This is to certify that the

thesis entitled

Structural Barriers For Continuing Use of Community Services Among Family Caregivers of Relatives With Dementia

presented by

Bridget M. Cashin

has been accepted towards fulfillment
of the requirements for

Masters degree in Nursing

Clare E Collins
Major professor

Date 5/4/98

STRUCTURAL BARRIERS FOR CONTINUING USE OF COMMUNITY SERVICES AMONG FAMILY CAREGIVERS OF RELATIVES WITH DEMENTIA

By

Bridget M. Cashin

A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

MASTER OF SCIENCE IN NURSING

College of Nursing

1998

ABSTRACT

STRUCTURAL BARRIERS FOR CONTINUING USE OF COMMUNITY SERVICES AMONG FAMILY CAREGIVERS OF RELATIVES WITH DEMENTIA

By

Bridget M. Cashin

The purpose of the current study is to describe the most frequent structural barriers for continuing use of community services (Visiting nurse services, home health aides/sitters/companions, adult day care, family support groups) among family caregivers of relatives with dementia who reside in the community and have stopped utilizing these services. The sample consisted of ninety-four family caregivers who participated in extensive telephone interviews. Findings of this study indicate that although time, provider characteristics, organization of services, and cost were the major structural barriers to continued service use, their elimination will not prevent service cessation among family caregivers of relatives with dementia. A major nonstructural barrier was "did not need". Service satisfaction and service importance ranked high among this sample despite discontinuing these services. The implications for nursing practice include the need to thoroughly assess caregivers perceptions and attitudes towards the caregiver experience, and their informal and formal support network.

To my Aunt, Claire Corriveau
for all her love and support
through all of my educational endeavors.

ACKNOWLEDGMENTS

I would like to thank the members of my thesis committee, Dr. Clare Collins, Dr. Sharon King, and Dr. Louise Selanders for all their assistance with this thesis.

I would also like to thank Dr. Clare Collins for all of the support and encouragement she gave me throughout my graduate studies.

A special thanks to my parents, Patrick and Janet Cashin for all of their love and support throughout all of my educational endeavors. Also, special thanks to my sisters, Colette Cashin and Andrea VanSurksum, for all their love and support.

Finally, I would like to thank Elizabeth Christensen for her support and encouragement throughout all of my professional endeavors.

TABLE OF CONTENTS

TABLE OF CONTENTS (cont.)

APPENDICES

LIST OF TABLES

LIST OF FIGURES

INTRODUCTION

A growing health problem facing adult elders and their families is dementia and related disorders. Dementia is a progressive intellectual deterioration of all cognitive functioning (Katzman, 1986). Dementia begins with subtle mental changes such as forgetfulness and disorientation, and progresses to loss of short term memory, judgment, and eventually the ability to perform activities of daily living independently (Blazer, 1990).

Family caregivers often provide the day to day care and responsibilities for these adults, which is often enormous. The physical, mental, and emotional demands of caring for a relative with dementia may have serious health consequences for family caregivers (Bunting, 1989; Haley, Levine, Brown, Berry, & Hughes, 1987; Zarit, 1990). Assisting family caregivers of relatives with dementia with the stress associated with the caregiver role has been of particular interest to health care professionals.

Community services such as visiting nurses services (VNS), home health aides/sitters/companions, adult day care, and family support groups, may be available and may assist many caregivers with the burden associated with the caregiver role (Collins, 1991). Yet, the use of these services among family caregivers is low. Researchers have identified barriers to the availability of community services that may account for the low usage. For example, many services available in the community are fragmented and very difficult to access because of different provider rules, different eligibility requirements, and the lack of financial support (Office of Technology, 1990). However, once family caregivers locate and utilize community services, many discontinue their use. It is important to know why family caregivers of relatives with dementia discontinue utilizing services which should be helpful.

The reasons why family caregivers stop utilizing community services is not clearly understood and needs to be investigated. Therefore, this study will describe the most frequent barriers to continuing use of four types of community services (VNS, home health aides/sitters/companions, adult day care, and family support groups) among family caregivers of relatives with dementia who reside in the community and have stopped utilizing these services.

Importance of the Study to Advanced Nursing Practice

Nurses in advanced practice remain key members of the health care team providing services which are available, accessible, and affordable to patients and families. In addition, nurses in advanced practice provide a vital linkage to families and community-based services (Neary, 1993). However, the responsibilities of advanced practice nurses go beyond just identifying available services, but must identify outcomes and service quality issues associated with the services recommended to consumers. After all, there is no reason to have a service which is of no service. Thus, identifying the most frequent structural barriers for continuing use of community services may provide the key to improving the service and result in a wealth of positive outcomes for patients, families, and providers.

Furthermore, the number of older and disabled adults is predicted to continue to soar well into the next century (Harel, Noelker, & Blake, 1995). It will be essential for advanced practice nurses to understand, and hopefully decrease, the structural barriers associated with the use and continuation of services which may be beneficial to family caregivers and their community.

Importance of the Study Within A Public Policy Context

This study occurs within a broader public policy context. The issues associated with community service use among family caregivers are embedded in the current changes occurring within the delivery of long term care services. Currently, the Medicare reimbursable long term care services for the elderly have largely been composed of institutional care and home health care (Cohen, 1998). As the growth of Medicare expenditures for long term care services continues to soar, major changes in the structure, philosophy, and funding sources for long term care services will occur. These changes will have an impact on both existing and future community services that are utilized by family caregivers of relatives with dementia. Three issues of political importance to this study that will be discussed in greater detail at the end of this paper center on the following ideas: 1) what should be the Medicare health care benefit?; 2) what models of service delivery would be helpful to family caregivers and remain equitable, assure quality care, and benefit the recipient of the service(s)?; and 3) who should subsidize and/or implement the service(s)? Ultimately, the answer to each of these questions will impact each other and have an effect on community services for family caregivers of relatives with dementia.

It will be important to identify the structural barriers that impede continued service among family caregivers of relatives with dementia since many new models of long term care services are focusing on the use of community services. The identification of structural barriers may assist in reducing the barriers to new and existing services and allow caregivers to continue utilizing services.

REVIEW OF LITERATURE

Use of Community Services

Over the past decade, there has been an increased interest in the health and well-being of caregivers of relatives with dementia. Research has focused on the physical, mental, and emotional stress associated with the caregiver role (Chenoweth & Spencer, 1986; George & Gwyther,1986; Haley et al., 1987; Rabins, Mace & Lucas, 1982; Zarit, 1990). Fatigue and depression are common symptoms identified by caregivers as a result of the physical and emotional stress associated with the caregiver role (Gallagher, Rose, Rivera, Lovett, & Thompson, 1989; Goldman & Luchins, 1984; Moritz, Kasl & Berkinan, 1989). Ultimately, this stress can lead to negative health consequences for caregivers.

Several types of community services may be beneficial to family caregivers of relatives with dementia. Family caregivers have identified specific services that have been beneficial. Respite services providing temporary rest and relief of personal care responsibilities have been identified as the most helpful and needed services among family caregivers of relatives with dementia (Caserta, Lund, Wright, & Redburn, 1987; Feinberg & Kelly, 1995; Fortinsky & Hathaway, 1990; Lawton, Brody, & Saperstein, 1989). Respite services include community services such as adult day care, and in-home services such as home health aides/sitters/ companions. The goal of respite services is to provide the needed care to the impaired person while allowing the caregiver time away from the caregiving role (Montgomery & Kosloski, 1995; Panella, Lilliston, Brush & McDowell, 1989; Sands & Suzuki, 1983). Thus, respite services are intended to benefit both the relative and the caregiver.

Adult day care centers are the most commonly utilized out-of-home community service among family caregivers of relatives with dementia (Montgomery & Kosloski, 1995).

These centers are designed to create a structured meaningful environment for the impaired person, and thus help to maintain their highest level of cognitive function. Many family caregivers prefer leaving their relative with staff who can provide a meaningful structured environment. In addition, the milieu allows the impaired person contact with other individuals that may not otherwise occur. Most often, family caregivers must provide the transportation to and from the center. Adult day care centers may be available two to five days a week, for a period of four to eight hours per day.

In-home services such as visiting nurse services and home health aides/sitters/companions are the most frequently requested and utilized in-home services among family caregivers of relatives with dementia (Montgomery & Kosloski, 1995; Silverstein & Hyde, 1987). In-home services may be provided by a visiting nurse or home health aide. A visiting nurse may provide skilled nursing care to the relative which may include physical exams, dressing changes, and medication administration. Home health aides may provide basic nursing care and assistance with performing basic activities of daily living, such as bathing, and toileting. The service may also include a sitter/companion who would stay and watch the impaired person for a few hours. The sitter/companion may or may not do simple housekeeping tasks. No transportation is required by the caregiver for in-home services. Many family caregivers may prefer having services provided in their home, especially if the impaired relative is not able to be easily transported to services.

Family support groups are also utilized frequently by family caregivers of relatives with dementia. Family support groups are intended to give caregivers a support system and a group of people who are going through similar caregiver experiences and emotions (Gonyea & Silverstein, 1991). Family support groups may be psychoeducational or purely supportive. Psychoeducational family support groups may focus on educating the caregiver about Alzheimer's disease and management of problem behaviors (Haley, Brown, & Levine, 1987). Family support groups generally require the caregiver to leave their relative for a short time in order to attend the group session.

Although adult day care centers, VNS, home health aides/sitters/companions and family support groups are the most frequently utilized community services among family caregivers of relatives with dementia, the rate of service use is considered well below what might be predicted, given the demands of dementia care (Caserta et al., 1987; Collins, King, Given & Given, 1994; Harel, Noelker & Blake, 1985; Noelker & Bass, 1989). Availability of community services does not always guarantee utilization by family caregivers.

Many factors influence the use of community services among family caregivers of relatives with dementia. Investigators have identified predictors of service use among family caregivers. Findings indicate that the more physical impairments, health changes, and care required by the impaired person, the more likely use of formal services (Noelker & Bass, 1989). In particular, in-home services were utilized more frequently as the physical impairments of the caregiver's relative increased. Unfortunately, many community services are only sought and utilized after the caregiver has already been adversely affected by the caregiver experience (Noelker & Bass, 1989).

In addition, family caregiver attitudes that may impact service utilization have also been identified by researchers. Among the most common caregiver attitude affecting service use is the caregiver's belief that they should be able to handle all of the care responsibilities of the impaired relative (Collins, 1991). When caregivers finally realize they need assistance, many only feel comfortable asking family and friends. Another common caregiver attitude affecting service use is the caregiver's comfort with their current caregiver situation (Collins, 1991). Many caregivers caring for relatives in the early stages of Alzheimer's disease may decline services because they feel they are able to cope with their situation.

Finally, many caregiver attitudes may occur because the caregivers are unfamiliar with community services and/or they may have concerns regarding the quality of the services (Collins, 1991). A family may be reluctant to use services which they know little about. Many caregivers may be unhappy with previous service use. Ultimately, these caregiver attitudes may cause caregivers to discontinue utilizing community services. However, no specific researcher has investigated this hypothesis.

Despite the low rate of service use among family caregivers of relatives with dementia, several studies have identified the effectiveness of community services in assisting family caregivers with the caregiver experience. For example, adult day care centers have been shown to delay institutionalization of the impaired relative (Lawton, Brody & Saperstein, 1989; Palley, Hanley & Watson,1994), and the hiring of additional assistance (Panella et al., 1989). Thus, the structured milieu helped the impaired person to function at their highest level and remain in the community for a longer time.

Feinberg & Kelly's (1995) study of respite programs in California, found that in-home services such as home health aides and visiting nurse services were often utilized first when caregivers needed assistance. Caregiver satisfaction was high with services providing personal care such as bathing, dressing, and supervision. The satisfaction with these services was related to the respite the services provided to the caregiver, as well as the control the caregiver had over the care the service provided. For example, the caregiver could decide the personal care the home health aide would provide.

Several researchers have identified the effectiveness of family support groups in assisting family caregivers of relatives with dementia with the caregiver experience. In particular, psychoeducational support groups have been beneficial in building the caregiver's confidence in dealing with the daily demands of caring for a relative with dementia (Chiverton & Caine, 1989), reducing caregiver depression, and increasing caregiver morale (Lovett & Gallagher, 1988).

Barriers to Use of Community Services

No studies have been identified regarding barriers for continuing use of community services among family caregivers of relatives with dementia. Researchers have identified barriers related to non-use of community services among caregivers. Availability, access, cost, and caregiver resistance have been identified as common reasons or barriers for non-use of community services among caregivers (McCabe, Sand, Yeaworkth & Nieveen, 1995). Wallace's (1990) study on community-based long-term care services, identified the "no care zone" as gaps in the continuum of services for the elderly caused by the barriers of accessibility, availability, and acceptability. Ultimately these "no care zones" decrease the elders chances of remaining in the community or improving their quality of life (Wallace, 1990).

Interestingly, Neary's (1993) study of community service utilization among family caregivers suggested that the barriers associated with non-use of a community service among family caregiver's may be directly related to the reasons for cessation of community services. However, no specific study has investigated this hypothesis, indicating one more reason for studying those who have stopped the use of community services.

Researchers have specifically identified barriers to non-use of home health aides among family caregivers of relatives with dementia. The barriers associated with non-use of home health aides among family caregiver's included: 1) difficulty in finding a provider willing to care for the impaired person exhibiting specific symptoms of dementia; 2) reactions of caregiver and/or client to service provider; 3) lack of provider knowledge and expertise regarding care of individuals with dementia (Liken, 1993; Office of Technology, 1990).

The concept of barriers to health services has emerged over the past few decades. However, few researchers have defined the concept of barriers. Rosenstock (1966) first introduced the concept of barriers as part of this Health Belief Model. Rosenstock (1966) defined barriers as costs or negative aspects associated with a particular health action.

Aday and Andersen (1974) defined barriers from their Health Service Utilization Model to describe a person's use of preventative health services. Barriers originally identified as "enabling factors" was defined as the "absence of certain resources", which included a lack of or reduced access to primary care providers, as well as, other enabling factors. The enabling factors represent the "means" individuals have available to them to access services. These factors may relate to the resources of the individual (ie: income, insurance coverage), or they may relate to resources in the community (ie: rural-urban area, region) and affect access to medical care (Aday & Anderson, 1974).

For the purpose of this study, barriers are defined as perceived problems that prevent continued use of community services (VNS, home health aides, adult day care, family support groups). These problems may include, but are not limited to, difficulties encountered after seeking and/or utilizing services. Melnyk's barrier framework will be used to assist in the categorization of barriers for data analysis.

Conceptualization of Melnyk's Barrier Framework

Melnyk (1985) identified barriers to use of health services based on Rosenstock's Health Belief Model. Her research investigated the barriers associated with preventive health behavior, specifically blood pressure screening and dental prophylaxis. Melnyk identified three categories of barriers to service use, including macrosystem, structural, and individual barriers. For the purpose of this research only structural barriers will be considered. Structural barriers are those characteristics that relate to the health care system and/or service provider. In Melnyk's (1988) framework, structural barriers include availability, cost, discrimination, distance, organization of services, provider characteristics, and time.

Availability refers to service accessibility, low provider/consumer ratio, and hours of service. The availability of services is a major barrier for family caregivers of relatives with dementia. Many family caregivers have difficulty finding services which are available in their community. When services are available, the hours of service may not be work into the family caregiver's schedule.

Cost refers to the cost of services, lack of adequate coverage of services from insurance, complexity of reimbursement for specific health services, cost of transportation, and cost from lost time at work. Cost is a major barrier for family caregivers of relatives with dementia. Caring for an impaired relative at home is very costly for family caregivers, particularly in the later stages of the disease. When coverage for available services is denied, it is not feasible for many family caregivers to subsidize additional care. Unfortunately, reimbursement for community services such as respite and adult day care is not covered by the fee-for-service model that currently exists (Colenda, 1997). Thus, most formal services must be payed by out-of-pocket expenses by family caregivers and can impoverish a family quickly.

Discrimination refers to the withholding of, or limiting of services because of an individual's race, gender, age, economic and social status, or mental capacity. Discrimination may occur to the consumer presenting with a chronic disease including mental health illness and dementing disorders. For example, the relative with dementia may be declined health services based on the behaviors associated with dementia. The health care services may be available in the community but persons requiring dementia care are excluded. Discrimination may also occur with the consumer. For example, the consumer may only want a provider of the same race, religion, or ethnicity to provide their care. Thus, discrimination may occur from within the health care service or from the consumer.

Distance refers to the proximity to services and transportation to and from services. Family caregivers may have to travel a distance in order to receive a particular service because of eligibility requirements of participants. Out-of-home services require transportation to and from services. Depending on the physical, emotional, and cognitive impairments of the impaired relative, it may be difficult to transport the impaired relative to services. Due to the fragmentation and inaccessibility of many services, many caregivers may have to travel longer distances to receive services, which may not be feasible because of other time commitments. Also, the caregiver may be in an age group that no longer feels comfortable driving long distances, and/or the impaired relative's physical condition may not warrant driving long distances.

Organization of services refers to the fragmentation of services and inconsistencies within services, that may be related to shortage of qualified personnel, inappropriate referrals for health care services, lack of primary care providers and preventative care. Since community services are established and maintained at the community level, the fragmentation and inconsistencies of services certainly create barriers for family caregivers. For example, the relative with dementia may meet the eligibility for one particular day care service and be ineligible for another based on different eligibility requirements. Also, the relative's condition may not allow for use of a service. For example, the day care may not take patients that are incontinent. The inconsistencies among services makes it difficult for family caregivers to utilize and continue services.

Provider characteristics refer to the provider's educational level and expertise, interest in client's problem, knowledge of insurance payment mechanisms, discomfort with client characteristics, and personal prejudices. The provider's characteristics may impact the consumer's perception and attitude toward the care they are receiving. If the consumer perceives the provider as uninterested and uncomfortable with their situation, they may not utilize the service. Provider characteristics are a barrier to continued service use among family caregivers of relatives with dementia. For example, family caregivers may not feel that the provider was knowledgeable regarding the management of specific behaviors associated with dementia. Thus, the relative or caregiver may not find the quality of the service acceptable or helpful.

Time refers to the time required to access the health care service, travel time, waiting time at service, and the time required to receive the service (Melnyk, 1988). Time is a precious commodity for family caregivers of relatives with dementia. A great deal of caregiver time is consumed in taking care of the physical demands of the relative with dementia, leaving little time to investigate available services. In addition, most out-of-home services require transportation to and from the service and have rigid formal schedules of starting and ending times, that may not meet the caregiver and/or care recipients time frames. Also, in-home services often require caregivers to be available for large periods of time, since many services do not give exact arrival times.

Melnyk's barrier framework will be used in this study to provide structure and categorize the barriers associated with continuing use of four types of community services (VNS, home health aides, adult day care, and family support groups) among family caregivers of relatives with dementia. Melnyk's Framework was used as a framework for this research for several reasons. First, the literature is scarce regarding barriers and Melnyk has identified barriers to health services. Secondly, the framework is simple and she characterizes barriers that are logical and understandable. Finally, this framework provides a systematic way to view barriers to continuing service use. Figure 1 illustrates Melnyk's original model that identified variables associated with the utilization of preventive health services.

Figure 2 presents this author's adaptation of Melnyk's framework specifically identifying components of Melnyk's perceived barriers and their relationship to continued service utilization among family caregivers of relatives with dementia. Thus, Figure 2 depicts categories of Melnyk's structural barriers which interfere with family caregivers ability to continue service use.

Definition of Community Services used in this Study

The definitions in this study are consistent with those presented in the primary quantitative longitudinal study (1988-1991) by Dr. Clare Collins entitled "Impact of Alzheimer's Disease on Family Caregiver's".

Visiting Nurse. A Registered Nurse or Licensed Practical Nurse hired through an agency who comes to the home to provide skilled nursing care such as physical exams, dressing changes, catheterizations, drawing blood, and administering medications.

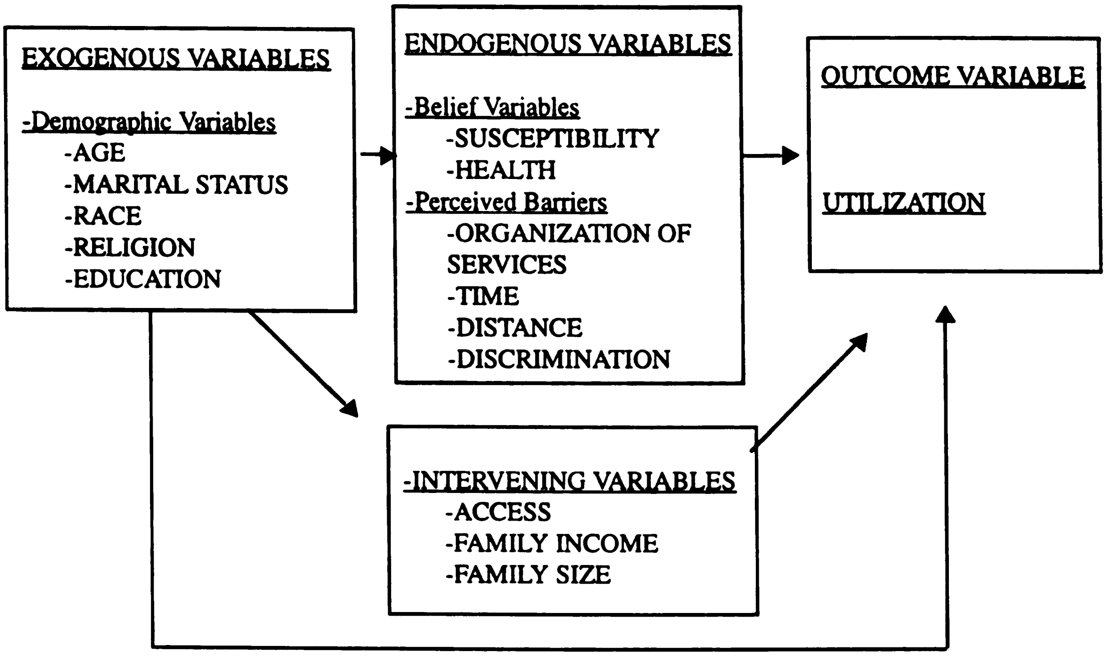

Figure 1. Melnyk's Model of variables associated with the utilization of preventative health services.

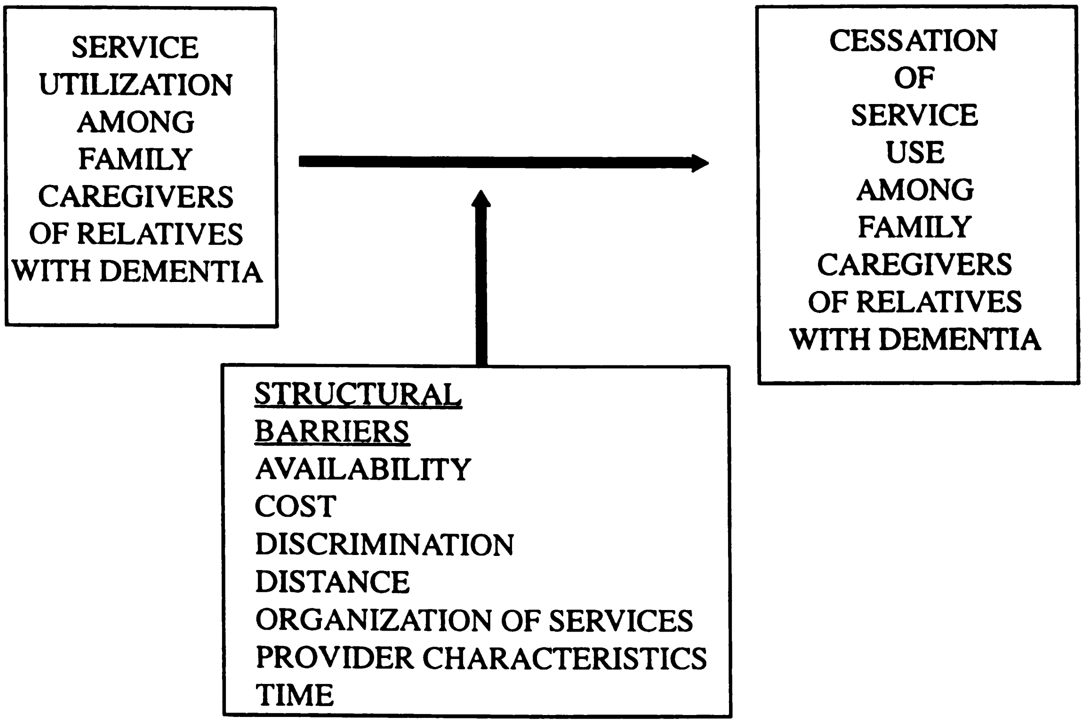

Figure 2. Categories of Melnyk's structural barriers which interfere with family caregivers' abilities to continue service use.

Home Health Aides/Companions/Sitters. Individuals hired privately or through an agency providing basic personal care such as bathing, simple health care such as vital signs or medication administration, as well as light housekeeping, meal preparations in the home, and basic supervision of the impaired relative.

Adult day care centers. A service provided away from the home at a day care center during the daytime hours and usually includes recreational activities, supervision, and meals.

Family Support Groups. A group consisting of family and/or friends who come together to discuss problems, provide and give emotional support, learn about issues important to the group.

Purpose of the Study

The purpose of this study is to describe the most frequently occurring structural barriers for continuing use of four types of community services (VNS, home health aides/companions/sitters, adult day care, and family support groups) among family caregivers of relatives with dementia who reside in the community, and have stopped utilizing these services.

Methodology and Procedures

Primary Research Design

Secondary data will be collected and analyzed from a quantitative longitudinal study conducted over a four year period (1988-1991) entitled, "Impact of Alzheimer's Disease on Family Caregiver's" Grant #2 R01 MH 41766, Dr. Clare Collins, Principal Investigator. The aim of Dr. Collins study was to collect information on the current impact of Alzheimer's Disease on family caregivers, as well as at three future occasions to understand the family caregiver experience. The three measurement points occurred at the original entry into the study (WAVE 1), twenty-two months following the WAVE 1 (WAVE 2), and approximately fourteen months after wave 2 (WAVE 3).

Secondary Research Design

A descriptive design will be used in this study in order to describe the most frequently occurring structural barriers for continuing use of community services among family caregivers of relatives with dementia, who reside in the community and have stopped utilizing these services. Descriptive studies aim to describe phenomena and are important in setting the groundwork for future studies (Polit & Hungler, 1991). This approach is appropriate to the purpose of this study as little is known about the structural barriers for continuing use of community services among family caregivers of relatives with dementia.

A secondary data analysis was chosen for this descriptive study because the data was collected for the specific purpose of this study in the primary research study. Also, the level of knowledge regarding this study is low enough that any information that can add to the body of knowledge will assist nurses in future studies.

The limitations for using secondary data is that this investigator is limited in the questions that can be asked and the definition of variables. For example, the definition of community services in the primary study was duplicated in the secondary study as family caregivers responded to the interview questions based on the primary study definition.

Primary Research Sample

The primary research study used a convenience sample of 350 family caregivers recruited through the Alzheimer's Association and Health Agencies in Southeast Michigan from 1988-1991. The criteria for family caregiver/relative enrollment in the primary sample (WAVE 1) included: 1) the caregiver identified themselves as the family member providing the most care to a relative with Alzheimer's disease or related dementia; 2) the family member with Alzheimer's (dementia) disease was independent in at least one activity of daily living (ADL) and one independent activity of daily living (IADL), and was at least 55 years old; 3) the family member had received a diagnosis of Alzheimer's disease or related dementia (per caregiver report only); 4) the patient and caregiver were living in the community at the time of entry into the study (Collins, 1991).

Secondary Research Sample

A convenience sample was taken from Wave 2 of the primary research sample and consisted of 210 family caregivers. A convenience sample was selected for this study because the sample of family caregivers of relatives with dementia was available in the primary study. Although a convenience sample is the most frequent sampling method used in nursing studies, it is the weakest form of sampling because of the risk of bias in the sample (Polit & Hungler, 1991). Wave 2 data will be used in this study because it contains the question being studied. The secondary research sample was homogenous, and largely consisted of Caucasian, middle class and well educated family caregivers.

The criteria for family caregiver/relative enrollment will include all the criteria in the primary sample, as well as require family caregivers to have stopped utilizing at least one community service (VNS, home health aide/sitter/companion, adult day care, family support group). Family caregiver eligibility will be determined during the analysis.

Primary Research Method

Family caregivers participated in telephone interviews using open ended questions, lasting one to one-half hours and completed a mailed self administered booklet, at each collection point in the study. Wave 2 data was collected at the College of Nursing, Michigan State University. The Alzheimer's Association and Health Care Agencies distributed a description of the study and included a post card for interested participants to return to the principal investigator. Trained interviewers screened the caregivers over the telephone to determine study eligibility. The consent procedures for the primary study conformed to the guidelines of the Health and Human Services and included: 1) a verbal explanation of the study discussed by the interviewer at the screening interview; 2) completion of a written consent form at the first interview followed by an explanation and verbal consent at each future interview (Collins, 1991).

Secondary Research Method

Responses from open ended telephone interviews taken from the "health service utilization" portion of the telephone interview will be used as the method of data collection for this study. The specific telephone interview questions which will be the focus of this study relates to the open ended question, "What were the reasons for stopping use of this service?" The question will be asked separately for each community service defined in this paper. The structured interview in this study allowed family caregivers to give their own perceptions and feelings. See Appendix A for specific open ended questions and coded data.

In addition, two questions related to service satisfaction and service importance will be answered by the family caregivers of relatives with dementia that have discontinued using at least one community service. The specific telephone interview questions that will be answered will be taken from the "health service utilization" portion of the interview. The exact questions that will be analyzed in each service include: 1) how satisfied were you with the service? and 2) how important was this service to you?" The questions used a Likert scale (ordinal) and ranked satisfaction and importance on a scale of increasing magnitude. Although these questions are not the main focus of this study, they were available from the primary study and may be interesting to observe in the sample of family caregivers of relatives with dementia who have discontinued using at least one community service. See Appendix B for the specific open ended questions and coded data.

Reliability and Validity

Validity refers to the degree to which the instrument actually measured the concept being studied. Exploratory descriptive studies, by their nature have low validity and must rely on reliability (Brink & Wood, 1991). Since the literature is scarce regarding the barriers for continuing use of community services by family caregivers of relatives with dementia, only self-evident measures were used. The telephone interview has face validity as the question asked makes sense and can elicit a response. Social desirability may occur during the interview which may contaminate the interview process.

The data collector coded the results immediately after the respondent answered, making the questionnaire subjective and possibly identifying inter-rater reliability problems. Since this was a secondary research study, this investigator couldn't compensate for any inter-rater reliability problems that may have existed.

In addition, the information obtained on caregiver satisfaction and importance used a Likert scale which may cause errors in the results because often respondents have difficulty remembering the details of the questions necessary to accurately answer the question (Brink & Wood, 1991). Thus, the information obtained when using a Likert scale question in an interview may be less reliable.

Protection of Human Rights

In the primary study, the principle investigator protected the right of respondents through adherence to the standard criteria established by the Michigan State University Committee on Research Involving Human Subjects. The investigator of the secondary data analysis also protected the rights of the subjects through adherence to standard criteria established by the Michigan State University Committee on Research Involving Human Subjects (UCRIHS). The confidentiality of the subjects was maintained by this investigator as respondents were only identified using an identification number. The UCRIHS letter of approval for this study is in Appendix C.

Reasons sorted into Melnyk's Categories

The twelve coded category of reasons obtained from each of the four open ended questions taken from the primary research question, were sorted into Melnyk's structural barrier categories using definitions of Melnyk's structural barriers as a guide. The coded reasons did identify three nonstructural barriers to continued service use. For completeness of the data analysis, the frequency of the nonstructural barriers for continuing use of each service will be mentioned. A separate category of "other" was used to designate reasons that did not fit into Melnyk's structural barrier categories or any of the reasons coded as nonstructural barriers. This investigator used three nurse researchers knowledgeable in the content area to validate the accuracy of the reasons sorted into Melnyk's barrier categories.

The structural barriers that will be used in this study include: availability, cost, discrimination, organization of services, provider characteristics, and time. Distance was not used as a structural barrier category in this study because the category of availability is broad and relates to issues of transportation and distance. The reasons coded in the primary study that may have fit Melnyk's definition of distance were more closely related to her category availability. The caregiver reasons that were sorted in Melnyk's structural barrier categories are depicted in Table 1.

Results/Findings

Interpretation and Study Findings

The results of this study will include descriptive summaries of data categories. Frequency tables and modes were obtained. Tables will be used to display the data.

Table 1.

Caregiver Reasons for Discontinuing Services Sorted into Melnyk's Categories.

STRUCTURAL BARRIER	CAREGIVER REASONS
Availability	Transportation Distance
Cost	Cost Insurance
Discrimination	Service Refused To Continue Care
Organization of Services	Relative No Longer Eligible Relatives Condition Did Not Allow For Services
Provider Characteristics	Quality of Service
Time	Inconvenience

One hundred eighty-two caregivers participated in the "health service utilization" portion of the telephone interview. These caregivers were sorted into current users of community services or past service users. Ninety-four caregivers had stopped utilizing at least one community service in the past and therefore met the criteria to be included in the secondary data analysis.

Service Use Patterns Among All Caregivers Participating in Wave II

To facilitate initial discussion of this data, a summary of the service use patterns among the caregivers participating in the health service utilization portion of the primary study (WAVE II) will be presented. The service use patterns among the larger sample will provide a broader context for understanding the discontinuation of services among those caregivers who have discontinued at least one community service in the past. The service use patterns that are summarized include the following: 1) the frequency of use of each community service (VNS, home health aide, adult day care, and family support group); 2) the number of services currently used, used in the past, and never used; and 3) the number of services ever used (current users and past users) (Collins, 1991).

Service use patterns were obtained in the primary study by separating caregivers into the following categories: 1) those that had used a service at least once in the last three months; 2) those who had used the service in the past excluding the last three months; and 3) those who had never used the specific service (Collins, 1991).

Looking at the percentage of caregivers who have used each service, it is interesting to note that 49.7% of family caregivers of relatives with dementia have never used home health aides (Table 2). Visiting nurse services were not used by 70.7% of caregivers. The most frequently used service was family support group (77%). However, over 30% of caregivers who have used this service in the past are no longer using the service (Collins, 1991).

Looking at the number of services used by the 182 caregivers surveyed, 8.2% had never used any of the four services (visiting nurse, home health aides, adult day care, and family support groups). 42.3% of caregivers had used two services in the care of their relative with dementia (Table 3). 35.7% of caregivers are currently using one

Table 2.

Service Use by all Caregivers from Wave II Who Used Services Recently, in the Past, and Never Used (n=182)

	Within 3 months		Used in past but not in last 3 mos.		Not used	
	Freq	%	Freq	%	Freq	%
Home Health Aide	74	40.9	17	9.4	90	49.7
Adult Day Care	36	20.1	20	11.2	123	68.7
Family Support Groups	82	46.1	55	30.9	41	23.0
Visiting Nurse	22	12.2	31	17.1	128	70.7

Table 3.

Summary of the Number of Services Used Among Four Services by Family Caregivers

	Current use		Used in Past (Not within 1st 3 months)		Number of Services Used. In past (not within last 3 months)	
	Freq	%	Freq	%	Freq	%
.00 (no service used)	49	26.9	86	47.3	15	8.2
1.00 (1 service used)	65	35.7	73	49.1	48	26.4
2.00 (2 services used)	55	30.2	18	9.9	77	42.3
3.00 (3 services used)	13	7.1	5	2.7	32	17.6
4.00 (4 services used)					10	5.5
TOTAL	X=1.2	SD=.91	X=.67	SD=.76	X=1.8	SD=.99

service, but 40% of caregivers who had used one service in the past have stopped using the one service.

Sociodemographic and Past Service Use Findings

Sociodemographics of Sample and Relatives with Dementia. The caregivers in the sample for this study had discontinued at least one of the following services: Visiting nurse services, home health aides, adult day care, and family support groups. The ninety-four caregivers represented in this sample were primarily Caucasian female spouses. Most of the caregivers had some college education and were not employed probably due to retirement. The majority were living with the impaired relative. The mean caregiver age was sixty-three years (Table 4). The ninety-four relatives with dementia were primarily Caucasian married males. The majority of the relatives were high school graduates and had an annual income between $10,000 - $29,999. The mean age of the relative was seventy-three years.

Past Service Use Patterns Among Sample

Service use patterns among the ninety-four caregivers in this study are summarized in three ways: 1) the frequency of past service use cited by caregivers for each service; 2) the number of services discontinued among caregivers; and 3) length of time each service was used before discontinuation. Looking at the percentage of caregivers who had used each service area, it is important to note that 57.4% of

Table 4.

Sociodemographic Variables Among Caregivers Who Have Discontinued One or More Services and the Relatives With Dementia.

VARIABLE	Relative (n=94) (n)	(%)	Caregiver (n=94) (n)	(%)
SEX				
FEMALE	44	(46.8)	74	(78.7)
MALE	50	(53.2)	20	(21.3)
CAREGIVER RACE				
WHITE	87	(92.5)	87	(92.5)
BLACK	6	(6.4)	6	(6.4)
HISPANIC	1	(1.1)	1	(1.1)
RELATIONSHIP TO CLIENT				
SPOUSE			68	(72.3)
CHILD/CHILD-IN-LAW/OTHER			26	(27.7)
EMPLOYMENT				
EMPLOYED			27	(28.7)
NOT EMPLOYED			67	(71.3)
EDUCATION	(n=93)			
<HIGH SCHOOL	34	(36.6)	14	(14.9)
HIGH SCHOOL GRAD	33	(35.1)	27	(28.7)
COLLEGE	26	(27.9)	53	(56.4)
MARITAL STATUS				
SINGLE	2	(2.1)		
MARRIED	70	(74.4)	85	(90.4)
OTHER	24	(25.6)	7	(7.4)
LIVING ARRANGEMENT				
LIVING TOGETHER	86	(91.5)		
LIVING APART	7	(7.4)		
HOUSEHOLD INCOME				
< $10,000	4	(4.3)		
$10,000 - $29,999	59	(63.4)		
$30,000 - $49,999	14	(15.1)		
> $50,000	16	(17.2)		

VARIABLE	RANGE	MEAN	SD
AGE			
CAREGIVER	39 - 84 years	63 years	11
RELATIVE	56 - 92 years	73 years	9

caregivers had used family support groups in the past, while only 18.1% of caregivers had used home health aide services (Table 5). These percentages reflect the service use patterns among the larger caregiver sample.

The length of time each service was utilized by caregivers varied widely within each service (note mean and SD, Table 5). Of those caregivers who used family support groups, 24.1% had used the service for more than one year. The majority of caregivers (51.6%) who used visiting nurse services in the past had only used the service for one to four months.

Table 5.

Past Service Use Patterns Cited Among Sample (*n=121)

SERVICE USE	Family Support Groups		VNS		Adult Day Care		Home Health Aides	
	n	%	n	%	n	%	n	%
USED IN PAST Length of Time Service Was Used	54	57.4	31	32.9	19	20.0	17	18.1
0-<1 month	6	11.1	8	25.8	2	10.5	3	17.6
1-4 months	11	20.4	16	51.6	5	26.3	8	47.1
5-8 months	3	9.3	2	6.5	2	10.5	2	11.8
9-12 months	5	9.3					1	5.9
> 1 year	13	24.1			2	10.5		
Missing	16	29.5	5	16.1	8	42.1	3	17.5
Total	X=15.4 mos SD=18.1 (*n=38)		X=1.3 mos. SD=1.6 (*n=26)		X=8.1 mos. SD=11.6 (*n=11)		X=3.1 mos. SD=2.9 (*n=14)	

Of the ninety-four caregivers in this sample, 76.6% had discontinued utilizing only one community service, while 18.1% of caregivers had discontinued utilizing two community services. The mean number of services used among these caregivers in the past was 1.3. Table 6 identifies the frequency of discontinued services occurring among this sample.

Frequency of Structural Barriers Occurring Across Services

Looking at the percentage of barriers cited by caregivers for discontinuing any service, it is significant to note that only 47.0% of the barriers cited were structural (Table 7). Time was the most frequent structural barrier cited for continuing use of any service by caregivers, comprising 11.4% of the barriers cited. Discrimination only accounted for 4.2% of the structural barriers cited. The most frequent nonstructural barriers cited by caregivers occurred in the "other" category and

Table 6.

Number of Services Discontinued Among Caregivers (n=94)

VARIABLE	(n)	%
1.00 (1 Service Discontinued)	72	76.6
2.00 (2 Services Discontinued)	17	18.1
3.00 (3 Services Discontinued)	5	5.3
Total X=1.3 SD=.56		

Table 7.

Types of Barriers Cited by Caregivers for Discontinuing any Service (*n=166)

STRUCTURAL BARRIERS CITED	(n)	%
Number of Structural Barriers Cited	78	47.0
Time	19	11.4
Provider Characteristics	17	10.2
Availability	13	7.8
Cost	12	7.2
Organization of Services	10	6.0
Discrimination	7	4.2
NONSTRUCTURAL BARRIERS CITED	**(n)**	**%**
Number of Nonstructural Barriers Cited	88	53
Did Not Need	34	20.5
Found Another Service	2	1.2
Resistant (Relative)	13	7.8
Other	39	23.5

* Number of Reasons Cited by Caregivers

accounted for 23.5% of the nonstructural barriers cited. Table 7 summarizes the frequency of structural barriers occurring across services.

Structural Versus Nonstructural Barriers

When viewing the percentage of barriers cited by caregivers within each service, it is important to note that within family support groups, 51% of barriers cited were structural and 49% were nonstructural (Table 8). Within visiting nurse services, 57.6% barriers cited were structural, while 70.8% of the barriers cited within home health aide services were nonstructural.

Table 8.

Most Frequently Occurring Structural Barriers Cited by Caregivers for Continuing use of Specific Community Services (*n=166)

STRUCTURAL BARRIERS CITED	FAMILY SUPPORT GROUP (*=82)		VNS (*n=33)		ADULT DAY CARE (*n=27)		HOME HEALTH AIDES (*=24)	
	n	%	n	%	n	%	n	%
Total Structural Barriers Cited	42	51.2	19	57.6	10	37.0	7	29.2
Availability	10	12.2			3	11.1		
Cost	2	2.4	5	15.2	1	3.7	4	16.7
Discrimination			5	15.2	1	3.7	1	4.2
Organization of Services	2	2.4	7	21.2	1	3.7		
Provider Characteristics	11	13.4	2	6.0	2	7.4	2	8.3
Time	17	20.9			2	7.4		
Nonstructural Barriers Total Nonstructural Barriers Cited	40	48.8	14	42.4	17	63.0	17	70.8
Did not need	12	14.6	10	30.3	4	14.8	8	33.3
Found another service	1	1.2	1	3.0				
Resistant (relative)					10	37.0	3	12.5
Other	27	32.9	3	9.1	3	11.1	6	25.0

Family Support Groups

Time accounted for 20.9% of the structural barriers cited by caregivers who used family support groups. Discrimination was not cited as a structural barrier. 32.9% of the structural barriers cited were in the "other" category (Table 8). "No time" was identified in the "other" category as the nonstructural barrier to continued use of family support groups by 24.1% of responses cited (Table 9).

Visiting Nurse Services

Looking at the percentage of structural barriers cited by caregivers who used visiting nurse services, it is significant to note that availability and time were not cited as structural barriers to continued service use. Organization of services accounted for 21.2% of the structural barriers cited by caregivers. 30.3% of the nonstructural barriers cited occurred within the category of "did not need".

Adult Day Care

Within adult day care services, the variability in the percentages of structural barriers cited by caregivers was between four and seven percent. Every structural barrier category was cited at least once by caregivers. 11.1% of the structural barriers cited were associated with the availability of services. Relative resistance accounted for 37% of the nonstructural barriers cited by caregivers to continued use of adult day care (Table 8).

Home Health Aide

Seventeen percent of the structural barriers cited by caregivers for discontinuing services related to the cost of the service. Availability, organization of services, and time were not cited as structural barriers by caregivers for discontinuing home health aide services. 33.3% of the

Table 9.

Most Frequently Occurring Nonstructural Barriers from the "Other" Category Cited by Caregivers for Continuing Use of Each Specific Community Service (*n=39)

"OTHER" CATEGORY SPECIFIED	FAMILY SUPPORT GROUPS (*n=27)		VNS (*n=3)		ADULT DAY CARE (**n=3)		HOME HEALTH AIDES (*n=6)	
	n	%	n	%	n	%	n	%
Patient Improved			2	66			2	33.3
No time/Other priorities								
Service no longer available	3	11.1					1	16.7
Other services to meet need	10	37.0					1	16.7
Intrudes on privacy	1	3.7						
Other	13	48.1	1	33.3			2	33.3

nonstructural barriers cited related to the category of "did not need" (Table 8).

Service Importance and Service Satisfaction

Looking at the percentage of responses cited by caregivers regarding the importance of each service, it is significant to note that more than 63% of all responses cited by caregivers in each service identified the service they had utilized as very important/somewhat important (Table 10). Eighty-two percent of the responses by caregivers who had utilized home health aide services identified the service as very important/somewhat important.

Table 10.

Caregiver Satisfaction Responses With Community Service utilized (*n=121)

VARIABLE	FAMILY SUPPORT GROUP (n=54)		VNS (n=31)		ADULT DAY CARE (n=19)		HOME HEALTH AIDES (n=17)	
SERVICE IMPORTANCE (n=119)	n	%	n	%	n	%	n	%
Very Important/Somewhat Important	34	62.9	20	69.8	13	68.4	14	82.4
Not Important	20	37.0	9	31.0	6	31.6	3	17.6
SATISFACTION WITH SERVICE (n=117)	(n=51)		(n=30)					
Very Satisfied/ Satisfied	38	74.5	27	90.0	16	84.2	14	82.4
Dissatisfied/Very Dissatisfied	13	25.5	3	10.0	3	15.8	3	17.6

*Number of Responses Cited

Of those caregivers who utilized family support groups, 37% of the responses identified the service as not helpful.

Similarly, more than 74% of caregiver responses regarding service satisfaction in each service identified the service they had stopped utilizing as very satisfied/ satisfied (Table 10). Ninety percent of caregiver responses within visiting nurse services identified the service as very satisfied/satisfied. Of those caregivers using family support groups, 25.5% of the responses cited the service as dissatisfied/very dissatisfied.

Discussion

Methodological Limitations

The present study used a convenience sample taken from the original study that consisted of a small, unrandomized, homogenous selection of study participants.

Therefore, the research findings cannot be generalized to a larger population of family caregivers. The original sample consisted of caregivers who were motivated to respond to a request to participate in a study and/or who were already receiving services or were referred to the study. Thus, the external validity is low since the caregivers do not represent the entire population of caregivers. Random sampling would have been the preferred method to use in this study because it would have increased the variability with the population of caregivers. Also, a larger sample would have allowed broader use of and interpretation of findings.

Instrumentation Limitations

The use of telephone interviews using open ended questions is an appropriate method for generating a large amount of information when little is known about the variables (Brink & Wood, 1988). However, in the present study, a certain amount of subjective bias may have been introduced by the trained interviewer in order to code the caregivers reasons for discontinuing service use. The open ended questions posed to caregivers were categorized in some way by the trained interviewer. Thus, the investigator in this study was dependent on the information that was coded by the trained interviewer.

In addition, the questionnaire used in this study was not specifically designed to answer this study question and therefore limited this investigator's study question to the specific question that was posed to caregivers in the original study. Thus, this investigator was restricted in how the question was asked and how the data is interpreted. For example, the question posed in this study asked caregivers to identify their reasons for discontinuing service use. The question did not ask caregivers to rank the reasons for discontinuing service use in any specific order.

Interpretation of Study Findings

Structural and Nonstructural Barriers

Structural barriers only accounted for 47% of the barriers cited by caregivers across any service. Within each service, family support groups and visiting nurse services were the only services that had more structural barriers cited than nonstructural. Thus, the findings of this study indicate that although structural barriers can be attributed to service cessation among this sample of caregivers, nonstructural barriers also contributed significantly to the cessation of community services.

Fundamental Differences Between Services

When looking at the percentage of structural barriers cited by caregivers in each service (visiting nurse services, home health aide, adult day care, and family support groups) it is interesting to view them in relation to the differences in service reimbursement, recipients, and availability (publicly and privately). For example, home health aide services cut across all reimbursement issues and are most commonly operated at the community level. Thus, it was not surprising to see that cost and provider characteristics were barriers, while availability was not a major barrier. However, it is interesting that cost was not a major barrier to the use of adult day care or family support group, which are out-of-pocket expenses for family caregivers. In relation to the recipient of services, it is interesting to note that when the primary recipient of the service are family caregivers, time was a major structural barrier to continued use.

Types of Service Barriers

Time was the most frequent structural barrier to continuing use of any service as well as family support groups. It seems reasonable that time would be a barrier to caregivers using family support groups since caregivers are the recipients of the service. Many family caregivers may not be able to take time away from caring for their relative to attend the service. Also, the caregiver may not be able to find anyone who can take the time to spend with their relative. The findings of this study does support the literature regarding time as a reason for attendance problems at support group meetings (Monohan, Greene, & Coleman, 1992).

Provider characteristics was the second most frequent barrier cited among caregivers who used family support groups. Provider characteristics within Melnyk's framework, refers to the quality of the service and the provider, which may include personal prejudices. Quality issues were a frequent structural barrier cited by caregivers using family support groups. This may occur because support groups often vary in their structure and purpose. Interestingly, provider characteristics was not identified as a major barriers for caregivers utilizing adult day care, since they are established at the community level and differ in purpose and eligibility requirements. Provider characteristics did account for 8.3% of barriers to continued use of home health aides which seems reasonable since home health agencies operate at the local level and can be established by almost anyone.

Organization of services was the most frequently occurring structural barrier to continued use of visiting nurse services. According to Melnyk's framework, organization of services refers to the fragmentation of services and inconsistencies within services. Visiting nurse services operate at the community level. Although most skilled care is reimbursable, the services may vary in services offered and the number of visits permitted.

Discrimination was the second most frequent structural barrier to visiting nurse services. Discrimination using Melnyk's framework refers to the withholding of, or limiting of services based on an individual's race, gender, age, economic, social status, or mental capacity. Discrimination may occur between the consumer or the provider. It is interesting to note that discrimination was not identified as a major barrier to continued use of home health aides, but was identified by caregivers utilizing visiting nurse services.

Cost was only identified as a major barrier to home health aide services. This finding is not suprising since relatives with dementia often require basic custodial and unskilled care that is often not reimbursable. Therefore, home health aide services are almost always an out-of-pocket expense for family caregivers with dementia that continues throughout the course of the disease. The findings of this study do not support the literature regarding cost as a major barrier to service utilization among family caregivers of relatives with dementia (McCabe et al. 1995). The findings of this study do support the findings by Neary (1993) that community service utilization occurred more frequently among caregivers who had a lower household income.

Availability was identified as a major structural barrier to continued use of family support groups and adult day care. These findings were not surprising because although these services may be available in the community, they may not be able to be utilized by caregivers based on the eligibility requirements of the service or the focus or purpose of the service. For example, family caregivers may have a difficult time finding a family support group for caregivers of relatives with dementia in their neighborhood. In addition, family caregivers may have difficulty finding a support group for relatives in the early stages of dementia. Thus, service availability may become more difficult as the service needs become more specific.

Moreover, the nonstructural barriers that prevented family caregivers from continuing with service use is particularly interesting. For example, the category "did not need" was cited by caregivers within each service. Those caregivers who had utilized visiting nurse services and home health aide services cited `did not need' as the highest nonstructural barrier to continued service use. These findings support the literature by Collins (1991) regarding caregiver attitudes towards service utilization. Collins (1991) found that caregivers often feel responsible to provide all of the physical care to the relative with dementia. Interestingly, the caregivers who cited `did not need' services in this study were those who were utilizing services providing basic care.

Within adult day care services, it was not unusual to see "resistant (relative)" as the largest nonstructural barrier to continued service use. Resistance among relatives with dementia has been identified as a barrier to use of adult day care service (Palley et al, 1994).

Interpretation of Caregiver Satisfaction and Service Importance

Interestingly, the caregivers who had stopped using a community service (visiting nurse, home health aides, adult day care, and family support groups) still regarded the service as very important and were very satisfied with the service. This was an unexpected response from the caregivers since they were no longer using the service. The findings of this study may relate to the large percentage of nonstructural barriers identified by caregivers. Almost all of the nonstructural barriers identified by caregivers for discontinuing community services related to the caregiver's decision to stop utilizing a service rather than a barrier caused by the service itself.

Summary of Interpretation of Study Findings

In conclusion, the findings of this study indicate that structural barriers only tell part of the story as to why family caregivers of relatives with dementia stop utilizing community services (visiting nurse services, home health aides, adult day care, and family support groups). The most frequently occurring structural barriers for continuing use varied widely across services and less within services which point to the heterogeneity within and among community services that are utilized by family caregivers of relatives with dementia. Although time, provider characteristics, organization of services, and cost were the major structural barriers to continued service use, their elimination will not prevent service cessation among family caregivers of relatives with dementia. A major nonstructural barrier to continued service use was "did not need" service which may relate to caregivers attitudes towards service use and the caregiver experience. Finally, service satisfaction and importance were ranked high among this sample of family caregivers of relatives with dementia who had stopped utilizing community services.

Critique of Melnyk's Framework

Melnyk's framework helped to guide the categorization of reasons for discontinuing service use. The categories assisted in analyzing the structural barriers to continued use of community services among family caregivers of relatives with dementia. However, Melnyk's framework had some limitations. First, many of Melnyk's terms are vague and not completely explicit. For example, Melnyk definition of "barriers" implies "service problems" but does not clearly denote that caregivers were prevented from continuing service use.

In addition, the simplicity of Melnyk's barrier definitions made it difficult to easily categorize the caregiver reasons for cessation of community service use. For example, the caregiver reason "relative no longer eligible" may have fit Melnyk's definition of discrimination and organization of services. For the purposes of this study, each caregiver reason was separated into one structural barrier category.

In addition, some of Melnyk's definition of barriers were broad and could have been combined with other structural barriers. For example, distance and transportation fit Melnyk's definition of availability. Availability was referred to as the inaccessibility of services and hours of service. Distance and time could have fit into this definition of availability. Thus, Melnyk's definitions are not commonly agreed upon definitions by all readers.

Melnyk's model looks at a far less complex family system and disease system perspective than from a chronic care perspective. While this model provided some categorization of reasons, chronic care is different than acute care and preventive care. The barrier categories may have different meanings and implications to caregivers depending on the type of disease present among relatives and type of care situation. For example, caregivers of relatives with dementia may define and categorize time differently than caregivers of relatives with terminal cancer. Thus, it would be beneficial to develop client specific measures in particular caregivers situations within each barrier category. It would also be beneficial for this this model to be restructured to account for chronic and changing care situations for researchers utilizing this model.

The findings of this study suggest that the model of service cessation among family caregivers of relatives with dementia may not be as linear as Melnyk's model. The nonstructural barrier "did not need" contributed significantly to the cessation of community services and therefore may be related to Melnyk's endogenous variables (ie: susceptability, beliefs). Thus, endogenous variables may have contributed in a nonlinear fashion to the cessation of community services among family caregivers of relatives with dementia. In the future, a more comprehensive model is neccessary to incorporate the nonlinearity of the caregiver experience. For example a nonlinear model that incorporates the endogenous variables, client perceptions, and structural barriers to continued service use would be beneficial to researchers utilizing this model.

Implications For Advanced Practice Nurses and Primary Care

The findings of this study suggest several opportunities for the APN to utilize the role of assessor, educator, counselor, and collaborator. First, structural barriers only tell part of the story as to why family caregivers of relatives with dementia stop utilizing services that they identify as very satisfied with and regard as very important. Therefore, it is will be important for the APN not to focus solely on the structural barriers that may impede continued service use because family caregivers may still discontinue utilizing them. Instead, the APN must thoroughly assess the family caregiver's perceptions and attitudes towards their caregiving experience and their informal and formal support network. An assessment of the caregiver's current caregiving experience will not only assist the APN in understanding the caregiver's experience, but may assist in developing strategies that support the caregiver throughout the caregiving experience. The APN may be able to reintroduce the use of community services to caregivers who have discontinued them, offering them a different focus or perspective on their caregiver role.

Although the elimination of structural barriers will not stop caregivers from discontinuing services, it is important for APN's to be aware of the structural and nonstructural barriers that impede continued service use. The APN can utilize the role of educator in identifying services that caregivers may not know are available. For example, the findings of this study suggest that it may be helpful for the APN to educate the family caregiver about the family support groups that are available to caregivers of relatives with dementia.

In addition, the APN must work with caregivers in developing strategies that assist the caregiver in finding time to attend family support groups. The findings of this study found that the most frequently utilized service used among family caregivers were family support groups, but within three months, thirty percent had stopped using the service. If family support groups are beneficial to caregivers it would be helpful to find ways for caregivers to find the time to participate in these groups.

The APN must be knowledgeable regarding the changes occurring within the delivery of long term care services. The APN must use the role of collaborator in working with health care agencies and services in identifying the structural and nonstructural barriers to continued service use among family caregivers of relatives with dementia. The APN must collaborate with other health care agencies and services in eliminating the structural barriers that exist within community services. However, the APN must work towards making sure that family caregivers are participants in the decisions that surround the long term health services that are created. For it is unfortunate that community services exist that caregivers are very satisfied with but aren't utilizing because they feel they don't need the service.

Moreover, the APN must be knowledgeable regarding the longitudinal perspective of the dementia caregiving experience. The findings of this study suggest that service use may be beneficial and needed for family caregivers for brief periods of time throughout the illness trojectory. Although the illness trojectory of the sample of relatives with dementia were unknown in this study, the discontinuation of services among family caregivers may have been influenced by the relatives stage of dementia. For many people, the use of community services is perceived as a crisis solving modality. When the crisis is over, or is no longer perceived, the caregiver is open to discontinuing the community services, even though they still perceive the service as helpful. Thus, it will be important for the APN be knowledgeable regarding the complexity of chronic diseases such as dementia.

Finally, the APN should not view service cessation as a negative event. The goal is not that every caregiver use services, but that caregivers who perceive the need and perceive the benefit of services are able to access services. For family caregivers of relatives with dementia, the perceived need for services may fluctuate and change because of the unpredictability of the disease trojectory. Thus, service use may be used by caregivers for brief periods of time throughout the course of the dementia disease. The APN must educate caregivers regarding the unpredictability of the illness trojectory and support them in times of perceived need.

Implications From A Public Policy Context

The results of this study have significant relevance in today's changing health care environment and are important to keep in mind as the demand for long term care services continues to grow. Lawhorne (1997) defined long term care as "the full spectrum of medical, psychological, rehabilitative, and maintenance/custodial services required to achieve a person's highest practical level of functioning and well-being" (p. 55). For family caregivers of relatives with dementia these services will need to be available intermittently and over a long period of time.

The first public policy issue that is being discussed by politicians and advocacy groups is "what should be the Medicare benefit?" This is not an easy question to answer. Financing a long term care system will not be able to rest entirely on the Federal government (Cohen, 1998). The already overburdened Medicare and Medicaid budget has led to the creation of other medical plans that may be better for family caregivers of relatives with dementia.

The latest trend in financing services for the elderly are through long term managed care plans and long term care insurance plans (Cohen, 1998). These health plans are being piloted in many parts of the country and offer elders with chronic diseases alternative to institutional care. For example, the Social Health Maintenance Organization (SHMO) is a demonstration program that offers community care services and short term nursing care to a Medicare and Medicaid eligible population (Cohen, 1998). The goal of many of these programs is to offer needed health services to elders, that allow them to remain in the community and cost less than institutional care.

The results of this study suggest that cost was a major barrier to continued use of home health aide services. Thus, it will be important for these managed care plans to offer basic care services to relatives for a long period of time. However, cost was not identified as a major barrier to use of adult day care, visiting nurse services, or family support groups.

The second issue of political importance focuses on what types of service models would be beneficial to family caregivers that will assure quality and benefit the recipients? The findings of this study suggest that services caregivers find important and rank high in satisfaction may not lead to continued service use. Thus it will be important for health care providers and others to listen to consumer preferences and expectations regarding their care needs. The MI CHOICE project that is being initiated in Michigan is an example of a long term care initiative that allows consumers to choose the health services that they would like, instead of going to a nursing home (James, 1997). Hopefully, this will allow caregivers to decide the services they find helpful and stop caregivers from discontinuing services which they find satisfying and important.

The third public policy issue is, "who should implement these services?" In the future more emphasis will need to be placed on the state government and local agencies to begin experimenting and partnering to implement long term care services (Cohen, 1998). The inconsistencies and fragmentation are well documented regarding community based services (Wallace, 1990; Office of Technology, 1987). However, the results of this study suggest that the organization of services was not a major barrier to continued service use among family caregivers of relatives with dementia. The most important finding from this study that will need to be kept in perspective as services are implemented is that caregivers may not utilize the services even if they are reimbursable or available. The nonstructural barrier that related to "did not need" service suggests that caregivers attitudes and perceptions were a major barrier to continued service use. Thus, it will be important for consumers to be able to participate in the implementation of services at the state and local level. For consumer involvement may have an impact on their attitudes and perceptions towards service use. The more invested the consumer is in the implementation of the service the more they may continue to utilize the service (Cohen, 1988).

Finally, many people working towards developing new models of long term care services believe in the "Woodwork Hypothesis", which postulates that if community services are made available to people at a reasonable cost, everyone will "latch on" to services. However, the results of this study suggest that cost and availability did not equate to continued service use among family caregivers of relatives with dementia. In fact, the service use patterns among this sample were low. The services may be used by caregivers for short periods of times throughout the illness trojectory. Because of the unpredictability of the illness course in dementia care, caregivers may not be able to predict when services will be needed and the length of time the service will be needed. This is another reason why the care needs of family caregivers of relatives with dementia needs to be heard and understood by politicians and health care providers.

Implications For Future Research Studies

This study prompts the need to look at all of the factors that may impede the continuation of community service use, particularly the nonstructural barriers that may relate to caregiver attitudes and perceptions. This study did not identify the informal support network or the relative's condition at the time services were discontinued. Future research studies are needed regarding barriers to continued service use and patient condition at the time services were discontinued. The presence of an informal support network may have been present among the family caregivers who discontinued community services and may be a reason as to why many "did not need" the service.

In addition, future research studies focusing on barriers to continued service use and presence of an informal support network may be beneficial. The high satisfaction with services among the family caregivers in this study raises an interesting question regarding the relationship between service satisfaction, and the type of structural barrier cited for cessation of community services. Thus, future research studies regarding the relationship between service satisfaction and the identification of structural barriers to continued service use may result in valuable information that will add to the body of knowledge related to cessation of community services among family caregivers of relatives with dementia.

Moreover, future research studies that focus on a more comprehensive conceptual model and the barriers to continued service use among family caregivers of relatives with dementia is needed to incorporate the nonlinearity of the caregiver experience. Finally, future studies regarding reasons for service cessation among family caregivers who are adult children of relatives with dementia may provide a different perspective on the reasons for service cessation. For this sample included spousal caregivers and the reasons for service cessation may differ among caregivers who are adult children.

LIST OF REFERENCES

LIST OF REFERENCES

Aday, L.A., & Andersen, R. (1974). A framework for the study of access to medical care. Health Service Research, 9, 208-220.

Alzheimers Association (June 1997). Public Policy Update: Federal News Release [On-line]. Available: http://www.alz.org/pubpol/fedpol/testimony/98budget.htm

Brink, P.J., & Wood, M.J. (1988). Basic steps in planning nursing research: From question to proposal (3rd ed.). Boston: Jones & Bartlett Publishers.

Bunting, S.M. (1989). Stress on caregivers of the elderly. Advanced Nursing Science, 11(2), 63-73.

Caserta, M.S., Lund, D.A., Wright, S.D., & Redburn, D.E. (1987). Caregivers to dementia patients: The utilization of community services. The Gerontologist, 27 (2), 209-214.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of famiy caregivers. The Gerontologist, 26(3), 267-272.

Chiverton, P., & Caine, E. (1989). Education to assist spouses in coping with Alzheimer's disease. The American Geriatrics Society, 37, 593-598.

Cohen, M.A. (1998). Emerging trends in the financing and delivery of long-term care: Public and private opportunities and challenges. The Gerontologist, 38(1), 80-89.

Colenda, C. (1997, December). Financing Alzheimer's Disease Services in a Managed Care Environment. Paper presented at the 11th Annual Symposium on Geriatric Medicine, East Lansing, MI, pp. 37-50.

Collins, C. (Principal Investigator). (1988-1991). Impact of Alzheimer's Disease on family caregiver's . Public Health Service Grant. Department of Health and Human Services, National Institute of Mental Health, Grant, #2 R01 MH41766.

Collins, C. (1991). I don't need help: What do dementia caregivers really mean? Home Healthcare Nurse, 10(5), 53-56.

Collins, C., King, S., Given, C., & Given, C.W. (1994). When is a service of service? Understanding community service use among family caregivers of Alzheimer's patients. In E. Light, G. Neiderhe, & B. Lebowitz (Ed.). Stress effects on family caregivers of Alzheimer's patients. (pp. 317-329).

Feinberg, L.F., & Kelly, K.A. (1995). A well-deserved break: Respite programs offered by California statewide system of caregivers resource centers. The Gerontologist, 35(5), 701-706.

Fortinsky, R.H., & Hathaway, T.J. (1990). Information and service needs among active and former family caregivers of persons with Alzheimer's disease. The Gerontologist, 30(5), 604-609.

Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L.W. (1989). Prevalence of depression in family caregivers. The Gerontologist, 29(4), 449-456.

George, L,K., & Gwyther, L.P. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. The Gerontologist, 26(3), 253-259.

Goldman, L.S., & Luchins, D.J. (1984). Depressin in the spouses of demented patients. American Journal of Psychiatry, 141(11), 1467-1468.

Gonyea, J.G. & Silverstein, N.M. (1991). The role of Alzheimer's disease support groups in families utilization of community services. Journal of Gerontological Social Work, 16(3-4), 43-56.

Haley, W.E., Brown, S.L., & Levine, E.G. (1987). Experimental evaluation of the effectiveness of group intervention for dementia caregivers. The Gerontologist, 27 (3), 376-382.

Haley, W.E., Levine, E.G., Brown, S.L., Berry, J.W., & Hughes, G.H. (1987). Psychological, social, and health consequences of caring for a relative with senile dementia. Journal of American Geriatrics, 35, 405-411.

Harel, Z., Noelker, L. & Blake, B. (1995). Comprehensive services for the aged: Theoretical and empirical perspectives. The Gerontologist, 25, 644-649.

James, M.L. (1997, December). MI CHOICE: The Michigan Managed Long Term Care Initiative. Presented at the eleventh annual symposium on geriatric medicine, East Lansing, MI, pp. 77- 89.

Katzman, R. (1986). Alzheimer's disease. New England Journal of Medicine, 314, 964-973.

Lawhorne, L.W. (1997 December). The Managed Care - Long Term Care Interface. Paper presented at the eleventh annual symposium on geriatric medicine, East Lansing, MI, pp. 51-77.

Lawton, M.P., Brody E.M., & Saperstein, A.R. (1989). A controlled study of respite service for caregivers of Alzheimer's patients. The Gerontologist, 29(1), 8-16.

Liken, M.A. (1993). Structural barriers to use of home health aide services perceived by family caregivers of relatives with irreversible dementia. Master's Thesis, Michigan State University, Lansing, MI.

Lovett, S., & Gallagher, D. (1988). Psychoeducational interventions for family caregivers: Preliminary efficacy data. Behavior Therapy, 19, 321-330.

McCabe, B.W., Sand, B.J., Yeaworth, R.C., & Nieveen, J.L. (1995). Availability and utilization of services by Alzheimer's disease caregivers. Journal of Gerontological Nursing. January, 14-22.

Melnyk, K.A.M. (1985). Perceived barriers to preventive health care. Doctoral dissertation.

Melnyk, K.A.M. (1988). Barriers: A critical review of recent literature. Nursing Research, 37(4), 196-201.

Monahan, D.J., Greene, V.L. & Coleman, P.D. (1992). Caregiver support groups: Factors affecting use of services. Social Work, 37(3), 254-260.

Montgomery, R.J., & Kosloski, K. (1995). Respite revisited: Re-assessing the impact. In P.R. Katz, R.L. Kane, & M.D. Mezey (Ed.). Quality care in geriatric settings (pp. 47-67). New York: Springer.

Moritz, D.J., Kasl, S.V., & Berkinan, L.F. (1989). The health impact of living with a cognitively impaired spouse: Depressive symptoms and social functioning. Journal of Gerontology, 44(1), 517-527.

Neary, M.A. (1993). Community services in the 1990s: Are they meeting the needs of caregivers? Journal of Community Health Nursing, 10(2), 105-111.

Noelker, L.S., & Bass, D.S. (1989). Home care for elderly persons: Linkages between formal and informal caregivers. Journal of Gerontology, 44(2), 563-570.

Palley, H.A., Hanley, B.W., & Watson, D. (1994). Adult day care centers and the treatment of Alzheimer's disease patients: A critical analysis. The American Journal of Alzheimer's Care & Related Disorders & Research. Sept./Oct. 29-38.

Panella, J.J., Lilliston, B.A., Brush, D., & McDowell, F.H. (1989). Day care for dementia patients: An analysis of a four-year program. Journal of American Geriatric Society, 32(12), 883-886.

Polit, D.F. & Hungler, B.P. (1991). Nursing Research: Principles and methods (4th ed.). Philadelphia: J.B. Lippincott.

Rabins, P.V., Mace, N.L., & Lucas, M.F. (1982). The impact of dementia on the family. Journal of the American Medical Association, 248(3), 333-335.

Rosenstock, I.M. (1966). Why perople use health services. Milbank Memorial Fund Quarterly, 44, 94-127.

Sands, D., & Suzuki, T. (1983). Adult day care for Alzheimer's patients and their families. The Gerontologist, 23(1), 21-23.

Silverstein, N.M., & Hyde, J. (1987). Utilizing an existing service system to aid Alzheimer's clients and their families: The Massachusett's Home Care Network. The American Journal of Alzheimer's Care and Research. (March/April), 30-37.

United States Congress, Office of Technology Assessment. (1990). Confused minds, burdened families. OIA-BA-403. Washington, D.C: U.S. Government Printing Office.

United States Congress, Office of Technology Assessment. (1990). Losing a million minds: Confronting the tragedy of Alzheimer's Disease and related dementias. Washington, DC: U.S. Government Printing Office.

Vladeck, B.C. (1996, April). Statement of Bruce C. Vladeck Administrator, Health care financing administration long term care options: PACE and S/HMO before the subcommittee on health house committee on ways and means. [On-line]. Health Care Financing Administration. Available: http://www.hcfa.gov/testimony/t041896.htm

Wallace, S.P. (1990). The no care zone: availability, accessibility, and acceptability in community-based long-term care. 30(2), 254-262.

Zarit, S.H. (1990). Issues and directions in family interventions research. In E. Light, & B.D. Lebowitz (Ed.). Alzheimer's disease treatment and family stress: Directions for research. Washington: Library of Congress, 458-486.

APPENDIX A

Interview Questions

Interview Questions

Community Service Use

Visiting Nurse Services

What were your reasons for stopping use of this service? (Probe for reasons and check all that apply).

Did not need service
Cost
Insurance would not cover
Service refused to continue care (ie: relative disruptive)
Quality of service, service not helpful
Found another service to meet needs
Transportation/Distance to service
Relative no longer eligible for service
Relative resistant, not like/want service
Too inconvenient to use (ie: can't leave)
Relative's condition did not allow for use of service
Other

Home Health Aides/Sitters/Companions:

What were your reasons for stopping use of this service? (Probe for reasons and check all that apply).

Did not need service
Cost
Insurance would not cover
Service refused to continue care (ie: relative disruptive)
Quality of service, service not helpful
Found another service to meet needs
Transportation/Distance to service
Relative no longer eligible for service
Relative resistant, not like/want service
Too inconvenient to use (ie: can't leave)
Relative's condition did not allow for use of service
Other

Adult Day Care:

What were your reasons for stopping use of this service? (Probe for reasons and check all that apply).

Did not need service
Cost
Insurance would not cover
Service refused to continue care (ie: relative disruptive)
Quality of service, service not helpful
Found another service to meet needs
Transportation/Distance to service
Relative no longer eligible for service
Relative resistant, not like/want service
Too inconvenient to use (ie: can't leave)
Relative's condition did not allow for use of service
Other

Family Support Groups:

What were your reasons for stopping use of this service? (Probe for reasons and check all that apply).

Did not need service
Cost
Insurance would not cover
Service refused to continue care (ie: relative disruptive)
Quality of service, service not helpful
Found another service to meet needs
Transportation/Distance to service
Relative no longer eligible for service
Relative resistant, not like/want service
Too inconvenient to use (ie: can't leave)
Relative's condition did not allow for use of service
Other

APPENDIX B

Service Satisfaction and Service Importance

Service Satisfaction and Service Importance

Visiting Nurse

How satisfied were you with this service?
- Very Satisfied
- Satisfied
- Very Dissatisfied
- NA

How important was this service to you?
- Very Important
- Somewhat Important
- Not Important
- NA

Home Health Aides/Sitters/Companions

How satisfied were you with this service?
- Very Satisfied
- Satisfied
- Very Dissatisfied
- NA

How important was this service to you?
- Very Important
- Somewhat Important
- Not Important
- NA

Family Support Groups

How satisfied were you with this service?
- Very Satisfied
- Satisfied
- Very Dissatisfied
- NA

Family Support Group

How important was this service to you?
- Very Important
- Somewhat Important
- Not Important
- NA

Adult Day Care

How satisfied were you with this service?

- Very Satisfied
- Satisfied
- Very Dissatisfied
- NA

How important was this service to you?

- Very Important
- Somewhat Important
- Not Important
- NA

APPENDIX C

UCRIHS Approval Letter

MICHIGAN STATE
UNIVERSITY

OFFICE OF
RESEARCH
AND
GRADUATE
STUDIES

University Committee on
Research Involving
Human Subjects
(UCRIHS)

Michigan State University
246 Administration Building
East Lansing, Michigan
48824-1046

517/355-2180
FAX: 517/432-1171

April 25, 1997

TO: Clare Collins
A-129 Life Sciences

RE: IRB#: 97-284
TITLE: STRUCTURAL BARRIERS FOR CONTINUING USE OF COMMUNITY SERVICES AMONG FAMILY CAREGIVERS OF RELATIVES WITH DEMENTIA
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 04/22/97

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 and any revisions listed above.

RENEWAL: 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 use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. 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.

REVISIONS: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the green renewal form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable.

PROBLEMS/ CHANGES: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc.) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517)355-2180 or FAX (517)432-1171.

Sincerely,

D. E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Bridget Cashin