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PREDICTORS OF EXCLUSIVE CARE PROVISION BY PRIMARY CAREGIVERS OF DEMENTIA PATIENTS

By

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ABSTRACT

PREDICTORS OF EXCLUSIVE CARE PROVISION BY PRIMARY CAREGIVERS OF DEMENTIA PATIENTS

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This study investigated five factors, including caregiver gender and employment status, relationship and living arrangement of caregiver and care recipient, and care-recipient's functional disability, that predict whether a caregiver of a demented elderly serves as the exclusive care provider or shares caregiving tasks with secondary caregivers in the community. It was a secondary analysis of data from the first waves of two panel studies conducted at Michigan State University by Barbara A. Given and Charles W. Given, Principal Investigators. The sample included 265 primary caregivers who cared for care-recipients with dementia. Using logistic regression analysis, the caregiver employment status, the caregiver/care-recipient relationship, and the care-recipient functional disability were shown to be significant predictors of being exclusive care providers. Implications for nursing practice and future caregiving research are presented.

To my husband Mingher and our new child Eric

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INTRODUCTION

Dementia is among the most common cognitive disorders found in older people (Reifler, 1990). Among the various dementias, Alzheimer's disease is the most frequent and accounts for about 66% of all dementia cases (Office of Technology Assessment, 1987). Dementia elders may experience forgetfulness, confusion, and phases of absentmindedness over time; the disease affects the brain progressively. Ordinarily the person will compensate for the early symptoms; neither the victim nor those around her/him may suspect a medical problem at first. The slow but progressive damages to the brain often are not noticed until the person experiences greater than normal stresses, pressures, or losses that stretch her/his coping abilities to the breaking point. The individual gradually loses intellectual capacities, demonstrates impaired occupational functioning, becomes unable to perform social roles, and ultimately depends on others for assistance with activities of daily living (Pallett, 1990). Therefore, throughout the disease process, family caregivers are responsible for the supervisory and direct-care needs of the patient. In the early stages, caregivers take over higher-level functions, such as managing medications and finances. As the dementia advances, caregivers become increasingly involved with self-care tasks such as bathing, dressing, and feeding. Patient safety becomes a widening concern, and problems such as incontinence often develop. Behavioral problems, such as patient depression, agitation, and wandering, are rated as most stressful by caregivers, as they can occur unpredictably and often require continuous monitoring (Haley, Brown, & Levine, 1987; Teri, et al., 1992).

The role of informal helpers is clearly critical in maintaining a functionally dependent dementia elder in the community. At the present time, formal services (services given by paid professional care providers) play a much more limited and supplementary role than do informal services (unpaid care provided by family members, relatives, and friends). Even when an older person receives both kinds of care, informal care predominates (Stommel & Collins, 1994; Tennstedt, Sullivan, McKinlay, & D'Agostino, 1990; Tennstedt, Harrow, & Crawford, 1996).

In addition to stresses directly related to caregiving, families often experience secondary stresses that proliferate as a result of the caregiving career (Pearlin, Mullan, Semple, & Skaff, 1990). Competing demands may produce family conflict, strains on finances and employment, and changes in self-concept as caregiving spills over into all aspects of life (Stephen & Franks, 1995).

The literature on elder caregiving indicates that, typically, multiple caregivers provide assistance to frail elders. These studies report caregiving support systems averaging between two and four persons per elder with between 21% to 33% of elders having a single caregiver (Given, King, Collins, & Given, 1988; Stone, Cafferata, &

Sangl, 1987; Tausig, Fisher, & Tessler, 1992; Tennstedt, McKinlay, & Sullivan, 1989).

Many caregivers seek assistance with their caregiving duties from both formal and informal sources (Alel, 1990; Brody & Schonover, 1986; Brody, Johnsen, Fulcomer, & Lang, 1983). The extent of this assistance is related to the gender of the primary caregiver, the structure of sibling networks, the type and level of disability of the care receiver, employment status, living arrangement, family history and so on (Coward & Dwyer, 1990; Matthews & Rosner, 1988; Stommel, Given, Given, & Collins, 1995; Stone, Cafferata, & Sangl, 1987).

Informal caregiving is specially important in the case of dementia elderly. There are few formal services specifically geared towards this population since dementia patient care is long-term care that is usually not precipitated by an acute hospital episode. With no specific skills required for this kind of care, formal services do not cover it, and the care is not reimbursed. In addition, due to the progressive and irreversible nature of the disease, there is very little rehabilitation potential for the patients. Furthermore, caregiving for dementia people is usually a long drawn out process typically lasting between 9 and 15 years from onset to death. During this time, the elderly progressively deteriorate both mentally and physically imposing ever greater psychological and physical burdens on the primary caregiver. With few or no formal services available, the crucial question becomes: do primary caregivers get any assistance at all from other family members or friends to relieve them at least temporarily from their care burdens? Those caregivers who have an “empty caregiving network”, i. e., who have no additional helpers to provide hands-on care to the elderly at home, are particularly vulnerable.

In order to identify such primary caregivers, who are most vulnerable to negative psychological consequences as a result of inadequate support, it is particularly important to find the caregiver and care recipient characteristics which contribute to the lack of support from both informal and formal sources.

This study focuses on the identification of predictive factors, which may yield information that enables advanced practice nurses (APNs) in primary care settings to assess the family's circumstances. With the assurance that some situational clues help us identify problem cases, the APN is more likely to be more supportive in helping to arrange the appropriate caregiving strategies. Knowing those factors may make a difference in what the APN decides to do or suggest as a course of action.

Statement of the Problem

Little is known about factors that predict whether a caregiver of a demented elderly serves as the exclusive provider, i.e., gets no hands-on physical help from other providers, or shares caregiving tasks with secondary caregivers. In particular, lack of information on certain caregiver and care recipient characteristics, including the gender of the primary caregiver, the living arrangement of primary caregiver and care-recipient, the primary caregiver's relation to the care recipient, the caregiver's employment status, and the care recipient's functional disability, that contribute to being an exclusive care provider to the dementia care recipients. If these factors are predictive, the health care professional will be able to identify primary caregivers who are at risk for inadequate support, and thus be in a better position to assist the primary caregivers with the added responsibilities of caregiving. The focus of this investigation is to examine and describe those caregiver and care recipient characteristics that predict the likelihood of being an exclusive care provider among primary caregivers of dementia patients.

Research Questions

The research questions for this study are as follows:

1) Does the gender of the primary caregiver predict the likelihood of receiving hands-on assistance from secondary providers?
2) Does the employment status of the primary caregiver predict the likelihood of receiving hands-on assistance from secondary providers?
3) Does the living arrangement of the primary caregiver and care recipient predict the likelihood of receiving hands-on assistance from secondary providers?
4) Does the relationship between the primary caregiver and the care recipient predict the likelihood of receiving hands-on assistance from secondary providers?
5) Does the care recipient's level of functional disability predict the likelihood of receiving hands-on assistance from secondary providers?

LITERATURE REVIEW

Caregiving Involvement

Many home care studies have shown that informal care of the elderly at home is achieved mainly by a primary family caregiver with the assistance of other caregivers (Miller & McFall, 1991; Stoller & Puglesi, 1991; Stone, Cafferata, & Sangl, 1987), and that older people receive assistance from a network of helpers (Horowitz & Dobrof, 1982; Tennstedt, McKinlay, & Sullivan, 1989). The word "primary caregiver" implies that there are also secondary caregivers available, but this is not always the case in actual experience.

One study documented the caregiver support network and examined its influence on the experience of the primary caregiver for a sample of caregivers of impaired older persons 6 weeks after they left the hospital following treatment for a stroke or a hip fracture. Nearly 7% of the 242 primary caregiver/older person dyads reported caring for the older person without aid from anyone else, and the remaining 93% of the primary caregiver/older person dyads included one to six secondary helpers with direct care (Penrod, Kane, Kane, & Finch, 1995).

Data drawn from the 1982 National Long-Term Care Survey has shown that approximately 70% of the 2201 subjects, which represented 2.2 million persons caring for 1.6 million disabled elders, were primary caregivers with the remainder playing a secondary role. About one-third of the primary caregivers did not receive any assistance from other informal or formal caregivers and devoted an average of 4 hours a day to caregiving activities. Another one-third of the respondents were primary caregivers with one or more unpaid helpers and provided 4.4 hours of care per day. Finally, 10% of the primary caregivers received paid help in addition to unpaid assistance, and spent 5.4 hours each day to elderly care (Stone, Cafferata, & Sangl, 1987). Thus, it appears that greater patient demands result in greater use of secondary caregivers.

The National Long-Term Demonstration or Channeling Demonstration Project, investigated experiences of primary caregivers caring for elderly persons (age 65 years and older) with ADL or IADL impairments, cognitive or behavioral difficulties who were at risk of institutionalization in the community. Based on these data, Stephens and Christianson (1986) found that 40% of all primary caregivers (N=1940) were the only source of informal care for the elderly care recipient, and devoted 5.7 hours per day to provide care.

A community-based research study with a random sample of 635 frail elders and their 429 primary caregivers revealed that primary caregivers alone supplied much more care than secondary caregivers. Care by secondary caregivers was supplementary (different helpers engaged in the same care tasks jointly) rather than complementary (different helpers engaged in different care tasks). In this study, primary caregivers provided, on average, 57 hours per week while secondary helpers provided 20 hours per week. Care recipients with only a primary caregiver received 67 hours of informal care per week, whereas those with both primary and secondary caregivers received only 64 hours of care per week. Finally, elders with spousal primary caregivers used the least amount of formal services, whereas elders with nonrelatives as primary caregivers utilized the most (Tennstedt, McKinlay, & Sullivan, 1989).

In another research study, 233 spouses and adult children who assumed more responsibilities than anyone else caring for brain-impaired adults at home were selected. Findings indicated that primary caregivers spent almost 89 hours each week giving care, and received a total of 19 hours each week of help from unpaid family and friends (14 hours) and paid sources (5 hours) combined (Enright, 1991).

Using data from the first wave of two longitudinal studies which included 504 spouse and child caregivers of Alzheimer's or dementia patients and elderly care recipients with a variety of physical impairments, the division of labor between primary caregivers and other care providers was examined. Primary caregivers performed the bulk of the care: on average, almost 80% of all the care was provided by the primary caregiver which ranged from 8.6% to 100%. Half of this care was performed by the caregiver in an exclusive mode, i.e., as specialized or only provider, whereas half of this care was performed in a supplemental mode, i.e., shared with other providers (Stommel, Given, Given, & Collins, 1995).

Finally, the amount of care assistance that the caregivers received affected how many hours per week they themselves provided care to the frail elderly. That is to say, caregivers are likely to spend more hours of caring per week when there are fewer people to assist the caregiver on a regular basis (Merrill, 1991).

Living arrangement

Despite the limited number of studies focusing on a primary caregiver's and care recipient's living arrangement in relation to getting additional hands-on assistance from formal and/or informal resources, several investigations did offer some insight into this issue. For instance, primary caregivers living with a noninstitutionalized disabled care recipient are more likely to assume full responsibility and to be the only providers. By contrast, primary caregivers with informal and/or formal help are less likely to share the household with the care recipients (Stone, Cafferata, & Sangl, 1987).

Using data from the Channeling Experiment, Kemper (1992) indicated that the amount of care received by the disabled elderly was large, namely 46 hours per week on average. Of this care, 27 hours per week was provided by primary caregivers living in the same households, but only 12 hours per week by primary caregiver living in separate households.

Finally, secondary helpers' contributions to hands-on care of the impaired older persons was the focus of a study conducted by Penrod, Kane, Kane, & Finch (1995). Results showed that the average number of secondary helpers was smaller when the primary caregiver and care receiver shared a household.

Employment status

Although a number of studies have reported that employed caregivers provide about as many hours of assistance as do those who are not employed, other studies have found that caregiver employment is significantly associated with the amount or the number of hours spent giving care. The number of weekly hours of unpaid help provided by each caregiver depends on the type of employment. Full-time employment, when compared with no market work, reduced informal caregiving by 20 to 25 hours per week, but part-time employment had no statistically significant effect on hours of caregiving (Boaz & Muller, 1992; Boaz, 1996).

Seventy seven women who were both working full-time and as primary caregivers for an elderly family member reported that they spent an average of 16 hours per week in caregiving. This average figure was nearly the equivalent of a half-time job. In addition, almost half of the sample (47%) obtained no help in caregiving from their families (Gibeau & Anastas, 1989).

Though employed and not employed married daughters' average contributions of help per week to their widowed mothers differed significantly for only two (personal care and meal preparation) out of the seven tasks, Brody & Schoonover (1986) found that this difference was accompanied by the increased involvement of various other providers. Thus, when daughters worked, the combined contributions of various members of the informal network and helpers paid by the family offset the fewer hours of help given by working daughters themselves. Also, the support networks of the working caregivers were more complex than those in the nonworking group. That is to say, when daughters were in the labor force, their caregiving networks tended to involve a greater number of helpers in more varied combinations.

In another study, married working and non-working daughters as principal caregivers caring for their noninstitutionalized elderly mothers were the target of the investigation. This study reported that employed daughters provided fewer hours of care per week when compared to non-working daughters. In addition, mothers whose working daughters had not considered reducing their working hours or quitting their jobs received more help from all sources each week than mothers whose daughters were considering quitting their jobs, not working, or had just left the labor force (Brody, Kelban, Johnsen, Hoffman, & Schoonover, 1987).

Primary caregivers who work and care for brain-impaired family members received more help from a combination of sources, i.e., family members, friends, and paid services than those not employed. There were 28 weekly hours of combined help for working primary caregivers and 13 weekly hours of combined help for non-working caregivers (Enright, 1991).

Similarly, compared with primary caregivers who were employed, not employed caregivers who care for elderly had a lower probability of receiving high levels of involvement from secondary caregivers (Given, Given, Stommel, & Lin, 1994), had a smaller than average number of secondary helpers (Penrod, Kane, Kane, & Finch, 1995), and used a greater number of hours of paid help (Enright & Friss, 1987).

Gender

Like other forms of domestic labor, care for the elderly continues to be allocated on the basis of gender. There are significant gender differences in the provision of care. In almost every category of caregiving help, women offered higher levels of overall assistance to elderly care recipients than did men (Anastas, Gibeau, & Larson, 1990; Coward & Dwyer, 1990; Finley, 1989; Honeywell, Inc., 1986; Horowitz, 1985; Stoller, 1990). Caregiving studies have shown that informal caregivers to the frail aged were primarily female, and spent an average of 16 hours a week in this caregiving role (Stone, Cafferata, & Sangl, 1987; Wood, 1987). Even in mixed-gender family networks, women caregivers supplied more hours per day in caregiving activities than did their male counterparts (Coward & Dwyer, 1990). In addition, male primary caregivers differ from female primary caregivers in that a woman's responsibilities of caring for a chronically ill relative tend not to be shared (Brody, 1990).

Gender differences are believed to influence the amount of care provided and access to social resources that may alleviate caregiver strain. An investigation employing data from a subsample of 554 spouse caregivers from the 1982 National Long Term Care Survey of Caregivers of the Frail Elderly reported that overall, the level of help received from others was low: 62% of the spouse primary caregivers had no other helpers; 60% had no backup help; and 90% did not receive any paid help. In particular, male spouse primary caregivers used more paid help than female spouse primary caregivers although they had less backup helpers when comparing to female spouse primary caregivers (Miller, 1990).

In regard to the difference between husbands and wives in giving informal care, it has been reported that elderly husbands were more likely to receive support from both informal and formal caregivers (John, 1983). Among caregiver husbands and wives, 60% of the wives and 55% of the husbands were the sole providers of care and provided care with no informal or paid assistance (Stone, Cafferata, & Sangl, 1987).

Daughters or daughters-in-law who provided care were twice as much likely as sons to assume the primary responsibility with no assistance (Stone, Cafferata, & Sangl, 1987), and spent more hours each week in parent-care than did sons (Montgomery & Kamo, 1989; Stoller & Earl, 1983).

<u>Caregiver and care recipient relationship</u>

Assistance to frail elders from informal caregivers outside the immediate family is rare. Friends and neighbors may provide crisis or short-term help, particularly when family members are not available to provide direct care, but their involvement typically does not extend to day-to-day tasks of caregiving (Cantor, 1983; Litwak, 1985; Stoller, 1990).

Several studies have shown that caregiving involvement of primary caregivers and the amount of help from other care providers were associated with the relationship of the primary caregiver to the elderly. Spousal primary caregivers had fewer persons helping them with caregiving tasks (Given, Stommel, Collins, King & Given, 1990). Wives received less assistance from family members and friends than did adult daughters (Enright, 1991).

Tennstedt, McKinlay, & Sullivan (1989) reported that one quarter of the elders (N=791) had only one caregiver. Among those with both primary caregivers and secondary caregivers, there were significant ($p < .00$) differences in the average amounts of informal care depending on the relationship of the primary caregiver to the elder: spouses, in the primary caregiver role, provided the most help of all caregivers and are much less likely to have assistance with care from secondary caregivers. Other family members, who provided less care on average than spouses have more secondary caregiver involvement. Thus, if the primary caregiver was a spouse, the older person was less likely to have informal help from other caregivers.

Similarly, it was found that spousal primary caregivers were less likely to receive direct help from secondary caregivers than adult children, friends, or more distantly related relatives (Matthews & Rosner, 1988; Penrod, Kane, Kane, & Finch, 1995).

In her study of 167 post discharge individuals aged 65 years and older, Johnson (1983) indicated that when the primary caregiver was a spouse, 51% of all care, including transportation, housekeeping, legal/financial, meal preparation, and shopping was provided by the spouse. However, when the primary caregiver was a child, 58% of all care came from other sources.

In another study, interviews were conducted with 315 white women who were providing care in the community to a spouse diagnosed with Alzheimer's disease or a related disorder. Pruchno (1990) found that caregiving spouses performed extensive hands-on care for their impaired partners and had minimal assistance from other people. About 30% of the caregivers had no helpers at all.

As part of a longitudinal study focusing on spouse and adult child primary caregivers' perception of social support to dependent elderly, it was found that adult child primary caregivers received more assistance from their family and friends in the amount of instrumental support than did spouse primary caregivers (Lyles, King, Given, & Given, 1990).

Finally, among 196 primary caregivers who were spouses, daughters, and daughters-in-law, 59% of the spouse caregivers reported low involvement by secondary caregivers, regardless of whether they were living alone or with others. In contrast, nonspouse caregivers who lived alone or with another were significantly more likely to experience high involvement of secondary caregivers (Given, Given, Stommel, & Lin, 1994).

Functional disability of care recipient

It is known that more hours of care per week from the caregiver is associated with greater impairment of the elder care recipient. When compared to elders who have less than 3 limitations in the daily functions of personal care, caregivers who helped those with 3 to 5 limitations devoted 5.5 additional hours of care, and 12 additional hours to elders with 6 to 7 limitations (Boaz & Muller, 1992).

The likelihood of the older person in the community using formal home care at 6 weeks after hospital discharge increased with each additional ADL impairment (Penrod, Kane, Kane, & Finch, 1995).

Likewise, a study assessed the extent to which formally provided comprehensive community care tended to substitute for informal care provided by family and friends to impaired elderly persons (N=124) living in the community. Greene (1983) indicated that the level of ADL impairment of the elderly was the most statistically significant single predictor of level of formally provided support. That is, more seriously ADL-impaired individuals received higher levels of formal supportive care.

Based on cross-sectional data, the number of people assisting the primary caregiver increased with greater functional dependencies of the patient. Formal service use was the highest at the most severe level of functional impairment elder (Tennstedt, McKilay, & Sullivan, 1989).

Research examining the impact over time of changes in older people's health and functional capacity on the composition of their support network revealed that with the onset of a decline in health status, persons received assistance from sources increasingly distant from the older persons (Stoller & Pugliesi, 1988).

Another study which explored both formal and informal sources of instrumental support for older persons of varying levels of functional capacity residing in the community found that caregiving support networks increased in size as the level of capacity of the older persons decreased (Stoller & Earl, 1983).

Research hypotheses

Based on the findings in the current literature, the research questions are formulated into the following specific hypotheses as a more precise guide to the research.

Hypothesis 1: Female primary caregivers are less likely to receive hands-on physical assistance from secondary providers.

Hypothesis 2: Not employed primary caregivers are less likely to receive hands-on physical assistance from secondary providers.

Hypothesis 3: Primary caregivers who live with the care recipient are less likely to receive hands-on physical assistance from secondary providers.

Hypothesis 4: Spousal primary caregivers are less likely to receive hands-on physical assistance from secondary providers.

Hypothesis 5: Primary caregivers are less likely to receive hands-on physical assistance from secondary providers when care recipients' levels of functional disability are low.

METHODS

In this section, the research design, sample, data collection procedure, operational definitions of study variables, analytic approach, and protection of human rights are discussed.

Research Design

The present study is a secondary data analysis of information from the first waves of two panel studies entitled "Impact of Alzheimer's Disease on Family Caregivers" (Given & Given, 1987), and "Caregiver Responses to Managing Elderly Patients at Home" (Given & Given, 1989).

Sample

The sample for the analysis (N=265; 1987 study: N=229, 1989 study: N=36) comes from two convenience samples of family caregivers of relatives with dementia who reside in the community. Criteria for selection of caregiver and care recipient dyads in both panel studies were similar and included the following:

1. The care recipient was a least 55 years of age.
2. The care recipient had to be dependent in at least two activity of daily living (ADL) or instrumental activity of daily living (IADL).
3. The care recipient had received a diagnosis of Alzheimer's Disease or other progressive dementia.

4. The caregiver was self-identified as the family member providing the most care to the care recipient with dementia (i.e. primary caregiver).
5. The care recipient and caregiver were residing in the community at the time of data collection.

Data Collection Procedures

Subjects for both studies were initially recruited through an extensive mailing distributed by local chapters of the Alzheimer's Association, the Michigan Association of Adult Day Care Centers and health agencies in southwest Michigan. Caregivers who were eligible to be included in the study participated in a personal or telephone interview and completed a mailed self-administered booklet. These primary caregivers were the exclusive source of information for themselves and the person for whom they were caring. Results from both interview and the self-administered booklet were then compiled and entered into the computer for analysis.

Operational Definitions of Study Variables

Independent variables

Gender -- Female and male primary caregivers were identified based on self-report.

Employment status -- Primary caregivers were divided into working full time, part time or not employed groups.

Relationships -- Primary caregivers were identified as husbands, wives, sons, daughters, sons/daughters-in-law, brothers/sisters-in-law, other relatives, friends, or formal care providers. Because of the small numbers of non-spouse caregivers, in the current study, spouses will be compared to all non-spouse caregivers.

Living arrangements -- The sample was divided according to whether the primary caregiver and the care recipient lived in the same household or lived apart based on primary caregiver's self-report.

Physical impairment -- The primary caregiver rated the care recipients' dependency in any of 25 activity areas including the traditional ADL (walking, eating, bathing, dressing, toileting, grooming) and IADL (shopping, cooking, etc.). Also included were various health and medical care tasks requiring special skills such as giving injections, tube feeding, or catheter care.

Mental impairment -- Patients' mental health as characterized by their cognitive behaviors was measured. The measure was a scale composed of seven 4-points Likert items that describe a patient's level of mental activity and alertness. It was developed by Given and Given (1989), and its reliability and validity has been confirmed with Alzheimer's patients in two samples: Cronbach's alpha = .87, and .89 (Stommel, Given, & Given, 1990). High numbers represent greater level of cognitive impairment.

Dependent variable

Involvement of other helpers -- Each time the existence of a patient dependency was confirmed, the primary caregiver was asked to indicate how often she/he and how often other people helped with ADLs and IADLs activities during a typical week. Answer categories included no involvement (0), once a week (1), several (two to six) times a week (3.5), once a day (7), and several times a day (14).

From the information on both the involvement of primary caregivers and other helpers, a simple index was constructed, i.e., a score of 1 if only the primary caregiver was involved, and a score of 0 if others were also involved. Those primary caregivers who scored 1 across all tasks are the sole, exclusive providers of hands-on care to their care recipients. Thus, an overall dichotomous index was created: a score of 1 was equal to being an exclusive provider, and 0 was equal to being a non-exclusive provider (or having other helpers), as the criterion outcome variable in this study.

Analytic Approach

Given the dichotomous outcome variable and a mix of independent variables (both categorical/nominal and interval level measures), logistic regression was utilized as the appropriate statistical model (Demaris, 1990). This model can be used to predict the changes in the odds of being an exclusive care provider depending on variations in the independent variables which represent characteristics of the primary caregiver and the care recipient.

Protection of Human Rights

The original studies were reviewed and approved by the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University. Consent for the longitudinal studies was obtained by the Researchers regarding participation in the study. An explanation of the research study and goals, the nature of the questions to be asked, and assurances of anonymity were provided each participant as part of the letter of explanation. Signed consent forms were required from both caregiver and care recipient.

The use of this secondary data was approved by UCRIHS at Michigan State University. There were no new risks to the subjects who participated in the original study. Confidentiality was provided by the use of case numbers versus names in the current data set.

RESULTS

Sociodemographic Characteristics of Sample

The sociodemographic information in the present study covers age, gender, education, living arrangement, relationship of primary caregiver and patient, employment status, household income, patient's functional status, and total number of care activities provided by caregivers. According to Table 1 and 2, the age of the caregivers ranged from 27 to 86 years with a mean age of 62 years and a standard deviation of 11.2 years. The majority of the caregivers were Caucasians (97%). They were husbands (23%), wives (45%), daughters (19%), sons (9%), daughters/sons-in-law (1.5%), brothers/sisters-in-law (1.5%), and others (1%) in relation to care recipients. Slightly less than three quarters (74%) of them were women. Most of the respondents (88%) were married, 6% had never married, and 6% were widowed, divorced or separated. In terms of educational achievement, 8% had grade school education, 8% had attended some high school, 24% had high school diplomas, 38% had some college education, and 22% had baccalaureate or higher degrees. About 70% of the caregivers were not employed at the time of the interview, but 11% were working full-time and 19% were working part-time. The care recipient household income varied greatly, ranged from \$1000 to \$152,503, with an average of \$25,790, and standard deviation of \$18,183. A great majority (94%) of primary caregivers lived with their care recipients, and the remainder lived apart from the care recipients.

Table 1 - Demographic Characteristics of Caregiver and Care Recipient

	Caregiver (N=265)		Care recipient (N=265)	
Gender				
Female	195	(73.6%)	136	(51.3%)
Male	70	(26.4%)	129	(48.7%)
Marital Status				
Single	17	(6.4%)	3	(1.1%)
Married	232	(87.5%)	189	(71.3%)
Widowed	8	(3.0%)	72	(27.2%)
Divorced/Separated	8	(3.0%)	1	(0.4%)
Race/Ethnicity				
White/Caucasian	256	(96.6%)	255	(96.4%)
Black	9	(3.4%)	9	(3.4%)
Other	0	(0%)	1	(0.4%)
Education				
Grade school	21	(7.9%)	60	(22.8%)
Some high school	21	(7.9%)	47	(17.9%)
High school graduate	64	(24.2%)	60	(22.8%)
Some college	100	(37.7%)	44	(16.7%)
BA/BS degree	30	(11.3%)	34	(12.9%)
Higher degree	29	(10.9%)	18	(6.8%)

Table 1 (cont'd)

	N	Percentage
Caregiver employment status		
Not employed	185	69.8
Part-time	28	10.6
Full-time	52	19.6
Caregiver and care recipient living arrangements		
Live together	248	93.6
Live apart	17	6.4
Caregiver relation to care recipient		
Husband	61	23.0
Wife	119	44.9
Daughter	51	19.3
Son	23	8.7
Daughter/Son-in-law	4	1.5
Brother/Sister-in-law	4	1.5
Other	3	1.1
No. of people living in care recipient household		
1	9	3.4
2	166	62.6
3	58	21.9
4	28	10.6
5	4	1.5

Table 2 - Mean, Standard Deviations, and Ranges of Selective Caregiving, Caregiver and Care Recipient' Background Information

	Mean	SD	Range
Age			
Caregiver	62	11.2	27-86
Care recipient	73	8.5	55-99
Care recipient household income	\$25,790	\$18,183	\$1,000 ~ 152,503
Care recipient functional status			
ADL score	5.2	3.5	0 ~ 10
Cognitive deficit score	1.7	0.7	0 ~ 3
Total No. of dependencies (25 tasks)	13.4	4.7	2 ~ 22
Total No. of instances of assistance (25 tasks)			
Caregiver	35.6	16.6	2 ~ 78
Other provider	16.7	16.7	0 ~ 73

Of the 25 caregiving tasks, including ADLs, IADLs, and medical care tasks, the total number of care activities primary caregivers provided ranged from 2 to 78, with an average of 36 care activities (SD = 17). However, other providers were involved in fewer instances of care assistance than primary caregivers, which varied from 0 to 73, with an average of 17 instances of assistance activities (SD=17).

The age of the care recipients ranged from 55 to 99 years with a mean age of 73 years and a standard deviation of 8.5 years. Most of the care recipients were Caucasians (96%). The numbers of female and male care recipients were similar (51% vs 49%). Majority of the care recipients (71%) were married, 1% had never married, and 28% were widowed, divorced or separated. Educational achievement among care recipients was from grade school to BS/BS degrees, with 7% had higher degrees. Most (63%) of the care recipients had two persons living in their households, 34% had three to five people coresiding with them, and only 3% lived alone.

Care recipients' functional status was measured in three areas, including dependency on activity of daily living, cognitive status, and episodes of negative/aggressive behaviors. On average, care recipients had 5 dependencies on help for ADLs, with ranging from 0 to 10 dependencies. In addition, they had moderate cognitive disability with a mean cognitive deficit score of 1.7 (SD=0.7). In sum, care recipients' average functional limitation of the 25 caregiving tasks was 13 dependencies, ranging from 2 to 22 dependencies (SD = 4.7).

Logistic Regression Results

Information on frequencies of primary caregivers who are exclusive care providers or receive outside assistance in this study is presented in Table 3. Overall, 14% of the primary caregivers are the sole care providers without any hands-on assistance from secondary providers, but 86% of them do share caregiving tasks with others.

Table 3 - Frequencies and Percents of the Dependent Variable in the Sample

	Frequency	Percent
Caregiver without help	37	14
Caregiver with help	228	86
Total	265	100

In order to address the five specific hypotheses of this study, an initial simple logistic regression model was run containing all five potential predictors of a caregiver's odds of being an exclusive care provider. Considering the high correlation between the living arrangement variable and the caregiver/recipient relationship variable, a second model was created excluding the living arrangement variable.

Table 4 presents the results of the first logistic regression analysis. These results suggest two significant determinants of being the exclusive care provider: caregiver employment status and care recipient's total number of dependencies. Consistent with previous studies, these findings show that, when comparing not employed to part-time caregivers or part-time caregivers to full-time caregivers, the odds of being the exclusive provider are reduced each time by 48% (odds ratio = .52). In other words, the odds of a part-time caregiver receiving no assistance are half those of a not employed caregiver, and a full-time employed caregiver has again half the odds of a part-time caregiver of not receiving assistance. Thus, the odds of a full-time caregiver being the exclusive care provider when compared to a not employed caregiver are one in five. Similarly, the functional limitations of the care recipients have a significant effect on the outcome variable. Since the variable is a count of the number of functional dependencies, for each additional care recipient dependency, the odds of being the exclusive provider decline by 20% (1 - 0.80 = .20). That means when the care recipient demonstrates higher functional dependency, he/she is less likely to have a primary caregiver who does all the care alone. Instead, the primary caregiver shares caregiving tasks with other providers.

In the model presented the variables of caregiver gender, caregiver's relation to the care recipient, caregiver and care recipient living arrangement, and care recipient cognitive deficit fail to reach statistical significance.

Overall, in terms of goodness of fit, the logistic regression (Model 1) predicts the outcome accurately in 87% of the cases.

Table 4 - Logistic Regression Predicting Exclusive Care by Caregiver (Model 1)

Predictor	Wald	Odds-Ratio	Sig.
Caregiver gender (0=female, 1=male)	.89	.61	.35
Caregiver employment (0=not employed, 1=part-time, 2=full-time)	4.74	.52	.03 *
Relationship (1=spouse, 0=others)	.00	1.02	.97
Living arrangement (0=live apart, 1=live together)	.11	1871.29	.74
Care recipient total No. of dependencies (1 ~ 22)	17.65	.80	.00 *
Care recipient cognitive deficit score (1 ~ 3)	.09	.90	.75
Model Chi-square = 38.95 df = 6 p = .0000 Overall goodness of fit = 86.80% N=265			

From the results of Model 1 (Table 4), it can be seen that the caregiver and care recipient relationship to the outcome variable is not statically significant. One of the reasons is that, in multivariate analysis, family relationship is confounded with living arrangement. In this sample, spousal caregivers always live together with their care recipients, but among the non-spousal caregivers, this is not always the case. Since family relationship and living arrangement overlap so much, that essentially means, that we cannot disintangle what effect is contributed by family relationship as opposed to living arrangement. In other words, the two variables are so highly correlated with each other that they no longer show any independent effect.

Based on the above rationale, a secondary logistic regression was constructed (Model 2) excluding the caregiver and care recipient living arrangement variable (Table 5). With very slight differences in the odds ratios, the results are generally consistent with the previous model, i.e., caregiver employment status and care recipient functional disability remain statistically significant. However, there is an important difference now. That is, the caregiver and care recipient relationship is also statistically significant. Since the dummy variable is coded 1 for spousal caregivers, 0 for non-spousal caregivers (mostly child caregivers), the odds of being the exclusive provider among spousal caregivers are almost three times as large as the odds of being the exclusive provider among non-spousal caregivers (Odds ratio = 2.79). Thus, spousal caregivers have three times the odds of non-spousal caregivers to care for their care recipients alone. All other predictive factors are consistent with the results in Model 1.

As a whole, the logistic regression predicts the outcome accurately in 80% of the cases in the Model 2.

In order to further elaborate the findings, two-way and three-way cross-tabulation techniques are applied and the sample results are presented here also.

Although caregiver gender is not a statistically significant determinant of being the exclusive provider, the sample results remain

Table 5 - Logistic Regression Predicting Exclusive Care by Caregiver: On All Independent Variables Except the Living Arrangement Variable (Model 2)

Predictor	Wald	Odds-Ratio	Sig.
Caregiver gender (0=female, 1=male)	.00	.97	.93
Caregiver employment (0=not employed, 1=part-time, 2=full-time)	9.44	.46	.00 *
Relationship (1=spouse, 0=others)	5.71	2.79	.02 *
Care recipient total No. of dependencies (1 ~ 22)	25.40	.81	.00 *
Care recipient cognitive deficit score (1 ~ 3)	.02	.96	.88
Model Chi-square = 56.40 df=5 p=.0000 Overall goodness of fit = 80.4% N=265			

suggestive (Table 6). 16% of the female caregivers do not receive any help while 84% get assistance. Thus, the sample odds of being an exclusive provider are .19 (16/84=.19) among female caregivers. That means every 1 in 6 female caregivers is the sole care provider in the study sample. However, the odds of being an exclusive provider are .10 (9/91=.099) among male caregivers, that is, only 1 in 11 male caregivers serves as the only care provider. According to the ratio of the two odds between female and male caregivers, the odds of being exclusive provider among female caregivers are twice as high as among male caregivers, i.e., a female is twice as likely to be an exclusive provider as male. While this pattern in the sample data is suggestive and consistent with expectations, the gender effect was not statistically significant, which means, it may be due to sampling chance.

Table 6 - Cross-Tabulation Results of Gender by Exclusive Care by Caregiver

	Caregiver Without Help	Caregiver With Help
Male	9%	91%
Female	16%	84%

According to cross-tabulation results (Table 7), spousal caregivers (16%) are more likely to be exclusive care providers than daughter/son caregivers and daughter/son-in-law caregivers combined (8%).

Table 7 - Cross-Tabulation Results of Family Relationship by Exclusive Care by Caregiver

	Caregiver Without Help		Caregiver With Help		Total	
Spouse	16%	(29)	84%	(151)	100%	(180)
Daughter/Son Daughter/Son-in-law	8%	(6)	92%	(72)	100%	(78)
Other	29%	(2)	71%	(5)	100%	(7)

When controlling for gender in addition to relationship (Table 8), female caregivers are more likely to be the sole care providers than male. Specifically, among spousal caregivers, 19% of the wives and only 10% of the husbands are without any assistance for caregiving activities. Moreover, among non-spousal caregivers, 10.5% of the female caregivers and none of the male caregivers are without any help for caregiving activities. In contrast, a large majority of husband caregivers (90%) and all male relatives caregivers (100%) share care tasks with others.

Table 8 - Cross-Tabulation Results of Gender by Exclusive Care Among Spousal and Non-Spousal Caregivers

	Caregiver Without Help		Caregiver With Help		Total	
Husbands	10%	(6)	90%	(55)	100%	(61)
Wives	19%	(23)	81%	(96)	100%	(119)
Other male relatives	0%	(0)	100%	(9)	100%	(9)
Other female relatives	10.5%	(8)	89.5%	(68)	100%	(76)

The relationship between gender, employment status and exclusive provision of care is explained in Table 9 and Table 10. As expected, women are less likely than men to be employed when assuming the caregiving responsibility. Among female caregivers (Table 9), 81% are not employed while approximate one-fifth (19%) are employed either part-time or full-time. By contrast, among male caregivers, only 51% are not employed.

Table 9 - Cross-Tabulation Results of Gender by Employment Status

	Not employed		Part-time		Full-time		Total	
Female	81%	(135)	12%	(20)	7%	(12)	100%	(167)
Male	51%	(50)	8%	(8)	41%	(40)	100%	(98)

When comparing not employed caregivers to part-time and full-time caregivers (Table 10), the not working caregivers are more likely to be the exclusive care providers than the working groups combined. That is, 20% of the not employed caregivers and 7.5% of the employed caregivers are without any assistance.

Table 10 - Cross-Tabulation Results of Care Employment Status by Exclusive Care by Caregiver

	Caregiver Without Help		Caregiver With Help		Total	
Not employed	20%	(31)	80%	(154)	100%	(185)
Part-time	7%	(2)	93%	(26)	100%	(28)
Full-time	8%	(4)	92%	(48)	100%	(52)

When comparing the not employed to the employed caregivers among men and women separately (Table 11), the not employed caregivers are more likely to perform the caregiving activities alone, regardless of their gender. That is, 12% of the not working men do not receive any help from other providers, but all of the employed men share caregiving tasks with others. Moreover, 18.5% of the not employed women are without any help from others but only 10% of the working women are without assistance.

Table 11 - Cross-Tabulation Results of Gender by Exclusive Care by Caregiver Among the Not Employed and Employed Caregivers

	Caregiver Without Help		Caregiver With Help		Total	
Male (not employed)	12%	(6)	88%	(44)	100%	(50)
Female (not employed)	18.5%	(25)	81.5%	(110)	100%	(135)
Male (employed)	0%	(0)	100%	(20)	100%	(20)
Female (employed)	10%	(6)	90%	(54)	100%	(60)

As stated earlier, the caregiver and care recipient relationship is confounded with living arrangement. Cross-tabulation (Table 12) reveals that 94% of the caregiver/recipient dyads live together versus 6% of the caregiver/recipient dyads live apart, with all husbands and wives living together.

Table 12 - Cross-Tabulation Results of Family Relationship by Caregiver and Care Recipient Living Arrangement

	Caregiver/Care Recipient live together	Caregiver/Care Recipient live apart	Row Total	
Spouse	180	0	68%	(180)
Daughter/Son Daughter/ Son-in-law	65	13	29%	(78)
Other	3	4	3%	(7)
Total	94% (248)	6% (17)	100%	(265)

Caregiver and care recipient living arrangement affects the proportion who get no help from other providers among non-spousal caregivers (Table 13). When non-spousal caregivers and their care recipients share the same household, 12% of them are exclusive care providers. However, when non-spousal caregivers and their care recipients live apart, all of them receive assistance from other providers and never do they provide care alone. Overall, a small percentage (9%) of the non-spousal caregivers are without any help from other providers no matter whether they live together with or live apart from the care recipient.

Table 13 - Cross-Tabulation Results of Living Arrangement by Exclusive Care by Caregiver Among Non-Spouse Caregivers

	Caregiver Without Help		Caregiver With Help		Total	
Caregiver/care recipient live apart	0%	(0)	100%	(17)	100%	(17)
Caregiver/care recipient live together	12%	(8)	88%	(60)	100%	(68)
Total	9%	(8)	91%	(77)	100%	(85)

DISCUSSION

Interpretation Related To Literature

This study investigated five primary caregiver and care recipient characteristics, including caregiver's gender and employment status, caregiver/care recipient relationship and living arrangement, and care recipient's functional status. It was hypothesized that all of these characteristics would be associated with the odds of a family primary caregiver to serve as the exclusive provider or share caregiving responsibility with secondary caregivers. The results of the multivariate analysis suggested three significant determinants of being the exclusive care provider: the primary caregiver's employment status, the care recipient's total number of dependencies, and the caregiver and care recipient relationship.

The logistic regression model showed that the odds of a part-time caregiver receiving no assistance were half those of a not employed caregiver, that a full-time employed caregiver had again half the odds of a part-time caregiver of not receiving assistance, and that the full-time caregiver had only one quarter the odds of being the exclusive care provider when compared to a not employed caregiver. The reasons for the employment effect are that full-time employment reduces informal caregiving hours per week (Boaz & Muller, 1992) and caregiving networks of employed caregivers tend to involve a greater number of helpers (Brody & Schoonover, 1986).

The study results also indicated that for each additional care recipient dependency, the odds of being the exclusive care provider declined by 20%. These results support the findings of Tennstedt, McKilay, & Sullivan (1989), i.e., the higher the number of functional dependencies demonstrated by the care recipient, the less likely the primary caregiver does all the care independently, and greater the likelihood will the primary caregiver share caregiving tasks with other providers.

The last significant predictor of being the exclusive care provider was the caregiver and care recipient relationship. The findings revealed that the odds of being the exclusive provider among spousal caregivers were almost three times as large as the odds of being the exclusive provider among non-spousal caregivers (mainly child caregivers). Consistent with previous findings, which did not specifically focus on dementia patients, spousal caregivers had fewer persons helping them with caregiving tasks (Given, Stommel, Collins, King, & Given, 1990), and were less likely to have assistance with care from secondary caregivers than did adult child caregivers (Enright, 1991; Penrod, Kane, Kane, & Finch, 1995; Tennstedt, McKinlay, & Sullivan, 1989).

Studies have revealed that the primary caregiver usually assumes full responsibilities and is the only care provider (Stone, Cafferata, & Sangl, 1987) to the frail elderly, or have small numbers of secondary helpers if they share households with their patients (Penrod, Kane, Kane, & Finch, 1995). This study supports these findings: among non-spousal primary caregivers in the sample, 12% receives no additional hands-on assistance from others when they live with their care recipients, and none of the non-spousal primary caregivers provides the care alone if they live apart from their care recipients.

Although caregiver gender was not a significant predictor of being the exclusive care provider, cross-tabulation results in this study showed that among female caregivers, every one in six caregivers was the sole care provider, whereas, among male caregivers, every one in ten caregivers was the only care provider. This pattern was consistent with expectations that a woman is more likely than a man to be a primary caregiver and provide the care without any assistance (Brody, 1990; Stone, Cafferata, & Sangl, 1987). Yet, after controlling for the effects of employment, relationship, care recipient dependencies and cognitive deficits in the multivariate logistic model, this gender effect disappears suggesting that it is due to these other factors.

Pruchno (1990) reported that about 30% of female spousal caregivers who care for a patient with Alzheimer's disease or a related disorder, had no helpers at all. However, in this study, only 19% of female spousal caregivers were the sole care provider to the dementia care recipient. This may be due to the sampling differences in two studies, such as age of the primary caregivers (70 vs 62), and primary caregiver and care recipient relationship (spouses only vs spouses and children). In addition, the physical and cognitive deficits of the dementia care recipient may not be equal in both studies. It is possible that the primary caregiver cared for more severe functionally disabled care recipients in this study than in Prucho's study. It also possible that primary caregivers substantially under-report or over-report the true extent to which others were involved in providing care.

Again, the current study shows a relatively low percentage of primary caregiver who do not obtain any assistance (14%) when compared to previous research findings which ranged from 25% to 62% of primary caregiver who did the care alone. Those studies did not target specifically dementia care recipients, but focused on caregiving provided to elders who had various medical problems including dementia, stroke, hip fracture, or Parkinson's disease (Miller, 1990; Stephen & Christianson, 1986; Stone, Cafferata, & Sangl, 1987; Tennstedt, McKinlay, & Sullivan, 1989). The difference may result from the unique demands that dementia patient care places on a primary caregiver, such as the need to handle a patient's behavioral problems due to cognitive deficit as compared to the need to care for his/her ADLs and IADLs only, which may decrease the likelihood of being the exclusive care provider. Thus, it seems that caregivers caring for care recipients with physical dependencies lead to more outside assistance, but caregivers caring for care recipients with cognitive deficits do not get that much outside help.

Given the total number of weekly instances of assistance across 25 tasks by the primary caregiver (36 instances) and the mean age of the primary caregivers (62 years old), this data suggests that elderly spousal caregivers, who themselves may be frail, may be less able to assist dementia care recipients with such activities as bathing or assisting with mobility than the younger caregivers.

Methodological Limitations

One of the limitations of this study was the use of a convenience sample. The sample only included caregiver/recipient dyads who used adult day care centers, health agencies or were included on the Alzheimer's Association mailing list. It is possible that caregivers connected with these types of agencies may receive support services that ease a general sense of burden, and thus allow caregivers to be more tolerant of the demands associated with caregiving tasks. However, the sample did not encompass caregivers who are “doing it alone”, who do not seek outside assistance or perceive that no assistance is necessary. In turn, these may influence the extent of being an exclusive care provider.

The reader should be cautious in generalizing these research findings to clinical settings. The lack of random selection of study participants limits the usefulness of study results.

Although most of the dementia caregivers are spouses in general, homogeneity among primary caregivers in relation to care recipient may influence the significance of findings. Most of the subjects in this research were spousal primary caregivers (68%); this fact restricted the comparison of various relationships between the primary caregiver and care recipients, and limited further informative findings.

Dementia care is a complex process that encompasses the family and not just a single individual. A limitation of this analysis is that it disregards the distinction between family and professional support.

Implications for Advanced Nursing Practice

The findings of this study would require minimal cost to incorporate into practice but would require the APN to use his/her case management role to provide the necessary holistic care to both the caregivers and their dementia patients. The APN may use the research role to replicate this study to determine the significance of predictors of being an exclusive care provider by the primary caregiver of dementia patient over time.

Upon entry into the health care system, the assessment of primary caregiver and care recipient characteristics, including caregiver's employment status, caregiver's and care recipient's living arrangement, and care recipient's functional status, is important before making recommendations for change in the current caregiving situation. Recognizing these factors may make a difference to the APN in anticipating and identifying primary caregivers who perform the daily caregiving responsibility alone, and who are at risk for inadequate support, i.e., the primary caregiver who is the spouse of care recipient, not employed, and caring for care recipient with fewer functional disabilities. This information may assist the APN in developing intervention strategies that are based on a family's unique caregiving needs. For instance, an attempt to mobilize potential family social support networks to give the primary caregiver "time out" on a regular basis is crucial to the not employed caregivers. This may help them to continue their caregiving role and to relieve the burden of performing the role. Providing some amount of formal services to primary caregivers and/or teaching the caregivers how to do the caring may be of interest to the working primary caregivers. Teaching the necessary skills in areas of weakness of the caregivers is necessary, when they care for dementia care recipients with more functional disabilities. This can help them to gain confidence and to decrease time involved with specific tasks. All of such strategies would need to be negotiated with the primary caregiver and delivered in a manner perceived as helpful.

Knowing the caregiver is the spouse of the care recipient, attention must be drawn to the potential fact that he/she is the exclusive care provider, and provides high level of overall care. As a result, the APN needs to be aware of the caregiver's health status and his/her ability to performing the caregiving tasks safely and exclusively. In addition, the adult child caregivers may need assistance in setting priorities to manage the competitive demands of multiple roles, i.e., patient care, employment, marriage, or dependent child care. For caregivers caring for dementia patients with fewer functional disabilities, open communication about the diagnosis of dementia and the nature of dementia may help the caregiver to make sense of the disturbing behaviors of the dementia patient, enable families to explain the patient's behaviors to others, and encourage families to plan ahead.

When a primary caregiver is the spouse of the care recipient, not employed, and caring for the care recipient with fewer functional deficits, this caregiver has a greater probability of being the exclusive care provider. This group of primary caregivers is an especially vulnerable population which deserves the APN's attention and priority care. Discovering the reasons of being an exclusive care provider would be critical before initiating care assistance. For instance, some long-term caregivers may have developed expectations according to which they feel that they alone are responsible for providing care to their dementia spouses. Thus, they have minimized the degree to which they rely on children, relatives, or friends. The use of a reliable behavior profile targeted to dementia sufferers can also be helpful to the primary caregiver and the APN. The caregiver can use the frequency of a behavior to plan the necessary degree of assistance and supervision. He/she can also complete the profile and refer to it to see how behaviors change and how their perception of problems change. If the frequency of numerous behaviors changes abruptly, an underlying medical condition may have developed. Medications might need to be reviewed. APN should have this knowledge when performing the clinician role. If the person has not been diagnosed, the completed profile will provide information to the APN about the individual's functioning and the caregiver's concerns. Especially when a person is not testable, reliable family information can offer a more complete picture of functioning based on the profile. As a counselor, the APN can use the profile to identify quickly behavior areas that are of great concern to the caregiver and thus provide additional support and/or interventions. For example, if the dementia person's wandering behavior is a concern to the primary caregiver, interventions should be taken immediately. At first, it helps to understand the possible causes of the wandering, such as if the wandering is an attempt to gain something (stimulation, food, security, or physical activity), a response to stressful environmental factors (too much noise or demands placed on the person), a reaction to fear, or created by medications. Then teach the caregiver specific strategies to handle it successfully, such as supervising the wandering constructively by walking with the dementia person in a safe and moderately stimulating area, involving him/her in an activity that helps burn off excess energy or ask him/her to do something with the caregiver, placing locks on outside doors that cannot be undone by the impaired person but which the caregiver can open easily, having the dementia person wear a MedAlert-type bracelet with his/her name and phone number on it, and so on. A physical examination on the dementia person can indicate the potentially dangerous outcomes of the wandering behavior, such as burn marks or bruises that come from unconsciously touching the stove or fall. Finally, in order to ensure the quality of formal care and informal care provided to the caregiver and the care recipient, evaluation of the care outcomes must be done on each caregiver and patient's follow up visit.

An APN evaluation of the actual caregiving involvement by the primary caregiver and/or other providers is essential even if the primary caregivers are not predicted to be the exclusive care provider. The APN may want to ask questions of the primary caregiver that would provide information about the time associated with caregiving activities. For example, it may prove useful to know the specific caring tasks required of the caregiver; the caregiver's perceived time spent on particular tasks, the number of instances of assistance the primary caregiver provides in a typical week, or number of hours spent in a day.

Being the only informal care provider to a dementia care recipient in a relatively long period of time places the primary caregiver at risk of suffering from negative psychological consequences. The APN must remember to explore the mental health of the caregiver. The APN's determination of the caregiver's ability to meet caregiving demands is crucial for the positive well-being of the caregiver. The APN may use her/his counseling role to evaluate the mental health status of the caregiver and provide assistance when the caregiver is in need of emotional support.

The APN should prepare to address the concerns of caregivers across all stages of dementia. Caregivers look to the APN for much more than medical evaluations; they also view the APN as a key source of information and referrals. Because many caregivers initially present the dementia patients for evaluation in primary care settings, there is a need for the APN to improve detection of dementia and initiate referral and education of caregiving families during early stages of dementia. APNs are in the prime position to deliver holistic care and examine all aspects of the caregiving process.

On the other hand, some primary caregivers of dementia patients choose not to access the formal system. They isolate themselves from the society, either because of the extensive time demand of caring that restricts them from social activities, or their perceptions of unavailability of informal or formal services. The APN must be aware of the presence of this hidden population in the community, find a way to discover them, and assist in providing care for both the dementia patients and their primary caregivers. In addition, it is necessary to understand that this problem can be offset to some extent if the caregiver is well supported by other family members or their community.

Information on resources of formal support should be given to primary caregivers, including home helps, meals on wheels, laundry services, visit from district nurses, and the provision of day care and respite care, enabling them to continue functioning, as well as improving the quality of life of the dementia patient.

Because issues associated with dementia have become a major public health issue, the APN will need to define her/his role within the health care delivery system in dealing with these issues. The APN in the primary care setting is in a key position to influence the care of dementia patients and the health of their caregivers.

Recommendations for future Research

Now that the characteristics of primary caregiver's employment status, care recipient's functional status and caregiver and care recipient relationship have been shown to be factors that predict a caregiver to be an exclusive care provider, further research on the topic needs to be done. Longitudinal research studies need to be undertaken to examine the predictive relationships between these factors and being the sole provider over time. Do the predictive effects between these variables remain stable; do they change; and what influences the change?

This study focused on the evaluation of five predictors (primary caregiver's gender and employment status, primary caregiver and care recipient relationship and living arrangement, and care recipient's functional status) of exclusive care provision by primary caregivers of dementia patients. Future research on this topic needs to include other variables that have the potential to be predictors of being the only care provider, such as primary caregiver's physical and mental health, household income, etc.

An experimental study that would examine factors that can be manipulated and that predict primary caregiver well-being would be interesting. Such an intervention study could include a time-out arrangement for exclusive care providers to see if it leads to the avoidance of negative psychological effects on the primary caregiver.

On the other hand, as the health care system continues to seek ways to transfer responsibility for continuing care from the formal system to the family system, future research needs to examine how the formal system can assist caregivers to manage caregiving in cost-effective ways that will promote and achieve optimal patient outcomes, especially for the primary caregiver who is not sharing care duties with others. For example, the outcomes of patients cared for by spouses who have no assistance might be compared with age and problem matched patients cared for by spouses assisted by families and/or formal care providers.

Participants in this study were predominantly female, spouses, and white. Future research should attempt to persuade more male caregivers, nonspousal caregivers and minority caregivers to participate in research studies. Research studies also need to find a way to include the elusive caregivers who have isolated themselves and their dementia patients from formal caregiving programs or who have chosen not to use services or seek assistance in their caregiving role.

APPENDICES

APPENDIX A

APPENDIX A

Patient Cognitive Deficit Scale

Primary caregivers were asked: “How frequently has your relative displayed the following behaviors?” Answers categories included “not at all” (=0), “sometimes” (=1), “most of the time” (=2), “always” (=3). The scale includes the following seven items:

Does your relative recognize familiar people?
Does your relative seem confused?
Does your relative forget what day it is?
Does your relative get the present mixed up with the past?
Does your relative ever forget where he/she is?
Does your relative ever forget important or recent events?
Does your relative repeat himself/herself or ask the same question over and over again?

Cronbach’s Alpha = .87

APPENDIX B

APPENDIX B

MICHIGAN STATE
UNIVERSITY

March 5, 1998

TO: Manfred Stommel
A-230 Life Sciences Building

RE: IRB#: 98-075
TITLE: PREDICTORS OF EXCLUSIVE CARE PROVISION BY PRIMARY CAREGIVERS OF DEMENTIA PATIENTS
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 02/13/98

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

RENEWAL: UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the green renewal form (enclosed with the original approval letter or when a project is renewed) to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

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

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

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

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:bed

cc: Nga-Lee Shum

OFFICE OF
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**University Committee on
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