
Personal Decisionmaking Styles and Long-Term Care Choices

Susan K. Maloney, M.H.S.; Jeffrey Finn, M.A.; Diane L. Bloom, Ph.D., M.P.H.; and Julie Andresen, M.P.A.

To learn more about how older people make decisions about long-term care (LTC), in-depth interviews were conducted with 63 elderly individuals and 56 of their relatives to obtain information on the decisionmaking process. This qualitative research showed that LTC decisionmaking does not always follow typical consumer decisionmaking models, in which a consumer seeks a product or service, selects among the alternatives, and assesses the choice. Further, the interviews yielded four long-term care decisionmaking styles among older adults related to their degree of planning or not planning. This study underscores the need to develop tailored communications for older people and their families aimed at encouraging appropriate and cost-effective use of LTC services.

INTRODUCTION

Approximately 7 million of the more than 33 million Americans 65 years of age or over now need LTC services. Of these, 1.3 million live in nursing homes and 5.6 million are living at home. The Pepper Commission estimated that by 2030 the number of seniors in nursing homes will jump to 5.3 million, from about 1.3 million today. During this same period, the number of seniors living at home in need of LTC services will swell to 13.8 million

from 5.6 million today (Pepper Commission, 1990).

Medicare program outlays for LTC services have increased during the past decade. For home health care, HCFA data show that the average annual rate of change for home health agency outlays from 1983 to 1993 topped 21 percent. Although this annual rate of change in spending slowed to less than 14 percent in 1994, home health was the second fastest growing sector of Medicare outlays (Levit et al., 1996).

Given the growth in Medicare LTC spending and in the number of older adults needing those services, health policymakers increasingly recognize the importance of helping individuals make wise choices about LTC services. Informed choices may help assure that the right services will be delivered to the right person at the right time.

Failing health or increasing frailty or confusion can launch older adults and their family members into a search for ways to meet LTC needs. The decisions are complex and multilayered. They are not simply decisions about where to live or how to meet and monitor medical needs, but about how to handle the most personal of daily care and how to maintain the integrity of a lifetime. The decisions often signal an upheaval in established social roles, changing the relationships of husbands and wives, parents and children, neighbors, friends, and relatives. Yet it is often difficult for consumers to find, use, and finance home, community, and institutional-based LTC services for frail elderly and disabled

Susan K. Maloney and Jeffrey Finn are with the SPRY Foundation. Diane L. Bloom and Julie Andresen are with Bloom Research. The opinions expressed are those of the authors and do not necessarily reflect the opinions of the SPRY Foundation, Bloom Research, or the Health Care Financing Administration (HCFA).

persons. Even when resources and funding are available, selecting LTC is a complex decisionmaking process.

To better understand this decisionmaking process, the Setting Priorities for Retirement Years (SPRY) Foundation conducted qualitative, indepth interviews to describe how elderly people and their families made decisions about the continuum of services that are available to individuals in need of LTC. Included in the study were decisions about LTC delivered at home, in community-based settings, in congregate living facilities, and in skilled nursing facilities (SNFs) by both formal and informal caregivers. The care included medical and personal care services, help with daily living tasks, and social and emotional support and companionship.

This article focuses on the typology of decisionmaking styles that emerged from interviews with older adults and their family members, and implications of these decisionmaking styles for public policymakers. As with all qualitative studies, the participants in these interviews do not necessarily represent a cross-section of the aged population in the United States. In some cases, providers or facility directors who helped identify persons meeting the study criteria may have identified the most outgoing and positive individuals for interviews. It also is possible that individuals selected for the interviews were those who successfully "negotiated the system" and were relatively happy with their new situations. To the extent that these study participants were selected or self-selected, they may not represent the diversity of views about LTC decisionmaking.

METHODS

Trained interviewers conducted indepth interviews with 63 aged persons living in a variety of LTC settings. The settings in

Table 1
Living Situations of Elderly Respondents

Setting	Males	Females
Nursing Home	2	2
Assisted Living in Various Types of Facilities	4	20
At Home With Help	4	15
Independent Living in a CCRC	6	10

NOTE: CCRC is continuing care retirement community.

SOURCE: Maloney, S.K., Finn, M.A., Bloom, D.L., and Andresen, J., 1996.

which the respondents resided at the time of their interview are shown in Table 1. Each respondent was at least 65 years of age, had made a change in his or her living arrangement in the last 6 months, and was lucid and able to communicate with an interviewer. In addition, none was eligible for Medicaid at the time the change in living arrangements was made. This criterion was chosen because, in many jurisdictions, Medicaid eligibility greatly increases the LTC options available to an older person. In addition, each of the respondents who lived in nursing homes, assisted living settings, or at home with help needed assistance with three or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs). The individuals residing in independent living in a continuing care retirement community (CCRC) did not meet the ADL or IADL criterion of limited functioning. These individuals were included in the study to explore the decisions of individuals who planned for their long-term needs while they were still healthy.

Each respondent also indicated a relative or friend who participated in the decision and was willing to be interviewed. Following the interview with the aged respondent, 56 relatives or friends who helped in the search for and selection of LTC arrangements were interviewed in person or by telephone. The relationship of

Table 2
Relationship to Primary Respondent

Relationship	Number
Daughter	33
Son	7
Friend	5
Sister/Brother	4
Niece/Nephew	3
Other	3
Spouse	1

SOURCE: Maloney, S.K., Finn, J., Bloom, D.L., and Andresen, J., 1996.

this person to the primary respondent is shown in Table 2.

Most of the elderly respondents were aided by daughters. Thirty-one were aided by their own daughters, one was helped by a daughter-in-law, and one by a step-daughter. Sons, nieces, nephews, friends, siblings, and, in one case, the spouse were identified by the elderly people as those most involved in the decisionmaking process. Three respondents cited another person—a minister, social worker, and a paid caregiver—as the other significant decisionmaker.

Interviews were conducted in or near Portland, Oregon; Dennison, Texas; Hartford, Connecticut; Chapel Hill, North Carolina; and Williamsburg, Virginia. These sites were chosen to include locations with different mixes of LTC services. Sites were also selected to provide geographic diversity. At each site, SPRY staff contacted health and social service providers to enlist their help in identifying persons eligible to participate in the study.

Staff of area agencies on aging, American Association of Retired Persons regional offices, senior living facilities, and home health agencies were among those contacted. Written information about the study, criteria for participation in the interviews, and the informed consent procedure were provided to each contact person. If needed, this contact person helped obtain the approval of a facility director or other key person.

Names of potential interviewees were provided to SPRY interviewers, who contacted each elderly person to obtain permission and schedule the interview. All participants were interviewed at their residences for about 1 hour. Interviews were tape recorded. Before the interview, participants reviewed a consent form that explained the purpose of the study, the voluntary nature of participation, and that their responses would not be associated with their names or the name of the facility in which they resided. The interview covered the events that triggered a change in living situations and the decisionmaking process that led there. Demographic questions were asked at the end of the interview.

Interviewers began analysis by listening to audio tapes of each interview and preparing detailed notes. Notes were taken on the steps in the decisionmaking process and on other areas of interest that emerged from the interviews, such as precipitating events and strategies for coping with aging. SPRY staff also listened to the tapes and reviewed the prepared notes, clarifying points and enhancing their understanding of the information that was collected. Each pair of tapes—aged person and relative or friend—was examined together to obtain a complete picture of decisions. After analyzing all of the tapes and notes, interviewers identified categories of decisionmaking styles, which were fine-tuned in conjunction with SPRY staff. Then interviewers and SPRY staff independently assigned interview pairs to decisionmaking style categories. Agreement on the assignment to categories was consistent between interviewers and SPRY staff with only one exception. The exception, for which neither interviewers nor SPRY staff had made a designation, was how to assign one atypical situation in which the daughter,

rather than the older person, functioned as the advance planner. It was agreed that that interview would be classified as an advance planner and clarify who was actually the planner. Interview data were then reexamined within each of the decision styles, in order to search for commonalities and differences among the styles of decisionmakers.

Characteristics of the Respondents

Participants ranged in age from 67 to 103 with a mean age of 81.5 years and median age of 82. Of the 63 interview participants, 46 were widowed, 13 were married, 2 were divorced, and 2 were single. Sixteen of the interview participants completed or attended college, 31 had completed high school, and 16 had less than a high school education. Of the 16 college graduates, 14 resided in the CCRC. Incomes of the participants were reported by 14 as being under \$400 per month, by 12 as between \$400-\$999 monthly, and \$1,000 or more by 32 participants. All 16 residents of the CCRC reported their monthly incomes as \$1,000 or more. Five participants chose not to report their incomes.

Additional interviews were conducted with 56 relatives or friends of the elderly respondents who were involved in decisionmaking. Family members or friends agreed to an in-person or telephone interview to describe the decisionmaking process and offer a different perspective. Twelve respondents (six couples) were married couples; for each couple, only one relative was interviewed. For one respondent, the identified family member was not able to participate because of medical problems.

Long-Term Care Options

It must be noted that there is a range of possible living situations available to elderly people who need LTC. The options range from informal assistance on an as-needed basis for relatively healthy older adults living independently to around-the-clock skilled nursing care for dependent persons with complex care needs. The available choices for meeting these diverse needs vary from community to community. There are no universally agreed-on definitions for all of these options. Similar programs or services go by different names in different locales. Definitions and licensing and regulatory requirements vary by State. At this time, new service arrangements and facilities are being introduced in some communities. This study did not evaluate which type of living situation was best. Each alternative has benefits and drawbacks, and each provides a different balance between independence and security.

To clarify the types of living situations where the elderly participants in this study resided, the following descriptions of LTC options are provided.

Independent Living

Healthy older persons can live independently in a variety of housing choices from single-family homes to small apartments designed for seniors. There is usually access to an attendant 24 hours a day. In this study, persons who were living independently were in a CCRC-a facility or campus for older people that houses several progressively intensified levels of care suited to the individual's needs at a given time. In a CCRC, the elderly person can live independently, or when health deteriorates, can rely on assisted living or skilled nursing care. Residents pay entrance and monthly maintenance fees and are guaranteed a

place to live and LTC services. Most CCRCs require that residents enter when they are healthy and able to function independently.

Living at Home With Help

In his or her own home or in the home of a relative or friend, the elderly person receives a mix of services on an as-needed basis, formal and informal, from paid and unpaid caregivers, including assistance with meals, housework, transportation, shopping, personal care, or nursing care. For some, this was an alternative to moving from home to a nursing home or assisted living facility.

Assisted Living

Elderly persons are provided with assistance with tasks such as meals, housework, transportation, some personal care, and supervision of medication on an as-needed basis. Assisted living is offered in many settings. In this study, some elderly individuals lived in small, private apartments in a free-standing assisted living facility. Some facilities offered assisted living as a "step" in a continuum of care. Assisted living was also provided in some communities in community-based foster or boarding homes. In all cases, the elderly people interviewed had a private room or apartment furnished with their own belongings. Assisted living is designed as an intermediate step to encourage independent function and to avoid the full-time nursing care and regimentation of a nursing home if it is not needed.

Nursing Home

Elderly residents receive skilled nursing care, rehabilitation services, and medical care in a facility that usually provides licensed nursing coverage 24 hours a day.

Rooms are usually occupied by two or more residents. With the focus on skilled care, nursing homes are somewhat hospital-like in the appearance of the rooms and generally offer less personal privacy than other LTC settings.

RESULTS

Decisionmaking Styles

Many decisions that consumers make are variations on a fairly typical pattern. First, the consumer determines that a product or service is needed or wanted. Next, the consumer searches for and identifies options for obtaining the product or service. Information is obtained from formal channels, such as advertising, consumer articles, brokers, or salespeople, and from informal channels, such as friends and relatives and the consumer's personal experience. More detailed comparative information may be solicited about potential choices, and the pros and cons of those choices are assessed. Finally, a selection is made from among the options. With use of the product or service, the consumer may reassess and reevaluate his or her choice making changes and modifications.

In making decisions about LTC, most of the elderly consumers interviewed did not follow a typical consumer decisionmaking model. Rather than variations of the consumer choice decision process previously outlined, a typology of four distinct decisionmaking styles emerged from the interviews. These styles range across a continuum from consumers who made no plans at all for LTC and waited for a crisis, to the planned approach that corresponds more closely to the model previously noted. When the interviews were examined within these decisionmaking style categories, strong themes and patterns appeared.

The decisionmaking style categories are as follows:

- “Scramblers” are forced to change in response to a crisis when a serious injury or illness forces a search for a quick fix.
- “Reluctant Consenters” are pushed to make a change in living arrangements by relatives or health care professionals who notice a decline in their health and ability to function independently.
- “Wake-Up Call” decisionmakers change their living arrangements in response to a near crisis, such as a fall that could have resulted in a serious injury but did not. For many, health gradually deteriorates and a mishap emphasizes the need for a greater level of care and supervision.
- “Advance Planners” research LTC alternatives and plan for LTC while they are still healthy.

In exploring these decisionmaking styles, it should be noted that all decisions involve tradeoffs between independence and flexibility on the one hand and security and certainty on the other. In addition, as previously noted, finances and available care alternatives in the community impact heavily on decisions. Moreover, luck often plays a role in determining a participant's decisionmaking style category. For example, an Advance Planner who moved to a CCRC while still healthy at age 82 could just as easily have been a Scrambler if she had suffered a debilitating stroke at age 78.

The following sections discuss each decisionmaking style. For each category, the decision process will be explored, describing the decision style, characteristic themes, and patterns. The first two styles discussed are the Scramblers and Reluctant Consenters. Older adults who fit into these categories made no contingency

plan for LTC arrangements until it became clear to a relative, close friend, or a health professional that they could no longer continue to live as they had been living.

Scramblers

The Scrambler makes changes in response to a crisis when a serious injury or illness forces a search for LTC. In this study, 11 people who were interviewed lived at home until they experienced a major health crisis that made it permanently impossible for them to continue living independently. This crisis launched them and their relatives into a quick search for a new living arrangement. In all cases, a hasty placement in a nursing home was required to meet the medical needs of the elderly individual.

The typical Scrambler progressed through three steps to arrange LTC. A health crisis resulting in hospitalization occurred and, based on advice from physicians and hospital social workers, a family member initiated a search for ongoing care arrangements.

As the period of hospitalization came to a close, relatives scrambled to find a facility to provide the elderly person with longer-term care or rehabilitation. A cursory and limited, as opposed to extensive and systematic, search for a care facility was managed by a family member with little input from the elderly person.

Interviews with the relatives of Scramblers brought back memories of extremely stressful times as they tried to understand LTC options, locate openings, understand financing options, negotiate medical and social service systems, and make the right choice for their family member or friend. Pressure to move quickly did not allow time for the thought or care they would have liked to bring to this important decision. Scramblers found it

particularly difficult to locate the information they needed. Lists of facilities from a hospital discharge planner or a doctor's office did not sufficiently outline LTC options. Not understanding the different types of LTC arrangements, they were frustrated to find many facilities would not meet the needs of the person for whom they were seeking care. Medical needs, bed availability, and financing often dictated choice. Limited time and lack of information ruled out home care and other possible community-based care options before they were considered. In a service-rich environment, location might be considered in the decisionmaking. Cleanliness was the only factor related to quality that was mentioned.

For some Scramblers, a nursing home proved to be a short-term choice. In cases where the elderly person had a close, caring relationship with a relative or friend, another move to a more home-like arrangement was undertaken after he or she recovered somewhat. The second move was to a setting that provided less intensive physical care and, according to those interviewed, better met the emotional needs of the older person.

In other cases, no second placement was considered even after the elderly person's health improved. These individuals did not have a close relative or friend to assist them in their search for less restrictive care arrangements. The determining factor of a second move appeared to be the quality of the elderly person's relationship with the decisionmaking relative. Those who reported a positive and close relationship with supportive family members, especially their own children, were likely to move to a different type of living facility that better fit their improved health status. Most of the elderly people and the relatives who engaged in a second search for more appropriate arrangements said that the

nursing home did not continue to meet social and emotional needs of a resident after some recovery from a health crisis.

This second process generally involved a more extensive and systematic search by the relatives than the initial hasty scramble to find a nursing home. The search was still directed primarily by the relative who did not feel the elderly person was in a position to seek out information about options for him or herself. The decisionmaking process for the second arrangement had the following characteristics: The children or other relative served as the clearinghouse for information on possible alternatives to the nursing home; the children or other relative tried to present the elderly person with a short, concise list of the pros and cons of each place so that the elderly person would be able to make an informed choice; the elderly person was more involved in choosing the second care situation than in choosing the first one; and usually, the elderly person wasn't aware of how much behind-the-scenes research the children or other relative did.

According to relatives, one frustrating aspect of this second search was that the elderly person possessed limited knowledge or experience of the options available and did not usually always know what factors were most important to him or her.

Reluctant Consenters

Another group that gave little prior thought to the advance planning of their LTC were the Reluctant Consenters. In 18 cases, a family member or physician noticed a decline in health of the elderly person, which caused concern about safety. Although the family or physician pushed for an immediate change, the elderly person resisted it.

The driving force behind the move was fear on the part of the relative or a profes-

sional that an accident would incapacitate the elderly person. In some cases, relatives noticed a gradual but unmistakable decline in the elderly person's ability to handle life's logistics. Cumulative indicators signaled that the elderly person could not live alone safely. Minor scares caused great concern. Family members also worried that their relative was not getting adequate nutrition. Failing memory and confusion were also considered potentially dangerous. Several relatives mentioned an elderly relative forgetting to turn off the stove. Medication mishaps were also a concern of family members and friends.

The Reluctant Consenters eventually agreed to change their living situations. Because of differences in their health, the availability of services in their geographic location, or the quality of relationships with relatives, this group chose a variety of living situations, including moving in with a relative with paid help, staying at home with paid help, assisted living, and nursing homes.

Generally, the decisions made by and for the Reluctant Consenters shared the following characteristics. Little prior thought had been given to LTC; those who chose home care did not initially know how to locate appropriate services and complete paperwork for reimbursement; where there was a strained relationship between the elderly person and a decision-assisting relative, basic emotional needs of the elderly person were not considered in decisionmaking; and in some cases, relatives chose assisted living or home care to avoid a potential nursing home placement.

This was a group of people who let life events happen to them and did not systematically plan for the future. They continued to live at home as before and tried to cope with daily tasks despite their growing incapacity. Most likely, they would have continued to struggle at home, unless a

professional or a relative had intervened to convince them to make a change.

Interviews with elderly individuals using home care in Texas, North Carolina, and Oregon revealed that these Reluctant Consenters and their relatives did not know initially how to find services. At first, they perceived this option as too expensive for them to afford, not covered by insurance, and difficult to obtain. However, after making telephone calls, the relatives connected with someone who referred them to a social service agency or an Area Agency on Aging (AAA) that helped make arrangements. Often, a doctor or social worker gave the relative a contact person. The relatives and elderly person were surprised and grateful that these services existed, that someone would coordinate care arrangements, and that they qualified for financial assistance.

This was particularly apparent in one community where the AAA operated an extensive home-care program as an alternative to nursing-home placement. Even in communities with strong home care programs, respondents did not have prior knowledge of home care as an option and were not familiar with the agencies that could help them arrange and pay for home care. In three cases in which the relationship between the elderly person and relative appeared to be strained, the family member sought a care option to meet safety needs and to provide good medical care, but, according to the elderly person, did not seem to address his or her emotional needs. Two people had been placed in nursing homes, one on a locked Alzheimer's unit. The third person was placed in a foster home. In each instance, they reported they were the only lucid person in that situation.

Some of the relatives of Reluctant Consenters reported that they feared nursing homes as a choice for their

relatives. They were concerned that if no action were taken, a potential injury or health emergency would force the elderly person to be placed in a SNF. Having some knowledge of LTC options, these relatives saw home care or assisted living as a way to prevent nursing-home placement or at least to delay it until absolutely necessary.

Three Reluctant Consenters were atypical in their view that they no longer really needed the home care services that had been arranged for them after a hospitalization. While we could not independently confirm their assessment of their medical needs, it did seem that they were more independent than others in this study. These individuals were surprised and delighted to be eligible for home care services following a hospitalization. They were unsure exactly how they qualified for services and did not have the details of what agency provided and paid for their continuing services.

Wake-Up Call Decisionmakers

Fourteen Wake-Up Call decisionmakers were interviewed in this study. They lived either in assisted living facilities or at home, with a mix of formal and informal services. They had observed that their health was deteriorating. Although they managed to live at home as before, it was becoming increasingly more difficult to manage the ordinary demands of caring for oneself. Unlike the Reluctant Consenters, the Wake-Up Call decisionmakers recognized the need for help themselves and initiated a change. For some, a precipitating event called their attention to the need for a change in their living arrangements. For others, cumulative events spurred them to action or a health scare provided the impetus to change. Several had a fall during some everyday activity which, though not

serious, foreshadowed the potential for serious injury or incapacity.

Sometimes this scare added incrementally to other problems. Emphysema, arthritis or osteoporosis were common health problems mentioned. The precipitating event functioned like the proverbial straw that broke the camel's back.

From time to time, some of these elderly people considered moving or getting more help, but took no steps to do so. Then they experienced a potentially serious event, encouraging them to change living arrangements. In some cases, health professionals also played a powerful role by suggesting that something be done to prevent a catastrophe.

In addition to initiating the search for care themselves, several other themes characterized the respondents who reacted to a wake-up call. These Wake-Up Call decisionmakers, like the Advance Planners and Reluctant Consenters, and some Scramblers, said they didn't want to burden their relatives with their care. As their health declined and they were able to do less for themselves, they depended more heavily on their children.

The decision to make a change was difficult for the Wake-Up Call decisionmakers because it was not essential for them to find new care arrangements. They wanted to prevent a crisis, but did not want sacrifice their autonomy. The Wake-Up Call decisionmakers did not want to risk living at home alone and having an incapacitating accident. Instead, they decided that it was time to get help at home or enter an assisted living facility.

Advance Planners

Advance Planners made plans for their retirement years while they were still healthy. Sixteen of the Advance Planners interviewed in this study lived in a CCRC.

Three lived in assisted living situations or lived at home with help. In addition, one Advance Planner was a relative of an elderly person who laid out a long-range plan, encompassing all possible contingencies for her mother. No major external precipitating event launched Advance Planners on a search for a change in living arrangements. Instead, they set their own deadlines for moving into a new situation, deadlines that often coincided with a milestone. For example, one couple moved after celebrating their fiftieth wedding anniversary in the home they had lived in their entire married life. Another wanted to be in his new home by Christmas. Some recognized that old age often brings a decline in health and wanted to change living situations before that happened.

The Advance Planners who resided in a CCRC were a homogeneous group: wealthy, well traveled, educated, and healthy. Several were couples. Their personal financial resources left all retirement options open to them. As they planned for their retirement years, they realized that if they lived long enough, eventually they could become frail, incapacitated, and unable to continue living as before. Several themes emerged in the interviews with Advance Planners. They made plans in other areas of their lives; believed that denial was the reason why other elderly people don't plan for their senior years; accepted "old age" as a natural phase of life; wanted to enjoy a high quality of life; were concerned about future health care requirements; wanted to retain autonomy to make independent decisions; and did not want to become a burden to their children.

In interviewing people from the CCRC, it became clear that they were planners by nature. In fact, they couldn't imagine life without short-term and long-term planning. These Advance Planners were

perplexed by people who did not plan. Some Advance Planners speculated that denying one's impending old age was one reason that some people did not plan for their retirement years. They believed that many elderly people fear that making this radical change in lifestyle would be overwhelming, consequently they choose not to think about it. Several others thought that elderly people may not plan ahead because they do not have the financial resources to choose desirable options. Others pointed out that when a couple is involved, both the husband and wife must perceive the need to change. If one does not want to sell the family home and move on, the other spouse may just "go along," possibly missing the opportunities for planned approaches. Some Advance Planners thought that others did not plan ahead for their senior years to avoid the unsettling fact that someday they will die. These Advance Planners accepted old age as a period of potential decline. In a similar manner, they accepted the inevitability of their own death and did not seem depressed or threatened by the eventuality. They realized that sooner or later their health would probably fail or they would be too frail to carry on as they had previously. Most saw planning for retirement years as the logical next step.

The Advance Planners who chose a CCRC wanted to do so while they were relatively young and healthy. Moreover, they recognized that old age could bring about a decline in health and function and they wanted to enjoy life first, as well as prepare themselves for the worst. In fact, the retirement communities generally require that applicants be healthy to enter. The marketing offices and staff emphasize residents' vitality rather than the weakness and frailty of old age. These people wanted a chance to make new friends, have fun, and continue to grow. These Advance Planners

sought a high quality of life in several ways. They wanted to feel a sense of community, enjoy activities, assume community leadership roles, and have fun with their healthy peers. Respondents also said the homogeneity of the residents allowed interaction with people of similar interests.

The respondents, however, noted that the initial cost of entering a CCRC was the major drawback to joining such a community. Most CCRCs require a significant down payment that may or may not be refunded. Additionally, high monthly fees make this care option unaffordable to many older adults. One important reason for choosing a CCRC was the fact that once they were in the retirement community, the CCRC would manage their health care. Almost all of those interviewed at the CCRC said that the availability of onsite health care was one of the most important factors in their choice of this type of facility. They believed they would receive excellent medical treatment if they needed more care. This provided a sense of security about their future. They wouldn't need to call on their children, or even decide where to go for care. Even if they ran out of money, they were guaranteed health care. If they needed skilled nursing, they knew where they would go, and believed it was better than typical nursing homes. Moreover, if one member of a couple needed more intense care, such as assisted living or skilled nursing, the other could be close by. Although the thought of the nursing home section depressed most of those interviewed- they described it as "morbid," or "God's waiting room"-they were reassured by knowing they would be well cared for and well treated onsite.

Advance Planners interviewed at the CCRC were adamant about making the decision to change living arrangements by themselves. They insisted on setting their own priorities. A recurrent theme was their

refusal to let their children decide how they should spend their final years. Not being a burden to one's children was a theme heard in interviews across all decision styles. Advance Planners in the CCRC expressed this view strongly. They said they wanted their children to live their own lives without having to worry about their parents. These people were also influenced by what they had seen. Several had known an aging relative who had been a burden to them. The unpleasant experiences made them more likely to take steps to assure that they would not burden their own children. Several interviewees described this type of situation. Some of those interviewed did not want to test their children's loyalty and love by setting up a situation in which they had to ask for help. If their children refused, the rejection would be too painful.

Advance Planners in Assisted Living

Three Advanced Planners chose assisted living situations. These three Advance Planners were older and less well educated than their counterparts in the CCRC. Nevertheless, they shared many common traits and views. They were planners by nature, seemed to accept old age as a natural part of life, and wanted to make their decision independently. Their search, however, was much more limited than that of the CCRC advanced planners. They moved into the first and only place they considered-in each case a facility close to home with which they were familiar. They obtained literature about these facilities and discussed the move with children or other relatives. Visiting the site was a decisive factor in deciding to move. In making a change, these three Advance Planners focused primarily on the security of knowing they and their spouses would be cared for in the event of a medical

problem. The Advance Planners in the CCRCs, in contrast, were focusing mostly on the quality of life they would enjoy for the last years of their lives. Like the CCRC Advance Planners, they did not want to burden children with their care and respondents made the decision about living situations by themselves, with minimal input from their relatives.

Daughter as Advance Planner

In one instance, a daughter was an Advance Planner for her mother's LTC. She mapped out a plan, working closely with her own husband and with her mother. The mother had recently moved in with her daughter's family as planned, and the daughter had arranged complex formal and informal services at home for her mother's care.

OTHER RESULTS

Another key purpose of this study was to better understand the role and availability of information about LTC options. This study demonstrated that for many consumers, existing LTC information is incomplete and can be hard to find.

Perhaps an even greater impediment to finding appropriate LTC services, and one which is more difficult to define precisely, is the consumer's lack of familiarity with LTC issues and the choices available to address these issues. Most elderly consumers and their relatives were not familiar with the range of LTC options. They did not assess the needs of the elderly person and then decide which services or type of service, i.e., home care, assisted living, adult day care, etc., would best meet those needs. An overview of the types of options and the advantages and disadvantages of each seemed to be completely missing from the information available to respondents.

Information on home care appeared particularly difficult to find where there was no specialized agency arranging home care as an alternative to nursing home admissions. Older persons and their family members who chose institutional settings knew little about home health care options or about how to find information regarding home services.

Almost all relatives of the Scramblers, for example, dismissed home care as an option after the elderly person's discharge from the hospital, thinking it prohibitively expensive and problematic to arrange around the clock. Moreover, the relatives feared that hired help would be unreliable.

Similarly, the Reluctant Consenters or Wake-Up Call decisionmakers who considered home care but selected other options, either could not contact a person who knew about these services, or believed they did not live near a strong home health program. They also believed this option was beyond their financial reach. Unsuccessful attempts to find information about home health services frustrated many.

One relative suggested a home health services telephone hotline, which could be publicized on television or in large print in local newspapers. Another relative who could not find appropriate home care services suggested having an agency that customized options to meet differing individual needs of elderly living at home. She sought a caring person as her mother's companion, but could never obtain information on whether that type of care existed in her area.

Achieving goals related to getting the right service to the right person at the right time depends on people identifying a need for assistance, understanding the options available to them to address that need, and then knowing how to locate the needed care. These goals cannot be achieved when consumers are not aware of

or knowledgeable enough about LTC services to avail themselves of them at the appropriate time—a time when services can serve a preventive and supportive role for them. We found that both general LTC information and specific community-based information referral services were nonexistent. Some relatives of elderly individuals suggested ways to ease the search for people like themselves. Most of these ideas reflected a desire for an objective, unbiased clearinghouse for information—a “one-stop shop” to compare and contrast options available in a particular geographic location. According to many interviewed, this clearinghouse for information would make it easier to find the right care situation. Several relatives offered suggestions for making information about institutional care settings easier to access. One relative suggested that a case manager could serve as a clearinghouse for all the different facilities in a particular geographic area. Her mother, for example, hired a private agent who tried to match people with places. However, the agent was paid by facilities for placements, and did not show clients all available options—only the ones from which she might profit.

We found instances in which information seemed to flow appropriately to consumers. The study found that once consumers have zeroed in on a particular option, such as a nursing home or CCRC, individual facilities are able to provide information and answer questions. Consumers were also able to access services readily in situations where a community had a single, well-known agency that served as a focal point for aging services. In these cases, consumers and professionals knew who to call for information and assistance.

IMPLICATIONS

The qualitative research findings related to differing personal approaches to making LTC decisions have implications for health policymakers interested in effectively reaching older people and their families with information and support that will encourage them to make timely, appropriate, and cost-effective use of formal and informal LTC services. Consumers lack general knowledge about LTC options. The study findings underscore the general lack of knowledge about or understanding of long-term options among consumers. Most of those interviewed approached a search for LTC with no framework for decision-making, for assessing which options could best meet their own or family member’s needs, for judging strengths and weaknesses of alternatives, or for judging quality. As noted in this article, many in-depth interview respondents did nothing until a crisis occurred. Some relatives said the older person did not know what he or she wanted in a LTC situation. Changing LTC choices, no personal experience with trying to care for an elderly person, limited exposure to chronic health problems, perceptions that care is costly or difficult to arrange, and limited resources leave many people with no incentives for planning for LTC.

Consumers would benefit from increased public understanding of LTC options, including some sense of which types of care are appropriate for which circumstances. General public education is needed to improve awareness and understanding. Moreover, because of the rapidly evolving spectrum of LTC services available to consumers, sustained and evolving education campaigns will need to be implemented at both national and community levels. Individual consumers could also benefit from communications tailored to their own circumstances. Many confront

frailty and old age by denying its limitations and special needs. Lack of familiarity with what old age can bring and lack of understanding of the various LTC options can interact to reinforce denial.

People need time to explore their own values and deal with the emotions that life changes bring. Unquestionably, these are difficult decisions for many families to face. While sustained general public education helps build awareness, individual consumers could benefit from programs and services to educate and stimulate family discussion about these issues. HCFA already has initiated some steps to begin changing the dialogue on LTC among older adults and family members. These steps include a new publication on post-hospitalization choices that asks older adults to weigh not only their medical needs but also their emotional and spiritual concerns when developing a plan of care with their physicians once they leave the acute-care setting.

HCFA is also funding an effort to create consumer materials that will be used by community-based education facilities, such as faith-based education programs and cooperative extension services, to foster dialogue on the complex psychosocial issues involved in LTC decisionmaking. Consumers could also benefit from access to a well-publicized source of information about services in their local communities. In fact, both consumers and professionals who were interviewed in a related study asked for a local clearinghouse for information about services. Some suggested that a single telephone service accessed by dialing 711 (like 911 for emergencies) should replace the piecemeal approaches to consumer information and referral that are now available. Consumers also requested specific comparative data about

programs and services. Consumers clearly believed that most current information systems were inadequate, lacking the depth and breadth of information to meet their needs.

Health professionals can also play a more assertive and consistent role in guiding elderly people to appropriate LTC. In these interviews with older adults, physicians were held in high esteem. A physician can give "permission" to seek help and is in an excellent position to guide an individual in finding the services that meet his or her needs. Family members also noted that not all physicians were helpful in dealing with LTC concerns. None mentioned a physician providing much beyond a list of facilities for family members to check out.

To become effective, health care professionals need to become familiar with the range of LTC options, the benefits and drawbacks of each, and with the facilities and services in their own communities or with someone their patients can call to get trusted information on service availability and quality. The study also suggests areas for further research. Determining how these decisionmaking styles are distributed throughout the older population and if and how decisionmaking styles are related to sociodemographic factors is one area for further study. In addition, working to develop a short instrument that can be used in clinical and social service settings to determine an individual's decisionmaking style could help identify how best to communicate with older adults about long term care needs. Other work could explore how social and emotional issues and the relationship between the older person and relatives assisting with decisionmaking influence decisions.

ACKNOWLEDGMENTS

This qualitative research study was supported by a grant from the Robert Wood Johnson Foundation.

REFERENCES

Levit, K. R., Lazenby, H.C., Sivarajan, L.: Health Care Spending in 1994: Slowest in Decades. *Health Affairs* 15(2):130-144, Summer 1996.

The Pepper Commission (U.S. Bipartisan Commission on Health Care Reform): Final Report. Washington. U.S. Government Printing Office, 1990.

Reprint Requests: The SPRY Foundation, Suite 845, 2000 K Street, NW, Washington, DC 20006.