicates that activation is changeable, and when activation changes, behaviors appear to change in the same direction (Hibbard et al., 2007). That is, when people start to feel more "in charge" of their health, they appear to change several different behaviors. Further, interventions have been successful in increasing activation, particularly interventions that are designed to increase empowerment and self-efficacy (Alegria, Polo, Gao, Santana, et al., 2008; Hibbard et al., 2007). A recent study indicated that closing the gap between Whites and African Americans on activation would also close the gap on one-third to one-half the gap in racial differences in health behaviors and health outcomes (Hibbard, Greene, et al., 2008).

The fact that activation is changeable means that it may be a key lever for bringing about change in individuals and in populations. Emerging evidence suggests that people who work and live in social-environments that are more supportive and encourage proactive health behaviors are more activated. Becker and Roblin (2007; 2008) found that workplaces, neighborhoods, and clinics where people are encouraged to take a proactive role in their health were actually more activated and engaged in more health promoting behaviors. In neighborhoods and worksites where there were opportunities to exercise and choose healthy foods, people engaged in more of these healthy behaviors. That is to say, supportive environments appear to foster activation. Supportive environments are those where there is normative support and encouragement from peers and authority figures (e.g. supervisors, physicians, etc.); there

are opportunities to engage in pro-active health behaviors or it is easier to make the healthier choice; and where others are observed engaging in pro-active behaviors (the behaviors are modeled).

Becoming adept at all the skills required of patients is not the sole responsibility of the individual. Providers, who are in a key position to influence patient behaviors, have responsibility in this arena as well. For example, patients who are receiving high quality care should be gaining in their capabilities for self-management or showing gains in activation over time. Thus, measurement of activation can potentially provide an indicator of clinician performance in their role in supporting patient self-management.

What Does this Mean for Preparing Children to Be Effective Managers of Their Health?

It has been known for some time that people with more education tend to live longer and have better health. We also know that more education is related to a greater ability to process information and to use that information in choice (Frederick, 2005).

These outcomes of education are clearly important contributors to health. However, the educational process needs to be more specifically focused on supporting the health skills of the next generation. In the past, health education was largely focused on teaching health facts. In today's world, a health fact has a very short shelf life. At the least, children must understand that their own choices and behaviors will largely determine their health and longevity. What they do in their everyday life will likely have a greater impact on their health, ability to function and their longevity than anything that doctors or medical care will do for them. In addition, they need to gain skills and confidence in all the tasks involved in managing their health and health care. Research shows that people often do know what it is they should be doing to protect their health, but they lack confidence that they can actually do it. People gain confidence in their ability to do something when they experience some success in doing it, when they see others like themselves successfully engaging in the behavior, and when they get encouragement (Bandura, 1991). Curricula can be created which specifically targets the acquisition of key self-care and healthy behavior skills. Problem solving, coping, and planning for the future are skills that are foundational to effective self-management in health.

In creating a curriculum for students to learn the basics of health and health care, schools also can strive to create an environment that is supportive of healthy behaviors. Creating a school environment where there is support and encouragement from peers and teachers for healthy behaviors would help students see that these are normal behaviors. When there are opportunities to engage in health behaviors, such as healthy food options in the cafeteria and in vending machines, then the healthy choice is the easier choice to make. When students see others engaging in healthy behaviors then this, too, makes those behaviors seem normal.

The health care environment today presents enormous challenges for consumers. Every indication is that the three trends described here (increased cost burden on consumers, increased information availability and choices, and increased complexity of the health care options and the tasks) will accelerate over time.

Preparing students to meet this challenge is essential, not only for the health of the next generation, but also for reducing racial, ethnic, and economic disparities, for the health of our economy, and for our ability as a country to meet our collective health care needs.

References

Alegria, M., Polo, Gao, Santana, et al. (2008). Evaluation of a patient activation and empowerment intervention in mental healthcare. *Medical Care, 46* (3), 247-256.

American Diabetes Association. (2004). Standards of medical care for diabetes. *Diabetes Care 27*, S15-S35.

Bandura, A. (1991). Self-efficacy mechanism in physiological activation and health-promoting behavior. In Madden, S. Matthysse, & J. Barchas (Eds.). *Learning and Affect* (226-269). New York, NY: Raven Press.

Bandura, A. (2004). Health promotion by social cognitive means. *Health Education & Behavior 31*,143-164.

Becker E., Roblin, D. (2007). *Psychosocial circumstances and health status in a managed care population*. Presented at Academy Health Annual Research Meeting. Orlando, FL.

Becker, E., Roblin, D. (2008). Translating primary care practice climate into patient activation: The role of patient trust in physician. *Medical Care 46* (8), 795-805.

Employee Benefits Research Institute. (2008). *The 2008 health confidence survey: Rising costs continue to change the way Americans use the health care system*. Retrieved October 27, 2008 from http://www.ebri.org/publications/notes/index.cfm?fa=notesDisp&content_id=3987

Frederick S. (2005). Cognitive reflection and decision making. *Journal of Economic Perspectives 19* (4), 25-42.

Hibbard, J.H. (February, 2008). Increasing patient activation: Recent findings. Presented at the Med Impact Meeting. San Diego, CA.

Hibbard, J.H., & Cunningham, P. (October, 2008). How engaged are consumers in their health and health care, and why does it matter? *Center for Studying Health Systems Change Research Brief.*

Hibbard, J.H., Greene, J., Painter, M., Perez, D., Burbank-Schmitt, E., & Tusler, M. (2008). Racial/ethnic disparities and consumer activation in health. *Health Affairs 27* (5), 1442-1453.

Hibbard, J.H., Mahoney, E., Stock, R., & Tusler, M. (2007). Do increases in patient activation result in improved self-management behaviors? *Health Services Research. 42*(4), 1443-63.

Hibbard, J. H., Mahoney, E.R., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the patient activation measure. H*ealth Services Research 40*, 1918-1930.

Hibbard, J. H., Stockard, J., Mahoney, E.R., & Tusler, M. (2004). Development of the Patient Activation Measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Services Research 39*, 1005-1026.

Institute of Medicine. (1999). *To Err is Human: Building a Safer Health Care Environment*. Need publisher information.

Institute of Medicine. (2008). *Learning health care system concepts v. 2008*. Retrieved October 27, 2008 from http://www.iom.edu/Object.File/Master/57/381/Learning%20Healthcare%20System%20Concepts%20v200.pdf

McGlynn, E.A., Asch, S.M., Adams, J., Keesey, J., Hicks, J., DeCristofaro, A., et al. (2003). The quality of health care delivered to adults in the United States. *New England Journal of Medicine, 348*, 2635-2645.

Mosen, D., Schmittdiel, J., Hibbard, J.H., Sobel, D., Remmers, C., & Bellows, J. (2007). Is patient activation associated with outcomes of care for adults with chronic conditions? *Journal of Ambulatory Care Management, 30* (1), 21-29.

Reinhardt, U., Hussey, P., & Anderson, G. (2004). U.S. health care spending in an international context. *Health Affairs, 23*(3), 10-25.Retrieved from http://content.healthaffairs.org/cgi/reprint/23/3/10.pdf

Author Note

Judith H. Hibbard

Professor of Health Policy, Department of Planning, Public Policy and Management, University of Oregon

Correspondence concerning this article should be addressed to Judith H. Hibbard, Department of Planning, Public Policy and Management, University of Oregon, 119 Hendricks Hall, Eugene, Oregon 97403-1209.
E-mail: jhibbard@uoregon.edu