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USEFULNESS OF HOME HEALTH AIDE SERVICES AS PERCEIVED
BY WIFE AND DAUGHTER CAREGIVERS OF RELATIVES WITH
DEMENTIA

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of the requirements for

MASTER OF SCIENCE degree in NURSING

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**USEFULNESS OF HOME HEALTH AIDE SERVICES AS
PERCEIVED BY WIFE AND DAUGHTER CAREGIVERS
OF RELATIVES WITH DEMENTIA**

By

Barbara J. Holtrop

A THESIS

**Submitted to
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ABSTRACT

USEFULNESS OF HOME HEALTH AIDE SERVICES AS PERCEIVED BY WIFE AND DAUGHTER CAREGIVERS OF RELATIVES WITH DEMENTIA

By

Barbara J. Holtrop

This study examined and compared the perception of the usefulness of home health aide services between wife and daughter caregivers of dementia patients using the services. It was a secondary analysis of data from the study of family caregivers of dementia patients conducted by the College of Nursing, Michigan State University, Clare Collins, R. N., Ph.D., Principal Investigator. The sample included 24 wives and 19 daughters and focused on responses to questions regarding importance and satisfaction with home health aide services. Unexpectedly, bivariate analysis found no significant differences between wives and daughters on either usefulness indicator. There was little variation in responses. Wife and daughter users perceived services to be both important to them and were highly satisfied. Implications of the findings for research and practice are presented.

To mother, whose whole life has been a model of caregiving.

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This paper would not have been possible without the help and encouragement of my professors, colleagues, and family. The information and advice from Clare Collins, principal investigator for the original study was much appreciated. The hours spent by Manfred Stommel and Diane Krasnewich helping me run data for analysis were not only helpful, but a good learning experience. The assistance of Betty Marshall in obtaining literature was also appreciated.

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TABLE OF CONTENTS

LIST OF TABLES.....	vii
LIST OF FIGURES.....	viii
THE PROBLEM.....	1
Background of the Problem.....	1
Statement of the Problem.....	4
REVIEW OF LITERATURE.....	4
Conceptual Definitions and Review of Empirical Evidence.....	4
Type of Relationship: Wives and Daughters.....	5
Perceived Usefulness of Home Health Aide Service.....	8
Conceptual and Methodological Problems.....	11
Conceptual Framework.....	13
Aday and Andersen Expanded Behavioral Model.....	14
Adaptation of Aday and Andersen Model to This Study.....	16
Present Study Relative to Literature Review.....	18
Relevance of This Study.....	19
METHODS.....	21
Sample Selection.....	21
Field and Data Collection Procedures.....	22
Protection of Human Subjects.....	23
Operational Definiton of Variables.....	23
Instrumentation and Scoring.....	24
Research Design and Analysis.....	25
RESULTS.....	27
Sample and Background Material.....	27
Overall Sample Characteristics.....	27
Comparison of Characteristics of Wife and Daughter Samples.....	28
Preliminary Evaluation of Usefulness and Possible Confounders.....	31
Correlation between indicators of usefulness	31

Correlation of Usefulness Indicators with Possible Confounders.....	32
Comparison of Usefulness Between Wives and Daughters.....	32
DISCUSSION.....	34
Interpretation Relative to Framework and Literature.....	34
Limitations and Methodological Problems.....	36
Implications.....	40
Recommendations for Future Research.....	40
Implications for Nursing Practice.....	41
APPENDICES.....	44
Appendix A: Health Service Utilization Questionnaire.....	44
Appendix B: UCRIHS Approval.....	45
LIST OF REFERENCES.....	46

LIST OF TABLES

Table 1 - Demographic Variables for Wives and Daughters	29
Table 2 - Analysis of Dependent Variables.....	33

LIST OF FIGURES

Figure 1 - Association Between Relationship Type and Caregiver Perception of Usefulness of Service.....	17
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The Problem

Background of the Problem

A major problem facing those who make health care decisions in America, due the growing number of elderly citizens, is how best to help the large number of dementia patients and their family caregivers. One of the "most debilitating of illnesses (of old age) is Alzheimer's Disease (AD), which affects memory, cognition, and behavior" (Ganzer & England, 1994 p. 175). AD, the leading cause of dementia, is a progressive degenerative disease leading to severe mental and physical incapacitation and death. The prevalence of severe dementia increases with age, "from less than 1 percent of the population under the age of 65 ... to 25 percent of those over the age of 85" (U. S. Congress, Office of Technology Assessment, 1990, p. 11). It is estimated that the number of severe dementia patients, those who need someone to care for them continually, is approximately 1.8 million, and that there are up to five million more with mild or moderate dementia (U. S. Congress, OTA, 1990).

Families assume primary responsibility for the care of their members who are chronically ill or disabled. (Montgomery, Gonyea, & Hooyman, 1985). Estimates of numbers of all caregivers range from 2.2 million (Stone, Cafferata, & Sangl, 1987) to 7 million

(Fletcher & Winslow, 1991), over 70 % of whom are women, with one third over the age of 65 (Stone et al., 1987).

While many female caregivers are wives, it is now a normative experience for daughters to be the caregiver to an elderly parent, with the caregiving period spanning "several of the caregiver's age periods or stages" (Brody, 1985, p 22). Caregiving encompasses a wide variety of tasks (Clark & Rakowski, 1983; Montgomery et al., 1985), which for many wives and daughters leads to physical and mental strain or "burden" (Cantor, 1983; Lieberman & Fisher, 1985; Montgomery et al., 1985; and Sheehan & Nuttall, 1988).

For caregivers of progressive dementia patients, the effects are especially far-reaching, since the course of the disease "varies from two to twenty years and there is no cure" (Ganzer & England, 1994, p. 174). The tasks of caring for and supervising a dementia patient increase as the disease progresses, and can become so unrelenting that many overwhelmed caregivers place the dementia patient in long term care facilities (Collins, King, & Kokinakis, 1994; U.S. Congress, OTA, 1987; 1990).

There are wide variations in the self-care deficits and cognitive and behavioral problems associated with dementia, depending on the type and stage of progression of the disease, so a variety of services may be needed by dementia patients and caregivers over the course of the disease (Fortinsky & Hathaway, 1990; U. S. Congress, OTA, 1990). A home health aide who can give a portion of the physical

care, help with household tasks, or aid in supervision of the relative could provide some relief to the dementia caregiver.

In spite of these possible benefits, actual use of services of any kind by family caregivers of dementia patients is low and occurs quite late in the caregiving process (Caserta, Lund, Wright, & Redburn, 1987; Stone et al., 1987; U. S. Congress, OTA, 1990). The reasons for this are complex and not fully understood. Some areas that have been previously studied and appear to provide some explanation are "related to the health and behavioral status of the patient, the services available in the community, and the knowledge and appraisals of the caregiver" (Collins, King, Given, & Given, 1994, p. 327). Collins, King, & Given, et al., (1994) urge further study of which services caregivers regard as helpful. It may be that caregivers do not perceive the services to be useful enough to truly benefit them.

The Advanced Practice Nurse (APN) who cares for the dementia patient is frequently in a position to counsel both patients and their caregivers, most of whom are wives or daughters. While it is the patient who initially receives the "care", as the disease progresses, the caregiver increasingly needs advice and support from the APN. The APN needs to understand caregivers' perceptions of the usefulness of services, such as a home health aide, so she/he can work with the caregiver to plan strategies that will help the caregiver better cope with the stress of caring for a relative with dementia. How helpful, and thus how important, do wife and daughter caregivers

consider home health aid services? How satisfied are they with such services? Is there a difference in perception between wives and daughters? If the APN understood these caregiver perceptions better, he/she would then be better equipped to counsel wife or daughter caregivers regarding service options. This would also help in development of care plans, including plans for referrals for the individual dementia patients and caregivers that the APN serves.

Statement of the Problem

The purpose of this study was to investigate whether the perceptions of the usefulness of home health aide services differ between wife and daughter caregivers of dementia patients who were using those services. The specific question asked in this study was: Among current users of home health aide services for assistance in care of dementia patients, is there a difference between wife and daughter caregivers in their perception of the usefulness of the services?

Review of Literature

Conceptual Definitions and Review of Empirical Evidence

In recent years a vast amount of research has been done that describes and seeks to find relationships among various aspects of caregiving for dementia patients. The focus of this review will be on what is known about a specific type of relationship to the dementia caregiver, that of wife or daughter caregiver, and whether there have been differences noted in these caregivers' perception of the usefulness

of the home health aide services they use. Specific aspects of the perception of usefulness examined will be that of the importance of the above service in helping them with the care of their family member and their satisfaction with the service.

Type of relationship: Wives and daughters.

A person's kinship bond, or family relationship type, such as wife to husband or daughter to mother or father, may lead to differences in one's perception of many experiences in life. The experience of caregiving that leads to the caregiver's perception of the usefulness of a service may also differ for wives and for daughters. Both gender and relationship have been shown to impact a person's responses to caregiving (Toseland & Rossiter 1989). Most caregivers are female, but studies that compare wives to daughters as caregivers are rare. Spouses and adult children are frequently compared, instead of separating out wives and daughters, blurring the effects of gender and relationship.

Two researchers who did specifically examine wives versus daughters, reported that different patient symptoms or behaviors led to differences in the amount or type of strain experienced by wives or daughters (Harper & Lund, 1990; Quayhagen & Quayhagen, 1988). They did not, however, examine perceptions of wives and daughters regarding the usefulness of services. Some factors that make the experience of caregiving different for wives compared to daughters are discussed below. These may contribute to differences in how

each perceives the usefulness of a service.

The extent of the impact of caregiving has been shown to be associated with the closeness of the kinship bond: the spouse closest, then the adult child (Cantor, 1983). Due to the marital bond, spouses have different "feelings of affection and obligation toward one another than do adult children for parents" (Zarit & Toseland 1989 p. 482; see also Montgomery, Kosloski, & Borgatta, 1990; Toseland & Rossiter, 1989). The spouse's caregiving is often "done out of love and personal commitment ... (and spouses) expressed more of a sense of positive reaction" (Given, King, Collins, & Given, 1988, p. 286) than did children.

When a daughter serves as a caregiver to her parent, her filial relationship brings with it several differences that can possibly be perceived as problems for her. She takes on new roles, which bring with it relationship changes. There is a "shift in intimacy" (Green, 1991, p. 7) resulting from the increase in involvement in the parent's daily life, with tasks like feeding or personal hygiene. Coupled with this, is the "shift in dependency" (Green, 1991, p. 8) that results when the daughter takes on positions of power and leadership that formerly belonged to the parent, thus "parenting (her) own parent" (p. 8).

A wife has generally been involved in the day to day "care" of her husband and home for many years. So although she now adds additional caregiving tasks for her husband with dementia, there may

not be as great a change in the role for her as for the daughter caregiver (Brody, Johnsen, Fulcomer, & Lang 1983). The daughter is usually in midlife, the "woman in the middle" (Brody, 1981, p. 471) and may find the experience filled with competing demands from husband, children under 18, and employment, in addition to the demands of caregiving for her parent (Bowers & Liegel, 1990; Brody, 1985).

Wife caregivers not only have "fewer defined roles to perform" (Given, Collins, & Given, 1988, p. 72), but tend to be more isolated than the daughter. This is due to "role regression and role entrenchment" (Johnson and Catalano, 1983, p. 617), by which wives give up social and family roles and focus on the caregiving role. The wife is also more likely to prefer not to have a "stranger" in the house (Caserta, et al., 1987; U. S. Congress, OTA, 1990). This may be a privacy issue that could be more important to a wife than a daughter. She may also prefer to continue giving "exclusive care" (Collins, King, Given, et al., 1994, p.321) for a longer period of time than a daughter.

These factors, which make the experience of caregiving different for wives from that of daughters led to the hypothesis that daughter caregivers would report that they found the home health aide services they used to be more useful than wife caregivers. The assumption here is that perceptions of usefulness formed during use of the service may have parallels to that of seeking out and starting the service. Therefore, the factors described above that have been

associated with possible effects on use may also influence perception of usefulness. The independent variable in this study was the relationship type (wife or daughter) of the primary caregiver to the dementia patient who reported using the home health aide service during the three months prior to data collection.

Perceived usefulness of home health aide service.

To be useful is defined as "to be able to produce good results, or be used for some practical or beneficial purpose" (Ehrlich, Flexner, Carruth, & Hawkins, 1980, p. 764). In other words, is it of practical worth, really helping with a need? Is it beneficial and of good quality or value? In this study, usefulness, the dependent variable, was measured in terms of the perceived importance of and satisfaction with use of the home health aide services. This was based on the assumption that to be useful, something should be of importance and, having led to good results, produce a satisfied user.

Importance is "having or able to have a great effect or influence on something" (Ehrlich et al., 1980, p. 329). Thus, if a service is perceived by the caregiver to have importance, it is seen to be something that has a great effect, or is helpful or of value to them in the caregiving situation. In this study, importance was linked with the idea of value and helpfulness, when the specific question was asked of the caregiver: "How important is this service in helping you care for your relative?"

Satisfaction means to give someone "what he wants or demands

or needs, to make pleased or contented... to consider that this is enough" (Ehrlich et al, 1980, p. 601). Inherent in the idea of satisfaction is one's perception of whether or not the service met one's expectations or needs. Did the quality of the home health aid service make one pleased, was it good enough? That is the sense in which satisfaction was defined for this study, when the caregiver was asked: "Overall, how satisfied are you with the service?".

Use of various services has been studied frequently, but usefulness infrequently. No studies could be found which evaluated the usefulness of home health aide services for wife and daughter caregivers.

A home health aide is someone who is paid to provide in-home health related services, supervision, or companionship. The person is usually not a nurse and is not necessarily hired through an agency. Examples of care provided are: bathing, dressing, feeding, exercising, household chores, shopping, socializing, and supervising (U. S. Congress, OTA, 1990). A home health aide may also be identified as an adult companion or "sitter", but for the purpose of this study the service provider will be referred to as a home health aide.

There is little in the literature regarding the use of home health aide services, specifically. Collins, Stommel, Given, & King (1991) reported that although over one third of a sample of 93 caregivers of dementia patients used home health aide services, the

frequency of use varied widely. Although use of home health aides was evaluated in an attempt to predict use patterns by Bass & Noelker (1987), these researchers did not address perceptions of the caregivers related to the usefulness of the service.

Something of the possible usefulness of home health aide services can be gleaned from studies that list which services caregivers reported to be important to them, although no indication is given of whether comparisons were made between wife and daughter caregivers. Family caregivers report services that give temporary relief from caregiving responsibilities to be the most important to them (Caserta et al., 1987; Collins, King, Given, et al., 1994; U. S. Congress, OTA, 1990). There is also an indication that the importance of a service may also depend on the patient's stage of dementia. Fortinsky & Hathaway (1990), reported that family caregivers stated that their most important needs when AD was first diagnosed, were for information and support, but as the patient became more dependent, direct support, such as in-home care and practical information on behavior management were most important. As reported to Wilson (1989) in a qualitative study, most useful at that stage was help in "changing pants and cleaning the floor" (p.97). Attending to the daily care and supervision to protect the patient from injury are important caregiver activities, and have been found to be confining and burdensome (Montgomery, Gonyea, & Hooyman, 1985), so it might be assumed that the use of a home health aid would be

considered useful by the caregiver.

Whether the service brings good results is also a part of its usefulness, and relates to the quality of the service and user satisfaction with the service. No studies regarding satisfaction with use of home health aide service were found in the literature. However, Liken & King (1995) discussed barriers to their use, which seems to indicate a lack of satisfaction on the part of some who had used services. Concerns expressed by users were the high financial and psychological costs involved with arranging for the care, then finding the service often "did not meet with their expectations" (p.63), lack of knowledge about dementia care by the aide, and incongruence between the caregiver's needs and the amount and type of help received. The perception of non-importance or dissatisfaction with a service is cited as a barrier to the use or continuation of a service (U. S. Congress, OTA, 1990). Other problems related to the quality of services that reportedly have led some caregivers to complain about and sometimes quit a service are: Poorly trained or late workers, inflexibility of scheduling the care, lack of continuity, and theft (U. S. congress, OTA, 1990). Such problems could be expected to affect one's satisfaction with use of the service, thus it's perceived usefulness.

Conceptual and Methodological Problems

Numerous caregiver and patient characteristics have been studied to find out their effects on caregivers and predictors of caregivers' use of services. Some characteristics that have been

shown to explain a portion of the effects on caregivers and their use of services are: caregiver employment, co-residence with the care recipient, care recipient and caregiver gender, severity of patient behaviors or dependencies, particularly such intimate problems as incontinence (Caserta, et al., 1987; George & Gwyther, 1986; Harper & Lund, 1990; Lieberman & Fisher, 1995; Montgomery et al., 1990). It is not known, however, whether these may affect either the wife or daughter caregiver's perception of the usefulness of the service.

Studies of service use and knowledge are often plagued by two shortcomings: They tend to treat caregivers as a homogeneous group, regardless of patient and caregiver characteristics (Cantor, 1983; Harper & Lund, 1990; Wolinsky & Arnold, 1988), or they lump service use into one generic category whether the services are elderly meal sites, physician or nurse visits, case management services, a variety of home health care or respite services, or group educational and support interventions (Caserta, et al., 1987; Collins, Stommel, Given, & King, 1991; Kushman & Freeman, 1986; see also reviews by Krout, 1983; and McCaslin, 1988; Wolinsky & Arnold, 1988). As a result, findings concerning which factors contribute to service use are often inconsistent.

In addition, some intervention studies are made up of a combination of different interventions and services, not just one intervention (Green & Monahan, 1989; Haley, 1989; Lawton, Brody, & Sapperstein, 1989; Mohide, et al., 1990; & Montgomery &

Borgatta, 1989) and there are often differences in study methods, so it is difficult to compare them with one another (Collins, Stommel, Given, & King, 1991). It is also difficult to know just which of the interventions or services made the differences found in the study. It would be expected that the type of service used may make a difference in the caregiver's perception of the usefulness of the service.

The above problems make it hard to evaluate services or interventions across studies to make valid comparisons. Also, few studies evaluate the quality of specific services or interventions to support family caregivers of dementia patients and obtain judgments from the perspective of the caregiver. (Collins, Given, & Given, 1994). Perhaps what is needed in future studies are those that compare smaller homogeneous groups of caregivers, such as wives versus daughters, that also use less "all- inclusive" categories of services or interventions.

Conceptual Framework

Since there are multiple factors that affect a person's use and perception of the usefulness of health care services, a comprehensive conceptual model to guide policy makers, service providers, and researchers is important. One of the earliest models was Andersen's 1968 "Behavioral Model for Health Services Utilization" (Aday & Shortell, 1988, p.53), which was based on systems theory and attempts to show the relationship between the factors affecting

service use. It also has a component that relates to the consumer satisfaction with the service. The model was expanded by Aday & Andersen (1974) and modified further by others, such as Bass & Noelker (1987), who included caregivers, as well as added in-home nursing and aide services to the medical services which had been originally part of the framework. Andersen's model, some modification of it, or portions of it continue to be used by researchers as they examine various aspects of service use. A portion of the 1974 version of the model was adapted for use in this study to examine the perceived usefulness of the home health aide service used by wife and daughter caregivers to the dementia patient.

Aday and Andersen expanded behavioral model.

The Aday & Andersen model (Aday & Andersen, 1974) presents a framework from which to view the interactions among the variables affecting service use. It begins with the health policy component (financing and organization), which sets the scene for the types of programs and services that will be available to the consumers. The framework shows that policy has direct effects on two other components, characteristics of the health delivery system and characteristics of the population at risk.

Characteristics of the health delivery system include availability of health care resources and the organization of those resources. The health care system has a direct effect on three other components:

a) Characteristics of the population at risk, b) utilization of health

services, and c) consumer satisfaction.

The characteristics of the population are subdivided into three groups of characteristics: a) Predisposing, b) enabling, and c) need. These characteristics have direct effects on both utilization of health services and consumer satisfaction. Both predisposing ("propensity... to use services" p. 213) and enabling characteristics ("means ...to use services" p. 213) are further divided into those that are mutable and immutable. Predisposing characteristics are such items as beliefs, knowledge, attitudes, age, sex, race, education, and employment status. Enabling characteristics are such things as income and residence. Need characteristics relate to level of illness.

In evaluating the population at risk, the unit of analysis is the individual who may need the service. The characteristics of the delivery system and of the population at risk are considered to be process indicators.

The utilization of health services can be evaluated relative to type of service, site, purpose, and time (contact or volume of use). Utilization is shown in the framework to have a direct effect on consumer satisfaction.

Consumer satisfaction refers to the attitudes or subjective perceptions of the user toward the service used regarding the quality of care received. Satisfaction or lack of satisfaction can have a direct effect on future service utilization, and thus is used as a predictor of service use. Consumer satisfaction and utilization of services are also

both considered to be outcome indicators by the authors (Aday & Andersen, 1974).

Adaptation of Aday and Andersen Model to this study.

The focus of this study was to describe and contrast the perception of usefulness that wife or daughter primary caregivers of dementia patients reported regarding their use of home health aide services. Therefore, the following modifications were made in the framework: a) The consumer was the caregiver rather than the patient; b) The predisposing characteristic studied was the relationship type of the caregiver to patient (wife or daughter); c) The consumer satisfaction component was relabeled "Caregiver Perception of Usefulness"; d) Perceived importance of the service was added to the perceived satisfaction to depict more completely the "perceived usefulness" concept (see figure 1).

The analysis of the usefulness of the service addresses the question of whether the type of relationship of the caregiver to the patient (wife or daughter) makes a difference in perceived usefulness of the service. The hypothesis was that the daughters would perceive the service to be more useful.

All caregivers in the selected study sample were using services, so predictors of service use was not a focus of this study. The predisposing characteristic (wife or daughter relationship) was the focus and the selected caregiver socio-demographic and background characteristics that described the sample reflect predisposing and

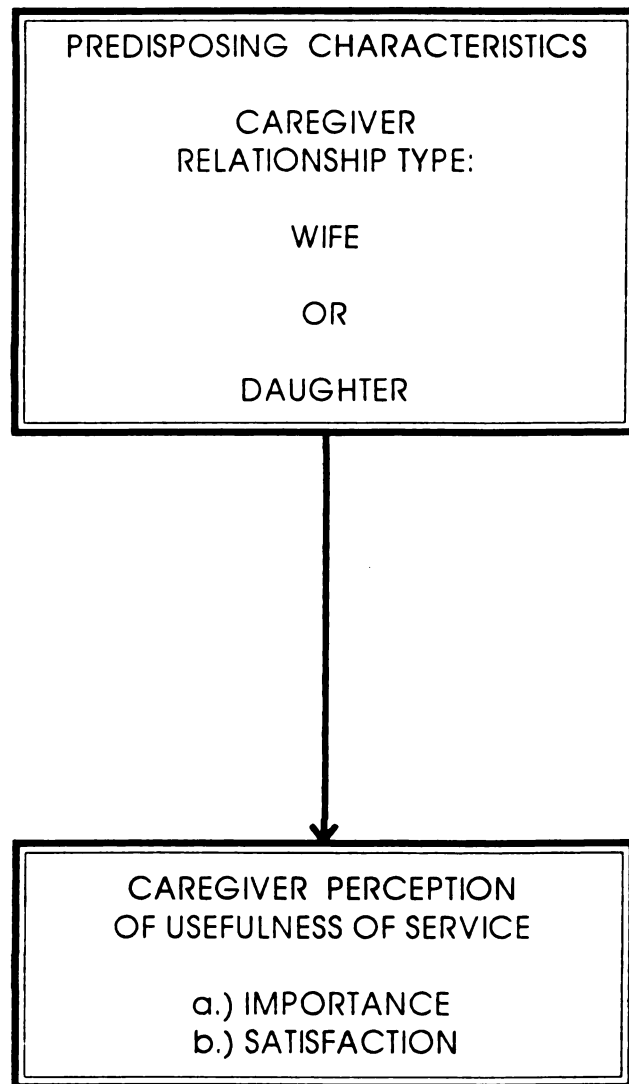


FIGURE 1-- Association between Relationship Type and Caregiver Perception of Usefulness of Service. Adapted from Aday & Andersen, 1974, Health Service Research, p. 212.

enabling characteristics. These were treated as descriptive in this study, however some were further analyzed to identify possible confounding influences.

Present Study Relative to Literature Review

The purpose of this study was to describe and contrast the usefulness of home health aide service as perceived by wife and daughter caregivers of dementia patients currently using the service. Levels of importance and satisfaction were used to measure the usefulness of the service and analyzed.

From the above review of the literature, other characteristics were found that needed to be described and evaluated as possible confounding variables or rival hypotheses. For example, such variables as employment or a higher number of the patient's ADL dependencies may increase one's perception of the usefulness of the service; or co-residence, a fixed income, or the long standing patterns of an older caregiver may decrease the perception of its usefulness. Therefore, the sample was described and compared in terms of selected sociodemographic characteristics for each group, such as: Age, income, education, employment status, caregiver health, co-residence with the care recipient, length of time giving care, and relationship of the patient to the caregiver (e.g. mother, father, husband). Additional background data that could confound the perceived usefulness of the service, such as the amount of use (frequency and duration) and patient dependencies were also described and compared.

To promote homogeneity in the sample, it was limited to caregivers of dementia patients, thus using care recipients with the same type of disease process. Use of wife and daughter caregivers addressed the issue of the type of relationship to the recipient and avoided gender bias since the caregivers were all female. This also adds to our understanding of these subgroups of caregivers, since few studies have compared wives and daughters.

Home health aide services are considered important to the care of the dementia patient, according to the literature, but they have been infrequently studied separately from other services, such as support groups or respite services. This study was limited to an evaluation relative to the use of these services. Caregivers were only included in the study if they reported using the services within the three months prior to the interview, to avoid the effect of remote memory.

Relevance of This Study

Government agencies, home health service providers, nurses, caregivers, and patients all have an interest in the quality and helpfulness of services. It is important for all, especially for those receiving the service, that the service really be of help or benefit to the one it is meant to serve. Too often the voice of the recipient of the service is hidden or ignored. A service useful to one person may not be of use to another. The APN often functions as a link between patients, caregivers, service providers, and planners at the government level. How

these caregivers perceive this most common of services to the dementia patient needs to be communicated to service providers and government planners. Does the wife or daughter relationship of the caregiver to the dementia patient make a difference to the perception of the caregiver regarding the usefulness of home health aide services? This information, although only a "piece of the puzzle" can be added to that from other sources and used in planning for improved quality and helpfulness of services. It can also be used by home health agencies in planning marketing strategy geared towards wife and daughter caregivers.

The most relevant aspect for the APN's own practice, is the usefulness of understanding the wife - daughter perceptions as the APN develops the care plan for the dementia patient and caregiver and as she/he counsels the patient and caregiver. Most of the caregivers the APN will see will be wives or daughters. They will be seeking advice from the APN, who will be assessing their needs and working with them in mutual goal setting and planning for care from a variety of service options. Understanding what, if any, differences there are between wife and daughter perceptions of the usefulness of a service can be helpful both in making planning decisions, and in strategies for the APN to use in encouraging a needy but reluctant caregiver to take advantage of a service that may be helpful to her, based on what other's experiences have been shown to be. The APN may also provide information relating to service use that increases caregiver awareness that use of the service

is "normal" and expected, not a sign that the caregiver is deficient in performing the role. Results of this study can also be used as a basis for further exploration of caregiver attitudes and values in qualitative studies of caregiver perceptions, particularly regarding the "Why" of the caregiver perceptions.

Methods

This study represents a secondary analysis of data from the second wave of a three-wave longitudinal study of family caregivers of relatives with dementia residing in the community (Collins, Stommel, King, Given, 1991). The study was supported by Grant #2 R01-MH-41766, "The impact of Alzheimer's Disease on Family Caregivers", funded by the U.S. Department of Health and Human Services, National Institutes of Mental Health. Principal Investigator was Clare Collins, R.N., PhD. The study was conducted at the College of Nursing at Michigan State University from 1989 - 1993. The grant objective that relates specifically to this study was to describe dementia patient family caregivers' patterns of community service use, including needs for and barriers to use (Collins, 1994, Executive summary).

Sample Selection

The target population for the original study was family caregivers of dementia patients residing in the community. The 210 subjects (Collins, personal communication by phone, January 16, 1996) were a convenience sample of family caregivers "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" (Collins, Stommel, & King, et al., 1991, p. 757). A cover letter that explained the study was included with the mailings. 350 subjects mailed back a post card to be considered for enrollment in the study.

To qualify to be a part of the study, the following criteria were met: The patient was at least 55 years of age, dependent in at least one instrumental activity of daily living (IADL) and one activity of daily living (ADL), diagnosed with Alzheimer's Disease (AD) or other progressive dementia, and residing in the community. The caregiver was the family member providing the most care to the dementia patient.

Criteria for inclusion as sample subjects for this secondary analysis were that the participant must be the self-acknowledged wife or daughter primary caregiver of a dementia patient who had used the services of a home health aide within the three months prior to the survey.

Field and Data Collection Procedures

The method of collecting information used in this analysis was an extensive 90 minute telephone interview, using the "Health Service Utilization" questionnaire (See Appendix A). Trained staff was used for telephone interviews as described in Collins, Given, Given, & King (1988). Information was gathered on four types of services,

home health aides, adult day care, skilled nursing services, and family support groups. Further information needed for the initial study was gathered by use of a mailed, self-administered booklet. Data gathered in this analysis was from the second data collection point of this study.

Subjects in the original study were asked whether they had ever used any of the services for their relative, if they had used the service in the past three months, and how long and how many times they used the service. Study participants were also asked a number of other questions about their use. Specific questions that were the focus of this secondary analysis relate only to the use of home health aide services.

Protection of Human Subjects

Explanation of the voluntary nature of the study, its confidentiality, and study procedures was given to the study participants and signed informed consent was obtained prior to data collection. Prior approval for the original study was obtained from the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University. Additional permission for secondary data analysis of the identified sample was received by this researcher prior to data analysis (See Appendix B).

Operational Definition of Variables

The dependent variable studied in this secondary analysis was the perception of the usefulness of the home health aide currently

used. The variable was operationalized by the questions: "How important is this service in helping you care for your relative?" and "Overall, how satisfied are you with the service?" (Michigan State University, 1990). The independent variable was the type of relationship of the caregiver to the patient (wife or daughter).

Instrumentation and Scoring

The "Health Service Utilization questionnaire" (Michigan State University, 1990) contains a number of one item measures. It is a structured instrument.

Pre-testing of the instrument was not done with caregivers for reliability. However it was pre-tested for clarity, adequacy, and freedom from bias among the researchers and their staff and later among the interviewers. This led to several revisions in the questions used. One problem with clarity, that of confusion on the part of caregivers about the difference between home health aides and companions in a prior study, led to the use of the combined grouping for this service (M. Stommel, personal communication by phone, Nov 29, 1995). To improve inter-rater reliability of the study, the interviewers were extensively trained and supervised in the use of the instrument (Collins, Given, Given, & King, 1988).

The level of measurement of the questions regarding satisfaction and importance of the services are ordinal measures with graded alternatives as responses. However, consistent with current practice, they were treated as interval measures in this study, since

"the distortion introduced by treating them as interval measures is too small to warrant an abandonment of powerful statistical analysis" (Polit & Hungler, 1991, p. 398). The "How important" question has three alternatives, and the "how satisfied" question has four alternatives. The numerical responses of the subjects were scored and the mean and standard deviation for each of the two sample groups were summarized for comparison.

Research Design and Analysis

The original study upon which this analysis was based was a non-experimental survey panel study. This study was a secondary analysis of the data as follows.

Descriptive statistics were used to analyze and compare selected caregiver characteristics of the wife and daughter subsamples to look for any systematic differences between the two groups, based on the reports in the literature. The number and percent were given for categorical data and non- categorical characteristics were summarized using mean and standard deviation (SD). T-test or Chi-square tests of significance were utilized as indicated in order to establish whether wives and daughters differed, on average, with respect to background characteristics that may also have been potential confounders.

Prior to the comparison of wives and daughters with respect to their responses to the two questions about their perception of usefulness of the home health aide, the responses for importance and

satisfaction were correlated using the Pearson Product Moment Correlation procedure. The purpose was to determine if responses to these two questions indicated similar or distinct dimensions of usefulness. A correlation of 0.6 or greater was considered to be necessary to justify combining the two indicators into a single index of usefulness.

In a final preliminary step, scores on the usefulness variable were correlated with the potential confounder variables. Only if a background variable correlated both with the usefulness variable and with the relationship variable (wives or daughters) would it be considered a confounder to the question studied.

Finally, mean differences between wives and daughters on the usefulness scores were explored by means of a two-tailed t-test for independent samples as well as by a Chi-square test. The alpha level used for all significance tests used was $p = .05$. The unit of analysis was the individual caregiver. Data were analyzed using the SPSS statistical program.

The primary goal of this analysis was to obtain a better understanding of whether the wife or daughter relationship between caregiver and patient made a difference in the caregivers' perception of usefulness of home health aide services. This study did not attempt to show causality nor to predict length or intensity of service use.

Results

Sample and Background Material

Overall sample characteristics.

The primary caregivers in this sample (n=43) were the wives (n=24) and daughters (n=19) of dementia patients residing in the community who had used the services of a home health aide within the three months prior to the survey. They were a subset of the 121 wife (n=84) and daughter (n=36) caregivers who responded to the survey. Thus, 28.6 percent of wives and 52.8 percent of daughters used the services in the prior 3 months. It appears that the daughter caregivers in this study were nearly twice as likely as wives to make use of the service! The caregivers in the study sample (n=43) were, on average, 60.8 years old ranging in age from 39 to 83 years. Mean household income was \$33,081, with a range from \$9,000 to \$65,000. Most (81%, n=35) had incomes \$17,000 and above. This sample was highly educated, since a majority (79%, n=34) had graduated from high school. Eighty-six percent (n=37) of the caregivers lived with the patient and 37 percent (n=16) were employed. The mean length of time of caregiving was 4.7 years (range: 6 months to 12 years), with a mean of 1.9 years (range: < 1 month to 9 years) for duration of use of home health aide services. Mean number of times that the aide service was used during the period was 42.4 (SD 36.1, range: 1 - 132). An interesting fact noted in this sample, which is quite different from those others who have been reported in the literature, is the high

number of times the service was used by these caregivers. Only 6 of the 43 caregivers used the services less than 1 time per week, 15 used services 3 times per week, but less than 4 times per week, 7 caregivers used the services 4-5 times per week, and 11 used the services, on average, at least 1 time per day. Figures relative to skewness of the sample in this regard are not remarkable (.603). In contrast to this, the skewness for importance rating and satisfaction with the service for the sample as a whole was 2.5 for Importance (mean 1.1, SD .324) and 1.7 for Satisfaction (mean 1.4, SD .667).

Comparison of characteristics of wife and daughter samples.

Table 1 presents the sociodemographic and background characteristics of the wife and daughter caregivers who indicated use of home health aides within three months. T-tests for differences in group means (Table 1) showed that the wife and daughter groups differed significantly in respect to age ($p=.000$), education ($p=.010$), and income ($p=.023$). Chi-square tests for differences in group proportions (Table 1) revealed significant differences between groups in living arrangements ($p=.003$), employment status ($p=.006$), and patient sex ($p=.000$). As is also shown in Table 1, the 24 wives cared for husbands, 17 of the daughters were caregivers to their mothers, and only two cared for their fathers. Not unexpectedly, daughters were younger (mean age 51.3 years versus 68.2 years) and had more education (mean 14.7 years versus 11.8 years) and higher income

Table 1. Demographic Variables for Wives and Daughters

<u>Characteristic</u>	<u>Wives</u> (n=24)	<u>Daughters</u> (n=19)	<u>Sig Level*</u>
Age (yrs.)			.000 ^c
Mean	68.2	51.3	
SD	8.2	7.3	
Education (yrs.)			.010 ^c
Mean	11.8	14.7	
SD	3.9	3.0	
Income			.023 ^c
Mean	\$27313	\$40368	
SD	\$12209	\$21014	
Caregiver health ^a			.908 ^c
Mean	1.9	1.8	
SD	0.8	0.8	
Patient Dependency ^b			.106 ^c
Mean	3.1	2.6	
SD	1.0	1.1	
Duration of care (yrs.)			.199 ^c
Mean	5.3	4.0	
SD	3.4	2.8	
Months service used			.629 ^c
Mean	2.0	1.7	
SD	2.3	1.2	
Times service used			.161 ^c
Mean	35.2	51.0	
SD	33.5	38.1	
Living arrangement			.003 ^d
Lives with	100% (24)	68% (13)	
Does not live with		32% (6)	
Employment			.006 ^d
Full Time	8% (2)	42% (8)	
Part Time	8% (2)	21% (4)	
Not Employed	83% (20)	37% (37)	
Pt. relationship to caregiver			.000 ^d
Husband	100% (24)		
Father		11% (2)	
Mother		90% (17)	

(table continues)

Table 1. (cont'd.)

Note. Values for all t-tests except income were figured as equal variances based on Levene's test.

^a self-rating of health compared to age peers (Range: 1 = excellent to 4 = poor).

^b average of ADL dependencies in : bathing, dressing, toileting, eating, grooming, walking (1 = Independent, 2 = supervision only, 3 = some physical health, 4 = total help).

^c t-test results. ^d Chi-square test results.

*p < .05

(\$40,368 versus \$27313) than wives. Daughters (63%) were more likely to be employed than wives (16%) and 32 % of daughters resided in separate households. There was not a significant difference between groups with respect to self-rated caregiver health, duration of care, duration of use of home health aide service, the number of times the service was used, or patient ADL dependencies. Although patients of wives and daughters did not differ greatly in their dependencies overall, they had a high percentage of dependencies of a more intimate nature, such as bathing (total help n=28 or 65%), dressing (total help n=21 or 49%), and toileting (total help n=21 or 49%), indicating a fairly high need for home health aide services.

In summary, the wife and daughter samples are composed mainly of middle-class, middle-aged daughters and elderly wives with at least a high school education, who have been taking care of their relative for 4-5 years. The majority live with the patient and consider their health to be good compared with others their age. Most wives are unemployed and most of the daughters are employed. Groups seem to be alike with

respect to variables such as duration of care, patient dependencies, caregiver health, and the duration and number of times that the service was used. Characteristics that showed a significant difference between wife and daughter groups and could possibly be confounders in evaluation of the study question were: age, income, education, living arrangement, employment status, and relationship to the patient (husband, father, or mother). These were evaluated further by means of correlation procedures and will be discussed later.

Preliminary Evaluation of Usefulness and Possible Confounders

Correlation between indicators of usefulness.

A correlation was computed for the entire sample ($n=43$) between the two questions regarding importance of the service and caregiver satisfaction, both of which were considered indicators of overall usefulness of the service. Correlation was found to be very low and non-significant: $r=.08$, $p=.58$. This finding seems to indicate that the questions represent distinct aspects of usefulness, thus the two questions were retained for separate analysis. However, as the data in Table 2 show, there is little variation in the responses to these two questions, so it would not be unexpected to find little or no linear correlation.

The response pattern shows a bunching of the responses in the first 2 options for each question, with 88.4 % ($n=38$) stating that the service was very important in helping them care for their relative and 62.8 % ($n=27$) stating that they were very satisfied with the service.

Crosstabulation shows that 25 of the respondents (58%) were both very satisfied and rated the service to be very important, while 11 respondents (26%) were both satisfied and rated the service to be very important.

Correlation of usefulness indicators with possible confounders.

As a final preliminary evaluation, the responses to the questions on Importance and Satisfaction with the service were correlated with variables that had previously been shown to differ significantly between wife and daughter caregiver groups. These variables were: age, education, income, living arrangement, employment status, patient sex and relationship of caregiver to the patient (husband, father, mother). None of these showed a significant relationship to either importance or satisfaction, so they will not be considered as confounders in the evaluation of the hypothesis.

Comparison of Usefulness Between Wives and Daughters

When wives and daughters were compared on the question of the importance of the home health aide service in helping them care for their relative, 92% (n=22) of the wives and 84% (n=16) of the daughters stated that the service was very important and the rest stated it was somewhat important (see Table 2). There was not a significant difference between the groups by either a Chi-square or t- test for significance (Again, the lack of variation in responses is a major reason for this).

Table 2. Analysis of Dependent Variables

<u>Chi-Square evaluation for differences in group proportions</u>									
<u>Variable</u>		<u>Wife</u>		<u>Daughter</u>		<u>Phi</u>	<u>Significance</u>		
		<u>%</u>	<u>n</u>	<u>%</u>	<u>n</u>				
Importance						.12	.45 NS		
Very	(1)	92	22	84	16				
Somewhat	(2)	8	2	16	3				
Satisfaction						.31	.25 NS		
Very	(1)	54	13	74	14				
Satisfied	(2)	42	10	21	4				
Dissat.	(3)	4	1		0				
Very dissat.	(4)		0	5	1				
<u>Independent T-test evaluation for differences in group means</u>									
		<u>Wife</u>			<u>Daughter</u>			<u>Equal variances</u>	
		<u>Mean</u>	<u>SD</u>	<u>SE</u>	<u>Mean</u>	<u>SD</u>	<u>SE</u>	<u>t-value</u>	<u>2-tailsig</u>
Importance		1.1	.28	.06	1.2	.38	.09	-.74	.46 NS
Satisfaction		1.5	.59	.12	1.4	.76	.21	.64	.53 NS

Comparison on the question of satisfaction with the services showed that 54% (n=13) of the wives and 74% (n=14) of the daughters were very satisfied. One wife (4%) was dissatisfied and one daughter (5%) was very dissatisfied. The rest of the wives and daughters were satisfied with the service. This difference was likewise not significant by either a Chi-square or t-test. Two-tailed t-tests were used for both comparisons, and equal variance estimates were used, based on results of Levene's test. The Chi-square results are displayed in Table 2 along with the t-test results to show how the pattern of the responses are bunched into the first 2 responses.

Both of these major findings were unexpected. It was hypothesized that the daughters would find the services to be more important than the wives and that they would be more satisfied with the service. No differences between the two groups were found.

Discussion

Interpretation Relative to Framework and Literature

The framework used for this analysis was an adaptation of the Aday and Andersen expanded behavioral model (1974). It was expected that daughters would perceive home health aide services to be more important than wives and would be more satisfied with the service. This hypothesis was not supported by the results of this study.

The Aday and Andersen model was primarily designed to study use, not usefulness, of services. Since the focus of this study was the

wife-daughter relationship and its possible relationship to caregiver perception of usefulness, only a portion of this comprehensive model was adapted for use in this study. One must be aware that other service use factors not evaluated as part of the study could have affected the perception of usefulness and obscured some difference between the wife and daughter relationship.

Wife and daughter caregivers had not previously been compared relative to the usefulness of the services of home health aides. Also the home health aide services have not been studied separately from other interventions and services in this way, particularly regarding whether the service was actually considered to be useful. Even though the two groups of caregivers were not shown to differ in this perception, the service was found to be considered useful by both groups of caregivers. The information gained from this study can be added to the large body of research already completed regarding caregivers of dementia patients.

Other researchers had noted various differences in the impact of caregiving on wives and daughters (Cantor, 1983; Harper & Lund, 1990; Montgomery, Gonyea, & Hooyman, 1985; Quayhagen & Quayhagen, 1988). Due to differences in competing demands and the number of roles that a daughter might have (Brody, 1981; Johnson & Catalano, 1983), it was expected that the wife and daughter groups might vary in their perception of usefulness of the service. In view of the large number (63%) of the daughters that were employed, that nearly

1/3 lived in separate households, and that the older wife was expected to be less likely to want a stranger in her home, it was surprising that there was no significant difference noted between wife and daughter groups in either usefulness indicator. These are some of the variables that are noted in the literature as possible influences on use, and but it appears that while they may indeed have some influence on wife and daughter caregiver use of home health aide service, they do not influence their perception of usefulness of the service. Factors that lead to beginning a service and those leading to a sense of the importance of or satisfaction with a service are not necessarily the same. It may be that there truly is no difference between wives and daughters in respect to perceived usefulness of the service of home health aides for their relative with dementia, but it could also be that some methodological problem may account for the findings.

Limitations and Methodological Problems

An important limitation of this study is that the sample was a convenience sample, not random, and the caregivers were self-selected. This limits the generalizability of the study.

This sample appears to vary from the "norm" reported in the literature in several ways: The length of service use; high number of times the service was used; and high level of education of subjects are notable. Although these differences were non-significant, it appears from the figures regarding duration of caregiving and length of service use, that wives provide care longer before bringing in help and use

services less often on average than daughters. It may be that there are other fundamental differences that were not revealed because they were not a focus of this study.

Another limitation of this study that could possibly explain the lack of any significant difference between the groups was the selection of only the wife and daughter caregivers who had used the service within the three months prior to the interview. This time frame was chosen to obtain current perceptions on the part of caregivers. Non-users were not included in this study sample, since it was the perception of usefulness of those who were actually using the service that was the focus of the study. This limited the study to 43 participants and probably accounts for the small variation in responses of the participants.

Although others have found that caregivers often continue services even when they are faced with many "hassels" that could lead to dissatisfaction (Likien & King, 1995), it is possible that some dissatisfied caregivers quit the service, leaving primarily satisfied caregivers. This could explain why 100% of the participants felt the service was either very important or somewhat important in helping them care for their relative and 95 % were either very satisfied or satisfied with the service. If the group had been expanded to include persons who had formerly used the services as well as current users more variation in responses may have been found and may have led to discovery of differences between wife and daughter caregivers on the

study question.

This lack of variation, skewed responses to the main dependent variable, and small sample size may also account for the low and nonsignificant correlation between the two indicators of usefulness (importance and satisfaction) and a similar finding when possible confounding variables were evaluated by correlation with these indicators of the usefulness variable. However, due to these factors, both t-tests and Chi-square tests were done on the main variables to test for significance.

The study instrument consisted of one-item measures and was not intended to be scales. In using these two questions as indicators of usefulness, they were treated as scales in this study, although as distinct aspects of usefulness, since there was no linear correlation found between them. Reliability of the instrument was not tested by doing repeated measures with caregivers themselves, or using techniques such as diaries. However, the questions were short, clearly worded, and a clear definition of what was meant by the service was given prior to asking about it, so the questions should have been easily understood by the respondent. This made it possible to consistently obtain from caregivers a measurement of the degree of satisfaction and importance of home health aide service as perceived by the wife and daughter caregivers. Since there were only three or four graded alternatives, the instrument was relatively easy to use for the 90 minute telephone interviews (C. Collins, personal

communication by phone, April 6, 1993).

However, responses from the questions from this instrument may be more complex to evaluate for several reasons. Is the caregiver responding to the importance and satisfaction question based only on the most recent experience with their home health aide or is the response influenced by the overall experience with possibly several aides? Is the satisfaction with the service truly as complete as caregivers indicate, or is the response tempered by the fact that people often rationalize their decisions based on a variety of need factors?

Other factors that may increase the complexity of evaluating issues of usefulness of the service are: How might the appraisal of usefulness be complicated by the potential for the daughter to be caring for a parent who still has a spouse living in the home? What is the service like? Is the caregiver only using a home health aide, or are there other services included as part of a service package.

The indicator of need used in this study was an average of several ADL dependencies of the patient, however, behavioral aspects of need and cognitive deficits were not used. Use of these may have shown a significant difference.

These are some of the issues that may make the evaluation of home health aide services much more complex. While it is important to take homogeneous subsamples for evaluation, as was done in this study, it is also important to view the caregiver against the backdrop of the total picture.

Implications

Recommendations for future research.

This study is an investigation of only a small "piece of the puzzle" in the overall picture of what might be useful to caregivers of dementia patients to help them care for their relative. No difference was found in the usefulness of home health aide services between wife and daughter subgroups of caregivers. Both groups were found to perceive the service to be important to their care and to be highly satisfied with the service received. Only two caregivers among these users of services were dissatisfied with the care received.

This study should be replicated with larger groups of wife and daughter caregivers. It should also be repeated with other subsamples of caregivers to see how useful they find home health aide services. What it is about the service that leads to caregiver satisfaction, could be explored in a qualitative study. A study that compares the perceived importance and satisfaction with the use of this service by those who have used it in the past, but have stopped using the service, would be valuable information. This is especially important since home health aide service has been found to be the most common of services. Much research has been done in the past relating to caregivers, however, there still has been little done to investigate what it is that caregivers find to be most useful or helpful in their task, or whether specific subgroups of caregivers perceive different services to be more useful. Not only what service is helpful,

but also why it is helpful would be important to know. More research needs to be done in this area. Studies of a qualitative nature might yield results that are more enlightening, due to the subjective nature of perception.

The caregiving career for dementia caregivers usually spans several years, during which the needs have been shown to increase. Many patients eventually are institutionalized, but it has been shown in a previous study that caregivers report that this too can be delayed if they have the help of additional services such as home health aides (Collins, King, & Kokinakis, 1994). It is important that research continues to find out what services are truly helpful to caregivers, not only to delay institutionalization, but also to give added support to those who continue to care for their loved one at home.

Implications for nursing practice.

This study revealed that all the caregivers of dementia patients using the service of home health aides perceived the service to be either very important or somewhat important in helping with the care of their relative, and 95% were satisfied or very satisfied with the care received. It did not reveal any significant difference between the subgroups of wives or daughters in this sample. Although just a small number of caregivers were included in this study, this information can be helpful to the nurse who is working with dementia patients and their caregivers in planning for their care.

The nurse, whether in an acute care, home care, or primary care

setting, is active in assessing needs, mutual goal setting and planning to meet the varied patient and caregiver needs. It is also important for the nurse to explore with the caregiver different ways to organize the service in creative ways, such as the possibility of having the aide in the home for shorter time periods more often, longer time periods less often, or perhaps providing the service at night so the caregiver can obtain uninterrupted sleep. Education of the caregiver about various questions to ask and ways to evaluate the service being used, so that changes can be made if necessary is also an important consideration.

The nurse, especially the Advanced Practice Nurse, also serves as a link between patients, caregivers, service providers, and planners on a government level. Since dementia caregivers have been shown in other studies (U. S. Congress, OTA, 1990) to use these services less than other caregivers, it is important to know whether the service was useful when it was used.

Knowing that a number of other caregivers, both wives and daughters, who did use the services found them useful, can be an important tool for the APN in advising caregivers who may need such services. This information may be of help to the nurse who is considering referral of the dementia patient for this service. The nurse may also be counseling a caregiver who seems reluctant to make use of this service, although the assessment of the nurse indicates a need. The knowledge that others who tried the service found it useful may "normalize" the service to the caregiver and

make a difference in her decision-making process.

APPENDICES

APPENDIX A

☐ Very satisfied (1)
☐ Satisfied (2)
☐ Dissatisfied (3)
☐ Very dissatisfied (4)

APPENDIX B

APPENDIX B

MICHIGAN STATE UNIVERSITY

February 23, 1996

TO: Barbara Holtrop
3820 Michael St.
Muskegon, MI 49444

RE: IRB#: 96-090
TITLE: USEFULNESS OF HOME HEALTH AIDE SERVICES AS
PERCEIVED BY WIFE AND DAUGHTER CAREGIVERS OF
RELATIVES WITH DEMENTIA
REVISION REQUESTED: N/A
CATEGORY: 2-H
APPROVAL DATE: 02/22/96

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.



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RESEARCH
AND
GRADUATE
STUDIES

**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.

University Committee on
Research Involving
Human Subjects
(UCRIHS)

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

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

Sincerely,

David E. Wright
David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Sharon King

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