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A COMPARISON OF THE DIFFERENCE IN ATTITUDES
TOWARDS COMMUNITY SERVICES OF DEMENTIA CAREGIVERS
LIVING IN RURAL AND NON-RURAL AREAS

presented by

JANET SHANAHAN WOODS

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of the requirements for

M.S. degree in NURSING

Clare Collier RN, PhD, FAAN
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**A COMPARISON OF THE DIFFERENCE IN ATTITUDES TOWARDS
COMMUNITY SERVICES OF DEMENTIA CAREGIVERS LIVING IN RURAL
AND NON-RURAL AREAS**

By

Janet Shanahan Woods

A THESIS

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ABSTRACT

A COMPARISON OF THE DIFFERENCE IN ATTITUDES TOWARDS COMMUNITY SERVICES OF DEMENTIA CAREGIVERS LIVING IN RURAL AND NON-RURAL AREAS

By

Janet Shanahan Woods

The purpose of this study was to examine and compare the attitudes towards community services of rural and non-rural caregivers of relatives with dementia. The sample included 28 caregivers living in rural areas and 43 caregivers living in non-rural areas. With the exception of race, no significant sociodemographic differences were found between the two groups. Bivariate analysis revealed a significant difference between rural and non-rural caregivers in their preference for informal services, with rural caregivers preferring to use family and friends over formal community services. When the affect of race was controlled for using analysis of covariance, no significant differences were noted. Implications of the findings for research and practice are presented.

To Bob, Kate, Jessica and Colleen Woods

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Introduction

Family caregiving of a relative with Alzheimer's Disease or other dementing disorders affects millions of Americans and is projected to increase in numbers in the future. Support of caregivers may come from the individual's informal and formal support systems. Informal support includes assistance from family and friends while formal support consists of health care and social services. Community support services are one way in which the formal system can enhance caregiver effectiveness and improve patient functioning.

The issue of designing and providing effective community-based services for persons with dementia and their families is complex and multidimensional. Barriers to access, availability and affordability of services all contribute to the variation seen in patterns of service use. While it is widely acknowledged that individuals living in rural areas have greater difficulties with the availability of, access to and in many cases the affordability of services, the concept of the attitudes towards use of those services that are available has not been adequately studied in the rural population. The focus of this study is to examine and compare the attitudes towards community service use of rural and non-rural caregivers of individuals with dementia.

Overview of Dementia

Dementia is the loss of mental function in an otherwise awake and alert individual, requiring over time the continuous care of others. Alzheimer's Disease (A.D.) and related dementias such as multi-infarct dementia, progressive supranuclear palsy, Huntington's Disease and Parkinson's Disease with dementia cause slow loss of memory and personality, ultimately leading to physical disability and death. While A.D. may occur in individuals 30-40 years of age, the vast majority are over 65 years of age (United States Congress, Office of Technology Assessment, 1987).

Disorders which cause severe dementia affect approximately 1.8 million Americans today. An additional 1 to 5 million Americans suffer from mild to moderate dementia. Over the next 20 years these numbers will rise substantially as the population ages due to the aging of the large "baby boom" cohort. In addition, life expectancy at birth has risen from 47.3 years in 1900 to 74.5 years in 1982. The aging of the population, especially in the 85 + years category results in an increasing number of cases of dementia (OTA Report, 1987).

Family Care of Persons with Dementia

Due primarily to the efforts of family members, as many as 60% of the dependent elderly are able to reside in the community outside of institutions with 80% of their care assumed by informal providers (Hooyman, Gonyea & Montgomery, 1983). Noelker & Wallace (1985) found in their study of over 600 caregivers, that caregiving assistance was provided for an average of six years with the caregiver spending over two

hours daily on the elder's personal care alone.

Typically one family member assumes the majority or exclusive care of the impaired elder. Most often this individual is a female spouse or daughter (Bass & Noelker, 1985). While it has been reported that both spouse caregivers and daughters experience high levels of physical, emotional and financial strain, it has been hypothesized that spouse caregivers are at greater risk for the negative consequences of caregiving because they are frequently elderly themselves and may have physical problems that diminish their ability to respond to the demands of caregiving (Noelker & Wallace, 1985).

Role of Community Services

The burden of caring for a family member with dementia has been well documented in the literature (Kuhlman, Wilson, Hutchinson & Wallhagen, 1991). Caring for a patient with dementia may drain a caregiver physically, emotionally and financially (Yankelovich, Skelley & White, 1986; George & Gwyther, 1986). While burden is not the focus of this study, it is often the catalyst that prompts a caregiver to seek assistance.

It is commonly assumed by formal providers that the establishment of public policy to assist family caregivers with the demands of caregiving is essential if persons with dementia are to be maintained in their homes and communities. While the weight of empirical evidence does not support this assumption, i.e. the majority of caregivers do not use community services and yet manage to maintain their family member in the home, it is an assumption of this study that formal community services have the potential

to assist the caregiver in managing their role, lessening the burden and thereby increasing the chances of keeping the individual in the home.

Given, Collins & Given (1988) cite the use of community-based services as a part of the caregiving environment, i.e. "those conditions or forces that influence the quality and course of the caregiving relationship" (p. 74).

Despite these assumptions about the role of community services in easing caregiver burden and maximizing patient functioning, research shows that caregivers make little use of community services (Gwyther, 1988; Stone, Cafferata & Sangl, 1987). Stommel, Given, & Given (1990) in a study of caregiver burden and depression found that among caregivers of physically impaired elders, a pattern of service-use emerged where a few patients used many services often while the majority used few services either infrequently or not at all. In addition it was noted that individuals providing care to a family member with dementia used only half as many community services as caregivers of physically impaired family members. Prior research has also shown that knowledge of and access to services did not necessarily lead to service use (Caserta et al., 1987).

When services are used by caregivers it is often very late in the caregiving process. Lawton, Brody & Saperstein (1989) in their demonstration project to provide respite care to caregivers of A.D. patients, found that the impact of the intervention was minimized by the caregivers reluctance to seek assistance. These caregivers required much encouragement and education regarding the use of respite services before they were able to act.

Factors Influencing Service Use

Current research questions regarding dementia care are concerned with the issue of barriers to service use in terms of access and availability. The majority of the studies have described frequency and volume of use, while some intervention studies have attempted to increase use through increased availability.

In 1987, Noelker & Bass expanded Andersen's (1968) original conceptualization of service use to include the primary caregiver's characteristics along with the characteristics of the care recipient. They concluded that different predictive factors of both the care-recipient and caregiver were related to service use. While Noelker & Bass's inclusion of the primary caregiver's characteristics into the study of the factors that influence service use greatly expands the potential for understanding use, to date few research efforts have been directed towards examining the attitudinal differences that may exist within the population of caregivers and the relationship of these attitudes to the inclination to use services.

Rural Service Use

Many factors influence the use of community services including lack of knowledge about services, cost of services, inability of caregivers to arrange service, fear or distrust of service providers, lack of confidence in the quality of services and so on (OTA Report, 1989). To date, the majority of studies have been directed towards urban dwellers with little effort made to compare differences between urban and rural populations. The seriousness of this issue was brought to light in 1987 when the National

Rural Health Research Association and the Foundation for Health Services Research, responding to a congressional directive to develop a rural health research agenda, co-sponsored a national conference to address key health care issues facing rural Americans (Hersh & Van Hook, 1989). Two of the key issues for future research raised during this conference concerned long term care of the rural elderly and the extent to which rural families differ from urban families in their attitudes towards formal and informal health and social support services (Patton, 1989).

At least three factors may influence the use of community services by individuals living in rural areas; 1) access, 2) availability and 3) attitudes towards the use of community services. In terms of access and availability of services, rural residents have access to fewer specialized services thus restricting their long-term care options. In addition to limited access to health care providers and facilities, few areas have either adult day care or in-home care services. Due to the dispersed population in rural areas, participation in family support groups may require substantial travel time (United States Congress, Office of Technology Assessment, 1987).

The availability of community services for those living in rural areas differs from the network of services in urban areas in two important ways; 1) the range of services is more limited in rural areas, and 2) given any one type of service, fewer alternative forms are available to choose from (Coward & Cutler, 1989).

The third factor that may influence the use of community services by those living in rural areas is the different attitudes rural residents may hold towards community services. Long & Weinart (1989) emphasize the

importance of understanding the rural individual's perception of health, health needs and health care services in terms of their attitudes, values and belief systems. Others have noted that health care delivery models based on urban systems are not acceptable to or widely utilized by rural individuals unless they take into account the unique needs, attitudes and life styles of rural life (Scheidt, 1985).

Rural Attitudes

Rural sociologists are inconsistent regarding the existence of a unique set of rural values, beliefs and attitudes. Krout (1986) points out that classical studies theorize a predominant set of values which differ from values held by individuals in urban areas. Such values as practicality, efficiency, friendliness, honesty, patriotism, deep religious commitment, social conservatism and a mistrust of government have been cited as unique to the rural culture. Rogers (1983) describes rural people as having more self-reliance with a greater reluctance to seek assistance from others in comparison with urban individuals. Polk-Warner (1991) describes the rural family as often isolated with an "invisible fence" around them that serves to maintain the isolation and values of that particular family.

Technological changes, advances in communication systems and the industrialization of rural areas have led to changes in the social structure to the extent that it is now felt by some researchers that no significant differences exist between urban and rural areas. While acknowledging this fact, Krout (1986) argues that it does not necessarily follow that the

distinctive rural value structure has disappeared, especially among the elderly cohort who were socialized to early 1900 values. The few studies that address the issue of rural attitudes fail to provide empirical evidence of a difference between rural and non-rural residents. The focus of this study is to describe differences that may exist in rural and non-rural attitudes towards community services based on Krout's assumption that among the elderly cohort a distinctive set of rural values still exists.

Since individuals with Alzheimer's Disease and other dementing disorders are generally unable to request assistance, it is left to the caregiver to initiate the use of community services and to maintain contact with service providers. For this reason, the study of caregiver attitudes towards services is important in designing programs that fit the rural population's specific needs and lifestyle.

While the issues of access and availability of services to the rural population are complex and must be addressed at the national and community level, it is not within the scope of this study to investigate these factors. The focus of this study is simply to describe the attitudinal differences of caregivers that may exist towards community service use based on geographic residence. A limitation of this study is lack of control for length of residence in a particular area. This fact should be kept in mind when interpreting the study results.

Purpose of the Study

The purpose of this study is to describe the attitudinal differences of primary caregivers of individuals with dementia towards the use of community services based on geographic residence.

Research Question

The specific research question is "What are the differences in caregiver attitudes towards community services between rural and non-rural residents?"

Study Relevance

Clinical Nurse Specialist in primary care practice are at the forefront of the movement to provide efficient, cost-effective health care services at the community level. They have the unique opportunity to play an important role at the local, state and federal levels in developing policies and programs for delivering community-based services that assist families and caregivers in dealing with the burdens of caregiving. It is essential that research efforts be directed towards evaluating the benefits of and barriers to service utilization among this population not only in terms of access issues but also in terms of acceptability of services to clients. Once factors that influence the use of community-based services in rural areas have been identified, efforts can be focused on providing those services which best help caregivers provide care to their patients with AD.

Conceptual Framework

The need for a comprehensive model to study the issue of service use is becoming more apparent. Haril, Noelker, & Blake (1985) note that human service organizations are being pressured to be accountable for program effectiveness and efficiency. As the population ages, especially the frail elder, the demand for quality and quantity of services will increase. A comprehensive model of assessment, planning, organization and evaluation of services for the elderly takes into account variables related to service knowledge and awareness, access to services, preference for type of service and the predisposing, enabling and need characteristics of both the care recipient and the primary caregiver.

Andersen's (1968) Behavioral Model of Health Service Utilization represents one of the first attempts to describe a conceptual model to guide the study of the multiple factors that influence health service utilization. The framework emphasizes the importance of societal, health service system, and individual characteristics as they influence use. Societal determinants include those changes in medical technology and social norms that affect the definition and treatment of illness. Health service system characteristics describes the resources and organization of the health care system, i.e. what is available and how it is delivered. Individual determinants are those predisposing, enabling and need characteristics of the client that influence service use.

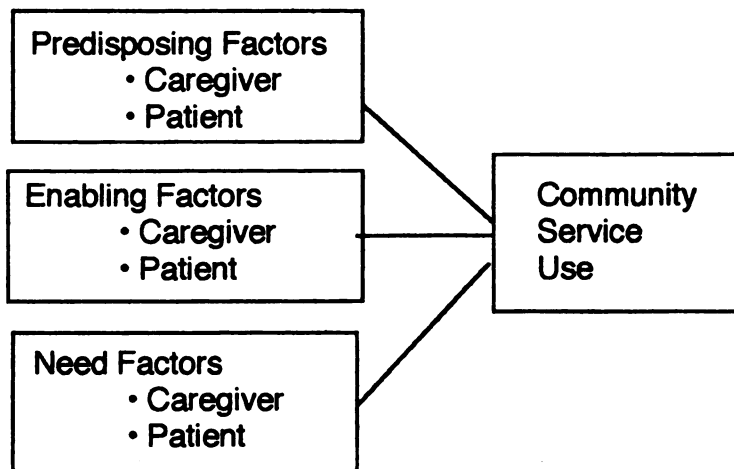
Andersen's model defines health service utilization as the use of medical services and does not address the use of other types of formal and

informal support. The patient/client is the focus of this model. The following section describes Noelker & Bass's (1987) modification of the Andersen framework to include the influence of family caretakers on the use of community services such as visiting nurses and respite care.

Noelker & Bass Model of Community Service Use

Noelker & Bass (1987) expanded Andersen's Behavioral Model of Health Service Utilization (1968) to include variables which reflect beliefs about service use and family care responsibilities. Service use was expanded to include community services. They proposed that because the primary caregiver may influence service use both directly and indirectly, especially if the caregiver is experiencing stress as a result of caregiving, that caregiver characteristics must be included in the framework. Finally, Noelker and Bass included secondary members of the informal support network because they may directly assist the primary caregiver with care or provide relief to the caregiver which may influence the use of and need for formal assistance. In the expanded framework the model is bifurcated to include predisposing, enabling and need factors of both the impaired elder and the primary caregiver.

Figure 1: Noelker & Bass Model of Community Service Use



Predisposing, enabling and need factors are the three components of individual determinants in the Noelker & Bass framework (See Figure 1). Predisposing factors are those characteristics that exist prior to service use and which affect the likelihood of use, including socio-demographic characteristics such as age, sex, race, family, educational level, employment status and occupation as well as health-related attitudes such as beliefs about health and illness. In the Noelker & Bass model, predisposing characteristics refer to the characteristics of both client and primary caregiver that exist prior to impairment or service need and influence community service use.

Social and economic resources that facilitate or impede service use are

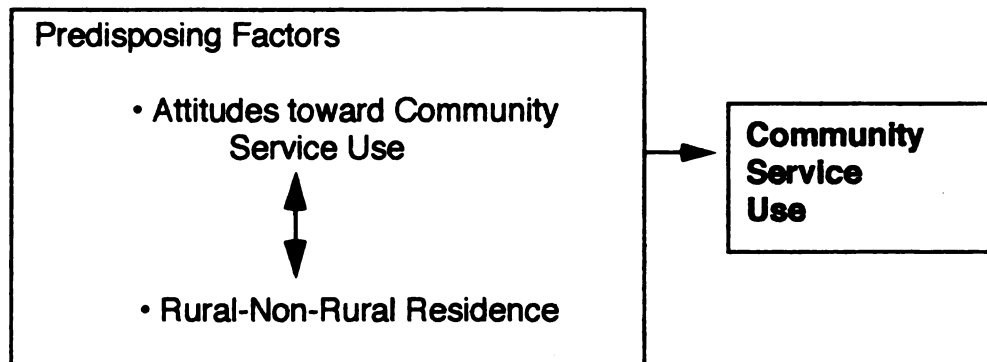
enabling factors. Enabling characteristics are those conditions that facilitate health service utilization including income, insurance, health care costs, assistance from informal support networks, availability and access to care. Noelker & Bass (1987) note that many enabling factors are identical for patient and caregiver, especially if they reside in the same residence. Factors such as educational level, which may be markedly different between patient and caregiver, may independently influence service use.

Need variables are the immediate factors that trigger the need for service use. These factors include the signs and symptoms of disease and are based on both the impaired elder's and the caregiver's perception of health and clinical evaluation by health care providers. Noelker & Bass modified the variable to include the care recipients' needs pertaining to illness and impairment level and the caregiver's needs such as stress resulting from the caregiving situation. Caregiver needs are likely to influence the use of community services due to the need to relieve the stress of caregiving

Adaptation of Noelker & Bass Model for Study of Caregiver Attitudes

In this study, attitudes and residence are discussed within the framework of predisposing variables. The focus of the study is to describe the relationship between geographic residence and attitudes towards community services as predisposing variables. The intention of the researcher is not to examine this relationship in terms of actual service use (See Figure 2).

Figure 2: Use of the Noelker & Bass Model to Study Rural/Non-Rural Attitudes



Predisposing variables are those individual characteristics that exist prior to service need and which influence the decision to use or not use services. Attitude and belief variables as well as geographic residence, although not solely responsible for service use, are likely to influence utilization. According to Andersen & Newman (1973), attitudinal differences do result in differences in inclination towards the use of services. Noelker & Bass (1987) postulate that caregiver beliefs about the acceptability and benefit of community services may influence service seeking and utilization. For example, those individuals who believe in the use of government assistance may be more inclined to seek community services earlier than an individual who disapproves of government

assistance programs. If the assumption that a unique set of rural attitudes exists is true, then rural residence can be viewed as a predisposing variable. In the case of the primary caregiver, who often serves as a proxy for the impaired elder, it is important to assess attitudinal predispositions and the differences that may exist between rural and non-rural residence.

Conceptual Definition of Study Variables

Caregiver attitudes towards community services is the focus of this study. The concept of attitudes has been studied by social psychologists since the turn of the century. Allport (1935) was among the first researcher to question the conceptualization of attitudes as unidimensional attributes. He postulated that attitudes should be viewed as multidimensional characteristics with an affective, cognitive, and behavioral component. The affective component consists of an individual's feelings of like or dislike about an object. The cognitive component consists of an individual's beliefs (whether or not they are in fact true) about an object. The individual organizes these affective and cognitive components into a system which predisposes him to respond (behavioral component) in a manner which is consistent with that system.

The work of Ajzen & Fishbein in the 70's and 80's regarding the theory and measurement of attitudes further elaborated this conceptualization. They postulated that while a person's attitudes towards an object influence his overall response to the object, it may or may not be predictive of a specific behavior. A specific behavior is determined by the intention to perform that behavior. Intentions are a function of the individual's attitudes

towards performing the behavior and his subjective norms (Ajzen & Fishbein, 1980). Intentions then can be viewed as rational decisions made by an individual based in part upon the influence of attitudes and perceptions towards an object which in turn are influenced by the individual's values and belief system. Attitudes then can be defined as latent biases or inclinations of individuals that will be translated into action only if a host of other conditions are met. For purposes of this study, attitudes towards community services will be conceptually defined as latent biases or inclinations of caregivers that will be translated into action only if a host of other conditions such as affordability, accessibility and availability of services are present (Collins et al, 1991).

Rural residence is defined by the U.S. Census Bureau as residence in a town with a population of less than 2,500 or in the open country. For purposes of this study rural residence is defined as residence in a town of 2,500 or less. Non-rural residence is defined as residence in a town with a population of 100,000 or greater.

Review of the Literature

In recent years extensive research examining service utilization has been conducted. Studies have focused broadly on those factors that influence the decision to use services. The focus of this review will be on what is known about community service use in general in rural and non-rural areas and specifically about the influence that attitudes may exert on the decision to use services.

Community Service Use in Rural and Non-Rural Areas

Many of the studies of rural service use focus on a comparison of the rural/urban service networks of impaired elders. Coward, Cutler & Mullens (1990), in their study of 3,761 impaired elders, found that those individuals residing in non-metropolitan communities were significantly less likely to be receiving aid from a formal provider and more likely to be receiving assistance from informal helpers exclusively. Even the most severely impaired elders living in rural areas were found to use the informal helping network almost exclusively. The authors speculate that this may be the result of the lack of formal services available to rural elders and/or the reluctance of rural elders to use these services. However, no empirical data exists to support this speculation.

In their study of 1,196 noninstitutionalized rural elders living in Virginia, Newhouse & McAuley (1987) found that these individuals receive almost all (91.7%) of their care from informal caregivers with 5.5% of their care coming from a combination of informal and formal sources.

Nyman, Sen, Chen & Commins (1991) studied data from the Wisconsin Annual Survey of Home Health Agencies to assess the urban/rural differences in home health service use. They found that urban dwellers are significantly more likely to use home health services than rural dwellers. They suggest that rural patients may have different needs both physically and in terms of life style. They conclude that in order to fully assess service use in rural areas it is also necessary to account for other aspects of use such as the availability of informal caregivers and preferred types of care they receive.

Finally, in a descriptive study of noninstitutionalized disabled elders from the longitudinal Long Term Care Study, Clark (1992) found that urban residents were significantly more likely to receive formal assistance in every aspect of ADL and IADL's than were their rural counterparts. Clark concludes that future research efforts must delineate the primary source of variations observed in rural service use.

As has been noted frequently in the literature, only approximately 9-25% of the variance seen in service utilization studies can be explained (Wolinsky & Arnold, 1988). While results of existing studies do provide a beginning understanding of the dynamics of community service use by caregivers of individuals with dementia, they also suggest the need for the study of other patient/caregiver characteristics. McCaslin (1988) in her review of four major studies of service use predictors notes the need for increased attention to the influence of attitudes.

Attitudes Towards Community Service Use

The influence of the attitudes of family caregivers on the decision to use community services has been frequently cited in anecdotal reports of dementia demonstration projects (Lawton et al, 1989; Montgomery & Borgatta, 1989). The need for expanding the study of the dimensions that influence attitudinal predispositions is cited in studies of the elderly in general (Krout, 1983; Wolinsky & Arnold, 1988).

Collins et al (1991) cite two categories of caregiver attitudes towards community services; 1) attitudes regarding the acceptability of formal services and, 2) attitudes about the quality of services. For purposes of this study the former category will be examined.

Caregiver attitudes about the acceptability of using formal services include the need to provide all the care required by the impaired elder and a preference for informal over formal services. Collins & King (1990) cite the preference to use assistance from family and friends in the care of a family member with dementia rather than from formal sources as a commonly occurring attitude among caregivers.

In a survey of a nationally representative sample of 723 adults aged 45 and older, Straw (1991) found that the majority of middle-aged and older adults (72%) preferred to provide care at home with 44% of these preferring to have family and friends provide care rather than formal providers. Perhaps more dramatically, Straw found that even when faced with around the clock care, 49% preferred to care for a family member at home.

King (1990) notes in a qualitative study of 37 caregivers of A.D. patients, four predominant caregiver attitudes; 1) a sense of family obligation and responsibility, 2) independence, 3) reciprocity and, 4) trust. The sample was drawn from a larger volunteer non-random group of caregivers recruited for a five year longitudinal study of the experience of providing care to a family member with A.D. King found that caregivers who expressed strong values of family obligation, independence and responsibility were most likely to provide care without assistance, while caregivers who valued reciprocity were more likely to use formal community services.

King's study represents an important effort in the study of the caregiving process. The use of qualitative data allows the researcher to evaluate what it is like to care for an individual with dementia. Information that is gleaned from qualitative studies enhances the understanding of what motivates individuals to use or not use services. The limitation of King's and other qualitative studies is the limited sample. King's sample was drawn from a small geographic region and may not be generalizable to both urban and rural areas.

The investigation of the influence of caregiver attitudes on the use of community services is in its infancy. Expanding the knowledge base is important for several reasons. Knowledge of caregiver attitudes may reveal when the caregiver is most likely to need services, what services would be preferred and what types of services would be acceptable. This information along with other caregiver and patient characteristics may lead to stronger predictive power in the study of service use. More importantly,

however, knowledge of caregiver attitudes may help providers design programs that better fit the preferences of users leading to more efficient and cost effective service delivery.

Rural Attitudes

The study of rural attitudes towards health care is descriptive and for the most part anecdotal. Barnett & Bigbee (1991) describe rural residents as strong, individualistic, independent and resistant to big government and welfare. Rural residents prefer to "tough it out" and will travel great distances to seek health care only if they are seriously ill. This attitude of self-reliance may also deter the caregiver/family from seeking assistance.

Bushy (1990) points out that the perception of illness as the inability to work predisposes the rural individual to seek services only when a crisis stage has been reached. Compounding this attitude is the rural work ethic where it is felt that those who cannot support themselves are morally deficient (Bushy, 1990). The thought of going on welfare "may be so impalatable that they choose to live without any assistance" (p. 32).

Weinert & Long (1987) studied the perceptions of rural Montanans towards health, and health needs and services. Descriptive data analyzed in the study was drawn from a six year study of health related trends in Montana. Both qualitative and quantitative research methods were used to better understand the phenomena of rural health.

Qualitative data collection involved ethnographic interviews. Care was taken to avoid superimposing the cultural biases of the graduate student

interviewers by training them as part of their course work. Domain analysis was conducted and concepts that emphasize the understanding of health and health needs from the perspective of those living in rural areas were delineated.

Quantitative analysis evaluated the results of a mailed questionnaire packet including measures of personal resources, depression, anxiety, perceptions of general health and a comprehensive background information form.

Results of the data revealed several predominant attitudes. Rural residents define health as the ability to work. Pain and disability were rated as less important in determining the individual's perception of overall health. The concepts of self-help and self-reliance emerged as strong attitudes among rural dwellers. The authors describe these attitudes as significant strategies that rural residents use to cope with illness. Family and close friends are relied upon for support rather than formal service agencies.

The concept of "newcomers and outsiders" emerged as significant in that it influences the willingness to accept outside help from the health care system. The authors suggest that this attitude should influence the type of community services provided in rural areas. Care must be taken to provide for continuity of service providers with the involvement of local individuals as care providers as much as possible in order to establish effective community based services.

Weinert and Long's study represents an initial attempt to describe the unique attitudes that rural residents hold towards health and community

services. Caution should be taken when interpreting the results of the study because of the nature of the sample. Rural Montana is uniquely isolated with much of the land devoted to ranching, which differs greatly from rural areas in other parts of the country. More studies are needed that examine rural areas in different geographic locations with comparisons to non-rural areas before a unified concept of unique set of rural attitudes can be established.

In summary, the use of community services is postulated to be influenced by the attitudes of both the individual and the community. Nurses in advanced practice must be knowledgeable about these attitudes and their impact on the decision to seek assistance at both the individual and community level in order to plan and implement programs that are consistent with the unique culture of the area. The environmental realities of rural living as well as the attitudes held by rural people must be taken into account when designing community-based services. It is not sufficient to simply transplant urban models to rural areas (Coward & Cutler, 1989). Bushy (1990) states "Because of the rural communities limited resources, concerted interdisciplinary effort and collaboration are necessary to make holistic health care a reality for the families who live there" (p. 37). Nurses in advanced practice can play an important role in this effort both at the individual, family and community level.

Methods

The methods utilized in this study are presented in this section. Research design, sample and data collection procedures, operational definitions, instrumentation and data analysis are outlined.

Research Design

A secondary analysis was conducted on data collected as part of a four year longitudinal study of family caregivers of relatives with dementia who reside in the community (R01-MH 417666-02, "The Impact of Alzheimer's Disease on Family Caregivers," Principal Investigator - Clare Collins, R.N.,Ph.D.). The study was funded by the National Institute of Mental Health and conducted at the College of Nursing at Michigan State University from 1988-1992. The aim of the grant specific to this study was to describe the level of community service use by the patient, the caregivers' perception of the availability of, need for and barriers to service use and sources of information about community services. Data for the analysis of rural and non-rural differences in attitudes towards community serv

Sample Procedures

The target population for this study was family caregivers of relatives with dementia who reside in the community. A convenience sample of family caregivers (n=180) was located through mailings distributed by local chapters of the Alzheimer's Association, the Michigan Association of Adult

Day Care Centers and health agencies in southwest Michigan. A cover letter explaining the study and a return postcard were sent to Adult Day Care Centers, home health care agencies, and geriatric clinics. Clinicians were asked to distribute information to the families in their agencies.

Families interested in participating in the study were asked to return the postcard indicating their name, address and the best time to contact them.

A direct mailing was done by the Michigan chapter of the Alzheimer's Association to individuals on their mailing list using the same card back system. In addition, recruitment was enhanced by the use of local radio and television spots and posted information about the study in local libraries and church bulletins. Potential participants were then screened by data collectors to determine if they met the eligibility criteria of the study.

The criteria for entry into the study by caregiver/patient dyads included the following: 1) the patient was at least 55 years old; 2) the patient was dependent in at least one instrumental activity of daily living (IADL) and one activity of daily living (ADL); 3) the patient had received a diagnosis of A.D. or other progressive dementia; 4) the caregiver was self-identified as the family member providing the most care to the relative with dementia; and 5) the patient with dementia was residing in the community at the time of data collection.

Data Collection Procedures

Participants in the study were informed that they were participating in a longitudinal study that would involve several encounters both by telephone and mail. They were told that participation in the study was entirely

voluntary and that they could withdraw at any point. Confidentiality was explained to the participant and informed consent was signed.

The subjects enrolled at the second data collection point of the study participated in an extensive telephone interview conducted by a trained research staff member. Interviewer training procedures are described in Collins et al, (1988). In addition, each study participant completed the self-administered booklet containing the Community Service Attitude Inventory (CSAI) which was mailed to them (Appendix A). Strategies used to retain participants in longitudinal studies are described in Given, Keilman & Collins (1990).

Demographic data are presented as it relates to this specific study. The data regarding demographic background information and results of the CSAI were analyzed. Prior to any data analysis, the University Committee on Research Involving Human Subjects at Michigan State University approved the use of the identified sample for this study (Appendix B).

Operational Definition of Variables

In this study attitudes towards community services are operationalized as scores on the five scales of the Community Service Attitudes Inventory (Collins et al, 1991). The five scales of the CSAI are: 1) concern for the opinion of others; 2) confidence in the service system; 3) caregiver preference for informal care; 4) belief in caregiver independence; and 5) acceptance of government services. The caregiver was asked to respond to 64 items of which 25 items constitute the final version of the instrument

that measure the five dimensions of attitudes towards community services. Answers to the individual items were recorded on a four-point Likert scale and ranged from strongly agree (1) to strongly disagree (4).

Rural residence is operationalized in this study according to the U.S. Census definition (U.S. Bureau of the Census, 1980). Those individuals residing in cities with populations $< 2,500$ will be considered rural. In order to optimize the distinction between rural and non-rural residence, non-rural residence will be operationalized as residence in a community with a population $> 100,000$.

The sample of the present study was formed by selecting all those cases that met the criteria for rural residence based on the 1980 Census data. City population size for each case was tabulated and those cases with populations $< 2,500$ and $> 100,000$ were selected for inclusion in the study. Utilizing this procedure, a sample of $n=28$ rural cases was identified. The non-rural sample was chosen by selecting all those cases located in communities with populations $> 100,000$ ($n=43$).

Instrumentation

To measure attitudes of family caregivers regarding the use of community services for the care of a relative with dementia, Collins et al (1991) developed the Community Service Attitudes Inventory (CSAI). The specific methods used to derive the items for the study are described elsewhere (Collins, Stommel, King & Given, 1991).

Subscales were identified through use of principle component factor analysis followed by a varimax rotation performed on the selected items

(Collins, 1991). Statistical requirements for inclusion of an item in a factor included a factor loading exceeding .5 on the primary factor with the next highest factor loading differing by at least .2. In addition, all items that met these statistical criteria were further examined for theoretical fit with the subscales. The formation of seven scales resulted from these procedures with a total of 34 items. Two of the derived subscales (Need for Information and Perception of Service Availability) did not measure attitudes towards community services and are not included in this study. Interscale correlations were low ranging from .11 to .38, suggesting that the scales reflect distinctive attitudes. Cronbach's Alpha was chosen to evaluate internal consistency of the CSAI scales. The coefficient alphas of the scales ranged from .74 to .84. The final version of the CSAI is a 25 item self-administered instrument using a four point Likert scale for scoring. A score of 1 = strongly agree, 2 = agree, 3 = disagree and 4 = strongly disagree.

Construct validation was tested by predicting a relationship between scores on the CSAI scales and two measures of present and past service use of three specific community services (visiting nurses, home-health aides and adult day care). Predictions were based on: 1) the frequency of current service use (within the 3 months prior to the interview), and 2) the number of these services (0-3) ever used for the care of the individual with dementia. Construct validity was supported by these analyses. There is further evidence to support content and construct validity based on the procedures utilized in the initial derivation of the items (Collins et al, 1991).

Limitations of the Instrument

The CSAI represents an initial attempt to measure one aspect of the complex issue of understanding the use of community services by caregivers of individuals with dementia. Initial analysis of the psychometric properties of the scales reveals adequate reliability and content validity of the instrument, however further testing of construct validity is needed. Criterion-related validity is incomplete due to the use of only three community services and only two measures of service use.

As of this date, the CSAI has been tested on only one sample of caregivers. This sample was 93% white with the majority having at least a high school education and residing in urban areas in Michigan.

In addition, the mean duration of caregiving was greater than 5 years. The instrument should be tested further in clinical settings with more heterogeneous samples of caregivers at different stages of caregiving including individuals with different socioeconomic backgrounds, living in different geographic regions and of different ethnic and cultural backgrounds.

Data Analysis

Descriptive statistics were utilized to analyze characteristics of the rural and non-rural samples. Demographic characteristics of the caregiver and the caregiving situation are presented. Caregiver characteristics include; sex, age, race, marital status, relationship to the patient, living arrangements, household income, educational level and employment status. Characteristics of the caregiving situation include patient diagnosis

and duration of caregiving. Differences in the demographic variables between the rural and non-rural groups were analyzed using Chi-Square and ANOVA statistics.

The demographic background variables that were found to be confounders for the dependent variables (attitude subscales) were controlled for using the analysis of covariance (ANCOVA) statistical technique. ANCOVA tests the significance of differences in group means after adjusting the scores on the dependent variable (attitudes) to eliminate the effects of the covariate (Polit & Hungler, 1987).

The unit of analysis for study was the individual respondents with two identified residential groups. Two-tailed tests with the level of significance at .05 were performed. Data was analyzed using the SPSS-PC statistical program.

Results

The findings described in this section are compiled from the self-reported CSAI questionnaires of the 28 rural and 43 non-rural subjects eligible for this study. Tables showing sociodemographic and scale characteristics of the samples and tables giving the results of the data analysis are included.

Sociodemographic Characteristics

The original sample (n=182) from which the rural and non-rural samples were drawn were predominantly white (85%), female (76%), spouses (68%) residing with the patient in the same household (90%). Ninety percent of the total sample were married with at least a high school education (85%). The majority of the caregivers were unemployed (67%) caring for a family member with a diagnosis of A.D. (81%). The average household income was approximately \$31,000 and the average caregiver age was 62.8 years. The average years of caregiving was more than five years ($X=5.1$, $SD=11.1$). Table 1 presents the sociodemographic characteristics of the rural (n=28) and non-rural (n=43) samples selected from the original sample.

Table 1
Demographic Variables for the Rural and Non-Rural Samples

Caregiver Characteristic	Rural Group (n = 28)	Non-Rural Group (n = 43)
Sex		
Male	14% (4)	23% (10)
Female	86% (24)	77% (33)
Race		
White	96% (27)	77% (33)
Non-White	4% (1)	23% (10)
Living Arrangement		
Lives with	89% (25)	95% (41)
Does not live with	11% (3)	5% (2)
Relationship		
Spouse	64% (18)	60% (26)
Non-Spouse	36% (10)	40% (17)
Marital Status		
Married	89% (25)	86% (37)
Not Married	11% (3)	14% (6)
Education		
Grade School	21% (6)	16% (7)
High School	72% (20)	54% (23)
College Grad	7% (2)	30% (13)
Employment		
Employed	25% (7)	37% (16)
Not Employed	75% (21)	63% (27)
Patient Diagnosis		
A.D.	82% (23)	81% (35)
Other	18% (5)	19% (8)
Household Income		
Mean	\$26,410	\$32,573
SD	\$17,353	\$20,020
Caregiver Age (years)		
Mean	61.0	62.6
SD	12.9	10.6
Duration of Caregiving		
Mean	5.6	4.8
SD	4.1	5.3

Chi-square tests of significance (Table2) between the rural and non-rural samples reveals a significant difference ($p=.025$) in the racial composition of the two groups with significantly more non-white caregivers residing in non-rural areas.

Table 2

Chi-Square Tests for Differences in Group Means

<u>Variable</u>	<u>Chi-Square</u>	<u>P-value</u>
Sex	.86	.35
Race	5.05	.02
Living Arrangement	.95	.33
Relationship to Pt.	.11	.75
Marital Status	.16	.69
Education	6.25	.18
Employment	.96	.33
Patient Diagnosis	1.03	.71

Table 3 presents the tests for the differences in mean income, caregiver age and duration of caregiving between the rural and non-rural samples. No statistically significant differences were found between the rural and non-rural samples on these variables.

Table 3
ANOVA for Differences in Group Means

<u>Source of Variance</u>	<u>df</u>	<u>Sum of squares</u>	<u>Mean square</u>	<u>F-ratio</u>	<u>F-probability</u>
Income					
Between Groups	1	631830407.6	631830407.6	1.75	.19
Within Groups	67	24163807274	360653839.9		
Total	68	24795637681			
Age					
Between Groups	1	42.41	42.41	.32	.57
Within Groups	69	9240.46	133.92		
Total	70	9282.87			
Duration of Care					
Between Groups	1	1636.53	1636.53	.48	.49
Within Groups	67	229078.80	3419.09		
Total	68	230715.33			

In summary, the rural and non-rural samples are composed of mainly elderly, white middle-classed women who are unemployed and caring for their spouses in the home. The majority of the sample has at least a high school education and have been caring for their relative for approximately five years. The only statistically significant demographic difference between the rural and non-rural samples was found to be in racial composition. The demographic characteristics of the caregivers in this study reflects the caregiver profile shown in previous studies with the

majority of dementia caregivers being female (spouses, daughters and daughters-in-law) and caring for their relative in the home (Bass, 1985). Noelker & Wallace (1985) described the average number of years of caregiving as approximately five years which is identical to the findings in the original sample and in the present study.

Scale Properties of the Rural and Non-Rural Samples

Subscale characteristics for both the rural and non-rural samples are presented in Tables 4 and 5. Cronbach's Alpha was utilized to determine the internal consistency of the Community Service Attitude Inventory subscales. Polit & Hungler (1987) describe alpha coefficients of .60 -.70 as adequate levels of reliability when making group-level comparisons. The coefficient alphas of the subscales for the original sample ranged from .74 to .84. Similar results were found with the rural and non-rural samples in the present study. Alpha coefficients for the rural sample ranged from .74 to .82 and for the non-rural sample from .74 to .84.

Table 4
Scale Characteristics of Rural Sample

<u>Subscales</u>	<u>Scale Mean</u>	<u>Scale S.D.</u>	<u>Scale Range</u>	<u>Cronbach's Alpha</u>	<u>Mean Interitem Correlation</u>
Concern for Opinion of Others	1.93	.30	1.3 - 2.2	.82	.57
Confidence in Service System	2.47	.21	2.0 - 2.8	.78	.47
Preference for Informal Care	2.27	.26	1.7 - 2.7	.76	.66
Belief in Care-giver Independence	2.61	.28	1.7 - 3.2	.74	.65
Acceptance of Gov't Assistance	2.77	.32	2.0 - 3.3	.74	.74

Table 5
Scale Characteristics of Non-Rural Sample

<u>Subscales</u>	<u>Scale Mean</u>	<u>Scale S.D.</u>	<u>Scale Range</u>	<u>Cronbach's Alpha</u>	<u>Mean Interitem Correlation</u>
Concern for Opinion Others	1.94	.31	1.3 - 2.5	.84	.60
Confidence in Service System	2.52	.19	2.1 - 3.0	.78	.46
Preference for Informal Care	2.43	.28	1.7 - 3.0	.76	.66
Belief in Care-giver Independence	2.48	.33	1.7 - 3.7	.74	.65
Acceptance of Gov't Services	2.70	.29	2.0 - 3.3	.74	.74

Interscale correlations for both samples were computed to test the degree of relationship between the individual subscales (Tables 6 & 7). Interscale correlations for the rural sample ranged from -.24 to .30. Ranges for the non-rural sample were from -.29 to .31. Directional changes in the correlations are noted between the two samples with absolute difference ranges from .09 - .59. For example in the rural sample Concern and Confidence are positively correlated (.30) while in the non-rural sample they are negatively correlated (-.29). These findings suggest that the attitude structure between the two groups may be different. Despite

directional differences, the over-all low interscale correlations suggest that the subscales do represent distinct attitudes and supports the use of the separate subscale scores to reflect individual attitudes rather than the use of the total CSAI score. Similar results were found with the original sample (Collins, 1991).

Table 6

Interscale Correlations of Rural Sample

<u>Subscales</u>	<u>Concern</u>	<u>Confidence</u>	<u>Informal</u>	<u>Independence</u>	<u>Gov't</u>
Concern		.30	-.12	.19	-.19
Confidence			.01	-.02	-.10
Informal				-.07	-.24
Independence					-.22
Gov't					

Table 7

Interscale Correlations of Non-Rural Sample

<u>Subscales</u>	<u>Concern</u>	<u>Confidence</u>	<u>Informal</u>	<u>Independence</u>	<u>Gov't</u>
Concern		-.29	.08	-.12	.01
Confidence			.07	.20	.04
Informal				.11	.31
Independence					-.13
Gov't					

Comparison of Mean Scores on Attitude Subscales

Two-tailed t-tests were computed to test for observed differences between group subscale means for the rural and non-rural samples (Table 8). Pooled variance estimates were utilized because the ratio of the sample variances to each other fell within acceptable limits (.5 - 2.0). Statistically significant differences between the rural and non-rural groups were found in attitudes towards the use of informal care. Significantly more non-rural caregivers preferred to use community services rather than family or friends, while caregivers in rural areas preferred the assistance of family and friends

Table 8
T-Tests for Observed Group Differences

<u>Scale</u>	<u>Mean</u>	<u>SD</u>	<u>SE</u>	<u>Pooled Variance Estimate</u>		<u>Probability</u>
Concern						
Rural	1.93	.30	.06	t = -.14	df = 62	p = .89
Non-Rural	1.94	.31	.05			
Confidence						
Rural	2.46	.21	.04	t = -1.07	df = 59	p = .29
Non-Rural	2.52	.19	.03			
Informal Care						
Rural	2.27	.26	.05	t = -2.29	df = 64	p = .02
Non-Rural	2.43	.27	.04			
Independence						
Rural	2.61	.28	.06	t = 1.60	df = 59	p = .12
Non-Rural	2.48	.33	.06			
Gov't						
Rural	2.77	.31	.06	t = .94	df = 62	p = .35
Non-Rural	2.70	.29	.05			

Analysis of Covariance

ANCOVA was computed next to test for the significance of differences in group means after first adjusting the scores on the dependent variables to control for the effects of race. Race was chosen as the covariate because a significant difference was noted in the racial composition of the rural and non-rural samples with more non-white caregivers living in rural than non-rural areas. In addition, the dimension of race has been shown historically to account for cultural and ethnic differences between groups which theoretically may influence attitudinal predispositions.

Table 9 presents the results of this analysis. When the demographic variable of race was controlled, no significant differences were noted between the two groups. The significant difference in the bivariate analysis on the dimension of preference for informal care became insignificant ($p = .055$) when the covariate was added to the equation.

Table 9
ANCOVA for Adjusted Group Differences

<u>Source of Variance</u>	<u>df</u>	<u>Sum of Squares</u>	<u>Mean Square</u>	<u>F-Ratio</u>	<u>F-Prob</u>
Concern for Opinion of Others					
Main Effect	2	.251	.125	1.405	.253
Race	1	.249	.249	2.290	.100
Group	1	.007	.007	.083	.775
Explained	2	.251	.125	1.405	.253
Residual	61	5.437	.089		
Total	63	5.687	.090		
Confidence in Service System					
Main Effect	2	.052	.026	.642	.530
Race	1	.006	.006	.157	.693
Group	1	.034	.034	.825	.367
Explained	2	.052	.026	.642	.530
Residual	58	2.369	.041		
Total	60	2.422	.040		
Preference for Informal Care					
Main Effect	2	.441	.221	3.032	.055
Race	1	.059	.059	.817	.370
Group	1	.282	.282	3.876	.053
Explained	2	.441	.221	3.032	.055
Residual	63	4.586	.073		
Total	65	5.027	.077		
Belief in Caregiver Independence					
Main Effect	2	.515	.258	2.694	.076
Race	1	.262	.262	2.746	.103
Group	1	.115	.115	1.207	.276
Explained	2	.515	.258	2.694	.076
Residual	58	5.544	.096		
Total	60	6.059	.101		
Acceptance of Gov't Service					
Main Effect	2	.124	.062	.670	.516
Race	1	.044	.044	.472	.495
Group	1	.107	.107	1.159	.286
Explained	2	.124	.062	.670	.516
Residual	61	5.626	.092		
Total	63	5.750	.091		

Discussion

Study findings are interpreted in this section. First, an overview of the findings is given, followed by discussion of the limitations of the study and suggestions for future research. Finally, implications of the study results in terms of Noelker & Bass's Model of Community Service Use and the Clinical Nurse Specialist's role in the primary health care setting are presented.

Research Question

The research question stated in the study was, "What are the differences in caregiver attitudes towards community service use between rural and non-rural residents?" Bivariate data analysis revealed no significant differences in the attitudes of rural and non-rural caregivers towards community service use on four of the five attitude subscales in this study. Significant differences were noted in the preference for the use of informal care. Rural caregivers preferred to use their informal support network of family and friends to provide care, while non-rural caregivers showed a preference for the use of community services. This interpretation supports the theory that a unique rural attitude of "self-reliance" may exist and that rural caregivers may chose to rely on informal networks to care for their family member. Such an attitude would serve as a predisposing factor which leads to an inclination to use or not use community services.

Demographic characteristics such as age, sex, race, residence, educational and economic level are some of the variables that define an

individuals unique set of attitudes and values. In the present study, only race was found to be significantly different between the rural and non-rural groups. Preliminary analysis of the affect of race on the preference for informal care revealed no significant residential differences. Interpretation of this finding, however, is limited and inconclusive due to the small size of the sample with only one non-white caregiver in the rural group and ten in the non-rural group. Other factors not measured in this study such as ethnic and cultural background may account for some of the variance noted between the groups on this subscale. Further study of the affect of race on the preference for informal care, utilizing a larger sample, is necessary to provide stronger evidence of its contribution to the observed variance between the two groups.

Availability and knowledge of services was not researched in this study so that it is not possible to determine if lack of community services in rural areas may have influenced the respondents preference for informal care rather than any innate attitudinal predisposition. Non-rural caregivers may show a preference for community services simply because they are available and accessible to them.

The subscale that assesses caregiver preference for informal care simply asks the question if the family caregiver would rather use members of their informal support network or community services to help care for their relative with dementia. This subscale may not be an adequate measure of the dimension of "self-reliance" in that other considerations such as transportation and finances may affect an individual's response. The rural health and dementia caregiver literature presents evidence that

both these populations prefer informal care and in fact tend to care for their loved ones independently until near institutionalization and/or death.

Caregiver attitudes regarding caring for a relative with dementia may not be reflective of an individual's general mode of responding. The need for independence in the care of a family member may not be equivalent to "self-reliance" in other areas. Caregiver attitudes may be more emotionally laden in that the burden that is associated with dementia care may serve to modify an individual's normal mode of response. Dementia care often carries with it the stigma of mental illness while care of the physically ill or frail elder does not. Dementia caregivers may choose to isolate themselves, providing all the care because of the shame associated with the behavior and actions of their demented relative.

Caring for an individual with dementia requires specialized training in order to cope with both the physical and behavioral manifestations of the disease. The availability of trained dementia caregivers may, therefore, play a role in a caregiver's preference for informal care. Caregivers may choose to rely on family and friends rather than the help of unskilled workers. Finally, reimbursement issues may also affect the choice of services. Lack of financial support for the use of such services as visiting nurses and respite care for the dementia patient may force families to rely on their informal support systems.

Also of interest are the non-significant findings of the study. Caregivers in both the rural and non-rural groups expressed lack of confidence in the service system and concern for the opinion of others as well as disagreement with the use of government assistance. These attitudes are

consistent with what is known about dementia caregivers in the existing literature. Contrary to these findings are the results of the caregiver independence subscale. The majority of caregivers disagreed with the idea of caring for their family member without outside assistance. These caregivers may be at a point in the caregiving situation where they are no longer able to cope without help and have modified their attitudes to accommodate.

Attitudes have been conceptualized as multidimensional characteristics rather than as unidimensional attributes (Allport, 1935). They are acquired through the influence of the environment around us but no strong conceptual definition of how attitudes interact with other factors exists. Attitudes have been described as latent and modifiable so that they may change as the stress level of a particular situation changes. Although not tested in this study, this may explain some of the apparently conflicting attitudes observed among the subscales. As stress and burden rises in the caregiving situation, the caregiver who previously preferred to be independent may be more inclined to, out of desperation, accept formal services.

In summary, the results of this study indicate that a significant difference in the preference for informal care over the use of formal community services exists between those caregivers living in rural and non-rural areas. Preliminary analysis of race as a covariate suggests that this factor may contribute to some of the variance observed, but due to the limited scope of this study, however, results are inconclusive at this point.

Limitations

This study utilized a convenience or non-probability sample. The rural and non-rural samples were drawn from the original convenience sample and were small and fairly homogenous. Sociodemographic characteristics of both samples were very similar. The majority of cases were white, married females who were unemployed caring for their family member with a diagnosis of A.D. In addition, the sample consisted of a narrow group of individuals who were motivated to respond to a request to participate in the study and does not represent the entire population of caregivers. The sample was further biased by the fact that a large proportion of individuals who were already receiving services were referred to the study.

Probability or random sampling would have been the preferred method to use in this study because it would have increased the variability within the sample reflecting the natural variability within the population of caregivers.

Care was taken to differentiate as much as possible the rural from the non-rural group, but because of the constraints of using secondary data it was impossible to determine the length of residence in a specific geographic region. The possibility exists that the rural sample did not truly reflect a "native" rural group but consisted of "transplanted" retirees from urban areas. It was also not possible to evaluate whether those cases in the rural sample were living in frontier (open country) versus farming communities. The unequal distribution of race among the two groups is also a limitation of this study, limiting its utility as a covariate in the analysis.

The CSAI is a new instrument and has not been tested on a variety of caregiving populations. Reliability and validity of the instrument have not been established conclusively. Validity with community service criteria has been established but validation with other attitudinal scales has yet to be performed.

Recommendations for Future Research

While results of this study fail to provide strong evidence for differences in attitudes towards community service use based on geographic residence, it does serve as an initial attempt to address the need to consider caregiver attitudes as predisposing factors which may influence the use of community services. This study should be replicated on a larger scale with a more heterogeneous caregiver sample.

Emphasis should be on inclusion of those caregivers who are not motivated to respond to study requests and who are not currently using community services. Length of residence should be assessed to differentiate between those rural dwellers who are "native" and those who are "transplanted". Efforts should be made to enroll participants from those areas defined as the "rural frontier" of the country. Finally, the contribution of racial, ethnic and cultural influences should be investigated thoroughly.

Further investigation and refinement of the Community Service Attitude Inventory is necessary. Correlation with other standardized attitude inventories will substantiate its construct validity. The CSAI should be tested on other diverse groups of caregivers within different clinical settings such as with individual's caring for physically disabled, chronically

ill, and terminal patients. The CSAI should be utilized to investigate patterns of attitudes and to examine those combinations of attitudes that lead to service use.

Finally, qualitative research should be conducted to better define the caregiving situation of dementia caregivers. Further investigation of the factors that motivate caregivers to seek services and those decision points that lead to service use should be explored utilizing qualitative and quantitative techniques. An examination of the relationship of attitudes and use would expand our knowledge of the combination of factors that contribute to service utilization and guide the design of more efficient, cost-effective programs.

Implications for Advanced Nursing Practice

Noelker & Bass's Model of Community Service Use postulates that "predisposing factors" are those characteristics that exist prior to service need which influence the decision to use or not use community services. Attitudes towards community service use and geographic residence were viewed within this study as predisposing factors which influence a caregiver's inclination to use or not use community services. Results of this study failed to support significant differences between rural and non-rural caregivers.

While findings from this study don't provide strong support for rural/non-rural differences, the CSAI along with the Noelker & Bass model may be useful if utilized on an individual case basis in clinical practice as a part of an assessment protocol. Information regarding a client/family's attitudes towards community services and other predisposing, enabling and need factors may help guide the provider's referral to the most appropriate and acceptable community service.

The Noelker & Bass model provides a non-nursing framework for viewing the factors which influence the decision to use or not use services. Leininger's (1978) theory of transcultural nursing provides a nursing framework for the assessment and intervention strategies employed by nurses in advanced practice. Leininger's theory was chosen because it views health in terms of the beliefs, values and action patterns that are culturally known and used to preserve and maintain personal or group well-being.

This perspective enables the CNS to assess individual caregivers as cultural beings who must be viewed in the context of physical, ecological, social and world views. Health in Leininger's theory may be perceived differently according to one's cultural background and should not be defined only in terms of criteria set by health care professionals. The CNS working with rural clients must be cautious to assess and recommend intervention strategies that are in keeping with the individual needs and perceptions of the area in which she is working. To simply transport services that may be appropriate in urban areas is not necessarily appropriate for rural areas.

Nursing in Leininger's theory is defined as providing human care to people in a way that is meaningful, congruent and respectful of cultural values and life styles. Leininger defines culture as "the learned, shared and transmitted values, beliefs, norms and lifelong practices of a particular group that guides thinking, decisions and actions in patterned ways (Leininger, 1985, p. 209). Culture as defined by Leininger can be as diverse as the multitude of ethnic groups that make up humankind or as specific as her study of inner-city Black families in Detroit. Using Leininger's framework, the CNS working with rural caregivers must fully appreciate the culture in which she practices before she can effectively

design intervention strategies to meet their needs. This includes not only beliefs about health and illness, but also the social structure in which they live, i.e. those predisposing and enabling factors which contribute to the decision to use or not use community services.

The CNS in primary care functions in many roles: communicator, collaborator, coordinator, educator and patient advocate. The CNS functioning in a case management model of care delivery incorporates all aspects of the role into her practice. Menard (1987) describes case management as a viable opportunity and alternative for the CNS who wants to extend her practice to groups of clients. Clients living in rural areas are one group that has been identified as appropriate for case management.

Case management provides the CNS with a means for assisting families and providers to use health and social services in the most appropriate, cost-effective and efficient means possible (Parker et al, 1990). Case management involves the assessment, planning, service coordination and/or referral, monitoring and reassessment of the multiple service needs of the client. The CNS functioning as a case manager may also carry her own case load providing expert clinical and educational skills.

Many barriers exist in rural case management such as fewer services and providers and poor transportation. The CNS can serve as a link between the use of those formal community services that do exist and the informal support network. The CNS may also act as a case-finder in rural areas, matching clients to the formal services and coordinating the informal support network of the individual by providing support, acceptance and assistance.

Sparacino, Cooper & Minarik (1990) describe case management as a model of health care delivery that has generated great enthusiasm for the CNS role. The CNS has the appropriate educational preparation and practice experience to address the issues of health assessment, resource assessment, planning and delivery of health care services and the advocacy that characterizes case management. The goals of case management are continuity of care, provision of personalized care along a continuum, and cost containment (American Nurses Association, 1988). The CNS who utilizes knowledge of predisposing, enabling and need factors as well as knowledge of the cultural influences predominant in the area in which she practices as a part of her assessment protocol will be better prepared to meet the health care needs of her clients.

Clinical Nurse Specialists in 1993 are in the position to affect the development of quality community service programs. CNS's have the advanced training necessary to evaluate health care needs and delivery at the client/family level as well as at the local and national level. The CNS serves as a patient advocate, enhancing consumer access to primary health care services by delivering those services in the community. The current move towards health care reform in the United States mandates that the issues of better access, affordability, availability and, acceptability be addressed. Nurses in advanced practice have the knowledge and skills to be at the forefront of this reform.

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APPENDIX A

APPENDIX A
Community Service Attitude Inventory Items

CSAI Subscales

Concern for the opinion of others

- People outside my family would think less of me if I used services.
- My family would think less of me if I used services for my relatives care.
- My family prevents me from using services for my relative.
- Families should not use community services to care for a relative with Alzheimer's disease.
- I do not want others to know my relative has Alzheimer's disease.
- My family supports my use of community services.

Confidence in the service system

- People from community services can take care of my relative as well as I can.
- I am fearful of having people from community services take care of my relative.
- I trust people from community services to take care of my relative.
- People from community services would follow my directions in caring for my relative.
- It is hard to trust someone from community services to take care of my relative.
- People from community services might be better at caring for my relative.
- I worry about my safety when someone else is taking care of him/her.
- Community services might have better ideas about caring for my relative.

Preference for informal care

I would rather use community services than ask for help from my family.

I would rather use community services than ask for help from friends.

I would rather ask my family for help than use community services.

I would rather ask my friends for help than use community services.

Belief in caregiver independence

I am proud of being able to care for my relative with little help from community services.

I believe in the idea that families should care for their own and not ask for outside help.

I think I should care for my relative without help from community services.

I feel good about using community services to help care for my relative.

Acceptance of government services

It is not the government's responsibility to help me find ways to care for my relative.

I would use more services if the government would provide more assistance.

I believe the government should support more community services to help families care for persons at home.

APPENDIX B

APPENDIX B

U.C.R.I.H.S. Approval

MICHIGAN STATE UNIVERSITY

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

EAST LANSING • MICHIGAN • 48824-1046

October 30, 1992

TO: Janet Woods
1647 Forest Hills Dr.
Okemos, MI 48864

RE: IRB #: 92-511
TITLE: A COMPARISON OF THE DIFFERENCE IN THE ATTITUDES TOWARD
COMMUNITY SERVICE USE OF DEMENTIA CARE GIVERS LIVING IN RURAL
AND NON-RURAL AREAS
CATEGORY: 1-E
REVISION REQUESTED: N/A
APPROVAL DATE: October 21, 1992

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

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

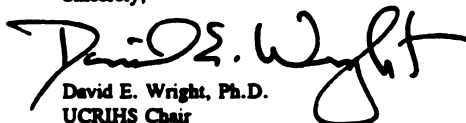
1. The human subjects protocol is the same as in previous studies.
2. There have been no ill effects suffered by the subjects due to their participation in the study.
3. There have been no complaints by the subjects or their representatives related to their participation in the study.
4. There has not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

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

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

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

Sincerely,


David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Dr. Clare Collins

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