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STRUCTURAL BARRIERS TO USE OF
HOME HEALTH AIDE SERVICES PERCEIVED BY
FAMILY CAREGIVERS OF RELATIVES
WITH IRREVERSIBLE DEMENTIA

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By

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ABSTRACT

STRUCTURAL BARRIERS TO USE OF HOME HEALTH AIDE SERVICES PERCEIVED BY FAMILY CAREGIVERS OF RELATIVES WITH IRREVERSIBLE DEMENTIA

By

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The purpose of the study presented in this thesis was to address the problem: What structural barriers to use of home health aide services are perceived by family caregivers of relatives with irreversible dementia? This study was a secondary data analysis of transcripts of data collected from interviews of 32 family caregivers of relatives with irreversible dementia.

The major finding of the study included the recurrent theme of cost/expectation, which was the major structural barrier that emerged. Although the caregivers in many cases indicated that the price paid for services outweighed the benefits, caregivers continued to use home health aide services. This finding has several implications for advanced practice nurses including the need for research aimed at decreasing structural barriers to use of home health aide services by family caregivers of relatives with irreversible dementia so that these caregivers can receive the help they need to care for their aging relatives.

To my father and mother,

Charles and Louise Liken,

for their love and support

during my educational endeavors.

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CHAPTER I

The Problem

Introduction

As the 21st century approaches, problems associated with aging are of growing concern because the aged segment of the population is rapidly increasing. A major problem facing the aged and their families is irreversible dementia. By the year 2000, experts estimate that over four million Americans will have symptoms associated with irreversible dementia (Staff, 1987).

Irreversible dementia is a progressive, degenerative disorder that results in deterioration of intellectual capabilities (Katzman, 1986). It is also referred to as senile dementia or Alzheimer's disease. As the disease progresses individuals with dementia rely on others to assist them with activities of daily living. Most often, family members become primary caregivers for relatives with irreversible dementia (Brody & Schoonover, 1986; Fitting, Rabins, Lucas, & Eastham, 1986; Horowitz, 1985; Stone, Cafferata, & Sangl, 1987).

Experts in the field of gerontology have documented that caring for a relative with irreversible dementia causes stress and that this stress can cause physical and emotional health problems (Haley, Levine, Brown, Berry & Hughes, 1987; Kinney & Stephens, 1989; Poulshock & Deimling, 1984). Chenoweth & Spencer (1986) report that caregivers cite being overwhelmed by 24-hour a day care responsibilities as the most frequently mentioned reason for placing a relative with irreversible dementia in a long term care facility.

Family caregivers may use community services, such as home health aides to assist them with caring for their relative with irreversible dementia. McCoy & Conley (1990) define a home health aide as an individual who provides personal care services and protective oversight in a client's home. Home health aide services can assist caregivers with care tasks that cause stress and fatigue for the caregiver. Interestingly, researchers have found that family caregivers infrequently use community services such as home health aides to help them care for their relatives (Caserta, Lund, Wright & Redburn, 1987). Reasons why caregivers do not use community services are not clearly understood and researchers continue to investigate this issue.

The purpose of this study was to investigate structural barriers to use of home health aide services as perceived by family caregivers of relatives with irreversible dementia. This investigation was accomplished via analysis of in-depth interviews with a sample of family caregivers of relatives with irreversible dementia.

Background of the Problem

For over a decade, there has been an interest in the impact of caring for a relative who has irreversible dementia. Several researchers focused on the physical and emotional stressors associated with caring for a relative who has irreversible dementia (Birkel & Jones, 1989; Chenoweth, & Spencer, 1986; Deimling & Bass, 1989; George & Gwyther, 1986; Moritz, Kasl & Berkinan, 1989; Pratt, Schmall, Wright & Cleland, 1985; Rabins, Mace & Lucas, 1982; and Zarit, Reever & Bach-Peterson, 1980). In these studies caregivers report fatigue, depression and many other problems associated with the physical and emotional stress of caring for a relative with irreversible dementia.

In the face of relentless physical and emotional strains associated with caregiving it seems that family caregivers of relatives with irreversible dementia would use services such as home health aides to assist them with their caregiving responsibilities. Several researchers have found, however, that family caregivers of relatives with irreversible dementia infrequently use community services such as home health aides (Birkel & Jones, 1989; Cryns & Gorey, 1989; Lawton, Brody & Saperstein, 1989; Montgomery, Stull & Borgatta, 1985; Stone, et al., 1987).

Few researchers have attempted to find answers why family caregivers of relatives with irreversible dementia infrequently use services such as home health aides (Office of Technology Assessment, 1987, 1990). Among reasons cited for why caregivers do not use services such as home health aides are: (1) specific symptoms of the client with irreversible dementia that may cause the caregivers to have difficulty finding someone willing to care for their relative (eg. combativeness), (2) caregiver and client reactions to service providers, and (3) lack of training of service providers in how to care for individuals with irreversible dementia (Office of Technology Assessment, 1987, 1990). Other reasons for low rates of service use may be related to specific attributes of family caregivers of relatives with irreversible dementia. These attributes include lack of knowledge of existing services, difficulty locating services, expense of services, and social stigma relating to mental illness (Office of Technology Assessment, 1987, 1990).

Melnyk (1985) calls "reasons" that individuals do not use health related services "barriers." To guide understanding of difficulties involved in use of health care services Melnyk operationalized the concept of barriers and proposed that there are three levels of barriers: macrosystem, structural, and individual variables. Study of perceived barriers can be used to facilitate understanding of why family caregivers of relatives with irreversible dementia infrequently use services such as home health aides to assist them with their caregiving tasks.

Advanced practice nurses need to understand factors affecting service utilization among family caregivers of relatives with irreversible dementia because the number of individuals affected is rapidly increasing. The federal government acknowledges the need to study service utilization of family caregivers of relatives with irreversible dementia and has already begun to report information in this area (The Office of Technology Assessment 1987, 1990). There is specifically a need for researchers to investigate the barriers to service utilization perceived by family caregivers of relatives with irreversible dementia so that advanced practice nurses can begin work on decreasing barriers and for families who might benefit from those services. In sum, few researchers have studied the reasons why caregivers of relatives with irreversible dementia infrequently use home health aides, thus, there is a need for further investigation into this problem.

Importance of the Study

The need for research regarding barriers to use of home health aide services perceived by family caregivers of relatives with irreversible dementia relates to the fact that clearer understanding of barriers may facilitate appropriate use of this service in the future. It is possible that outcomes of appropriate use of home health aide services might include a self-reported decrease in physical and emotional caregiver stress. In turn, decreased caregiver stress may lead to decrease abuse of the relative with dementia and improved quality of life for the relative.

A qualitative approach allows researchers to examine human experience, perceptions, and involvement via naturalistic inquiry (Munhall & Oiler, 1986). This approach is useful to investigate phenomenon such as <u>barriers</u> to use of home health aide services perceived by family caregivers of relatives with irreversible dementia because researchers have not yet clearly identified these barriers. Using Melnyk's (1985) barrier categories as a framework it should be possible to gain a clearer understanding of specific perceived barriers. In the primary care setting advanced practice nurses may help facilitate use of services based on a clearer understanding of barriers that impede use of home health aide services by family caregivers of relatives with irreversible dementia.

Purpose of the Study

The purpose of the study presented in this thesis is to describe structural barriers to use of home health aide services perceived by family caregivers of relatives with irreversible dementia. Melnyk's framework is used to guide the understanding of these identified structural barriers.

Scope of the Study

The study presented in this paper incorporates a secondary data analysis of transcripts of data collected from a sample of 32 family caregivers of relatives with irreversible dementia. During the initial data collection, nurse researchers asked family caregivers open-ended questions about the caregivers' experiences with a variety of community services. In this secondary data analysis, caregiver comments about barriers to home health aide services were analyzed. This analysis was limited to structural barriers because other in the researcher's clinical experience the majority of barriers associated with home health aide services are structural. However, because of the lack of clear distinction between Melnyk's barrier categories, which is discussed in Chapter 3, it is often difficult to clearly separate structural barriers from macrosystem barriers. If there appeared to be an overlap in barrier categories, for the purpose of this study the barriers were identified as structural.

Statement of the Problem

The problem addressed by this research is: What structural barriers to using home health aide services do family caregivers of relatives with irreversible dementia perceive?

Overview of Chapters

This thesis consists of six chapters. Chapter I included the background of the problem, the importance of the study, the purpose of the study, scope of the study, and a statement of the problem.

In Chapter II a discussion of the concepts used in the study is presented. A description of family caregivers, home health aide services, barriers, and Melnyk's barrier framework is described in Chapter II. This chapter also includes a discussion of rationale for use of Melnyk's structural barriers in this study, the relationship of the study variables and Melnyk's framework, and implications for advanced practice nurses.

A review of literature pertinent to the study is presented in Chapter III. Chapter III includes a discussion of use of home health aide services by family caregivers of relatives with irreversible dementia, barriers to use of home health aide services by family caregivers of relatives with irreversible, and a critique of literature.

In Chapter IV a discussion of methodology and procedures used in the study is presented. This chapter also includes a description of the primary research design, the sample, data collection, primary data analysis, secondary research procedures and secondary data analysis. Also included in Chapter IV is a discussion of validity and reliability, methodological assumptions about qualitative research, methodological limitations of qualitative research, and protection of human subjects.

In Chapter V the study findings are presented. Chapter VI includes a discussion of conclusions and implications for nursing interventions, education, and research.

CHAPTER II

Conceptual Framework

Overview

In chapter II concepts used for this study are discussed. This chapter includes a description of family caregivers, home health aide services, barriers, Melnyk's barrier framework, rationale for use of Melnyk's concept of structural barriers in this study, the relationship of the study variables and Melnyk's framework, and implications for advanced practice nurses.

Family Caregivers

Stone, et al. (1987) define caregivers by types of care provided as well as volume, intensity, and duration of care based on the care recipient's level of disability. For this study "family caregiver" is defined as the family member providing care to an elderly relative who has a diagnosis of Alzheimer's disease or other progressive dementias, in the home.

Home Health Aide Services

Different agencies provide varying definitions for home health aide services. The U.S. Department of Health and Human Services, Health Care Financing Administration (1988) defines home health aide services as "hands-on personal care that can be performed by a home health aide on a part-time or intermittent basis to maintain the beneficiary's health or facilitate treatment of the beneficiary's illness or injury" (p. 26). These services include assistance with bathing, dressing, grooming, caring for hair, nails, and oral hygiene, skin care, foot care, changing of bed linens, shaving, feeding, elimination needs, ambulation, changing of position in bed, and assistance with transfers and protective oversite of the client (McCoy & Conley, 1990 and U.S. Department of Health and Human Services, 1988). A home health aide may perform other tasks such as shopping, meal preparation, light household tasks, and assistance with medications and exercise (Office of Technology Assessment, 1987, 1990). For the study presented in this thesis, the investigator defines home health aide services as a formal (eg. hired through an agency) or informal service (eg. a neighbor or someone not affiliated with an agency) in which an individual provides personal care (including the personal services listed above) in the individual with irreversible dementia or the caregiver's home.

In sum, home health aides provide personal care and for clients in the client's home. Home health aide services may provide relief from caregiving responsibilities. An outcome of home health aide services may be a reduction in caregiver stress. However, barriers may prevent family caregivers from using home health aide services.

Barriers

Barriers to health care services is a concept that has evolved over the past few decades. Rosenstock (1966) is one of the first researchers to introduce the concept of barriers. In his Health Belief Model (1966) Rosenstock defined barriers as costs, or negative aspects of undertaking preventive health action.

Another definition of barriers emerged from Andersen's (1968) Health Service Utilization Model, a framework developed to describe clients' use of preventive health services. Andersen did not initially mention the term "barriers" however the "absence of certain resources," which Andersen called "enabling factors," later became the definition for "barriers. In his model, Andersen equated barriers with a lack of or reduced access to a primary care provider along with other enabling factors (Aday & Andersen, 1974).

For the purpose of the study presented in this thesis, barriers are defined as perceived problems to use of home health aide services. These problems may include, but are not limited to, difficulties encountered when seeking and/or using a service. Melnyk's barrier framework was used to aid in categorization of barriers for the data analysis.

Melnyk's Barrier Framework

To date only Melnyk (1985) has specifically researched barriers to use of health services. Her research regarding barriers was designed to explore preventive health behavior. Melnyk's definitions of barriers were derived from Rosenstock's Health Belief Model. Melnyk organized barriers to service use into three categories: macrosystem, structural, and individual variables.

Macrosystem barriers relate to the philosophy and policy that shape health care systems, or the traditions and values of empowered individuals that influence health care policies and the system's philosophy. Values influence the model of health care delivery, the organization of services, and the standard of health care practice. An example of macrosystem barriers is the valuing tertiary, highly technical care resulting in provision of funding in this area. Another example is the devaluation of elderly mental health care in the community which has resulted in decreased channelling of funds toward programs that would assist the chronically mentally ill and their families. Overall, macrosystem barriers are difficult to operationalize because of their global nature.

Structural barriers are frequently more concrete than macrosystem barriers and relate to characteristics of the health care system and/or the service provider. Structural barriers include, but are not limited to, time, distance, cost, availability, organization of services, discrimination, and provider characteristics.

Time refers to the time required to locate health care services, travel time, and waiting time to receive services. Distance refers to proximity to the service and to problems associated with transportation. Cost refers primarily to fees required to obtain services, but may also include transportation costs and lost time at work. Availability of services refers to a provider/consumer ratio, hours of services, and accessibility to services. Organization of services includes fragmentation of services into multiple providers and inconsistency of services.

Discrimination refers to racism, sexism, and ageism, ability to pay for services, and/or type of third-party payment. For example, some health care services do not accept payment from Medicaid. Another example of discrimination is the stigma associated with certain disease states such a chronic mental illness or certain treatments such as psychiatric services. Discrimination also refers to preferences for specific providers by consumers. For example, health care consumers may prefer providers who are of their same race, culture, age, and sex.

Provider characteristics include the service provider's actual or perceived lack of interest and/or expertise in the client's problems and/or solutions to these problems. This category includes inadequate knowledge of treatment and services available, inappropriate referrals, and lack of follow-up care. Provider characteristics also include discomfort toward certain client characteristics, such as low economic status or symptoms of mental illness. Overall, structural barriers are more definable than macrosystem barriers and include factors such as time, distance, cost, availability, organization of services, discrimination, and provider characteristics. It may be difficult to distinguish between macrosystem and structural barriers in some cases, as these categories are not mutually exclusive of each other.

Individual barriers consist of consumer (ie. both the caregiver and client) related factors. These factors include demographics, attitudes, knowledge, effort, and communication. Demographic factors include the consumer's educational level, socioeconomic status, and age of the service recipient. Attitudes involve fear and anxiety, nonacceptance of certain conditions and/or treatments, lack of interest in health care services, and lack of sensitivity to need for care, self-reliance and ethnocentricity. Knowledge refers to the awareness of health and the health care system. Lack of awareness or inadequate understanding of the health care system or health care services, and/or the relationship of specific needs to specific disease processes are examples of knowledge related barriers.

Effort refers to energy expended to seek care. Physical and/or emotional disability, competing demands such as family, employment, and caregiving tasks may influence effort. Another barrier is communication or language problems resulting from cultural, ethnic, or racial characteristics. For instance, some individuals may rely on folk medicine for treatment, look to kin for support, or may be unaware of services available in the broader community.

Other individual barriers include family characteristics, denial of the problem and the need for care by family members, prior negative experience with services and eligibility for services. In summary, individual barriers include multiple factors including demographics, attitudes, knowledge, effort, communication factors, and other specific individual characteristics.

Rationale for Use of Melnyk's Structural Barriers in This Study

The purpose of the study presented in this thesis was to describe structural barriers to use of home health aide services perceived by family caregivers of relatives with irreversible dementia. Study variables included family caregivers, home health aide services, and barriers. The investigator used Melnyk's (1985) barrier framework to facilitate understanding of barriers to use of home health aide services perceived by family caregivers of relatives with dementia.

The investigator only used Melnyk's structural barriers category for several reasons. First, Melnyk's macrosystem barriers were not used for this study because they are poorly operationalized and relate to global philosophies and policies that guide the health care system. Additionally, the investigator did not use individual barriers which include multiple factors such as demographics, attitudes, knowledge, effort, communication factors, and other characteristics specific to the individual because it may be more difficult to alter these barriers prior to changing the health care system.

The investigator only used structural barriers which include time, distance, cost, availability, organization of services, discrimination, and provider characteristics because in the researcher's clinical experience a majority of the barriers to use of home health aide services are structural. In addition, providers, such as advanced practice nurses may influence structural barriers from within the system and may assist in decreasing barriers to use of home health aide services.

Melnyk's barrier framework was used to facilitate categorization of barriers to home health aide services by family caregivers of relatives with irreversible dementia. For the purposes of the study presented in this thesis, "provider" refers to the home health aide and/or the organization for which the home health aide works (eg. home health agency). The "consumer" of services refers to the family caregiver of the individual with dementia.

If through better understanding of barriers to community services, health care providers, such as the advanced practice nurse in the primary care setting can decrease structural barriers to use of home health aides services individuals such as family caregivers of relatives with irreversible dementia may obtain much needed care that may help decrease caregiver stress.

Relationship of the Study Variables and Melnyk's Framework

In the presence of structural barriers, family caregivers may be unable to obtain home health aide services. Figure 1. is an illustration of the relationship between family caregivers of relatives with irreversible dementia use of home health aide services, and structural barriers to services as described by Melnyk.

Implications for Advanced Practice Nurses

Structural barriers to use of home health aide services perceived by family caregivers of relatives with irreversible dementia have several implications for advanced

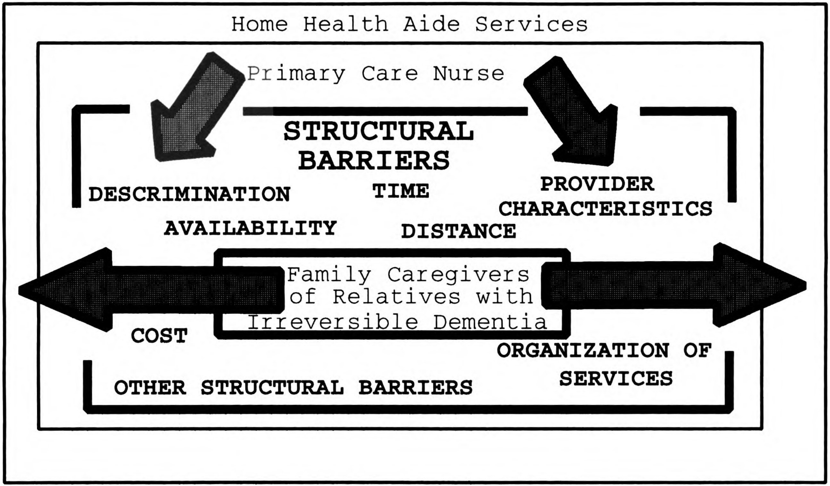

Figure 1. Relationship Between Melnyk's Structural Barriers, Home Health Aide Services, and Family Caregivers of a Relative with Irreversible Dementia.

practice nurses. First, advanced practice nurses are a part of the health care system. As such, advanced practice nurses may have insight into the mechanisms of services, such as home health aide services and may identify ways to decrease structural barriers. Second, advanced practice nurses may work directly with clients such as family caregivers of relatives with irreversible dementia and may help caregivers obtain home health aide services.

Through assessment of the caregiver's situation, the advanced practice nurses may gain insight into the specific problems or structural barriers to the use of home health aide services perceived by family caregivers of relatives with irreversible dementia. Advanced practice nurses may then work toward decreasing these structural barriers, through specific interventions, referrals or by providing information.

Finally, advanced practice nurses frequently have specialized training to work with specific segments of the population. Advanced practice nurses who work with family caregivers of relatives with irreversible dementia may become advocates for these individuals. As advocates, advanced practice nurses may work toward decreasing barriers to use of services such as home health aides by becoming involved in health care policy development. In sum, advanced practice nurses are a part of the health care system, have direct contact with clients, and have specialized training that may allow them to act as advocates for specific groups of clients such a family caregivers of relatives with irreversible dementia.

A description of family caregivers, home health aide services, barriers, Melnyk's barrier framework, rationale for use of Melnyk's structural barriers in this study, the relationship of the study variables and Melnyk's framework, and implications for advanced practice nurses were included in Chapter II. A review of pertinent literature is presented in Chapter III.

CHAPTER III

Review of Literature

Overview

The research question posed in this study is: What structural barriers to using home health aide services do family caregivers of relatives with irreversible dementia perceive? This chapter includes a discussion of use of home health aide services by family caregivers of relatives with irreversible dementia, barriers to use of home health aide services by family caregivers of relatives with irreversible dementia and a critique of literature.

Use of Home Health Aide Services by Family Caregivers of Relatives with Irreversible Dementia

During the past few years, use of community services by family caregivers of relatives with irreversible dementia has been a topic of interest among researchers. These researchers found that community service use among this population is surprisingly low (Brody & Schnoonover, 1986; Caserta, Lund, Wright, & Redburn, 1987; Office of Technology Assessment, 1987, 1990; Toseland & Rossiter, 1989).

Most researchers who studied use of community services by family caregivers of relatives with irreversible dementia examined service use as a whole rather than looking at specific services such as home health aides. Researchers who investigated specific services only looked at respite care and family support groups (Lawton, Brody, & Saperstein, 1989; Lundervold & Lewin, 1987; Mohide, Pringle, Streiner, Gilbert, Muir, & Tew, 1990; Montgomery & Borgetta, 1989; Toseland & Rossiter, 1989).

To date, only the federal government, in the Office of Technology Assessment Report (1987, 1990) and Collins, Stommel, Given & King (1991), have reported specifically about home health aide services. Researchers involved in development of the Office of Technology Report (1987, 1990) noted that 53% of caregivers in their study considered home health aides the most important service (regardless of cost and availability). While 62% of the caregivers in the study who reported that home health aide services were available in the area that they lived had, only 21% of these caregivers, were currently using the service and 49% had used home health aide services in the past. Approximately one third (39%) of the caregivers had never used home health aide services.

Like the work of the federal government in the Office of Technology Assessment Report, Collins et al. (1991) found that one third of the caregivers had used home health aide services in the past three months. Collins et al. also found that slightly less than half of the caregivers in their sample (42%) who were not using home health aide services knew that the service was available. Only 2% of the caregiver stated that home health aide services were not available, while 18% did not know of the service was available in their community.

In sum, most researchers interested in community service use have looked collectively at various or focused on services such as respite care and family support groups. Only the federal government in the Office of Technology Assessment Report (1987, 1990) and Collins et al. (1991) looked specifically at home health aide service use by family caregivers of relatives with irreversible dementia and found that approximately half of the caregivers in their study knew that home health aide services were available in their area, but only about one third of the caregivers were currently using the service.

Barriers to Use of Community Services by Family Caregivers of Relatives With Irreversible Dementia

Among factors addressed by researchers who investigated use of community services by family caregivers are reasons why caregivers do not use services (Caserta, Lund, Wright and Redburn, 1987; Collins et al., 1991, Office of Technology Assessment, 1987, 1990). To further clarify the barriers issue, it is useful to examine how researchers addressed barriers to services in the literature.

At least four different researchers (Bass & Noelker (1987), Collins et al. (1991), McCaslin (1988) and the federal government in the Office of Technology Assessment Report (1987, 1990) investigated reasons individuals do not use health care or community services. McCaslin (1988) looked at existing data and categorized barriers to use of services into four different classifications: (1) demographics, (2) individual functional capacity, (3) support systems, and (4) orientation to services. Like Melnyk's individual barriers, McCaslin's demographic variables include age, ethnicity, gender, marital status education, income, employment, social class, length of residence, community characteristics, and religious preference.

Individual functional capacity includes health status, mobility, transportation access, activities of family living, financial resources, religious service attendance, life satisfaction, and stress. Support system variables include household, children, other relatives, friends, and specific potential helpers.

Orientation to services includes perceived discrimination, past use with public assistance, knowledge of services, and need for services. In sum, McCaslin categorized barriers into four possible classifications, including, demographic, individual functional capacity, support system, and orientation to services. Several of

McCaslin's barrier categories are similar to Melnyk's barrier categories.

Bass & Noelker (1987) looked at in-home service use as a whole (ie. visiting nurses and home health aides) of 586 primary caregivers of individuals over age 60 via a semistructured interview and found that only one half of primary caregivers of an impaired elderly relative in their study used in-home health services. Bass & Noelker (1987) examined the differences between users and non-users of in-home services to predict the amount of caregiver service use by using a four-stage regression analysis. These researchers categorized factors that influence service use into three areas: predisposing, enabling factors, elder need and caregiver need factors.

The predisposing characteristics include age and race of the care recipient, sex and age of the caregivers, and the relationship between the family caregiver and care recipient. Enabling characteristics include variables such as household income, family support, number of family-assisted tasks, and the number of family-friend helpers. Household income was found to be a particularly strong enabling characteristic. Elder need characteristics include factors such as incontinence, number of chronic conditions, paralysis, and diagnosed mental impairments. Finally, caregiver need characteristics include activity restrictions, change in physical health, and task burden.

In sum, Bass & Noelker conducted a semistructured interview with a large sample of caregivers and via quantitative analysis of the data found that predisposing, enabling, and need characteristics of the elder and family caregiver influence service use. These characteristics are similar to Melnyk's categories. Bass & Noelker quantitatively analyzed their data and they did not specifically address structural barriers associated with use of in-home services.

Collins et al. (1991) looked at service use patterns among a convenience sample of 338 family caregivers of individuals with irreversible dementia and found, via quantitative analysis, that potential barriers to home health aide service use included, decreased availability and lack of knowledge of home health aide services. While Collins et al. did look specifically at a large sample of family caregiver's use of home health aide services, these researchers did not look specifically at structural barriers.

The federal government in the Office of Technology Assessment Report (1987, 1990) studied results of mailed questionnaires completed by 569 caregivers of relatives with irreversible dementia and identified reasons why family caregivers of relatives with irreversible dementia do not use home health aide services. In the federal government's Office of Technology Assessment Report it was found that availability of the services and lack of knowledge about availability of the services and lack of knowledge about existence of this service in their area were the primary causes for lack of home health aide service use among family caregivers of relatives with irreversible dementia. While The Office of Technology Assessment considered a large sample of family caregivers of relatives with irreversible dementia and did look specifically at home health aide services, their methods were limited to a quantitative nature and they did not specifically look at structural barriers.

In sum, Bass & Noelker (1987), McCaslin (1988), Collins et al. (1991), and the federal government in the Office of Technology Assessment Report (1987, 1990) posit reasons why individuals do not use health related services. Only Collins et al. the federal government specifically studied use of home health aide services by family caregivers of relatives with irreversible dementia. To date no researchers have used qualitative methods to discover structural barriers to use of home health aide services as perceived by family caregivers of relatives with irreversible dementia.

Critique of Literature

Review of literature regarding barriers to use of home health aide services by family caregivers of relatives with irreversible dementia reveals several gaps. Although researchers have examined service use among family caregivers of relatives with irreversible dementia, no researchers have looked at structural barriers to use of home health aide services via a qualitative method. Researchers have attempted to categorize reasons these caregivers do not use home health aide services using a conceptual framework to categorize barriers, however, no researchers have limited their studies to categorization of the barriers and have not analyzed specific barrier themes within the barrier categories.

In sum, to date no researchers have looked specifically and in-depth at structural barriers to use of home health aide services by family caregivers of relatives with irreversible dementia. There is a critical need for in-depth research into structural barriers to use of home health services perceived by family caregivers of relatives with irreversible dementia because very little has been done in this area.

Summary

This chapter included a review of relevant research related to use of home health aide services by family caregivers of relatives with irreversible dementia. While researchers have examined service utilization by family caregivers of relatives with irreversible dementia, few researchers looked specifically at home health aide services nor reasons why family caregivers do not use home health aide services using a qualitative research method, or a related to barriers. The next chapter of this thesis includes a discussion of the methodology that was used to complete this study of barriers to home health aide services by caregivers of relatives with irreversible dementia.

CHAPTER IV

Methodology and Procedures

Overview

This chapter includes a description of the methodological assumptions about qualitative research, a description of the primary research study, and an explanation of the secondary research sample, analysis, validity and reliability, methodological limitations of qualitative research and protection of human subjects.

Methodological Assumptions about Qualitative Research

The researcher used content analysis as a qualitative research method in this study. According to Burns & Grove (1993) content analysis is designed to classify the works in a text into a few categories according to their theoretical importance. Content analysis provides a systematic means for measuring the frequency, order or intensity of occurring words, phrases, or sentences. Content analysis involves counting of categories, therefore some qualitative researchers do not consider content analysis a qualitative method.

According to Burns & Grove (1993), with content analysis, initially, the researcher must define the specific characteristics of the content to be measured and then develop rules for identifying and recording these characteristics. The researcher first selects a specific unit of analysis (ie. words or themes) this unit of analysis if an indicator of an abstract concept.

To perform content analysis, the text is divided into units of meaning (ie. categories). These units are quantified according to specific rules. The construction of idea categories is a crucial phase of content analysis. Frequently the researcher is looking for relationships among ideas. After identification of terms, these must be interpreted to reflect the means of the ideas as full as possible.

Primary Research Design

The primary research project was a qualitative study, "Perceptions of Community Services by Alzheimer's caregivers," PRG-89-098, Dr. Sharon King, Principal investigator. The aim of Dr. King's study was to collect information regarding current and retrospective experiences with various community services perceived by family caregivers of relatives with irreversible dementia to better understand why these caregivers infrequently use community services. Specific information about the sample, data collection and analysis for the primary research project is contained in Appendix A.

Secondary Research Sample

The data used in the secondary analysis was taken from transcripts of qualitative research interviews with 32 family caregivers of relatives with irreversible dementia. Only data contained in segments of initial interview transcription coded in the categories "home health aide services" (INHOMECU) and "service problems" (SERVPROB) was used in the secondary data analysis.

Secondary Data Analysis

All segments of transcripts coded in the primary research study as "home health aide services" (INHOMECU) and "service problems" (SERVPROB) described by non-users, current users and past users of the service were used in the secondary data analysis. The researcher sorted the data contained in segments "home health aide services" (INHOMECU) and "service problems" (SERVPROB) into general categories of barriers to use of home health aide services using Melnyk's structural barrier categories as a guide. Given that there was information about barriers to home health aide services that did not fit into Melnyk's structural barrier categories, the researcher designated an "other" category for this type of information.

Two levels of analysis took place. At the first level, any caregiver who did not mention home health aide services in the interview or stated that they did not know any thing about home health aides, dropped out of the analysis because no further information could be obtained from these transcripts. This left 23 caregiver's transcripts to analyze further regarding barriers to home health aide service use.

The researcher then analyzed the data in each barrier category according to content. The researcher noted the percentage of caregivers who made statements about various barriers and drew inferences about the kinds of statements the caregivers made.

Next, the researcher sorted the data into a matrix to analyze the data for themes and relational statements. For each caregiver in the sample the researcher made a cell for the caregiver's age, relationship to client, services used and any statements make about barriers to use of home health aides according to Melnyk's structural barrier categories. From this matrix the researcher searched for themes regarding barriers to use of home health aide services by family caregivers of relatives with irreversible dementia.

Validity and Reliability

Validity and reliability are critical issues in evaluating research findings. In qualitative research reliability is an issue of consistency and accuracy, determined by identification and documentation of recurrent, accurate and consistent or inconsistent features (Leininger, 1985). Determination of validity in a qualitative study related to gaining knowledge and understanding of the true nature, essence meaning, attributes and characteristics of a particular phenomenon.

Methods of assuring reliability and validity in the primary search study are discussed in Appendix A. For the secondary data analysis additional measures were taken to assure validity and reliability. To assure validity only data contained in segments coding in the primary study as "home health aide services" (INHOMECU) and "service problems" (SERVPROB) were used. To assure reliability, a matrix of the transcripts was created and statements about structural barriers to home health aide services were studied first for each caregiver (considering the whole of each caregiver's comments), then for each category of service problems as a whole (considering the caregivers comments collectively).

To assure that segments of the transcripts initially coded as "home health aide services" and "service problems" accurately captured all of the pertinent data about barriers to use of home health aide services, three of the transcripts were selected at random and recoded by a member of the research staff trained in the coding process but not involved with initial coding of the selected transcripts. The independent coding resulted in greater than 90%

agreement. Transcripts, therefore, were used as originally coded.

Methodological Limitations of Qualitative Research

There are several limitations to use of qualitative research. These limitations relate to the type of research desired, the size of the sample, generalizability and data analysis. Qualitative methods are not suitable for establishing cause-and-effect relationships, or testing research hypothesis because qualitative research tends to be non-directive (Polit & Hungler, 1987).

Second, qualitative research tends to yield vast amounts of data. Therefore, it is difficult for researchers to use large, representative samples for obtaining the data. Given this fact, researchers need to question the extent to which they can generalize findings of qualitative data (Polit & Hungler, 1987).

Additionally, researchers have cited problems related to data management and analysis techniques with qualitative research which diminishes the credibility of qualitative research reports (Miles & Huberman, 1984). For example, selective attention to data and misinterpretation leading to misrepresentation of phenomenon can be problematic (Walker & Avant, 1988).

For the above cited reasons, researchers have criticized qualitative research, citing that it is limited because of the restriction of the types of research where this method is useful, the predominance of small samples, and possible misrepresentation of data. Limitations of using qualitative research methods in the research study presented in this thesis include the fact that a small sample of 32 caregivers of relatives with irreversible dementia was used, thus, it is difficult to generalize the results of this analysis to the general population of family caregivers of relatives with irreversible dementia. Since the purpose of this study is "discovery" of barriers to home health aide services, therefore the benefits of using qualitative research outweigh the limitations.

The main limitation related to this research study was use of secondary data. Because the research used transcripts from data collected for a prior research study, the researcher did not have the opportunity clarify issues or probe further issues that could have provided useful information for the secondary data analysis.

Protection of Human Subjects

In the initial study the principal investigator protected the right of the respondents through adherence to standard criteria set forth by the Michigan State University Committee on Research Involving Human Subjects. The investigator of the secondary data analysis also protected the right of the subjects through adherence to standard criteria of the Michigan State University Committee on Research Involving Human Subjects (UCRIHS) amended form.

The investigator maintained confidentiality of subjects by referring to the transcripts only by an identification number. The UCRIHS letter of approval for this study is in Appendix E.

Summary

Chapter IV included a description the methodological assumptions about qualitative research, primary research study, the secondary data analysis, an explanation of the secondary research sample, validity and reliability, methodological limitations of qualitative research and protection of human subjects. Chapter V includes a presentation of the result of the secondary data analysis.

CHAPTER V

Data Presentation and Analysis

Overview

The purpose of the study presented in thesis was to describe barriers to use of home health aide services as perceived by family caregivers of a relative with irreversible dementia. Chapter V consists of a description of the validation of transcript codes, a report of sociodemographic and service use findings, a presentation of the study findings and themes derived from those findings.

Validation of Transcript Codes

To assure that segments of the transcripts initially coded as "home health aide services" and "service problems" contained all of the pertinent data, three of the transcripts were selected at random and recoded by an individual trained in the coding process but not involved with initial coding of the selected transcripts. The recoding resulted in greater than 90% agreement, therefore transcripts were used as originally coded.

Sociodemographic and Service Use Findings

Sample

The caregivers represented in this sample of 32 transcripts were primarily female spouses, daughters or daughters-in-law. Most of the caregivers were not working primarily due to retirement. Their mean age was 53.5 years with a mean of 4 years of caregiving. A summary of the sociodemographic variables are depicted in Table 1.

Service Use

Overall, 40.6% (n = 13) never used home health aides. Of the caregivers who had never used the service, 69.2% (n = 9) mentioned that they hadn't heard of or didn't know anything about home health aide services. Half of the caregivers (n = 16) were currently using home health aide services. Of the caregivers who were currently using the service, half used privately hired home health aides and half used home health aides hired thorough an agency. Three caregivers had used the service in the past. All of the past service users had only used home health aides hired through an agency. A summary of caregiver use of home health aide services if presented in Table 2.

Presentation of Study Findings

This analysis was based on data included in segments of the transcribed interviews pertaining to home health aides and service problems. These segments of the transcripts

Table 1. Sociodemographic variables among subjects participating in interviews (n = 32)

VARIABLE	%	(n)
SEX		
FEMALE	78.1%	25
MALE	21.9%	7
CAREGIVER RELATIONSHIP TO CLIENT		
SPOUSE	50%	16
DAUGHTER/ DAUGHTER-IN-LAW	46.9%	15
SIBLING	3.1%	1
CAREGIVER EMPLOYMENT		
NOT WORKING	65.7%	21
RETIRED	53.1%	17
WORKING		
FULL-TIME	21.9%	7
PART-TIME	12.5%	4

	RANGE	MEAN
AGE		
SAMPLE	40-85 YEARS	63.5 YEARS
DAUGHTER/ DAUGHTER-IN- LAW (n = 15)	40-68 YEARS	52.7 YEARS
SPOUSE (n = 16)	59-85 YEARS	66.0 YEARS
OTHER (n = 1)	70.0 YEARS	
DURATION OF CAREGIVING	1-10 YEARS	3.78 YEARS

Table 2. Home health aide service use among subjects participating in interviews (n = 32).

SERVICE USE	%	(n)
CURRENTLY USING	50.0%	16
NEVER USED	40.6%	13
USED IN PAST	9.4%	3

were sorted into users and non-users of home health aide services and then into general categories of barriers to use of home health aide services identified by users of the service, using Melnyk's structural barrier category as a guide. Due to the structure of the initial study's interview guide, the interviewers did not probe further into structural barriers to use of the service. Therefore non-users of home health aide services were eliminated from the study at this point. In addition an "other" category was created for any barriers to home health aide services that did not fit into any of Melnyk's structural barrier categories.

An attempt was made to limit service problems to those defined by Melnyk as structural barrier, ie. time, distance, cost, availability, organization of services, discrimination, and provider characteristics. However, in cases where the delineation between structural, individual and macrosystem barriers was not clear the segment of the transcripts was included as a structural barrier, since structural barriers were the focus of the study.

Twenty-one (65.6%) of the caregivers in the study mentioned some type of structural barrier to use of home health aide services. A majority of the caregiver's statements about service barriers were associated with use of home health aides pertained to either cost or provider characteristics. Thirteen of the caregivers (40.6%) mentioned structural barriers regarding cost of home health aide services, 34.4% (n = 11) mentioned structural barriers related to provider characteristics, while 18.8% (n = 6) mentioned structural barriers about organization of services, 6.3% (n = 2) mentioned structural barriers related to discrimination, 9.4% (n = 3) mentioned availability, 18.8 (n = 6) mentioned structural barriers regarding distance, and 3.1 % (n = 1) mentioned structural barriers relating to time. A summary of structural barrier responses is shown in Table 3.

Of the 3 (9.4%) past users, 2 (66.6%) mentioned provider characteristics as a structural barrier, 1 (33.3%) mentioned cost as a structural barrier, 1 (33.3%) mentioned organization of services and 1 (33.3%) mentioned an "other" barriers, ie. that the person had a lot of control over things like bank accounts (see Table 4).

Table 3. Structural barrier responses regarding home health aides (HHA) by service users.

CATEGORY	%	(n)
TOTAL CAREGIVERS MENTIONING STRUCTURAL BARRIERS WITH HHA	65.6%	21
COST	40.6%	13
PROVIDER CHARACTERISTICS	34.4%	11
ORGANIZATION OF SERVICES	18.8%	6
DISTANCE	18.8%	6
AVAILABILITY	9.4%	3
DISCRIMINATION	6.3%	2
TIME	3.1%	1

Table 4. Structural barriers reported by caregivers who used home health aide services (HHA) in the past (n = 3).

STRUCTURAL BARRIERS	%	(n)
PROVIDER CHARACTERISTICS	66.6%	2
COST	33.3%	1
ORGANIZATION OF SERVICES	33.3%	1
"OTHER"	33.3%	1

All but one of the 16 current users mentioned at least one structural barrier related to use of home health aide services. Two (12.5%) mentioned availability, 1 (6.2%) mentioned distance, 5 (31.2%) mentioned organization of services, 1 (6.2%) mentioned time, 2 (12.5%) mentioned discrimination, 11 (68.8%) mentioned cost, 9 (56.3%) mentioned provider characteristics, 6 (37.5%) mentioned "other" barriers to use of home health aide services (see Table 5).

Table 5. Structural barriers with home health aide services (HHA) mentioned by current users (n = 16).

STRUCTURAL BARRIERS	%	(n)
COST	68.8%	11
PROVIDER CHARACTERISTICS	56.3%	9
"OTHER"	37.5%	6
ORGANIZATION OF SERVICES	31.2%	5
DISCRIMINATION	12.5%	2
AVAILABILITY	12.5%	2
DISTANCE	6.2%	1
TIME	6.2%	1

Overall, most of the caregivers who currently used home health aide services mentioned barriers related to cost and provider characteristics, however neither of these factors seemed to prevent caregivers from continued use of the service. Past users had made varied individualistic statements about service barriers, thus making it impossible to draw any inferences about particular barriers that prevent caregivers from continuing to use home health aide services.

Themes

After segments of the transcripts were sorted into general categories of barriers to use of home health aide services using Melnyk's structural barrier category as a guide, a matrix of study findings was created. The matrix included a division by category and by case number. Across the top of the matrix each of Melnyk's barrier categories and an "other" category was listed. Each caregiver identification number was listed down the side of the matrix. Segments of the code transcripts were entered into the matrix in the appropriate category on a case by case basis. This matrix allowed the researcher identify emergent themes through a two-step process. The first step was to consider each barrier category as a separate construct and collectively examine cases as a whole for each barrier category. The second step was to examine each caregiver as a separate entity and consider all barrier categories mentioned by that caregiver collectively. From the study findings several recurrent themes emerged. Cost/expectation was the major structural barrier theme that emerged.

Cost/Expectation

The major theme found in this study was cost/expectation. Cost/expectation encompassed caregivers' responses categorized as barriers in both Melnyk's cost and provider characteristic categories. Cost is defined as expenditures related to home health aide service use. These two expenditures or costs entailed two dimensions: 1) financial cost and 2) psychological costs. Financial cost related to out of pocket expenditures by the caregivers to maintain home health aide services. Psychological cost related to expenditure of emotional time and energy spent to find and maintain home health aide services. Two sub-themes that emerged regarding psychological cost were: 1) hassles and 2) control. These sub-themes are discussed later in this paper.

Expectation was defined as what the caregiver anticipates in terms of positive and negative aspects of using home health aide services. Expectations relate to both the care provider, and to the service itself. Caregivers mentioned problems related to both of these expectation categories. From these problems regarding expectation the sub-themes: 1) disease specific knowledge deficit, 2) goodness of fit, emerged. These sub-themes are discussed later in the paper.

As a whole, problems or service barriers related to cost/expectation ratio were a major recurrent them. The feeling that the price paid for home health aide services was high and that the service did not meet expectations was expressed by several caregivers.

Nine (69.2%) of the 13 caregivers who mentioned cost as a structural barrier to home health aide services also mentioned structural barriers regarding provider characteristics of the home health aides. For example, one caregiver who had used home health aide services in the past stated, "In a very short time I had spent over $7,000.00 to have someone come into my home to take care of my mother. They paid no attention to my parents. They were more interested in looking around my apartment. One girl stole a book from me and the company she worked for reimbursed me. These people weren't very bright. One woman smelled bad and she didn't even speak good English."

Another caregiver currently using home health aides stated, "We had to have a man because my father would be after a women. One man had a very low level for frustration. This was not the job he should have had. One guy was too young. He didn't show good judgement. Also things started to disappear from the apartment complex and the neighbors blamed my employees. I pay them 8.00 an hour plus an extra $20.00 a week bonus if they checked in with me three times a day. It means about $67,000 a year going out the door."

One current user of home health aide services stated, "I pay $8.00 an hour and that is considered very good in my area. I needed her 11 hours a day so that was $88.00. I

$10.00 an hour for sitting with her and $15.00 an hour if she had to have her nose blown. If any touching of the person is involved the price was $15.00 an hour and what would the person get out of that?"

Another current user stated, "For my son I can hire a babysitter for $1.50 to $2.00 an hour. For my mom they want $6.00 to $8.00 an hour. My mom is easier then my son. There is nothing to do for her...just be there to just make sure the stove isn't left on or something. I was really shocked about the prices that people were charging just to sit here and do nothing. When you babysit for a child you are expected to play with them at least not totally ignore them. I was depressed to find out how expensive it was."

Another current user of home health aide services stated, "So I am paying $9.00 to $12.00 an hour for what? For a lady to sit in a chair and watch her soap operas. And this lady is nice, but she is not trained with Alzheimer's."

One caregiver stated, "It probably would be worth paying $6.00 an hour when and if they really need care. But right now, all my mom needs is someone to sit there and make sure that the stove wasn't left on and watch T.V. You know, I just don't think it is worth paying someone $6.00 an hour to sit and watch television." In sum, several caregivers mentioned service barriers related to disproportionate cost/expectation ratio. Several sub-themes of cost/expectation emerged from the transcripts.

Hassles

Hassles is a sub-theme of the cost/expectation ratio that relates to psychological cost. Hassles are defined as inconveniences encountered with use of home health aide services. This sub-theme emerged from segments of the transcripts coded in Melnyk's provider characteristics, time, availability and organization of services categories.

Many caregivers mentioned generalized, time consuming problems they encountered as they particularly as they searched for home health aide services. One current user of home health aide services stated, "We keep no food in the house and when I have someone here I've got to get food. I don't know what they like to eat. It's really more of a hassle than to just forget it." Another current user of the services stated, "I hated to get involved with agency services because I knew it was something that would give me more work."

One current user stated, "It took me two weeks to track down an agency and weeks to try to find somebody who would even drive out this far. I was tying up my office phone for hours at a time so I would have to take time off to come home to make phone calls."

One current user stated, "What I have right now is a patch job. It can only be stretched so far. The lady I have works part-time and goes to school too. Tonight she can't be here until 7:30 and I have to take my husband to the airport so my daughter was have to come over."

One past user said, "I spent all night trying to get someone from the agency. One girl said, 'I can't come because I don't have a car.' I don't see how they can advertise themselves as being a 24 hour health care service."

One current user stated, "We were working with a lady who was trying to help us find someone. The first lady we tried to arrange to come out fell through for whatever reason so we had to go about three or four more weeks before we could find someone.

One current user of privately hired services stated, "I have to do their payroll. I have to figure their FICA. I have to pay quarterly and the unemployment compensation tax and in addition to that I have to manage all my fathers investments. It is a job that I don't like and on top of that I am an employer who is not on the scene. I call over there sometime and no one is there."

In sum, several of the caregivers mentioned psychological costs related to use of home health aide services in terms of "hassles." These hassles were particularly associated with obtaining and managing home health aide services. Despite the fact that caregivers faced a number of hassles, the majority of the caregivers continued to use home health aide services.

Control

A second sub-theme of cost/expectation relating to psychological cost is the issue of control. Control is defined as having to give up command of personal matters to a stranger. This theme encompasses caregiver statements from Melnyk's provider characteristics, organization of services and "other" categories.

Several caregivers mentioned issues related to having to give control of personal matters to another individual to obtain care for their relative. For example, one past user of home health aide services stated, "The person has a great deal of control over things like bank accounts and car payments. If they chose to they could really take advantage of those situations."

Another current user of privately hired services stated, "I didn't want to get in some kind of contract and I had to sign a contract with the agency. I wanted some flexibility and also to make sure that the person's compatible."

One current user stated that, "The best thing for someone in a situation like this is to know someone that does these kind of things and hire them on their own." Another current user of agency services stated, "I wanted to get a handle on where I could find someone and I really didn't want to advertise in the paper because it is difficult unless you personally hired someone that had intimate knowledge of your relative and how to deal them."

In sum, many caregivers indicated that they were uncomfortable with giving control over to an agency or an individual who would come into their home. Both hassles and control were sub-themes relating to the psychological cost related to the major theme of cost/expectation barriers to use of home health aide services.

Disease Specific Knowledge Deficit

In terms of expectations, several caregivers mentioned that the use of home health aide services were less beneficial than the caregiver had expected because the home health aides were not trained to work specifically with clients who had Alzheimer's disease. This problem is represented in the sub-theme, disease specific knowledge deficit.

Segments of transcripts pertaining the sub-theme, disease specific knowledge deficit, were taken from Melnyk's provider characteristic category. Many of the caregivers felt that the home health aides were ill-prepared to care for an individual with dementia. For example, one caregiver stated, "The people they send are not trained for people with Alzheimer's. They are shown how to help people up our of chairs but they don't know a flying fig about memory loss or how it affects people. They don't know that they can't walk in and ask, 'Hi honey, did you have your breakfast?' How does she know, she has no memory."

Another current user of agency services stated, "You have to take what they give you and for a lot of these people it is their first exposure to someone with Alzheimer's.

One current user of home health aide services stated, "I get very little help from the home health aides. They seemed to know very little about Alzheimer's." In sum, caregivers seemed to felt that home health aides were not adequately prepared to care for a client with Alzheimer's disease.

One current user of private services stated, "Right now these people are the best I can get. They are far from perfect. It would be nice if these people had a little more education." In sum, many caregivers specifically indicated that home health aides were not trained to work specifically with individuals with dementia. The fact that the home health aides was inadequately trained to work with individuals with dementia, did not however, cause the caregiver to stop using home health aide services.

Goodness of Fit

Another sub-theme of the expectation portion of the cost/expectation theme was goodness of fit. For the purpose of this paper goodness of fit will defined as something that is suitable or congruent with caregivers needs in terms of home health aide services. Several caregivers mentioned the discrepancy between the kind of help they needed and what was available to them.

Statements for this theme included caregiver statements from Melnyk's availability, provider characteristics and cost categories. For example, one past user of home health aide services stated, "It is not much help to have somebody come in and sit with her. What is more helpful to me it having her removed from the house. We don't really have a need now for someone to come in and bathe her and dress her and fix her hair. I don't see any need for in-home help. My need is for her to be away for a while so I can get that weight off my shoulders."

Another current user of home health aide services stated, "We have a girl come in on the weekends. It is a four hour minimum. It is not satisfactory because I really don't need her to do much more than to check in on her."

One current user stated, "The bad thing is you have to take what they give you and sometimes there isn't much to chose from. Another current user stated, "I know I am entitled to more help but I don't want it at night there is no sense of having someone here. They just can't do the job."

One current user of privately hired services stated, "The agency said they could send someone for a hour a week to give her a bath. I said forget it. I give her a bath everyday. I need more than an hour a week."

One current user stated, "I needed someone to go to Florida with me. They gave me the name of a man, but a man just wouldn't have worked out at all."

One current user of private services stated, "Dealing with them (home health aides) is very different for me, because their lifestyle is very different. It would probably be a lot easier if I could get people who are more like me, but I don't think people who are more like me do that. They have long hair and look kind of grubby. There is definitely a generation gap and maybe a few other gaps there."

In sum, a major recurrent theme from the caregivers' transcripts was a disproportionate cost/expectation ratio. Caregivers paid high financial and psychological costs in terms of hassles and control for services that did not meet their expectations because service providers were not knowledgeable about Alzheimer's disease and the services held restrictions that did not fit the caregivers' needs. Despite the fact that caregivers' indicated that services were costly and less beneficial than they had expected, caregivers continued to use home health aide services.

Summary

In sum, sociodemographic and service use results were presented in this chapter. Quantitative information regarding barriers statements was also presented. Cost/expectation was discussed as a major theme that emerged from analysis of coded transcripts regarding barriers to use of home health aide services perceived by family caregivers of relatives with irreversible dementia. Hassles and control were discussed as sub-themes of cost/expectation relating to the psychological cost of services and disease specific knowledge deficit and goodness of fit were discussed as sub-themes of the expectation portion of cost/expectation.

CHAPTER VI

Summary and Implications

Overview

The purpose of this study was to examine structural barriers to use of home health aide services as perceived by family caregivers of relatives with irreversible dementia. Chapter VI includes an interpretation of finding, strengths and limitations of the study, a critique of Melnyk's framework, implications for nursing education and practice, and implications for research.

Interpretation of Findings

Nearly half (40.6%) of the caregivers in this study had never used home health aides. Interestingly, the majority of the perceived barriers to use of home health aide services were mentioned by current users of the service. The two categories most frequently mentioned were provider characteristics and cost.

The overall structural barrier theme was related to cost/expectation. In many cases, caregivers indicated that they spent a great deal in terms of finances, psychological energy and time finding and keeping home health aides.

Although the caregivers indicated that they paid a high price for services, often the services did not meet their expectations. However, the caregivers continued to use home health aide services.

The major conclusion that can be reached from this analysis is that both the costs and expectations of use of home health aide services is of concern to caregivers. However, the cost/expectation barrier did not prevent caregivers who already use the service from continuing use of the service.

Critique of Melnyk's Framework

Melnyk's barriers framework was used as a guide for this study. Melnyk's framework helped guide categorization of barriers to service use, thus facilitating analysis of barriers to use of home health aide services as perceived by family caregivers of relatives with dementia.

Melnyk's framework has several limitations. First many of Melnyk's term are ill-defined. For example, Melnyk does not offer a clear definition of "barriers." The term "barriers" generally implies that use of a service, such as home health aides was "prevented" given some factor or factors.

Using Melnyk's framework for the study presented in this thesis, "barriers" was used to denote "service problems" and did not imply that the caregivers were prevented from using the service. In fact, the results were surprising in that the caregiver's mentioned many service problems or "barriers" to use of home health aide services, however the caregivers often continued to use home health aide services.

In addition, categorization of barriers using Melnyk's framework was difficult because in many cases there was not a clear distinction between structural and individual categories. For example, Melnyk's individual barrier category encompasses barrier related to "prior negative experience with services," and Melnyk's structural barrier categories encompasses provider characteristics. Any caregiver comments about service providers that caused a negative experience would need to be included as both structural and individual barriers.

In addition, Melnyk's categories lack service specificity and as such does not adequately account for problems specific to home health care services. For example, there is no mechanism for distinguishing between provider characteristics as the home health aide "agency" or the actual individual serving as the home health aide. In addition, Melnyk's model does not easily accommodate the multiple roles of the advanced practice nurse in terms of the nurse's relationship with family caregivers of relatives with irreversible dementia (eg. assessor, collaborator, educator and advocate). Suggestions for a enhancement of the model include the need for a model more specific to the problems related to community health care services, including differentiating between the "consumer" as the family caregiver vs. individual who was directly receive the care, and inclusion of the advanced practice nurse's roles as a component of the model.

Strengths and Limitations of the Study

The qualitative approach allowed for answers that may not have been options from quantitative studies. There is a need to acknowledge several methodological limitation to this study. First, the subjects who took part in the interviews were volunteer and were not randomly selected. The methods of recruitment of subjects for the original longitudinal study involved contacting subjects with the assistance of the Alzheimer's Association mailing list and primary care physicians. Therefore, it is possible that the potential subjects were more likely to be individuals who had already sought assistance of professionals and therefore were a group may be more able to seek out community resources. In addition this study sample was small and included a relatively homogenous cohort, ie. 32 individuals aged 50-70 who were white middle-class Americans. Only two of the subjects were classified as minorities. Therefore, it is difficult to determine if perceptions of barriers to home health aide services for this sample is reflective of a broader cohort.

Another limitation to this study is that when caregivers responded, "no" to the interviewer's question: "Have you ever heard of home health aide services?" This was not probed further to investigate if perhaps the caregiver had an individual who performed roles similar to a home health aide (eg. a relative), thus lending more information to reasons why family caregivers did not use home health aides.

Additionally, it was very difficult from reading the transcripts to determine if the caregivers were using privately hired or home health aides from an agency. Likewise, it was difficult to determine is the caregivers used multiple home health aides and thus it was difficult to distinguish whether reported problems were recurrent or isolated problems.

In sum, this study allowed for discovery of barriers to home health aide services as perceived by family caregivers of relatives with irreversible dementia, however, because of a small convenience sample the results are difficult to generalize. In addition, since secondary data were used caregiver comments that would have lent important information for this study were not probed.

Implications for Nursing Education and Practice

The results of this study suggest implications for nursing education and practice. In terms of education, there are two major needs. First, there is a need for nurses to conduct thorough assessments of their clients' caregiving situations, particularly when their clients are caring for a relative with irreversible dementia. Nurses need to teach caregivers about various services including home health aides, as well as the role and expectations of a home health aide. This would decrease the knowledge deficit and perhaps increase home health aide service use among family caregivers of relatives with irreversible dementia.

Nurses working in the community need to be able to match their clients needs to available services. The results of this study indicate that this "match" does not readily occur based on lack of knowledge. When the "match" does occur, as indicated in this study, many caregivers feel that the costs of the services outweigh their expectations in terms of financial cost, time and emotional hassles.

Nurses may work toward the long-term goal of decreasing the cost of services. However, the policy changes that are involved in financial matters may be more what Melnyk describes as a "macrosystem" barrier. Since this study dealt with structural barriers, it is more appropriate to deal with barriers at the structural level. At the structural level, nurses can work to decrease costs in terms of time and emotional hassles, as well as increase the benefit in several ways.

Nurses can work with caregivers of relatives with irreversible dementia to help them plan ahead for service needs. One useful intervention may be to help the caregiver envision the "perfect" service and list items that the perfect service would entail. It may also be helpful for the caregiver to envision what it was be like to have a stranger in their home or how their relative might react to having a stranger in their home.

In addition, as caregivers look for services such as home health aides, the nurse can help the caregiver by providing a checklist of questions to ask potential applicants, such as, "Have you ever worked with a person who has Alzheimer's disease or dementia before?" or "What kinds of things do you see yourself as doing while you are working in the home with my relative?" It may also be useful for the nurse to work the caregiver to make a list of anticipated problems such as, "What is my back-up plan if my home health aide can't make it to my home and I need to get to work?" or "What would I do if the home health aide and my relative just do not get along well together."

Caregivers need to be instructed in problem solving methods when working with home health aides. Optimally, a nurse would supervise the home health aide and make periodic evaluation visits. If the home health aide is hired privately, the caregiver needs to know that there are still mechanisms for monitoring quality. For example, the caregiver needs to know that they can contact local offices on aging or protective service departments if needed. Optimally, the nurse involved with the caregiver would be the primary nurse and can continue to guide the caregiver if problems occur.

Additionally, nurses need to do periodic and ongoing assessments of caregiver stress and work to find alternative plans if the current stress reduction interventions are not working. Given the results of this study, it seems as though having a home health aide in the home may cause a great deal of stress for the caregiver. Apparently this stress did not override the need to have the home health aide because cost/expectation issues did not cause caregivers to cease using home health aide services. Optimally nurses can work with family caregivers on an ongoing basis and work toward decreasing the caregiver's stress and hassles.

Another need is for nurses to be learn appropriate teaching and management of home health aides. Nurses must to do very disease specific teaching and supervision for home health aides who work with individuals who have irreversible dementia. Frequent supervision visits need to be made to assure quality of services. When a number of agencies are involved in providing care for families, the primary care nurse needs to work toward collaboration and organization of services. In sum, the nurse needs to take on the roles of educator, assessor, evaluator, and advocate when working with family caregivers of relatives with irreversible dementia. Specific instruction needs to occur at two levels-with the caregivers themselves and with home health aides.

Implications for Research

The findings of this study point to several implications for nursing research. First, the results of this study indicate that there is a need to look at both macrosystem and individual barriers. There is a particular need to examine a individual barrier, lack of knowledge about available services, since several caregivers indicated that they were not aware of home health aide services, or what to expect of a home health aide. Study results infer that there is also a need to work on intervention studies, and a need to evaluate outcomes. There is also a need to examine how cost can be controlled at the macrosystem level so that caregivers can afford home health aide services.

Clearly, there is a need for more exploratory research into the needs of family caregivers of relatives with irreversible dementia because not enough is known about how to provide adequate services at this point. It would help guide policy making if we know more about the needs of family caregivers of relatives with dementia. There is also a need to conduct intervention studies of the outcomes of home health aide services following appropriate teaching of caregivers and home health aides and to evaluate the impact of ongoing evaluation of home health aide services.

Summary

The purpose of this study was to explore structural barriers to use of home health aide services as perceived by family caregivers of relatives with irreversible dementia. The findings of this study differed from previous studies where it was found that family caregivers of relatives with dementia infrequently used community services such as home health aides to help them care for their relatives. In fact, half of the caregivers in this study had used home health aide services. Even in the face of high cost and, in some cases, unmet expectations, caregivers continued to use home health aide services.

The findings of this study overall were consistent with research findings in the literature, particularly those of the Office of Technology Assessment (1987, 1990) where it was reported that caregivers did not use services such as home health aides because of lack of knowledge about available services, specific symptoms of the client with irreversible dementia, reactions to service providers, and lack of training of service providers in how to care for individuals with irreversible dementia. This study confirms the finding of the Office of Technology Assessment (1987, 1990) and validates the need for caregiver education regarding source of assistance with the task and for home health aide education about the problems specified to irreversible dementia. Clearly, caregivers will not access services of which they have no knowledge and was not be satisfied with provides (home health aides) who have little knowledge of the problem which they face.

In sum, the most prominent structural barrier reported in this study was a disproportionate cost/expectation ratio for home health aide services. Suggestions for nursing education, practice and research that may decrease structural barriers to use of home health aide services by family caregivers of relatives with irreversible dementia were made. It is likely that as our population ages, and we move through the 21st century, the problems of finding adequate services to help care for aging relatives at home will continue. Barriers to use of community services such as home health aides will need to be addressed at the macrosystem and individual level in addition to the structural level so that family caregivers can receive the help they need to care for their aging relatives.

APPENDICES

APPENDIX A

PRIMARY RESEARCH STUDY

Sample

The sample in the primary research study consisted of 32 family caregivers of relatives with irreversible dementia. These caregivers were recruited from a larger quantitative longitudinal study, "Impact of Alzheimer's Disease on Family Caregivers," funded by the National Institute of Mental Health (2RO1 MH41766-03, Principal Investigator Dr. Clare E. Collins).

Data Collection

A trained member of the research staff interviewed each of the 32 subjects individually at tape-recorded sessions. The next step of the study included transcription of the tapes. A member of the research staff checked the transcriptions for accuracy and converted files to a computerized database, **The Ethnograph** computer program. This computer program facilitates management of qualitative research data (Sidel & Clark, 1988).

Data Analysis

Three nurse researchers familiar with the area of caregiver research developed a coding scheme. This coding scheme included developing categories for each specific service including, but not limited to family support groups, visiting nurses, and home health aide services. These nurse researchers included several other concepts in the coding categories. The coding categories are listed in Appendix B.

In addition, the codification scheme included categories that represented various concepts. For instance "caregiver roles" was a coding category designed to encompass data that described responsibilities in work, social, and family setting (besides their caregiving roles). The nurse researchers identified a coding category called "service problems." Included in this category were text related to problems with services use, including, but not limited to cost, transportation and hours.

Following development of the coding categories, the nurse researchers, including the principal investigator and a graduate assistant, trained in the coding procedure, independently coded each of the transcribed interviews. Next, the nurse researchers reviewed the transcripts together to resolve discrepancies in the coding. The nurse researchers then numbered the transcripts and entered the agreed-upon coded areas into the computer. The investigator of the secondary data analysis found all the segments of the transcripts that contain information needed for secondary analysis and enter the categories in a computerized data base.

Validity and Reliability

In the primary research, measures were take to assure validity and reliability during development of interview questions and the original coding categories, data collection, and initial data analysis. To assure validity the nurse researcher developed the interview question based on work with a consultant, Kathy Knafl, who is an experienced qualitative researcher. Pilot interviews and focus groups were also used in development of interview protocol. During the primary data collection, validity and reliability were assured by interviewing informants deliberately selected for their ability to answer questions based on their experience as family caregivers of relatives with irreversible dementia. A trained member of the research staff conducted the interview in a setting chosen by the informant. Usually the interview took place in the informant's home. During the interview the research staff probed informants and clarified ambiguities until the research questions were exhausted.

To assure reliability during the data analysis of the primary research study, two trained members of the research staff independently coded the transcripts for themes. The coders resolved discrepancies before computer entry.

Protection of Human Subjects

All subjects for this research were part of a larger longitudinal study of caregivers of relatives with irreversible dementia. Initially, the participants of the larger study were sent a letter describing the study and soliciting their participation. The letter described the study and its benefits, assured participants of anonymity and confidentiality, and requested that the caregiver return the enclosed self-addressed, tamped postcard if interested in participating. Select participants from the larger study contacted by telephone were asked to participate in an in-depth personal interview. IF the caregiver agreed, the interviewer scheduled a time for the interview.

Before the interview the interviewer explained the purpose and nature of the study to the caregiver and assured the caregiver anonymity in reports. The interview assured the participants that their responses were confidential the that there were no right or wrong answers. The interviewer emphasized that the experience and opinions of the participants were very important. The interviewer reminded each subject that he/she was free to interrupt the interview, ask questions at will, and withdraw from the study at any time without penalty. Although the subject had already signed a written consent form before the interview, the interviewer verbally reaffirmed permission to record the session before tuning on the tape recorder.

The nurse researchers protected the confidentiality and anonymity of subjects by masking references to any names mentioned on the tape recording and by assignment of an identification number to the transcript. The nurse researchers erased the tapes following transcription and verification of accuracy of the transcription.

APPENDIX B

CODING CATEGORIES

Appendix B

CODING CATEGORIES

PRIOR TO ILLNESS

VALUE	Caregiver expression of personal or family values
CGVSELFC	Caregiver self-concept
PTPASTID	Caregiver concept of patient identity
PTPASTBH	Patient's past professional identity
PTPASTCH	Caregiver's characterization of patient's past behavior traits
	Caregiver concept of caregiver/patient relationship
RELATEQU	Perceived Quality of Relationship
RELATECH	Characteristics of Relationship
PREVHELP	Previous help seeking behavior (Caregiver)
CGVROLES	Roles - (Work role, Social role, Family role)
FAMACTV	Family Activity
ALZEXP	Past Experience with Alzheimer's Disease
	Identified Support
SUPPNET	Network - (Quantity of supportive others - Who are supportive others? family, friend
SUPPQUAL	Quality of identified support

INITIAL SYMPTOMS

CGVREACT	Caregiver Reactions (Emotional)
CGVACT	Caregiver Actions
	Information Seeking (Family, Friends, Professional)
	Assistance Seeking (Family, Friends, Professional)
	Taking over Patient Responsibilities

PTREACT	Patient Reactions (Emotional) - (Anger, "Covering-up", Fear of Alzheimer's Disease
PATSYMPT	Patient Actions - (Memory loss, forgetting, Becoming lost, Confusion, Questionable judgment, "Inappropriate", Embarrassing, Continuity with past behavior, Discontinuity with past behavior)
PROVREAC	Professionals' Reactions (Emotional)
PROVACT	Professionals' Actions (Planning for future, Assistance in Accessing Services)
FFREACT	Family/friends Reactions (Emotional)
FFACT	Family/friends Actions

DIAGNOSIS

COSTDX	Cost
REACTDX	Caregiver reactions to diagnosis (Hopeless, Didn't like label, Depressed, Overwhelmed, Disappointed, Didn't want to admit, Upset, Change in behaviors with patient)
UNDERDX	Caregiver understanding of diagnosis
CONFIDX	Caregiver confidence in diagnosis
DXCONFIR	Confirmation of caregiver suspicions/beliefs
OBTDX	Experience of getting diagnosis

DESCRIPTION OF CAREGIVING

REASONCG	Reason for caregiving (Obligation, No one else available, "Kinship")
CGVTASK	Description of the caregiving job (Caregiving as a parallel existence with other life roles)
CGVFEARS	Caregiver Fears (Admitting that it may get worse, Potential

	patient injury/falls, Embarrassment-how to explain patient behavior to others, Loss of control in caregiving situation)
TASKREAC	Reaction to Caregiving (Closed in, lost freedom, Lost friends, social isolation, "Another job", Cranky)

COMMUNITY SERVICE USE

ACTCUE	Cues to seeking service - "Critical Event"
SERVKNOW	Knowledge of service availability
SERVPROV	Perceptions of service providers
SERVATT	Pre-existing attitude about service
INFOSOUR	Source of information about service (Formal, Informal)
SERVDM	Process of decision-making in use of service (Who took part/involvement of others, Stated reason for service use, Timing of service use - Cues: Patient Behavior/Caregiver Reaction/HC Provider)
SERVPTRE	Patient reaction to service (Observed, Anticipated)
SERVCGRE	Caregiver reaction to service
VALUE	Caregivers' values about outside assistance
SERVPROB	Stated problems associated with service use (cost, transportation, hours)
SERVBENE	Stated benefits associated with service use (Relief for caregiver, Make patient feel needed/pay attention to patient, Don't feel alone/know that someone is there
SERVSEEK	Description of the process of finding service
HELPNEED	Description of needed assistance
SUPPGR	Support Group
BOOK	"The 36 Hour Day", "Loss of Self"

AFCHOME	Adult Foster Care Home
NURHOME	Nursing Home
RESPITE	In-home respite program
DAYCARE	Out-of-home daycare program
INHOMESK	In-home skilled nursing service
INHOMECU	In-home custodial assistance (agency or private)
ASSESS	Assessment Center
HOUSE	Housekeeping Assistance
MEALS	Meals on Wheels, Mobile Meals, etc
MEDICAL	Medical services...hospitals, clinics, physicians
AGINGAG	Aging agency or commission
CLASS	Programs on Dementia or related issues
ALZASSOC	ALZ Association

APPENDIX C

INTERVIEW GUIDE

Appendix A

INTERVIEW GUIDE

Use Of Community Services By Alzheimer's Caregivers

The reason for this interview is to get a detailed picture of your experience taking care of a person with Alzheimer's Disease. We would like to know as much as possible about what kinds of help you need now or may have needed at times in the past. I'm interested in knowing what experiences you may have had in looking for help and what things you think are important for service providers to know when they are planning services for people in situations like yours.

A. FIRST AWARENESS: I would like to start out by talking about the history of your relative's Alzheimer's Disease and the events leading up to your awareness of the disease.

1. Describe the situation when you first noted difficulties or what you think was the beginning of the Alzheimer's Disease.
    a. How were you spending time? What was happening in your life at the time?
    b. How did you first suspect that something was wrong?
    c. What did you do before going to the doctor? Did you ask for or receive advice from friends or family?
    d. Tell me about the experience you had getting a diagnosis for you (parent/spouse). Was s/he diagnosed as having Alzheimer's Disease the first time that you went to the doctor?
    e. What was your reaction to finding out that your (parent/spouse) had Alzheimer's Disease?

f. What did you know about Alzheimer's Disease at the time your (parent/spouse) was diagnosed? Had you ever known anyone else who had it?

g. What did you need in the way of help when your (parent/spouse) was first diagnosed?

h. What help did you seek at that time?

i. How did you go about finding that help?

j. What help did you think about seeking but didn't? What prevented you?

2. Help-seeking patterns. I am interested in knowing more about the ways that you have gotten the kind of help for other problems that you may have had in the past.

a. Other time, has it been easy for you to ask for help from others?

b. What kind of help can you ask for?

c. What kind of help can you not ask for?

d. How does it make you feel when you face a situation that is so difficult to handle that you need to seek help from others?

3. Could you please describe yourself and your relationship with the patient before the problems with Alzheimer's Disease began.

B. THROUGH THE COURSE OF THE DISEASE: People with Alzheimer's Disease go through a lot of changes. I'm interested in knowing more about what those changes have been for you (parent/spouse) and how they have affected you.

a. As time progressed, what changes occurred in your (parent/spouse) as a result of the Alzheimer's Disease?

b. How did the demands of caregiving change for you as the disease progressed?

c. How did your life change as the Alzheimer's Disease became more severe?

d. What else was going on in your life at the same time (besides taking care of the patient)?

e. Describe the feelings you had as your patient developed different symptoms of Alzheimer's Disease. Were there times that you felt embarrassed? Inadequate? Afraid?

f. Did your feelings affect your ability or willingness to ask for help?

g. When did you first seek some kind of assistance with the care of your (<u>parent/spouse</u>)?

h. What kind of assistance was that? How did you know about that particular service? What did it cost for you to use it?

i. What prompted you to look for assistance at that time?

j. What did you get out of the service you used? How did they help your (<u>parent/spouse</u>)? How did they help you?

k. What were the disadvantages? How did it make you feel?

l. Tell me all of the good things and the bad things about the services that you used to help you take care of your (<u>parent/spouse</u>).

C. VIEW FROM THE CURRENT MOMENT: You have told me about what it was like when your (<u>parent/spouse</u>) first developed Alzheimer's Disease and the things that have taken place since that time. I'm, also interested in what it is like for you right now and how you think things may change in the future.

1. What services are you using to help you take care of your (<u>parent/spouse</u>) right now?
    a. How much help are those services to you?
    b. What would make them better?
    c. How did you locate these services?
2. Looking back, if you could have found just what you needed to make this whole experience easier for you, when would that have occurred?
    a. What would it have looked like?
    b. Would you have used it?
3. What are the most important areas, from your perspective, that people like you need assistance with?
    a. Is there a "right time" and a "wrong time" for certain kinds of services (ask for examples)?
    b. What kinds of things kept you from using services when you might have needed them?

D. SPECIFIC SERVICES: The things that you need to help you change over time and so do the things that you expect from different kinds of services. These questions are about what you have experienced with several different sorts of services. Answering the questions about some of these services may make you feel like you are repeating yourself. If that is the case, could you just summarize your experiences with the service?

1. Describe your experience with the following kinds of services; What do you know about them? Have you used them? Did they help?
    a. visiting nurses
    b. home health aides
    c. adult day care

   d. home companions/sitters
   e. family support groups
   f. housekeeping/chore services

2. What advice would you give other families about getting help?
3. Is there anything else that we should understand about how community services do and do not help you that hasn't been touched upon by any of the questions?

APPENDIX D

CONSENT FORM

10. CONSENT

The research study in which I am being asked to participate is being conducted for the purpose of better understanding what services are most helpful to people who are taking care of a family member who has Alzheimer's Disease. The purpose of this study also includes an attempt to understand what particular aspects of available services result in them not being helpful to caregivers.

I agree to participate in a study entitled "Use of Community Services by Alzheimer's Caregivers." This study is conducted by Sharon King, R.N., Ph.D., from Michigan State University College of Nursing.

I understand that participation includes taking part in a tape recorded interview which will take approximately two hours and that I will be asked questions about the community services which I have used for the care of my relative with Alzheimer's Disease.

I know that any comments that I make during the interview will be kept confidential. There will be no identification of me on the tape, and the tape will be destroyed after review.

I understand that there will be no direct benefits to me for participation in this interview. I know that I am free not to participate in the interview and that I may stop the interview at any point without penalty.

I have read this consent form and understand its content. My signature below means that I have freely agreed to participate in this interview and that I consent to it being tape recorded.

____
Signature of Participant

____
Date

APPENDIX E

HUMAN SUBJECTS

MICHIGAN STATE UNIVERSITY

OFFICE OF VICE PRESIDENT FOR RESEARCH
AND DEAN OF THE GRADUATE SCHOOL

EAST LANSING • MICHIGAN • 48824-1046

March 30, 1993

TO: Michelle A. Liken
3333 Moores River Dr. #812
Lansing, MI 48911

RE: **IRB #:** 93-128
TITLE: STRUCTURAL BARRIERS TO USE OF HOME HEALTH AIDE SERVICES AS PERCEIVED BY FAMILY CAREGIVERS OF RELATIVES WITH IRREVERSIBLE DEMENTIA
CATEGORY: 1-E
REVISION REQUESTED: N/A
APPROVAL DATE: March 29, 1993

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must seek updated certification. Request for renewed approval must be accompanied by all four of the following mandatory assurances.

1. The human subjects protocol is the same as in previous studies.
2. There have been no ill effects suffered by the subjects due to their participation in the study.
3. There have been no complaints by the subjects or their representatives related to their participation in the study.
4. There has not been a change in the research environment nor new information which would indicate greater risk to human subjects than that assumed when the protocol was initially reviewed and approved.

There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. Investigators must notify UCRIHS promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Dr. Sharon King

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