

WORKING P A P E R

Nursing Home Selection: How Do Consumers Choose?

Volume I: Findings from Focus Groups of Consumers and Information Intermediaries

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EXECUTIVE SUMMARY

Introduction

More than a million elders enter a nursing facility each year, yet we know little about how consumers of skilled and long-term nursing care select the facility to which they or their loved ones will be admitted. Many members of the Baby Boomer generation are currently faced with long-term care (LTC) decisions for their parents, and those on the leading edge of the generation will soon be dealing with these issues themselves. The aging of the population points to consumers' increasing need for useful and reliable information about their health- and social care options, including nursing homes.

The purpose of this study, commissioned by the Assistant Secretary for Planning and Evaluation (ASPE), Department of Health and Human Services, was to use qualitative methods to (1) systematically review the existence and accessibility of Internet-based resources intended to support the decision to enter a nursing facility and select the appropriate facility for one's needs and preferences; (2) examine how consumers select a nursing home; (3) explore if and how existing information resources are used in the decision-making process; and (4) identify gaps in needed information resources.

Approach and Methods

This study was conducted in two parts. To identify and examine the accessibility of consumer information on nursing home selection, we conducted an Internet search for information resources on nursing home selection and examined the accessibility of the sites and the information they provided. We provided the findings from the web content review in Volume II of this report. To learn about the factors that influenced decisions about selecting a nursing home and the use of information resources, we conducted a series of focus groups among individuals who had experienced short stays in nursing homes, individuals who had placed family members in long-term care, and information intermediaries (hospital discharge planners and community-based case managers), whose role was to assist people in finding LTC for a family member. We present the findings from these focus groups here.

Focus groups were conducted in four states. The locations for these focus groups were Santa Monica, CA; Des Moines, IA; Miami, Florida; and Arlington, VA. Six focus groups were conducted: two with former (Medicare-paid) short-stay nursing home residents, two with families of current nursing home residents, one with hospital discharge planners, and one with community-based case managers. The formulation of focus group questions was guided by a conceptual framework that assumes that the strategies consumers employ in choosing among facilities are expected to depend on many factors, including characteristics of the decision problem and the decision-maker, and the context in which the decision is made. The focus groups were conducted according to standard, well-defined methods designed to elicit participants' views and experiences.

Findings from Consumer and Information Intermediary Focus Groups

The strategies consumers employ (e.g., how consumers actually come to a decision) in choosing among nursing facilities depend on many factors, including characteristics of the *decision problem* (e.g., number of choices and time available to make a decision), the *decision-maker* (e.g., knowledge level and approach to seeking information), and the *social context* in which the decision is made (e.g., short vs. long-stay and social norms around caring for older

adults). These major types of factors can affect how readily one can access and process information designed to support the decision-making process. We organize the findings in this report around these three main factors.

The Decision Context

Timeframes: Consumers who participated in the focus groups, particularly those seeking short-stay placements, perceived that the timeframe for making decisions regarding nursing homes was too short, often only a day or two. Hospital discharge planners shared that the process of assisting patients with aftercare planning begins within a day of admission, but that patients and their families often avoid facing these decisions until a day or two before discharge, possibly due to denial. The discharge planners did acknowledge that the short timeframes patients or their families had for these decisions was sometimes necessitated by a change in the patient's condition over the course of the hospital stay.

Perception of Choice: Most consumers reported some choice of facilities, but some perceived their choices as narrow or constrained by factors such as managed care requirements or geographical location (specifically proximity to their residence, family, or referring physician).

Provision of Information: Information intermediaries support consumers throughout the nursing home selection process in a variety of ways. Most notably, participating discharge planners and community-based case managers mentioned that they provide a list of facilities to consumers to support them in the decision-making process. Information intermediaries also provide pamphlets, booklets, or magazines that include information about local long-term care resources. Information intermediaries indicated that they are often unwilling to or may even be prohibited from making specific facility recommendations. This unwillingness or inability to share information may be a barrier to informed decision-making by the consumer. In some cases, discharge planners and case managers were unwilling to provide specific recommendations because they did not want to be subject to the anger or disappointment of patients/families who may be dissatisfied with the recommendation.

Personal Characteristics of the Decisionmakers

Knowledge Level: Consumers generally expressed a lack of knowledge about nursing homes, LTC, and technical quality issues. Often what they considered to be a high quality facility was one that looked nice, smelled nice, and had nice amenities, rather than one that provided good quality care. In general, consumers (residents as well as family members) were also unaware of the costs of long-term care.

Information Gathering: Consumers in the focus groups reported using some of the resources provided by information intermediaries and supplemented what they received and used from the intermediaries with other sources of information they identified on their own. For short-stay residents, the list of facilities provided by the hospital discharge planner was generally the primary source of information. Both short-stay residents and families of LTC residents also relied heavily on prior personal experience and the experiences of friends and family to help establish a list of facilities to consider or to narrow down a pre-existing list to those worth considering. Visits to a small number of facilities were also a primary source of information used in decision making. Written materials, other than lists generated by information intermediaries

were generally not used. In addition, few consumers mentioned using the Internet and those who did, used it primarily to develop a list of local facilities for their consideration.

Perceived Utility of the Internet by Consumers: Hospitalized patients and their family members were generally unable to access the Internet in a timely fashion to help aid their selection of short-stay care. Few consumers participating in the focus groups were aware of the Medicare.gov site or Nursing Home Compare. Those who did use these Internet sites reported that they were difficult to navigate and lacked up-to-date or timely information items of importance in the nursing home selection process.

Role of Information Intermediaries: Short-stay residents reported relying heavily on hospital discharge planners for information on nursing homes in their area, usually by providing lists of facilities in the local area. In some cases, these professionals were their only resource. Few former residents or family members reported getting support or information from their or their loved one's physician but several indicated that they would have liked greater involvement from their physician in providing information. Some discharge planners also felt that the physician should play a greater role in the process of searching for and selecting a facility. One discharge planner stated that more active involvement by the physician in preparing the family for the nursing home stay might make the family's decision-making process easier.

Priorities for Nursing Home Selection: The single most frequently cited factor in the selection of a facility was location. This finding held for both skilled nursing stays and long-term custodial stays. While most were concerned with the facility being located close to the resident's or family's home, some sought proximity to the hospital or to their referring physician. The second most common priority for nursing home care was that the facility staff took "good care" of the residents, information most often assessed by a visual inspection of a facility. Short-stay residents identified maintaining an existing relationship with a primary care physician as a priority in the selection of a facility, although this was not a priority for family members.

What Consumers Would Have Done Differently: In general, consumers expressed the belief that they had selected the best care option given the timeframe, information, and options available to support decision-making. A few consumers who articulated the desire to approach facility selection in a different manner wanted more information about specific facilities or options for care.

Social Context of Decision-Making

Social Pressures/Social Norms: In the case of placement of family members in LTC, a sense of stigma that care could not be provided in the family's residence was an important barrier to making a timely decision to place a loved one in a nursing facility. Often this barrier resulted in the decision being made under severe time pressures due to the emergent nature of the loved one's condition.

Effects of Differences in Type of Placement: Hospital patients always had the assistance of a discharge planner in preparing them for their discharge to a skilled nursing or rehabilitation facility. Former short-stay residents relied substantially on the lists provided by the discharge planner in helping them select a facility. Similar assistance was rarely available to families seeking a long-term custodial care facility for a loved one and who typically sought admission from the community rather than the hospital. Also, participants perceived that placements are

easier to find when the placement is expected to be short-term and the patient is expected to return home.

Role of Culture or Language in Decision-Making: Consumers and information intermediaries identified culture, language, and ethnicity as factors influencing nursing home selection. In particular, they pointed out that information materials are seldom available in a range of languages. Participants also perceived the role culture can play in determining attitudinal norms toward the concept of long-term care as a barrier to the selection process (both the process for deciding if placement is appropriate and the choice of a facility once the placement decision is made). Thus, facility support of a specific language and/or culture becomes the primary determinants in facility selection for some consumers.

Family Dynamics: The role of family members and the dynamics of family interaction during decision-making have a bearing on the social context in which selection occurs. Short-stay residents were unanimous in identifying the positive role or influence of family in decision-making, while families of current nursing home residents described experiences in which family dynamics supported or hindered decision-making.

Summary

Consumers generally do not avail themselves of the multitude of information resources available to them in the process of selecting a nursing facility. Even given the wide variety of information sources available either in print, by phone, or on the Internet, many of the focus group participants perceived that the information they needed or wanted was not available to them when they needed it. Several people mentioned the inability to find a particular type of information that is already available but about which they were not aware, such as facility inspection reports. Denial or lack of understanding about a loved one's condition and the circumstances around hospital discharge often resulted in little time to select a facility, making it difficult to seek out or use what formal information sources are available. In selecting a facility, consumers are most likely to rely on lists of facilities that provide general information such as location, supplemented by word of mouth and more easily observed characteristics of the facility that reflect a sense of quality of life. In contrast, consumers were less concerned with the clinical, more technical factors that influence quality of care.

Consumers based their selection of facility on information often not available on Internet-based resources. Most of the sites we reviewed as part of our content review did not include characteristics that were cited as important selection criteria for many consumers (e.g., information on costs and what activities were available in the facility). Both consumers and information intermediaries found that many of the available Internet resources, including Nursing Home Compare, were not "user-friendly," and intermediaries were reluctant to recommend the sites to consumers. Most sites are not available in languages other than English, which some consumers and intermediaries cited as an important barrier to their use.

We propose at the end of this report a set of actionable items and areas for future research that may lead to information resources that better meet consumers' needs and facilitate greater access to information resources for those seeking a nursing home.