Role of Consumer Information in Today's Health Care System

Judith A. Sangl and Linda F. Wolf

This overview discusses articles published in this issue of the Health Care Financing Review, *entitled "Consumer Information in a Changing Health Care System." The overview describes several trends promoting more active consumer participation in health decisions and how consumer information facilitates that role. Major issues in developing consumer information are presented, stressing how orientation to consumer needs and use of social marketing techniques can yield improvement. The majority of the articles published in this issue of the* Review *discuss different aspects of information for choice of health plan, ranging from consumer perspectives on their information needs and their comprehension of quality indicators, to methods used for providing such information, such as direct counseling and comparative health plan performance data. The article concludes with thoughts on how we will know if we succeed in developing effective consumer health information.*

Several trends have converged which promote active participation of the consumer in the health care system. First, society is stressing more prominently the concept of individual responsibility for health. Consumers are expected to assume more responsibility for their own behaviors and lifestyles (e.g., eating, exercise, and smoking habits) since these can have significant health consequences independent of any medical care. Second, the consumer movement has spread into the health care field, with many consumers (and in some cases, their advocates) requesting to be active participants in decisionmaking regarding their own health care treatments; providers can no longer presume to decide unilaterally what is the best treatment for a patient. Third, economists and other proponents of health care reform have identified informed consumer choice as one element of a better-functioning health care marketplace (Enthoven, 1993). The premise is that consumers could be motivated to compare health plans based on the cost, benefits, and quality-of-care information received, and then select health plans that give the best value. This informed choice process, in theory, would encourage health plans to be responsive to consumers' needs and to compete for enrollees on the basis of both cost and performance. Such a consumer role was an important feature of the Clinton Administration health care reform proposal. It is also one rationale for the current development of comparative performance information for health insurance plans, commonly referred to as "report cards." Many of these report cards use the Health Plan and Employer Data Information Set (HEDIS), the first set of standardized performance measures, developed by the National Committee on Quality Assurance (NCQA).

Regardless of any effects on the market,

Judith A. Sangl and Linda F. Wolf are with the Office of Research and Demonstrations, Health Care Financing Administration (HCFA). The opinions expressed are those of the authors and do not necessarily reflect those of HCFA.

some experts believe that an informed consumer should be a valued end itself (Sofaer, 1993). Benefits of active consumer involvement in health decisionmaking are believed to accrue to both individuals (e.g., improved health status, increased satisfaction with medical care, cost savings from better choices [Sofaer, 1992]) and purchasers of health insurance and providers (e.g., more productive employees, more satisfied patients).

Consumer-based information, i.e., information that has a consumer needs orientation and is useable for decisionmaking, can facilitate active involvement of consumers in their own health care and the health care system. The domain of health information is broad due to the variety of health care decisions consumers face. These decisions include which: (1) wellness, health promotion, and preventive health behaviors should be adopted; (2) treatments or services should be used for specific acute and chronic illnesses, disease conditions, or impairments; (3) providers, facilities or type of settings should be used; and (4) health insurance options (e.g., fee-for-service [FFS], health maintenance organizations [HMOs], preferred provider organizations [PPOs], and point-of-service plans) should be selected to meet their needs. These decisions are interactive and complex. The information needed to support these decisions comes from a variety of sources and requires different communication foci, styles and strategies in order to meet the needs of various groups. Consumers rely extensively on informal sources of information such as family and friends to help them make many of these decisions. To supplement these traditional informal sources, formal sources of health information have been expanding to assist consumers in decisionmaking. For consumers to use formal information in their health care decisions, research has shown that the information must be relevant, comprehensible, and credible.

Relevancy can vary widely; it is important to recognize legitimate differences in needs among the population—that "one size does not fit all"—for consumer information strategies. These needs differ along a number of sociodemographic and psychological dimensions, such as the consumer's motivation for change or stage of decisionmaking. For example, in developing a health education campaign for smoking cessation, messages should be tailored to smokers according to the stage they are in, such as those considering quitting versus those who are ready to plan quitting or in the process of staying smoke-free.

In the area of health insurance comparisons, consumers with chronic or serious disease, may think many performance measures are too general and prefer more detailed data specific to their individual concerns. A common consumer question about comparative plan information is, "Are there people like me, with my health care needs?" A person with chronic care needs may not be interested in responses of persons who are very healthy and place low demands on the health care system. On the other hand, currently healthy consumers should be concerned about how well a health plan treats persons who are ill, particularly with serious or chronic medical conditions. Griss (1996) and others have suggested that the litmus test for consumers should be, "How does the plan perform when I am sick?" This raises at least two issues: (1) adequacy of measures of quality of care for persons with serious illnesses or chronic conditions, particularly when current measures emphasize prevention and process rather than outcomes, and (2) ability to measure and present performance indicators for special subpopulations despite problems with small sample sizes. Findings by

Ware et al. (1996) underscore the need to look beyond averages. The study showed that, although outcomes were equivalent for the average chronically ill patient in HMOs and FFS, outcomes for elderly and poor chronically ill patients were worse in HMOs than in FFS.

Risk adjustment of performance indicators to reflect the underlying population is recommended for health insurance information, but is in its infancy. The pursuit of better measurement of health care quality processes, and particularly outcomes, for use in internal quality improvements and comparison of health plans must be continued. For instance, NCQA, with the release of HEDIS 3.0, has refined quality performance measures by including additional reporting measures and an additional set of testing measures, with more emphasis on outcomes. Major challenges for performance measures will be: (1) how to get objective and comparative data for both FFS and managed care systems; and (2) how to provide quality indicators at the level of medical groups or even individual providers, where care is actually delivered.

The movement to managed care provides additional challenges and issues. Consumers need information on managed care processes (e.g., the role of the primary care physician, specialist referral, out-of-network restrictions and rights to appeal decisions not to provide or pay for a service), incentive structures for managed care providers, and benefit details (e.g., copays based on either wholesale or retail drug prices). These details are likely to be relevant to consumers' health insurance choices. New York and several other States have passed legislation which requires health plans to provide such detailed information to current and prospective enrollees, and the American Association of Health Plans has announced support for provision of such information to consumers.

If the information provided is relevant but is not comprehensible, consumers are likely to simply ignore it, or perhaps draw the wrong conclusions. We should realize that "data" are not automatically equivalent to information but need to be translated to the needs of the consumer. Data have to be put in the context of why it is important to the health care needs of beneficiaries. More information is not necessarily better information. Consumers are limited in the amount they can process at a given time, even if the information is created expressly for their needs. The theory of consumer information processing recommends combining related bits of information into "chunks" in order to make choices faster and easier. Decision support techniques will likely be needed to assist consumers to break down the cognitive choice task into small steps, identify their values and preferences, understand trade-offs between different options and guide them in making health care decisions (Hibbard, 1996). Decision support techniques have been designed for making medical treatment decisions, such as the Comprehensive Health Enhancement Support System (CHESS) for breast cancer, and for health insurance choices, usually in the form of worksheets.

Some groups, such as the "oldest-old" (85 years of age or over) or those with less education, may have more difficulty than others dealing with the complexity of the information. They may prefer to rely on their doctor's advice or may choose family members or others to act as decisionmakers on their behalf for health care matters. Such groups or their advocates require special attention in consumer health information development.

The issue of trust and credibility of information is critical. Consumers may discount or ignore information if they believe that the person or organization which is the source of the data has a financial stake in their decision (e.g., by earning commissions from their enrollment). They also may be suspicious of data that they do not perceive as reliable or timely.

In order to address consumers' demands for reliable (i.e., standardized) and credible (i.e., audited) data, a consumer information infrastructure for plan and provider choices is now being developed. The Consumer Assessment of Health Plans Study (CAHPS), sponsored by the Agency for Health Care Policy and Research (AHCPR), will test and standardize survey questionnaires and report formats that can be used to collect and report meaningful and reliable information from health plan enrollees about their experiences and satisfaction with care. In addition to a basic core questionnaire, supplemental modules for Medicaid and Medicare beneficiaries and persons with chronic disease are being designed to provide additional information for these groups. AHCPR and HCFA are jointly sponsoring the development of a Medicare version of the CAHPS survey. AHCPR will also develop data collection procedures and prepare a user's manual. To establish credibility for its beneficiaries, HCFA will independently audit the HEDIS data submitted in 1997 from the Medicare managed care plans, as well as independently conducting the Medicare version of the CAHPS survey. NCQA is developing audit standards for validation for which they will train and certify others to conduct.

An orientation to consumer needs is essential to assure that information will be relevant, comprehensible, credible, and useable to consumers. In the health care field, however, less attention has been focused on the consumer because of the reliance on an expert-driven orientation, or a "we know what they need" approach (Lefebvre and Flora, 1988). Progress in consumer information for health behavior and insurance choice can occur by systematically following a consumer needs orientation, combined with social marketing techniques. The basics of social marketing include the three phases of research and planning, strategy design, and implementation and evaluation (Walsh et al., 1993).

The first phase includes analysis of consumers, the market and channels of communication. Identifying and understanding homogeneous subgroups within populations by demographic, psychosocial, and other characteristics (e.g., stage of readiness for change) is important for designing effective communication strategies. Although this specification of audience segments requires more effort, the result should be greater effectiveness in communicating to target groups. In some cases, a family member or advocate may be the user of the information materials rather than the individual. Examination of communication channels is important to determine which are best suited for reaching the target groups. For example, one research study showed that, of five communication methods tested for presenting HMO plan information, each one was most effective with enrolling a different type of Medicaid beneficiary (Andrews et al., 1989).

The second phase of strategy design involves testing the concepts and information product prototypes with the target groups prior to full-scale implementation. The objective of informed choice cannot be met without adequate pretesting for consumers' comprehension. Pretesting permits refinement and modification of the information strategy.

The third phase is the actual implementation of the information strategy and evaluation of process and outcomes. Process evaluation can identify both the strengths and weaknesses of a program's implementation. Carefully controlled outcome studies can provide the ultimate test of whether an information strategy actually makes a difference in what consumers do or even gives them confidence in their decisions. For instance, many consumers who use report card information may decide to stay in their current health plans because they are reassured by comparisons with other plans.

The lead article by McMullan in this issue discusses the HCFA approach to consumer information and current activities in the area. It emphasizes how HCFA has incorporated a beneficiary-centered focus and social marketing techniques in its activities. The next seven articles in this issue of the *Review* discuss different aspects of information for choice of health plans. McCormack, Garfinkel, Schnaier, Lee, and Sangl describe a number of the early efforts in comparative health plan and provider information materials at the State, community, and large purchaser levels. Initially, these efforts were developed to assist employers and other large purchasers in making health insurance contracting decisions for their constituencies on factors in addition to cost, such as quality, access to care, utilization, and financial measures. They have evolved to be disseminated for use by consumers in choice of health insurance and providers. The authors conclude, however, that the efforts have yet to be rigorously evaluated to determine if these information tools constitute "best practices," i.e., that they are useful to the consumer in decisionmaking.

Sainfort and Booske provide some insight into how consumers make health insurance decisions. They examined the relationship between information and problem perception, preference structure, choice of plan, and attitude towards the decision. One of the key findings is that, initially, consumers are not able to describe fully the features of plans that are important to them. However, provision of information about additional features makes them realize that these features are important as well. The policy implication of this finding is that consumers can be educated to consider additional features in health insurance choices, such as quality-of-care indicators.

Instead of relying on experts declaring what health information is needed by consumers, the trend is to ask consumers directly. Using results from 22 focus groups of Medicare, Medicaid, and privately insured individuals, Gibbs, Sangl, and Burrus provide consumers' perspectives on what information they view as important in selecting health plans. They describe possible barriers to use of comparative health insurance information and recommend how to provide this information in a user-friendly way.

Jewett and Hibbard describe in more detail the problems consumers have comprehending quality-of-care indicators. One factor is that many individuals, accustomed to the FFS system, are unfamiliar with the organization of the health care delivery system under a HMO and its variations. These individuals may have difficulty understanding the context of managed care and how a health plan's practices and incentives can influence their health outcomes. They tend to attribute health care outcomes solely to their doctors or think certain behaviors are primarily the individual's responsibility, e.g., getting preventive care such as childhood immunizations at the appropriate times. Such tendencies are discussed in the article by Jewitt and Hibbard, with the recommendation that consumers need to be educated about this concept of plan accountability. The authors found that comprehension of quality-of-care indicators varied with differing access and experiences with care, indicating the need for additional educational efforts for certain groups to use this type of information effectively.

Hibbard, Sofaer, and Jewett elaborate on how condition-specific performance measures are perceived by the general population without that disease condition. Their research found that a description of the health care context of breast cancer performance measures improves consumers' understanding of what the indicators represent for overall quality of health care.

Since consumer information is not free and involves resources for development and dissemination, it is necessary to evaluate cost effectiveness of the different types of information efforts. Knutson, Fowles, Finch, McGee, Dahms, Kind, and Adlis discuss the merits of multiple employer-specific report cards in comparison to a single community-wide report card for health plans. The authors describe how the latter could be viewed as less costly to produce than the former but may not be perceived as useful by the consumer.

Federal grants to States for Medicare beneficiary counseling programs began in 1992 in response to beneficiaries' needs for information on the Medicare program, their supplemental insurance options, and publicly sponsored health insurance programs for the poor. In the first evaluation of these health insurance counseling and assistance (ICA) programs, McCormack, Schnaier, Lee, and Garfinkel conclude that they have been effective in providing needed information to Medicare beneficiaries and fill an important gap in the community. The services generally include face-to-face counseling, a medium which the elderly particularly prefer for receiving complicated health insurance information.

Decisions about long-term-care (LTC) services, settings, and providers are just as complicated, if not more so, than decisions about acute health care. Qualitative research by Maloney, Finn, Bloom, and Andresen provides insights about how the elderly and their caregivers make decisions about LTC. The authors identify four decisionmaking styles related to the degree of planning. This research illustrates the need to understand audience segmentation, which can be used to tailor information for LTC care decisions for these different styles.

The final article on consumer information by McCormack, Fox, Rice, and Graham illustrates how reliance on consumer information disclosure was not sufficient to correct the Medicare supplemental insurance market problems. The authors describe the impact of the mandatory standardization on Medigap policies. Although standardization limited the number of insurance options, it facilitated informed consumer choice by permitting easier comparisons of policy benefits and premiums.

In the long term, we will see if we are succeeding in providing consumers with effective information for healthy behaviors, medical treatment alternatives, and health insurance options by looking for evidence on several levels (Sofaer, 1996). The evidence includes:

- Consumers will have greater confidence in their own ability to maintain their health and manage the health care services they need.
- More consumers will be satisfied with health insurance decisions they have made, or they will believe that they can choose a good health plan even if they don't like their current one.
- Consumers will have greater confidence in the health care system overall

because of its responsiveness to performance data. Health plans and providers which are judged to perform poorly will either improve or leave the market. The performance of good plans and providers will be maintained or improve in order to maintain or increase their market share.

We must also remind ourselves that, as valuable as consumer information is, it alone is not likely be sufficient for creating a better functioning health care marketplace (Epstein, 1995) due to difficulties and imperfections in information development as well as dissemination to and processing by consumers. One strategy, proposed by Rodwin (1996), is creating consumer advocacy organizations to pool resources and expertise for consumers to be strong enough to make insurers and providers responsive to consumer health interests. Hibbard (1996) also believes there may be a role for such intermediaries to process and screen information for assisting consumers with their health insurance choices because of the difficulty of the task.

Policymakers need to continue and consider other strategies for health care quality oversight and monitoring and cost control. In fact, most Americans (88 percent) believe there is a role for the Federal Government in the quality of health care (Kaiser Family Foundation and AHCPR, 1996). Most of them (52 percent) believe that the government should both monitor health providers to ensure a minimum standard of quality and make sure information about quality is available so persons can make judgments about quality themselves. A multiple approach of release of information to consumers for health care choices, combined with strong consumer advocacy organizations and public and private standards for health care will be needed to improve the health care marketplace.

REFERENCES

Andrews, R., Curbow, B., Owen, E., and Burke, A.: The Effects of Method of Presenting Health Plan Information on HMO Enrollment by Medicaid Beneficiaries. *Health Services Research* 24(3):311-327, August 1989.

Enthoven, A.: The History and Principles of Managed Competition. *Health Affairs* 1993 Supplement: 24-48, 1993.

Epstein, A.: Performance Reports on Quality—Prototypes, Problems and Prospects. *New England Journal of Medicine* 333(1): 57-61, July 6, 1995.

Griss, R.: Reaching Vulnerable Populations With Unique Information Needs. Presented at "Value and Choice: Providing Consumers With Information on the Quality of Health Care"—Conference sponsored by the Henry J. Kaiser Foundation and the Agency for Health Care Policy and Research, October 29-30, 1996.

Hibbard, J.: Drawing Inferences From Quality Measures: The $640,000 Question. Presented at "Value and Choice: Providing Consumers With Information on the Quality of Health Care"—Conference sponsored by the Henry J. Kaiser Foundation and the Agency for Health Care Policy and Research, October 29-30, 1996.

Kaiser Family Foundation and Agency for Health Care Policy and Research: Americans as Health Care Consumers: The Role of Quality Information. Presented at "Value and Choice: Providing Consumers With Information on the Quality of Health Care"—Conference sponsored by the Henry J. Kaiser Foundation and the Agency for Health Care Policy and Research, October 29-30, 1996.

Lefebvre, R., and Flora, J.: Social Marketing and Public Health Intervention. *Health Education Quarterly* 15(3):299-315, Fall 1988.

Rodwin, M.: Consumer Protection and Managed Care: The Need for Organized Consumers. *Health Affairs* 15(30): 110-123, 1996.

Sofaer, S., Kenney, E., and Davidson, B.: The Effect of the Illness Episode Approach on Medicare Beneficiaries' Health Insurance Decisions. *Health Services Research*, 1992.

Sofaer, S.: Informing and Protecting Consumers Under Managed Competition. *Health Affairs* 1993 Supplement: 76-86, 1993.

Sofaer, S.: How Will We Know If We Got It Right. Presented at "Value and Choice: Providing Consumers With Information on the Quality of Health Care"—Conference sponsored by the Henry J. Kaiser Foundation and the Agency for Health Care Policy and Research, October 29-30, 1996.

Walsh, D., Ruddy, R., Moeykens, B., and Moloney, T.: Social Marketing for Public Health. *Health Affairs* 12(2):104-119, Summer 1993.

Ware, J., Bayliss, M., Rogers, W., et al.: Differences in 4-Year Health Outcomes for Elderly and Poor, Chronically Ill Patients Treated in HMO and Fee-for-System. *Journal of the American Medical Association* 276(13):1039-1047, October 2, 1996.

Reprint Requests: Judith A. Sangl, Office of Research and Demonstrations, Health Care Financing Administration, 7500 Security Boulevard, C3-24-07, Baltimore, Maryland 21244-1850.