
Family Members and Friends Who Help Beneficiaries Make Health Decisions

Shoshanna Sofaer, Dr.PH., Barbara Kreling, Erin Kenney, Ph.D., Elaine K. Swift, Ph.D., and Tracey Dewart, Ph.D.

People enrolled in Medicare often turn to family members and friends for help in making health decisions, including Medicare health plan choices. To learn how family members and friends participate in decisionmaking, what information they currently use, and what information they would like, we held eight focus groups in San Diego and Baltimore. Although responses were different in the two markets, participants in both cities reported receiving inadequate information and indicated they were largely unaware of available CMS-supported information. Beneficiaries want easy-to-use print materials targeted to their needs and opportunities to participate in seminars and receive personal counseling.

INTRODUCTION

People enrolled in Medicare frequently turn to family members and friends when making a wide range of health-related decisions, including decisions about health care coverage. This is not surprising, given the many factors that can limit the ability of many older and disabled Americans to access and use complex information to make consequential decisions. These factors include:

- Serious limitations in both general literacy (National Center for Education Statistics, 1993) and health literacy (Jackson et al., 1994; Parker, 1997; Williams et al., 1995).

Shoshanna Sofaer, Barbara Kreling, Erin Kenney, and Tracey Dewart are with Baruch College. Elaine K. Swift is with the Institute of Medicine. The views expressed in this article are those of the authors and do not necessarily reflect the views of Baruch College, the Institute of Medicine, or the Centers for Medicare & Medicaid Services (CMS).

- Being in only fair or poor health (National Center for Health Statistics, 2000).
- Having a sensory impairment (National Center for Health Statistics, 2000).
- Having a mobility impairment (National Aging Information Center, 2000).
- Perhaps most significantly, having a cognitive impairment (Kelman et al., 1994; Perkins et al., 1997; Gallo and Leibowitz, 1999).

However, little is known about the characteristics of those family members and friends who assist beneficiaries, what they do for these beneficiaries when they face difficult health care coverage decisions, and what support helpers might need to play their role more effectively.

To explore these issues, we designed and conducted eight focus groups with family members and friends of beneficiaries. The specific research questions we addressed included the following:

- What is the range of roles played by family members and friends in helping a beneficiary make a health care coverage decision? How comfortable do the family and friends feel in playing these roles?
- What kinds of coverage choices do these people help beneficiaries make? What triggers the need for support in making a coverage choice?
- What kinds of information have family and friends used in reviewing the coverage options available to their friends and relatives and from what information sources? How useful has this information been?

- How much do family members and friends know about and understand the coverage options available to beneficiaries? What are the attitudes of family and friends to these options?
- How have their own experiences in making health plan choices influenced or informed what they do when they are helping a beneficiary?
- What kinds of information and decision support would family and friends find useful to have when they are helping a beneficiary make a coverage choice? What media would be most useful and accessible to them? What information sources would they trust?

The results of these groups have implications not only for the development of the CMS National Medicare Education Program (NMEP) but for the work of countless publicly funded and community-based organizations. These organizations do, and could, play a role in supporting beneficiaries as well as family and friends, who often help the most vulnerable make significant health care coverage decisions. Although the research questions we addressed dealt with health care coverage choices, it may well be that the experiences of family members and friends in supporting choices of provider or facilities are similar.

BACKGROUND

Generally, family members and friends who support beneficiaries are viewed as informal “caregivers.” We therefore turned to the literature on caregivers for older people and people with disabilities for potential insights into the characteristics and needs of family members and friends who help beneficiaries with health care coverage decisions. There is a considerable literature on roles played by informal caregivers in the lives of those they assist, as well as on the impact of care-

giving on their own lives and even health. Caregivers are responsible for providing a range of supportive services, personal care, complex and skilled health care, and financial management. Horowitz (1985) conceptualized caregiving behavior as falling into four broad categories: emotional support, direct service provision, linkage with the formal sector, and financial assistance. Many caregivers find that they are unprepared for their new roles of decisionmaker and/or caregiver (Schmall, 1995).

The burdens of caregiving (both objective and perceived) have been documented in many studies (Archold, 1983; Stone, Cafferata, and Sangl, 1987; Brody et al., 1992; Jones et al., 1995). So have the positive aspects of caregiving, such as pride in one’s ability to meet challenges, self-worth (Louderback, 2000), and experiencing closer relationships (Archbold, 1983; Motenko, 1988). In addition, studies have examined how social support, as well as formal services such as respite care and information, can help alleviate the burdens of caregiving. Nevertheless, most studies conclude that the welfare of family caregivers needs to become a central societal goal (Robinson, 1997) and that, without appropriate supports, the caregiver will otherwise become the “hidden patient” (Fengler and Goodrich, 1979).

Research findings have led to intervention studies aimed at reducing caregiver stress (Toseland, Rossiter, and Labrecque, 1989), promoting competence, and enhancing caregiver well-being. More research is needed that examines how to enhance or increase the positive aspects of care provision or that identifies caregivers who are more or less likely to need intervention (Kramer, 1997). Recently, computer-based interventions have been designed to increase caregiver confidence in decisionmaking and social support (Brennan, Moore, and Smythe,

1995). Haug notes (1994) that the occurrence and effect of patient or caregiver involvement in decisionmaking, whether positive or not, is unknown.

Caregivers may encounter many barriers to gaining access to community-based services, such as services available to help people with Medicare-related information and decisions. One large-scale intervention project found that caregivers were difficult to reach and serve, tended not to use available services in the community, and sought help only in times of crisis, when they were fairly desperate (Montgomery and Borgatta, 1989). In one study, 36 percent of caregivers did not know whether services were available or not. Awareness and access alone, however, do not always lead to utilization (Caserta et al., 1987). Caregivers even find it difficult to obtain information from professionals. Toseland and Smith (1991) noted that merely providing information about community services is not enough. Springer and Brubaker (1984) reported that many caregivers have difficulty thinking about and identifying their specific needs. In the absence of services and support, decisions are often made with insufficient time, information, or alternatives (Robinson, 1997).

Although the provision of assistance in managing resources and decisionmaking is frequently identified as a critical role, this aspect of caregiving is not well defined or described. Research has begun to specify the different types of resources available to help caregivers assist in decisionmaking about health care plans. More research is needed on the most appropriate types of services and acceptable means of delivering those services to caregivers (Robinson, 1997).

As previously noted, the particular focus of our study was on access to and use of information by family friends and members. Very few studies have examined the

use of information by caregivers, but in general it would appear that perceived access to and use of information is limited. In one study, 25 percent of adult children caregivers said that their parents needed help with health information. One-third of adult children said they didn't know where to get such information (Barrett, 1998). Less than one-quarter of Alzheimer's caregivers have requested information about how to get financial help for their health care recipient (Alzheimer's Association and National Alliance for Caregiving, 1999).

A few studies have explored health information sources that caregivers find useful. One study (National Alliance for Caregiving, 1998) found that caregivers identified several channels as useful. These included written materials (81 percent) such as pamphlets (43 percent), magazine articles (24 percent), books (22 percent), and newspaper articles (8 percent); and watching or listening to television, radio, or tapes (69 percent). More than one-half would like their information over the telephone or in a face-to-face meeting or presentation. Compared with people enrolled in Medicare, a considerably higher number of caregivers (one-third) wanted to receive information on the computer or over the Internet.

In a study conducted by AARP (Wright and Howe, 2000) consisting of focus groups and surveys with caregivers, a majority of participants indicated that they would like to receive information about Medicare. Specifically, these caregivers preferred information sources such as doctors' offices, hospital social workers, insurance companies, the *Medicare & You* handbook, retiree benefits administrators, social services departments, friends, and the telephone book. Few focus group caregivers were aware of the Medicare toll-free telephone number or Web site. Caregiver information needs included specific

information when they need it; information tailored to their specific needs/situations; information about how to read and interpret Medicare forms; and information about Medicare eligibility, coverage, and out-of-pocket expenses. Caregivers indicated that they would like to receive information from doctors' offices, pharmacies, television and radio, an interactive Medicare Web site, libraries, newspapers, hospitals, and AARP.

In another study, 9.0 percent of caregivers expressed a need for a central information source of services available to care recipients, 7.6 percent expressed the need for information about paying for services such as nursing homes and adult day care, 3.2 percent wanted information about medications, and 2.7 percent wanted information about a care recipient's condition (National Alliance for Caregiving and the American Association of Retired Persons, 1997). In a later study by the same organization, of caregiving women aged 33-51 years, 6 in 10 participants said that information on paying for long-term care or managing prescription medicines would be helpful to them, more than one-half said that information on finding and evaluating nursing homes or assisted living facilities would be helpful, and almost one-half wanted information on buying long-term care insurance (National Alliance for Caregiving, 1998).

In sum, although there is a good deal of general information about informal caregivers who are often family members and friends of Medicare beneficiaries, there is relatively little about the specific issue of whether and how they actually provide support to beneficiaries who are trying to choose among different health care options. Even for beneficiaries who are not particularly frail or limited in functioning, this choice can be challenging. Years of research have documented the lack of

knowledge of the Medicare program among those it serves (Cafferata, 1984; Marquis, 1983; McCall, Rice, and Sangl, 1986; Sofaer, Kennedy, and Davidson, 1992).

More recently, concerns have focused on how difficult it has become for many beneficiaries to understand the differences between different types of health care plans, particularly Medicare managed care plans and the Original Medicare fee-for-service program (Hibbard et al., 1998). Yet such decisions are quite consequential in terms of costs, differences in access to providers, and ground rules for using services. The overall study under which these focus groups were conducted was designed to identify what kinds of information materials and dissemination strategies might be effective in helping beneficiaries understand these differences, make comparisons, and ultimately make choices. Our own and others' previous research makes it clear that this is a challenging task, if one assumes that it is the beneficiary her- or himself who will bear the entire burden of becoming aware that information is available, accessing the information, understanding it, and applying it to a decision (Dewart and Sofaer, 2000; McGee, Sofaer, and Kreling, 1996; Sofaer, 1999b; Sofaer, 2000).

METHODS

In addressing the research questions listed in the introduction, we were concerned not only about family members and friends in general but how the characteristics of their roles, their own experiences with Medicare, their education levels, and the market context in which they were providing support influenced their experiences and responses. Given limited previous research, this work was considered exploratory. Focus groups and other

qualitative methods are particularly well suited to exploratory research, in which questions need to be open-ended to avoid limiting the range of responses prematurely (Sofaer, 1999a). In analyzing focus groups, it is important to avoid quantifying a distribution of responses to a particular question. This can lead to the illusion that the data being presented are known to be representative of a larger population, rather than simply providing, for a limited number of purposively selected participants, an indepth picture of their experiences and understandings.

Sample Selection

A critical aspect of conducting focus groups is to specify the inclusion and exclusion criteria for participants. In this study, we determined that it would be important to conduct focus groups in two different markets, distinguished primarily by the extent of managed care penetration. In one market, San Diego, Medicare managed care plans have been actively operating for more than 15 years. Furthermore, managed care is a very common way of getting health benefits for working-age groups and has been present in the market for decades. We reasoned that people in a high-managed-care-penetration market would have a higher degree of familiarity with the basic differences between this kind of health plan and more traditional fee-for-service. Familiarity might affect not only knowledge levels but attitudes as well. We deemed it likely that many people helping beneficiaries would themselves be enrolled in a managed care plan. In the second market, Baltimore, although several managed care plans were then available to beneficiaries, such plans were relatively new entrants into the marketplace. Similarly, although people with employer-based insurance might have experience

with managed care, this was less likely and was likely to have been a more recent experience. Four groups were held in each of these two markets.

Within each market, other selection criteria were used to structure four groups with a desired 8-12 persons in each group. In all cases, individuals were excluded from groups if they had participated in a focus group for any purpose within the previous year or if they had ever participated in a health-related focus group. All participants were screened carefully to increase the likelihood that they had helped or might actually help beneficiaries with a coverage decision. The screener probed for specific experiences, including going to the doctor with the person; helping them make medical care decisions, such as having surgery or a diagnostic test; calling or meeting with someone to obtain specialized care for them; filling out medical insurance forms; and calling or meeting with someone to get information about what their health insurance covered. If a respondent had none of these experiences, they were not included in the group. Similarly, we asked whether the person they helped had Medicare Part A, Medicare Part B, Medicaid, or a supplement to Medicare. If the respondent did not know the answers to any of these questions, they were excluded from the group.

Within each market, we further divided the four groups so that one was limited to people age 65 or over (thus almost certainly covered by Medicare themselves) who had helped another beneficiary, and the other three included only people under age 65. Of the remaining three groups in each market, one was reserved for people who actually made decisions for their family members and friends, rather than simply helping with decisions to some extent. This group was overwhelmingly female in both markets, and almost all were making decisions for parents.

However, three were making decisions for grandparents, and one each for a godparent, a sister-in-law, and a friend. To a greater extent than in the other groups, these individuals were hands-on caregivers, typically for a frail or seriously unwell person. As documented in the literature, this group of people is typically juggling multiple obligations. Attending a focus group is unlikely to be an attractive way for them to spend time away from these obligations, even given the \$50 incentive paid for participation.

The remaining pair of groups in each market was divided by education level of the participant. Specifically, one group was designed to include individuals who had a high school education or less; in fact, all participants in this group had graduated from high school. The other group was for individuals who had some education beyond high school and included both college graduates and those with some college. Many studies have documented that education level has an effect on understanding of Medicare and on the ability to acquire and use new information about Medicare choices. CMS materials and dissemination strategies, however, must reach not only those who find these tasks relatively achievable, but those who find them quite challenging. Finally, we screened to ensure participation of individuals who were not white, including Hispanic persons, especially in San Diego. Table 1 summarizes, for each relevant dimension, the number of groups, the number of persons with given characteristics across the 8 focus groups, and the percent of the total 67 participants with a given characteristic.

Focus Topics

A focus group moderator's guide was developed and refined. The topics included in the guide tracked the research questions listed in the introduction of this arti-

cle. During the focus groups, in addition, we displayed sample pages from the *Medicare & You* handbook in order to get reactions to the value of comparative quality ratings.

Focus Group Recruitment and Moderation

Participants were recruited through focus group firms in the two cities. These firms also served as the location for the groups and paid participants their incentive. The facilities were structured so groups could be observed through a two-way mirror. Facility staff both audio- and video-taped all groups. Participants were assured of confidentiality of their responses; permission was requested from all participants before taping began. We asked people to use first names only as an additional protection of their anonymity. Groups were conducted by two facilitators, one in Baltimore and one in San Diego, using the same moderator's guide. Both facilitators not only have considerable general experience in conducting focus groups, they both have experience in conducting focus groups addressing issues related to Medicare and health care information, and both have participated in developing materials to help beneficiaries understand their health care coverage options.

Analysis

Content analysis of the videotapes served as the basis for the cross-site analysis of the focus group findings. The facilitator of the Baltimore groups reviewed all eight tapes (typically twice), made detailed notes on them, and used those notes to identify themes and patterns across the groups. In addition, she had a summary report from the facilitator of the San Diego

Table 1
Focus Group Participant Characteristics

Dimension and Characteristic	Number of Groups	Number of Participants	Percent of Participants N = 67
Market			
Baltimore	4	29	43.3
San Diego	4	38	56.7
Age			
65 Years or Over	2	16	23.9
Under 65 Years	6	51	76.1
Sex			
Female	—	45	67.2
Male	—	22	32.8
Role for Those Under Age 65			
Make Decisions	2	21	31.3
Help with Decisions	4	46	68.7
Relationship			
Spouse	—	11	16.4
Children	—	33	49.3
Other Family	—	18	26.9
Friends	—	6	9.0
Race/Ethnicity			
White	—	36	53.7
Hispanic	—	15	22.4
Black	—	16	23.9
Education Level			
More Than High School	2	16	23.9
For Under Age 65 Helpers			
High School Graduate	2	14	20.9

SOURCE: Sofaer, S., et al., Baruch College, New York, 2001.

groups that described each of the four groups held there. The draft report on findings was reviewed by the other facilitator, by our CMS project officer who observed some of the groups in Baltimore, and by the study director. The focus of the analysis was on identifying areas of convergence and divergence within each group, between groups of different composition, and between groups held in the two markets.

RESULTS

Range of Roles

In part because of sample selection, group members represented a wide range of involvement in helping beneficiaries

make health care coverage decisions, from those who provided virtually no help at all for this particular kind of decision to those who had power of attorney and actually made the decisions for the beneficiary. Roles played included gathering and reviewing information from a variety of sources; making telephone calls to follow-up on questions; reviewing options with physicians and social workers; discussing options with the person they were helping; and making recommendations to them. The range of help provided varied, based both on the characteristics of the caregivers, e.g., how much time they had available, their level of comfort in seeking out information of this kind, their expertise in related areas such as social services or insurance in general; and on the character-

istics of the person being helped, in particular their ability to acquire and comprehend complex information materials and their level of comfort in making decisions of this kind. Participants reported that those they helped were often uncomfortable using the telephone (especially using automated telephone systems with “buttons to push”) and were often confused by materials to which they had been exposed. Participants noted that in some cases, older persons who were able to make decisions about other areas of life required help with health insurance decisions because such issues were so complicated.

Participants varied in the level of comfort they expressed in their helping role. Most expressed comfort in the role; some went further and said it was both a responsibility and a privilege to help their older relatives in this way. As one woman put it: “It’s amazing how roles switch. If only I’d listened to my mother as much as I expect her to listen to me!”

On the other hand, in part because these participants take the role seriously, they do experience anxiety, especially when they think they do not have adequate information. This is most strongly felt among those who must make or help make decisions in crisis situations. It is also experienced by people helping older persons who are uncomfortable with change. But even those not facing these circumstances express worry about whether they have really done all they should do and whether they had made or helped to make the “right” decision for the beneficiary.

Coverage Choices

People helped their family members and friends choose between Original Medicare and Medicare managed care, including deciding between Medicare plus a supplement and joining a Medicare health main-

tenance organization (HMO). In addition, in Baltimore, people sometimes had another choice, enrolling a family member or friend, where eligible, in a State Pharmacy Assistance Program. A few participants also considered the Medicaid program or retiree benefits as an option.

Triggers for Help and Information

A wide range of events were triggers that led family members and friends to provide assistance. Several triggers were major life transitions, such as becoming eligible for Medicare; the death or retirement of a spouse; or in the case of those helping grandparents, the death of their own parents, who had been the caregivers to that point in time. Declines in health status, especially when these required the beneficiary to move closer to their child or other caregiver, were another trigger, as was the need to move a relative into a nursing home or assisted living facility.

Other health-related triggers included increasing cognitive impairments or increased need for expensive prescription medications or tests. In a few cases, children began helping when the parent began to experience a problem with the health care system or when premiums or copayments rose steeply. It is interesting to note that in some cases, group participants initiated their involvement in health care coverage decisions, rather than responding to a request to help, because they had become concerned about the quality of decisions those they were helping were making, or might make. In this set of focus groups, HMO withdrawals from the market were not mentioned, although there had been withdrawals in the Baltimore market. In some cases, participants indicated that they had been told that they had to make a choice or that they had to choose an HMO, although exactly the opposite has been stressed in the NMEP.

We found some evidence of patterns in the triggers across kinds of participants or markets. Decisionmakers in both markets were more likely to be reacting to crises rather than having time to explore alternatives and “comparison shop.” Participants in San Diego, where managed care is more established and familiar, were also more likely to recognize that they had choices and had to “be consumers” and “comparison shop.” Those in Baltimore were more likely to be overwhelmed by the choices they faced and seemed uncomfortable making such choices.

Availability and Sources of Information

At least some participants in all groups, and all participants in many groups, reported that they did not have enough information to play the role they had chosen. In many cases, but especially among those actually making decisions, participants reported considerable time pressure to make a decision and a sense of inadequacy even in knowing what questions to ask. Among those under age 65, several were surprised that simple comparison charts, such as they receive from their employer when they are choosing their own health benefits, were not available for beneficiaries. Noting the pressure of multiple obligations, participants expressed a need for information that was easy to understand and that had everything they would need to know about the specific options available to them in one place (details about the topics of greatest interest are discussed later in this article). Group members did not perceive that such information was available to them. It is important to know that the perceived inadequacy of information available, combined with the complexity of the issues, often led people to give up on the task and simply remain with current coverage or accept the first option offered (e.g., sign up for an HMO that sends a brochure in the mail).

A wide range of information sources was used, however, including physicians, hospital discharge planners, friends, HMOs, the Social Security office, senior centers, and other social service agencies. In Baltimore, where there is a State Pharmacy Assistance Program, social workers associated with that program were also cited as a source of information and assistance. However, the existence of the program also created a different, and somewhat more complex, decision context, which sometimes led to even greater confusion about what options were actually available and how they might be assessed.

Those over age 65 also used such sources as AARP and the public library and were more likely to report receiving and at least scanning *Medicare & You*. In San Diego, a publication called *Senior World* periodically includes comparison charts for locally available HMOs and in some cases, supplementary or even long-term care policies. Participants in San Diego groups mentioned that they used these charts.

Several participants in the groups for those under age 65 expressed concern that, unless their parents were living with them, the participants had no access to materials the beneficiaries received in the mail. They thus did not know when something such as the *Medicare & You* handbook had been delivered, or when HMOs or other insurers were sending promotional materials, or even when the person being helped was facing problems with claims, unless the older person chose to share that information with them. Several noted that to some extent, those they helped were ambivalent about sharing information they received, noting that a relative “only lets me see what she wants me to see.” For example, not one member of the group in Baltimore with helpers who had relatively less education had seen *Medicare & You*. When the moderator showed it to them at the end of the group, one said, “Now this is a

wonderful book. The people who have to make decisions never see it. I'm sure my mother threw it in the trash."

In addition to mailings from CMS, participants did not have the same access as beneficiaries to publications such as *Senior World* or in some cases to information from health plans warning of impending changes. They reported being frustrated at not knowing about such changes before they took effect.

Less than a handful of people knew about or used State Health Insurance Assistance Programs (SHIP) agencies at the local level. In fact, one participant seemed to presume, incorrectly, that the local SHIP was not available to people under age 65 and wished it were. None of the participants had used the Internet to gather information (including the Medicare Compare Web site), but some indicated they would be willing to do so.

Those with parents who did not speak English also reported frustration that materials were not available in Spanish. One woman said, "I try to translate the information for my Dad, and he says, 'It's inglés, it's inglés,' (English) and throws it away." If it were in Spanish, she noted, she could read it to him and "he would feel more comfortable that he was hearing exactly what was written." Given that some Spanish language materials have been developed by CMS, as well as by local agencies in areas with high percentages of Hispanic residents, it appears that beneficiaries are not always aware of available sources of such materials.

Not all participants reported frustration with respect to their roles, however. In one group, those with higher education levels in San Diego who were helping make decisions, almost all of the group members had steered those they were helping into the Kaiser Permanente Medicare HMO in the area and felt very comfortable with this

choice. The Kaiser plan, unlike more recently developed HMOs, is a tightly integrated group model. (Many people consider Kaiser to be a staff-model HMO. However, the Kaiser Foundation, the not-for-profit corporate entity that is the risk-bearing health plan, has contractual agreements with Kaiser Permanente Medical Groups, which are independent corporations that in turn employ physicians and other staff.) Kaiser physicians in this part of the country serve Kaiser members virtually exclusively or exclusively. Specialists and ancillary services are all organized under the same corporate structure of the Permanente Medical Group. This arrangement was attractive to group members because they felt that the full range of services that would be needed by the beneficiary would be available in one system. Some, but not all, were Kaiser members themselves, and others were in HMOs that were far less tightly integrated. Note, however, that these responses cannot easily be generalized to many other communities, both because tightly integrated HMOs are not available and because residents are less familiar and comfortable with the way any kind of HMO operates.

Knowledge and Attitudes About Options

Knowledge of different Medicare coverage options and attitudes toward those options differed substantially, as we had expected, between the two markets. In San Diego, focus group participants had a basic understanding of HMOs as well as supplements. They were more likely to realize that specific products within a plan type (different HMOs, different supplements) could be quite different. Participants approach the selection of health insurance as consumers in an economic marketplace. In Baltimore, on the other hand, participants

had little understanding of HMOs and were wary of the added complication of understanding the rules of the HMO, both for themselves and for their family member. In addition, because of the stress and time burden of caregiving, family members in Baltimore feared HMOs might increase their burden by increasing the number of trips or distance of trips to the doctor for referrals. Many were unclear about the differences between Original Medicare, with and without supplemental policies, and Medicare managed care. The existence of the State Pharmacy Assistance Program was also a source of confusion for them. When asked about seeking information on health care coverage options, they responded by talking about seeking help from social service agencies rather than operating as an individual consumer in an economic market.

Baltimore participants also reported depending on their physicians for information, and some physicians appear to have discouraged people from enrolling in HMOs. One woman reported asking three of her own physicians about the wisdom of joining an HMO and was discouraged by all three. On the other hand, another Baltimore participant asked three doctors which HMO his mother should join, and all three recommended the same one; this unanimity of recommendations made him feel comfortable with that choice.

Some of the negative attitudes about HMOs among Baltimore participants appear to be based on misinformation or lack of understanding. Many believed that joining a health plan meant leaving Medicare, or that once you joined you could not switch back to Original Medicare or to another HMO. Another participant thought that doctors in an HMO would not give her access to the best medications because “the cost comes out of the doctor’s pocket.”

Preferences About Information

Baltimore and San Diego participants also differed with respect to the kind of information they wanted in helping beneficiaries choose among health coverage options. Baltimore participants were generally uninterested in such information, but San Diego participants wanted very specific information about the differences in coverage (including home health care, long-term care, prescriptions [including brand name versus generic], eye care, hearing aids, and alternative treatments such as acupuncture and chiropractic); costs (including premiums, copayments, and any “hidden charges”); availability of doctors and hospitals; qualifications of the doctors in the plan; whether the plan used nurse practitioners; how long a person had to wait to see a specialist and/or obtain approvals of various kinds; other plan ground rules; and even the average length of stay in the hospital for certain conditions.

We asked specifically about the participants’ responses to comparative quality information, using as examples sections of the *Medicare & You* handbook that presented information from the Consumer Assessment of Health Plans Study (CAHPS®) surveys on interactions with physicians and the Health Employer Data and Information Set (HEDIS®) information on mammography rates. As with information in general, San Diego participants were much more interested in the quality data than were those from Baltimore. Baltimore participants’ reactions ranged from apathy and lack of comprehension to outright hostility and distrust. Some did not understand the information; others did not think it was relevant; still others did not trust the source. Most were exclusively interested in information on costs, coverage, and doctors in the network.

In San Diego groups, although there was interest in quality data, only those in the group of people age 65 or over liked the indicators used in the sample charts. Some did not like the use of opinions. One person noted that “You can’t extrapolate from this. If they are good at mammograms, it doesn’t mean they are good at something else. If you had a series of tests to compare, it would be very useful.” However, these groups were sufficiently engaged to suggest a number of indicators they would find useful, including referral rates for specialists and second opinions; rates of a wide range of preventive examinations such as eye exams, prostate cancer checks, colonoscopy, cardiovascular stress tests; complaint rates; qualifications of doctors; and patient satisfaction measures, such as how well people feel they are treated; whether patients are getting the care they need; how long the doctor spends with a patient; waiting times, etc. (Note that virtually all the patient satisfaction topics are in fact included in the CAHPS® instruments.)

When asked about what sources of information they would trust, the Federal Government was considered trustworthy in all groups except the Baltimore group for people with a high school education or less. Group members also trusted at least some (though not all) HMOs to give them information about their own plan, especially in writing; physicians; health insurance counseling programs sponsored by the government or by non-profit agencies; publications such as *Senior World*, and consumer groups. Insurance agents were not trusted, and in fact were treated by several participants as the quintessential “not to be trusted” information source. Some participants expressed distrust of information sources that had a “profit motive.”

Several participants under age 65 in the San Diego groups thought that they needed to have personal contact with providers

in order to judge quality. Especially for those in the lower education level group, with the greatest proportion of non-English speaking relatives, being there on an office or facility visit was more important than comparison charts.

Although the Baltimore and San Diego groups also varied with respect to the forms of information that would be most helpful to them, in both markets, certain key themes emerged. With respect to printed information, people want easy-to-understand comparison charts containing information specific to their local market that is not long but contains all the details they need and all the options. If print materials are too thick or long, or if they are in language that is too technical, they are not helpful. Indeed, people do not want material that, as one woman put it, “makes [her] feel stupid.” One participant thought the materials should be at third-grade reading level, with a check box for further information. In San Diego, not only Hispanic but non-Hispanic group members thought it was important for materials to be available in Spanish.

In both markets, many people, especially decisionmakers and those age 65 or over, thought interaction with a counselor would be most useful. In Baltimore in particular, people liked the idea of having seminars in “safe and convenient” locations, such as libraries, and other places in the community, such as hospitals and senior centers, where people generally go for help with health and related problems. Many Baltimore participants thought they did not know enough to even begin an information search that was specific; the idea of a seminar where they could both learn and ask questions was therefore attractive. In both markets, participants thought it was critical to market the availability of counseling services heavily, using television and radio, for example, so that caregivers

would know about them. Also in both markets, participants wanted the information and materials targeted specifically to family members and friends helping beneficiaries, and if possible mailed directly to the participants.

Some participants thought telephone counseling was an option but only if they could speak to a real person rather than getting caught in a telephone menu of some kind. Relatively few participants thought they would be likely to use the Internet; not surprisingly, most who did were in the higher education level groups.

CONCLUSIONS AND IMPLICATIONS

Friends and family help beneficiaries in response to trigger events such as the death or retirement of a spouse; the family member or spouse becoming eligible for Medicare; and declining health, especially when a parent is moved closer to the child. Crises such as a need for hospitalization for a serious medical problem or entering a nursing home are triggers for immediate information, whereas expensive prescriptions or procedures or a problem with the health care system are triggers that are less immediate. Many also help because the beneficiary has difficulty reading, or reading English, or understanding the information relevant to health care coverage options.

All groups in both sites reported an inadequate amount of information available to caregivers and a special need for clear, concise information. There were differences between sites, however, and between those making decisions in contrast to those providing help. San Diego respondents, because of their familiarity with managed care, were more likely to behave as consumers doing comparison shopping, whereas Baltimore respondents were

more often responding to a crisis and were less aware of having choices. In both sites, decisionmakers, rather than decision helpers, were more often responding to a crisis and were the most likely to have difficulty finding helpful information.

Very few group participants received information from Medicare directly. A very small number of participants obtained information from SHIP programs; an equally small number used the Internet; and a very few got information from *Medicare & You*. Few participants were aware of *Medicare & You*, and almost none of those read it. Some participants in San Diego got comparison information from a senior newspaper. Many of the others got information from HMOs and other insurers, although they said that was the source they trusted least. More, especially in Baltimore, received information from doctors, doctors' staff, State offices, Social Security offices, and social workers. Many participants complained that they did not have access to the beneficiary's mail. Others said they could not understand the information they received.

There are important differences between family and friend intermediaries and beneficiaries themselves. Family and friends often have limited time and may be in a stressful situation as a caregiver. They feel the pressure of making the right decision in a short period of time, often with information they do not understand. Many caregivers do not know the difference between the different programs and kinds of insurance and do not understand the materials they are given. They find themselves in the role of having to be knowledgeable advisors in situations they do not understand and with information they often cannot comprehend. This makes them averse to making changes and risking something new. Several participants

said that because they did not understand the materials, they had they decided to keep the supplement the beneficiary already had.

The knowledge, attitudes, and experiences of family members with their own health insurance often play a role in the kind of options they consider and the advice they give. Participants are most likely to advise the beneficiary to have the kind of insurance they (the participants) themselves have. Next most often, the participants try to keep beneficiaries on the insurance that the beneficiaries currently have to eliminate the risk of making changes. Thus, the lack of familiarity of Baltimore residents with Medicare HMOs led to wariness about this option, but in San Diego, where many participants were knowledgeable about HMOs in general, family members thought of a major and highly integrated Medicare HMO as an appropriate and desirable option for their parents.

There was a major difference between sites in the participants' understanding of the differences between fee-for-service and managed care. San Diego groups had more understanding of the differences. Similarly, they had more interest in comparisons of quality and made many suggestions about specific quality indicators that go beyond those currently available either in *Medicare & You* or on the Medicare Compare Web site.

Most participants from both sites trusted the government as a source of information; only a few from the Baltimore group with no more than a high school education were wary of the Federal Government because they feared being put in a health plan they did not choose.

The theme heard most often in all groups was the need for simple, accessible, concise written information, especially information about what is available, what it costs, and what it covers. As one man said,

“It could all be on a card, ‘These are the HMOs, these are the supplements, here’s what they cost, and here’s what they cover.’” Many had such information given to them by their employer and wanted the same simplicity. Caregivers who are frustrated by not having this kind of information are not interested in complicated quality information.

Many participants in both markets thought that in-person support from counselors would be very valuable. Baltimore participants overwhelmingly wanted seminars with trained counselors available to help, so they could find out which programs were available and ask questions. They suggested the seminars be advertised on television or radio and that there be educational spots on television and radio. Most did not use the Internet. They also wanted mail sent directly to them, the caregivers. San Diego groups wanted more detailed information on coverage and quality.

These findings have several implications for the NMEP and other efforts to support beneficiaries in making decisions. First, family members and friends are definitely an important audience, one that has largely been ignored. Second, information and materials need to be targeted specifically to this group. Identifying beneficiaries' helpers may be quite difficult, however, because CMS, for example, does not know who or where they are. In addition, these helpers clearly have very low levels of awareness of the information and assistance that actually is available to them. This implies the need for both (1) major marketing and outreach campaigns to let this audience know about the help that is available and (2) the creative use of partnerships with other organizations that can be effective channels to family members and friends. It also implies the need for further research, including not only additional

focus group research in a wider range of markets but perhaps systematic survey research based on focus group results that would make findings more generalizable. Although the distinctiveness of our two market sites was useful for drawing contrasts, we need information on the full range of people in this audience, across markets of different kinds.

Third, like other audiences, family members and friends need simple, easy-to-understand, concise, yet comprehensive, comparative information that is specific to local markets. Developing such materials is a challenging task on which work has to be initiated. One of the greatest challenges may be that information on physician networks and hospital affiliations may be deemed critical by this audience and is one of the most difficult types of information to gather, maintain, and organize. Another challenge may be that, although some family members and friends will want and be able to understand more detailed information, others will not. This implies the need for some kind of "layering" strategy to ensure flexibility in response to such individual differences. In addition, it is clear that, in some communities, information must be provided in languages other than English and be reviewed to ensure cultural appropriateness and attractiveness.

Fourth, especially in markets where Medicare managed care is relatively new, workshops and seminars, as well as individual counseling, may be essential supports for caregivers, and especially for those decisionmakers operating under intense time pressure, who do not have the time to undertake extended searches for information. In these markets, mass media campaigns may also be required not only to promote the availability of comparative information but also to communicate key messages that are clearly not being heard by this audience, such as the message that

no one ever has to choose an HMO or that you remain in Medicare when you join an HMO.

Friends and family members may have less time, more stress, but no better understanding about health care coverage choices than the average beneficiary. Sometimes, however, they are in a better position than those they are helping to acquire, understand, and use information. They represent both an important challenge and an important opportunity to those within the Medicare program and beyond, who want to ensure that beneficiaries have the information and support they need to make appropriate health care coverage choices.

REFERENCES

- Alzheimer's Association and the National Alliance for Caregiving: *Who Cares? Families Caring for Persons With Alzheimer's Disease*. Chicago, IL. 1999.
- Archbold, P.G.: Impact of Parent Caring on Women. *Family Relations* 32(1):39-45, 1983.
- Barrett, L.: *Independent Living: Do Older Parents and Adult Children See It The Same Way?* Public Policy Institute, AARP. Washington, DC. November 1998.
- Brennan, P.F., Moore, S.M., Smyth, K.A.: The Effects of a Special Computer Network on Caregivers of Persons with Alzheimer's Disease. *Nursing Research* 44(3):166-172, May-June 1995.
- Brody, E.M., Litvin, S.J. Hoffman, C., and Kleban, M.H.: Differential Effects of Daughters' Marital Status on Their Parent Care Experiences. *The Gerontologist* 32(1):58-67, 1992.
- Cafferata, G.L.: Knowledge of Their Health Insurance Coverage by the Elderly. *Medical Care* 22(9):835-847, September 1984.
- Caserta, M.S., Lund, D.A., Wright, S.D., and Redburn, D.E.: Caregivers to Dementia Patients: The Utilization of Community Services. *The Gerontologist* 27(2):209-214, 1987.
- Dewart, T., and Sofaer, S.: *Report on Cognitive Tests of Medicare HMO Materials with People on Medicare and Medicare Information Intermediaries in New York City*. Report to The Commonwealth Fund, School of Public Affairs, Baruch College. New York. May 2000.

- Fengler, A.P., and Goodrich, N.: Wives of Elderly Disabled Men: The Hidden Patients. *The Gerontologist* 19(2):175-183, 1979.
- Gallo, J.J., and Lebowitz, B.D.: The Epidemiology of Common Late-Life Mental Disorders in the Community: Themes for the New Century. *Psychiatric Services* 50(9):1158-1166, September 1999.
- Haug, M.: Elderly Patients, Caregivers, and Physicians: Theory and Research on Health Care Triads. *Journal of Health and Social Behavior* 35(1):1-12, 1994.
- Hibbard, J.H., Jewett, J.J., Engelmann, S., and Tusler, M.: Can Medicare Beneficiaries Make Informed Choices? *Health Affairs* 17(6):181-193, November-December 1998.
- Horowitz, A.: Family Caregiving to the Frail Elderly. In Eisdorfer, C., ed.: *Annual Review of Gerontology and Geriatrics*. Volume 5. Springer. New York. 1985.
- Jackson, R.H., Davis, T.C., Murphy, P., et al.: Reading Deficiencies in Older Patients. *American Journal of the Medical Sciences* 308(2):79-82, 1994.
- Jones, S., Roth, D., and Jones, P.: Effect of Demographic and Behavioral Variables on Burden of Caregivers of Chronic Mentally Ill Persons. *Psychiatric Services* 46(2):141-145, 1995.
- Kelman, H.R., Thomas, C., Kennedy, G.J., and Cheng, J.: Cognitive Impairment and Mortality in Older Community Residents. *American Journal of Public Health* 84(8):1255-1260, August 1994.
- Kramer, B.J.: Gain in the Caregiving Experience: Where Are We? What Next? *The Gerontologist* 37(2):218-232, 1997.
- Louderback, P.: What's Happening in Elder Care: A Positive Approach to Caregiving. *Journal of the American Academy of Nurse Practitioners* 12(3):97-99, 2000.
- Marquis, M.S.: Consumer's Knowledge About Their Health Insurance Coverage. *Health Care Financing Review* 5(1):65-80, Fall 1983.
- McCall, N., Rice, T., and Sangl, J.: Consumer Knowledge of Medicare and Supplemental Health Insurance Benefits. *Health Services Research* 20(6):633-657, February 1986.
- McGee, J., Sofaer, S., and Kreling, B.: *Final Report: Findings from Focus Groups Conducted for the National Committee for Quality Assurance Medicare and Medicaid Consumer Information Projects*. Report to the National Committee for Quality Assurance. Washington, DC. July 1996.
- Motenko, A.: Respite Care and Pride in Caregiving: The Experience of Six Older Men Caring for Their Disabled Wives. In Reinhartz, S., and Rowels, S., eds.: *Qualitative Gerontology*. Springer. New York. 1988.
- Montgomery, R.J., and Borgatta, E.F.: The Effects of Alternative Support Strategies on Family Caregiving. *The Gerontologist* 29(4):457-464, 1989.
- National Aging Information Center: *Older Persons with Mobility and Self-Care Limitations*: 1990. 2000. Internet address: <http://www.aoa.gov/aoa/stats/moblimit/mobilitylimit.html>
- National Alliance for Caregiving: *Baby Boomer Women Giving Care*. Bethesda, MD. September 1998.
- National Alliance for Caregiving and the American Association of Retired Persons. *Family Caregiving in the U.S.: Findings from a Survey*. Bethesda, MD. 1997.
- National Center for Education Statistics: Data from the 1992 National Adult Literacy Survey. 1993. Internet address: <http://nces.ed.gov/pubsearch/pubsinfo.asp?pubid=93275>
- National Center for Health Statistics: *Health and Aging Chartbook from Health United States, 1999*. Washington, DC. 2000.
- Parker, R.M.: *What Is Health Care Literacy?* Presented at Health Literacy: A National Conference. Washington, DC. June 3, 1997.
- Perkins, P., Annegers, J.F., Doody, R.S., et al.: Incidence and Prevalence of Dementia in a Multiethnic Cohort of Municipal Retirees. *Neurology* 49(1):44-50, July 1997.
- Robinson, K.: The Family's Role in Long-Term Care. *Journal of Gerontological Nursing* 23(9):7-11, September 1997.
- Schmall, V.L.: Family Caregiver Education and Training: Enhancing Self-Efficacy. *Journal of Case Management* 4(4):156-162, Winter 1995.
- Sofaer, S.: *Informing Older Consumers About Health Care Quality: Issues in Implementing a Research and Action Agenda*. December 2000. Internet address: <http://www.hsrnet.com/QUIC/540/Papers/sofaer1.htm>
- Sofaer, S.: Qualitative Research Methods: What Are They and Why Use Them? *Health Services Research* 34(5):1101-1118, December 1999a.
- Sofaer, S.: *Strategic Considerations in Providing Quality Information to Medicare Beneficiaries in a Changing Decision Environment*. Report to The Commonwealth Fund. Baruch College. New York. January 1999b.

Sofaer, S., Kenney, E., and Davidson, B.N.: The Impact of the Illness Episode Approach on Medicare Beneficiaries' Health Insurance Decisions. *Health Services Research* 27(5):671-694, December 1992.

Springer, D., and Brubaker, T.: *Family Caregivers and Dependent Elderly: Minimizing Stress and Maximizing Independence*. Sage Publications. Beverly Hills, CA. 1984.

Stone, R., Cafferata, G.L., and Sangl, J.: Caregivers of Frail Elderly: A National Profile. *The Gerontologist* 27(5):616-626, 1987.

Toseland, R.W., Rossiter, C.M., and Labrecque, M.S.: The Effectiveness of Peer-Led Professional Groups to Support Family Caregivers. *The Gerontologist* 29(4):465-471, 1989.

Toseland, R.W., and Smith, G.C.: Supporting Family Caregivers of the Frail Elderly. In Gitterman, ed.: *Handbook of Social Science Practice with People in Oppressive Life Circumstances*. Columbia University Press. New York. 1991.

Williams, M.V., Parker, R.M., Baker, D.W., et al.: Inadequate Functional Health Literacy Among Patients at Two Public Hospitals. *Journal of the American Medical Association* 274(21):1677-1682, 1995.

Wright, G., and Howe, D.: *AARP Research on Caregivers and Medicare Information*. AARP Presentation. Washington, DC. January 26-27, 2000.

Reprint Requests: Shoshanna Sofaer, Dr.P.H., School of Public Affairs, Baruch College, 17 Lexington Avenue, Box C-401, New York, NY 10010. E-mail: shoshanna_sofaer@baruch.cuny.edu