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SPOUSAL CAREGIVING INVOLVEMENT IN THE NURSING HOME

By

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ABSTRACT

SPOUSAL CAREGIVING INVOLVEMENT IN THE NURSING HOME

By

Frances L. Markley

A non-experimental ex post facto descriptive study of 53 spouse caregivers who had institutionalized a spouse with Alzheimer's disease or a related dementia was performed to look at visiting patterns and involvement with care within the institution.

Data were taken from an original study "The Impact of Alzheimer's Disease on Family Caregivers", funded by the National Institute of Mental Health, #NIMH 2R0141766, by Clare Collins, R.N., Ph.D., F.A.A.N., Principal Investigator. Data were analyzed using frequency and central tendency.

Spouse caregiver visiting and involvement of eight Activities of Daily Living were examined: eating, dressing, grooming, bathing, toileting, walking, getting in and out of bed and moving in bed. Spouse caregiver involvement was highest for eating, grooming and walking. They visited an average of 26 days a month with a mean time of 108 minutes. Results indicate spouse caregivers continue to care for their husbands or wives after placement in an institution.

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CHAPTER 1

INTRODUCTION

Problem background

The growth of the elderly population of the United States is now greater than at any other time in history. At the present time there are 11.3% Americans over age 65 and it is projected that both the number and the proportion of the elderly population will continue to grow (Greene, Monahan & Coleman, 1992). It is forecasted that 4.6 million Americans will be over age 85 by the year 2000, an increase of 30% since 1950 (U.S. Department of Public Health and Human Services, 1991). The distribution of the population is shifting toward the older end of the age distribution scale.

Two age classifications of the elderly are posited by Neugarten (1974): ages 55 to 74 as "young old", age 75 and older as "old-old". A third posited by Green et al.(1992) is 85 years and older as "oldest-old".

Corresponding to the increase in the elderly population is an increase in the number of elderly people with disabilities. Bowers (1987) describes 6.3% of the U.S. population under 70 as extremely impaired, with the percentage increasing to 22% for those over 85 years of age.

Projections indicate that increasing numbers of couples will be categorized as elderly and suffering chronic health problems (Deimling & Poulshock, 1985). A study of older adults in the community found one third of the elderly rated their health as fair or poor (Adams & Collins, 1987).

The increasing percentage of the population in the United States classified as elderly implies a greater demand for geriatric primary care services. Studies about the activities and abilities of the elderly are meaningful to healthcare providers because knowledge about their characteristics is essential for the provision of health maintenance and promotion services for elderly clients by Advanced Practice Nurses (APNs). Research in geriatric healthcare is relatively new. Researchers have historically utilized younger populations for healthcare studies. Consequently there are few healthcare protocols for the older population supported by research studies of older people. Surveys show there is lack of geriatric scientific knowledge to adequately educate healthcare professionals serving the elderly population. There is a need for more scientific data about the elderly population in order to increase the foundation of current geriatric knowledge (Green, et al., 1992).

This study will generate knowledge about activities and abilities of one segment of the geriatric population, the elderly spouse caregiver. Elderly spouse caregivers may present to primary care providers with health problems

related to caregiving. The potential for health problems increases as the spouse caregiver increases assistance with activities of daily living (ADLs) (Barnes, Given & Given, 1992). It is not unusual for spouse caregivers to experience a deterioration in their own health. This can occur while the spouse is caring for their husband or wife at home or in a long term care facility. When spouse caregiver presents to primary care for help, the APN will be able to utilize research knowledge about elderly spouse caregivers.

The transition from home care to institutional care is a momentous event for an elderly couple. Spouse caregivers of institutionalized persons may experience stress and negative emotions surrounding nursing home placement (Riddick, 1987). A study by Townsend, Heiselman and Deimling (1989) indicate some levels of stress may be chronic for the spouse caregiver and may persist for years after admission. In primary care the APN must be able to recognize negative psychological and social impact upon spouse caregivers of institutionalized residents.

Knowledge about spouse caregiving activities in the nursing home as well as the visiting frequency and duration may be useful for supporting the spouse caregiver in identifying effective coping strategies related to institutionalization (Pratt, Schmall, Wright & Cleland, 1985).

Caregiving

Historically caregiving is a family task with family members providing most of the care for the elderly (Montgomery, 1985). Caregiving begins in the family as a family member experiences a transition from an independent lifestyle to that of dependency. The principal family caregiver usually is the spouse, followed by adult daughters and then daughters-in-law (Brody, 1981). A study by Stone, Cafferata and Sangl (1987) found 65% of community elderly, with one or more limitations in activities of daily living (ADLs), were cared for by husbands, wives or adult daughters.

Dependency in one or more ADLS usually requires the assistance of a caregiver. ADLs are those activities which are regarded as essential for an independent lifestyle. ADLs address basic physical care needs such as bathing, dressing, toileting, mobility, and eating. Caregiver assistance with ADLs may range from minimal assistance to complete performance of an activity. For example, with bathing, assistance may range from minimal assistance such as washing the spouse's back to total assistance, washing the entire body. Assistance with dressing may range from getting clothes out of closets and drawers to dressing the spouse completely. Toileting assistance may range from helping reach the toilet to cleaning the spouse after elimination. Mobility caregiving assistance may range from providing support with an arm to extensive lifting the spouse, while

eating assistance may range from placing the food on the table to actually putting food in the spouse's mouth. (Katz, Downs, Cash & Grotz, 1970)

The onset of caregiving usually begins with providing help with Instrumental Activities of Daily Living (IADLs). These supportive activities do not involve direct physical care, but they include housekeeping, food preparation, use of the telephone, doing laundry, dispensing medicine, transportation, handling finances, shopping and performing home maintenance duties. Caregiving involving IADLs may range from minimal to maximal assistance. For example caregiver assistance with housekeeping may range from minimal assistance with heavy chores to total assistance with all housekeeping chores. IADL dependency typically begins with a spouse experiencing some difficulty with the activity and progressing to complete inability to perform any aspect of the IADL, resulting in the caregiver assuming full responsibility for the activity (Chenitz, Stone & Salisbury, 1991).

In addition to providing physical care, caregiving involves providing for psychological needs, which includes promoting and maintaining emotional and spiritual well-being (Perlin, Mullan, Semple & Skaff, 1990). Illness in the older population makes them more at risk for mental and social deficits than the younger population (Hogstel, 1990). The family caregiver most often serves as the counselor and

confidant for the impaired family member (Brody, Johnson & Fulcomer, 1984).

The role of caregiving can involve physical, financial, social, and interpersonal strains that may eventually exceed the capabilities of the caregiver (Stull, Kosloski & Kercher, 1994). Often the family caregiver performs the role until the strains of the caring tasks become too difficult to fulfill. There are two major conditions in the role that tend to determine the continuation of caregiving in the home: the caregiver's health and the spouse's level of impairment (Edelson & Lyons, 1985). Progressive deterioration of the spouse's health and mental status increase the need for more intense caregiving which may be beyond the physical and mental capabilities of the family caregiver (Johnson & Werner, 1987). Spouse caregivers are usually forced to consider placement of their husbands or wives in an institution.

Shared caregiving after institutionalization

In the population above age 65 about 5% are institutionalized and that number increases to 20% in the population over age 85 (Hing, 1989). In nursing homes the majority (70%) of the population suffers from either depression or a cognitive disorder (Rovner & Rabins, 1985). Dementia, a cognitive disorder, is characterized by impairment in memory and reasoning ability. Alzheimer's Disease is a non-reversible cognitive disorder with no known

treatment. It is characterized by change in the individual's emotional expression accompanied by persistent and progressive loss of mental abilities, disrupting daily life. Other behavioral symptoms include hallucinations, delusions, wandering, sleep disruption, crying, inability to care physically for self and inability to communicate (Cohen & Eisdorfer, 1986). Alzheimer's disease and depression are the primary mental health problems found in nursing home populations (Hogstel, 1990).

Spouses who provide care in the home may eventually be pressured to institutionalize their husbands or wives. Placement of a husband or wife is one of life's most difficult decisions (Dobrof & Litwak, 1977). Spouse caregivers resort to institutional placement only after exhausting all other possible alternatives for assistance with care (Brody, 1977).

It is not unusual for spouse caregivers who institutionalize their husband or wife to develop guilt feelings after placement (Edelson & Lyons,1985), and many family caregivers continue to provide care for their loved one after institutional placement (York & Calsyn, 1977). After placement, spouses frequently visit their husbands or wives in the nursing home. Institutionalization of husbands or wives does not completely take away all caregiving activities, some aspects of caregiving may actually increase after institutional placement (King, Collins, Given & Vredevoogd, 1991).

The role of the spouse caregiver changes after placement of their husband or wife in a long term care facility. After institutionalization the spouse caregiver relinquishes control of many caregiving responsibilities as well as how caregiving is carried out. These responsibilities are taken over by the institutional staff. Health care workers in the nursing home are prepared to provide most of the caregiving formerly provided by the spouse caregiver. At this point, the role of the spouse caregiver changes from primary caregiving to shared caregiving. The spouse caregiver may experience difficulty with the new shared caregiver role in the nursing home (Willoughby & Keating, 1991). The role transition for the spouse involves relinquishing caregiving responsibilities while at the same time adapting to a new and formal health care structure without defined caregiver responsibilities.

Clear descriptions of the role of the spouse caregiver after institutionalization of their husband or wife are not known. Surveys of nursing home personnel and families about the role responsibilities of both staff and family indicate overlapping of duties as well as ambiguity of role responsibilities (Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990). Litwak (1981) proposed a theory of shared functions and balanced coordination of caregiver behaviors between staff and family, suggesting staff have primary responsibility for technical tasks, while family members perform non-technical tasks, although some overlapping may

occur. Technical tasks are repetitive basic nursing direct care tasks which are distinguishable for billing purposes, whereas non-technical tasks are individualized such as applying make-up and supplying special preferred food for patients. A lack of coordination and shared caregiving role functions between the spouse and the staff will result in decreased quality of care (Litwak, 1981).

Spouse caregivers lose considerable control over the care of their husbands or wives after institutionalization (Bowers, 1987; Hasselkus, 1988; Rubin & Shuttlesworth, 1983,); and family caregiving becomes less task oriented, (Bowers, 1987; Hasselkus, 1988) as the physical care formerly provided by the spouse is now performed by the nursing home staff while the spouse assumes the responsibility of quality care assurance. Insuring quality care for their loved one is the highest priority for family caregivers (Bowers, 1987). After the surrender of responsibility for many tasks, the spouse may be anxious about the care the staff will provide (Edelson & Lyons, 1985). Spouses assign the staff to provide professional physical care for their loved one while they assign themselves the role of non-technical, social, spiritual and emotional care (Bowers, 1987). In the new situation, families expect to assume a recognized, responsible caring role within the institution (Schwartz & Vogel, 1990). Important elements of the shared caregiving role for the family include teaching, demonstrating, giving advice for

personalized care, observing staff and educating staff to relate personally rather than technically (Duncan & Morgan, 1994).

The stress of transferring total care in the home to sharing care with professional health care workers is compounded by the ambiguity of the role for spouse caregivers in the institution. Various studies describe failure on the part of the institution to support the families during the time of transition (Edelson & Lyons, 1985; Montgomery, 1982; Pratt, Schmall, Wright,& Hare, 1987). Nursing home staff are often described as adding to family distress (Vinton & Mazza, 1994) at the time families are seeking a shared role in caregiving, by resisting the families efforts (Hansen, Patterson & Wilson, 1988).

Families seek active involvement in caregiving within the institution (Hansen, et al., 1988). Studies (Bowers, 1987; Moss, Lawton Kelban & Duhamel, 1993; Shuttlesworth et al., 1982) advocate the cooperation of institutional staff with the families in caregiving activities. A study by York and Calsyn (1977) of 76 patients and their families suggested programs to help family members cope with stress resulting from institutionalization. Montgomery (1982) after interviewing 104 rural nursing home residents and 66 family members concluded family must also be viewed as a client by the institution. Duncan and Morgan (1994) in a study of 179 family caregivers of Alzheimer's Disease patients summarized

that families expect recognition from nursing home staff and that they possess expertise that could contribute to their family member's care.

Studies by several researchers demonstrate family caregivers continue to provide care after placement of their family member in a long term care facility. By their presence and activities in the nursing home they model a quality of care role for their institutionalized family member. By involving themselves in ADL care home they attempt to educate the staff about the appropriate methods of care for their family member.

Statement of the Problem

What is the frequency of visits and type of each ADL performed by spouses for their institutionalized husbands or wives in a long term care facility?

Purpose

The purpose of this descriptive study is to examine the frequency with which spouse caregivers assist with the ADLs of their institutionalized husbands and wives. Identification of those caregiving tasks performed by the spouse will provide information for the ANP in primary care. This information will provide guidance for nursing interventions in the plan of care for spouse caregivers in need of healthcare services. Knowledge about the spouse caregiver's daily activities guides the nursing process. The

process is holistic, involving not only the client's physical health but also the social and environmental aspects of the client's welfare. ANPs providing primary care for the older spouse caregiver should be aware of the amount of caregiving being done by the spouse in the nursing home. With this knowledge, APNs are able to plan nursing interventions for spouse caregivers.

Results of research studies call for further studies in long term care facilities and family involvement in the caregiving process (Bowers, 1988; Maas, Buckwalter and Kelly, 1988; Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth et al., 1982). A study focusing upon the specific care activities performed by spouses for their institutionalized husbands or wives would provide information about caregiving in nursing homes and may reveal the emotional needs of the spouse caregiver whose husband or wife has been institutionalized.

As an educator, the APN may educate the nursing home staff about involvement in ADL care demonstrated by spouse caregivers. It would be beneficial for nurse assistants to know how spouse caregivers can contribute to the care of their family member. Knowledge may improve cooperation between staff and spouse caregivers. Quality of resident care may improve when there is more cooperation between the staff and the residents' spouses. The APN demonstrates leadership demonstrated in the rapidly changing long term care environment when nursing education and actions are

based upon current knowledge generated from scientific nursing research.

Definition of concepts

Spouse caregiver:

The self-acknowledged caregiver who has had primary responsibility for providing assistance to his/her spouse who is over age 55, now institutionalized and in need of assistance in one or more ADLs.

Long term care facility or nursing home:

An institution which provides living accommodations and care for impaired elderly in need of personal health care.

Activities of Daily Living (ADLs):

Personal care related to eating, dressing, combing hair or shaving, showering or bathing, using toilet, bedpan or commode, walking, getting in and out of bed and moving in bed.

Level of involvement in ADL caregiving:

The number of times each week the caregiving spouse assists with the above described ADLs in the institution.

Research questions

1) With what frequency do spouse caregivers visit with their husbands or wives in a long term care facility?

2) What is the duration of the spouse caregiver visits with their husband or wife in a long term care facility?

3) What are the frequency and type of ADLs performed by the spouse caregiver for their husband or wife in a long term care facility?

Limitations

Limitations of the study include the following:

1) Volunteers composing the sample may possess characteristics different from caregivers who did not volunteer to participate in the study which are unknown to the researcher.

2) The varied length of institutionalized time among the participants at study intake may influence the study results by reflecting relocation adjustment levels.

3) The level of spouse activity of daily living (ADL) caregiving may be limited by their state of health and ability to perform ADL care.

Assumptions

The following methodological assumptions are made:

1) Caregiver responses reporting caregiving involvement are accurate.

2) The instrument used to measure caregiver involvement of the spouse accurately reflects ADL caregiving.

The following are conceptual caregiving involvements assumptions in this study:

1) Spouse caregivers can identify their husbands or wives needs for ADL care.
2) There are no barriers in the nursing home which prevent the spouse caregiver from performing ADL care.

Conceptual framework

The focus of this study is to investigate spouse involvement in caregiving after institutionalization of their husbands or wives. One component of Bower's theory of family caregiving, instrumental care, provides the basis for this study. The concepts of spousal caregiving and ADL involvement will be integrated into Bower's theoretical framework.

Bower (1987) investigated aspects of caregiving from the caregivers' perspective. Her qualitative study revealed that the process of caregiving is much more complex than the commonly used definitions of caregiving. Traditional caregiving has been defined in terms of performance of specific caregiving tasks, while Bowers, in addition to task performance, defines caregiving as being particular meaningful or purposeful for the caregiver.

Bower's description of caregiving from the caregiver's purposeful perspective has three important principles. First, observable behaviors and mental activities are included in the caregiving definition. Caregiver's plans and

decisions, which are not observable actions, have essential consequences in caregiving. Second, caregivers make the decisions for defining an activity as a caregiving act. Those who are not responsible for providing care tend to be unaware of all the components of caregiving. That is, caregivers are more likely to describe an activity as caregiving than would a non-caregiver. Lastly, caregivers may perceive an activity as having more than one purpose. For example, combing their spouse's hair may be perceived as a gesture of caring or a technical task or both. An activity such as combing hair may be used to communicate different messages and often the meaning or purpose intended by the caregiver is not the same meaning or purpose perceived by non-caregivers. Conflict and misunderstanding between caregivers and non-caregivers occurs in many situations in the caregiving process (Bowers, 1987).

Bower's (1988) study of family caregivers of relatives in nursing homes resulted in her categorical descriptions of caregiving. The caregiving activities of family caregivers are classified into five categories: preservative care, supervisory care, preventative care, anticipatory care and instrumental care. These five groupings have direct influence upon the actions of the family caregiver. Only instrumental care retains the traditional definition of caregiving, that of a "hands on" task specific activity. The tasks of ADLs are classified by Bower as instrumental

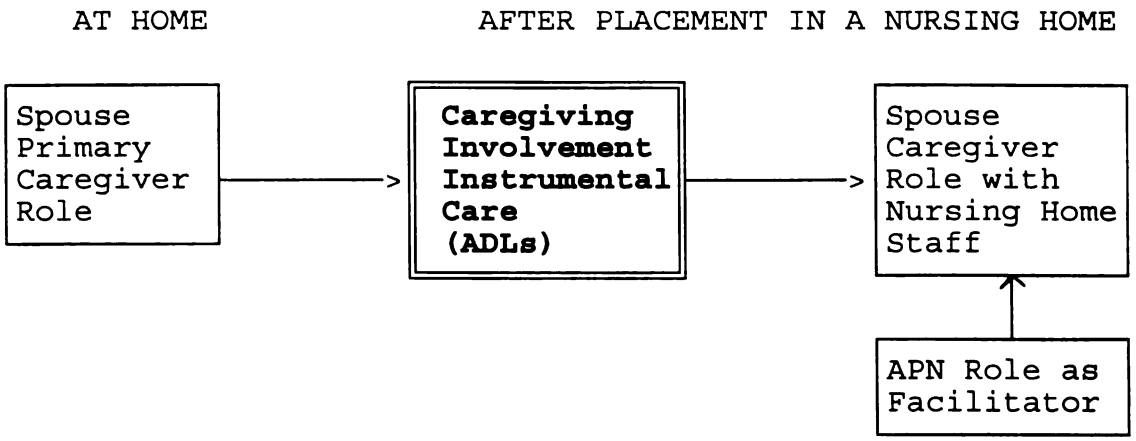
caregiving and are considered essential activities of caregiving.

Bower's concept of instrumental care will be used to guide this study. Assistance in the nursing home with performance of any of the basic ADLs will be examined. The activities include: eating, dressing, grooming, bathing, toileting, walking, getting in or out of bed and moving in bed.

Bower's family caregiving theory describes caregiving from the perspective of the family member who is considered to be primarily responsible for providing care for a family member. Family caregivers may be daughters, sons, wives, husbands, nieces and nephews. Utilizing the family caregiver concept, this study will focus only upon the activities of the family spouse caregiver. Bower's concepts for caregiving provide the framework for studying the type of spouse caregiving involvement after placement of their husband or wife in a long term care facility.

Bower's (1988) theory of family caregiving is an effective way of looking at the involvement in ADLs care by the spouse caregiver after institutionalization (see Figure 1). The theory describes caregiving activities performed by family members in the nursing home. Bower's theory provides the basic framework for this study and is utilized to illustrate one behavioral aspect of continued spouse caregiving, instrumental care, after institutionalization of a husband or wife in a nursing home.

Figure 1. Spouse Caregiving Role in the Nursing Home



CHAPTER 2

LITERATURE REVIEW

Caregiving involvement after institutionalization

Activities of ADL caregiving provided by family caregivers are investigated as involvement in ADL care by spouse caregivers is central to this review.

York and Calsyn (1977) performed a caregiver role study in long term care by comparing family involvement before and after nursing home placement of an elderly relative. Sample included 76 patients and their families. Caregivers were 64 adult children; the remaining 12 were either spouses, nieces, nephews, brothers or sisters. Data collected from family interviews indicated that in general, families do not abandon their older relatives. Many families help their older relatives prior to nursing home placement and tend to stay involved with their relatives after institutionalization. Results of the study were limited in describing actual activities performed by family members and by the small number of spouses in the sample.

A study was done by Shuttlesworth, Rubin and Duffy (1982) to determine whether the family caregiver or the nursing home staff felt obligated to perform predetermined caregiving tasks. Nursing home administrators (n = 56) and

relatives (n = 110) designated in the chart as "responsible party" were surveyed using a 100 item ("essential" services) inventory. Items on the inventory which are commonly described as duties of caregivers, were grouped in the following categories: personal care, housekeeping, diet, activities, patient care, counseling, medical care, security, family relations, administration, transportation, supplies and special needs. There was nearly complete agreement of responsibility for 55 of the tasks. There was considerable variation of claimed responsibility for the remaining 45 tasks items. Most significant discrepancies were demonstrated in the categories of: personal care, housekeeping, activities, patient care, family relations, supplies, counseling/emotional and extras. In these areas both the nursing home administrators and family members claimed responsibility for task performances, possibly leading to incongruent caregiver role expectations. This might suggest possible conflict with the nursing home staff and the spouse caregiver relevant to instrumental care.

This study on caregiving tasks was limited by a non-probability sample which limits generalization. The sample was exposed to a preselected task list which may not have included all possible task responses. Selecting only the nursing home administrators to participate in the survey along with relatives who visited the home with a relatively high degree of frequency excluded opinions of staff direct care workers and possibly other important family members.

Rubin and Shuttlesworth (1983) conducted a second study using the same measure and included the nursing home personnel (administrators, dietary, housekeeping, Rns, LVNs and nurses aides). Relatives of residents who described themselves as both highly involved and not involved with care were included in the sample. The results were similar to the first study resulting in both staff and family claiming responsibility for specific caregiving tasks. Results specific to spouses were not reported.

Schwartz and Vogel (1990) used the same 100 item ("essential" services) inventory but modified the scoring procedure to include family and staff shared responsibility of tasks. Administrative, direct care and supportive staff in 50 nursing homes in California and Ohio and 144 residents' family members responded to the survey. Overlapping of task assignment by both staff and family still occurred however, families who visited less often and those with relatives institutionalized one to three years assigned more responsibility to the staff for specific tasks. The staff rated personal care tasks as more their responsibility while relatives indicated a willingness to share in those activities. This study examined desired or projected behaviors and not the actual caregiving behaviors. Responses from spouse caregivers were not reported. All three of the above studies indicate over-lapping instrumental caregiving by family members and institutional staff.

Using a convenience sample (n = 315) of community spouse caregivers of Alzheimer's disease or a related disorder, Pruchno (1990) examined ADL caregiving. The sample was primarily female (68%) and white (86%) with a mean age of 70 years. Respondents reported the degree of caregiving involvement in 7 ADLs. The time spend in caregiving averaged 75 hours a week. The performance of ADL care was the following: toileting (47%), eating (53%), personal care (67%), bathing (66%), getting around (18%), dressing (73%), getting in and out of bed (30%). The results of this study are from community caregivers and probably would not reflect spousal caregiving involvement with ADLs in an institutional setting. What is notable is the amount time spent per week by the spouse in providing care in the home.

Dempsey and Pruchno (1993) sampled 107 children of elderly nursing home residents. From a list of 28 daily caregiving tasks, respondents were asked to indicate who was currently doing the task as well as who they felt should be doing the task. The tasks were identified as technical or non-technical. If 70% or more of the respondents assigned a task to the family the task was identified as non-technical. Tasks that received less than 70% of respondents' assignment of responsibility to family members were identified as technical. ADLs were termed technical tasks in the study. Half of the respondents reported not performing any technical tasks while the other half reported performing one

or more of the technical tasks. The study discovered significant relationships for the respondent family members involvement in technical tasks. Factors attributed to more family respondent involvement in technical tasks were: higher number of non-technical tasks done by the respondent, younger respondents, female respondent, greater frequency of visits, younger parent, female parent, parent's cognition status, greater number of parent's illness, larger nursing homes, staff doing more technical tasks and poorer perceptions of the staff. Using the sample responses to identify the technical and non-technical tasks was a limitation of the study as different sample sets may define technical and non-technical tasks differently. Also, adult children caregiving may not reflect caregiving by spouses.

A qualitative study of family caregiver focus groups, 76 spouses and 103 adult children of institutionalized Alzheimer's disease residents, revealed family members desired more emotional and social involvement than task involvements. Families expected the staff to perform technical or hands-on care with expertise, suggesting that spouses are on alert for the quality of ADL care the staff provides for their husbands or wives. The study was limited to institutionalized dementia residents possible preventing generalizing to nursing home populations (Duncan & Morgan 1994).

Moss et al. (1993) investigated time use of caregivers in a longitudinal study of impaired elders before and after

institutionalization. Subjects were recruited from applicants for admission to 12 nursing homes and from a state agency which screens prospective Medicaid candidates for nursing home admission. Interviews of 165 caregivers expecting to institutionalize their family member produced a sequential report of all activities of the waking day (Yesterday interview). At the Time 2 interview, at least 3 months post institutionalization, 77 elders had moved to a nursing home. ADLs examined were personal care and eating. Personal care dropped from a mean time of 42 minutes per day to 1 minute per day, and eating assistance mean was reduced from 8 minutes to 2 minutes per day. Caregivers averaged a daily gain of 107 free minutes after institutionalization. Only 10.3% of the sample were spouses. The study does not provide information for generalizing spouse caregivers involvement with caregiving activities, but it does infer that not as much time is spent for caregiving in the institution as was spent in the home, and that personal care time was reduced substantially after institutionalization. Another limitation is possible inaccuracies of recall by the respondents when using the "Yesterday" interview method.

These studies of family caregivers of institutionalized elderly indicate the desire of families to remain involved with caregiving after institutionalization. Some ADL care is provided by family members after institutionalization, but specificity and frequency is not reported. Family caregiving studies do not report particular activities of spouse

caregivers. Consequently the few spouse responses reported in the studies leave a lack of information about specific spouse caregiving activities in the nursing home.

Frequency of visits

The frequency of visitors to residents in a long term care facility remained stable for more than a year in a study by Spasoff et al. (1978). Data were collected approximately one year after institutionalization from 95 residents (67 women and 28 men). Friends and relatives visited frequently, with relatives visiting a few times more each week in most cases. The visiting pattern reported one month post institutionalization was the same as that reported a year later. The report does not detail the visiting patterns nor relationship of visitors to the residents in the institution. Although the study is of long duration it reveals only very general information about visiting frequency in institutions of long term care. The results may imply that spouse caregivers would continue to visit their husbands or wives for the duration of their institutionalization.

Visiting frequency of residents in nursing homes may be approached from the perspective of the amount of discretionary free time reported by elderly people in the community. Moss and Lawton (1982) studied four subject groups contrasting in both individual characteristics and in the environments which they lived. The groups were: 235

independent community residents, 158 independent public housing tenants, 91 recipients of high-intensity in-home service and 51 persons on an institutional waiting list. The mean age of the subject groups was 76 years, and 60% of the group subjects were women. The overall waking day time spent in obligatory activities (working) ranged from 34% in the community group to 27% in the waiting-list group, leaving approximately 7 hours of discretionary activity time for elderly people in the community. This might imply spouses would have several free hours each day to visit their husband or wife in the nursing home. The study participants were not caregivers and their reported free time could not be generalized to caregivers.

Hook, Sobal and Oak (1982) used a questionnaire to assess the frequency of visitation at three nursing homes on three consecutive Sundays, surveying 629 visitors. The sample contained very few spouses (1.1%). Travel distance to the nursing home had some influence upon visiting frequency as there were fewer visits by visitors living greater distances from the nursing homes. Few visited daily (5%), 14% visited semiweekly, 36% visited weekly, 18% visited semimonthly, and 11% visited monthly. Since the sample lacked spousal representation the results can not be generalized to that group. The short duration and reliability of the respondents for recalling answers to the questionnaire may be limiting factors of the study.

Zarit and Whitlach (1992) reported nursing home visiting frequency by sampling 77 family caregivers. Their family member had dementia and had been institutionalized an average time of 190 days. The sample contained about 19% wives, 23% husbands and 26% daughters. These caregivers continued to be involved in care in the institution, as more than half reported some type of ADL assistance. Frequency of visits was reported to be almost 4 days a week, with a mean of 6 hours on weekdays and 3.4 hours on weekends. This study revealed greater frequency and contact time than previous studies, but it does not indicate specific involvement in ADLs care frequency or visits by the spouse caregivers.

Summary

The reviewed studies indicate elderly people in general have several hours of free time each day which may be used for visiting. The results of visiting time in nursing home studies are generalized, providing little visiting information specific for each family member. Frequency of visits and length of visiting time specific for spouse caregivers to their husband or wives in the long term care facility are not found.

Literature review for spouse caregiver involvement post institutionalization has shown that several researchers refer to one type of caregiving as ADL care which would be classified by Bowers as instrumental care. Most of the research is directed toward community caregivers for

Alzheimer's disease and related disorders. ADL time allocation is often generalized as personal care. Most family caregivers studies do not distinguish between the caregiving provided by various family members. Few studies report caregiving characteristics specific for spouse caregivers. This literature review describes no clear picture of frequency in which spouse caregivers perform ADL care after institutionalization.

CHAPTER 3

METHODOLOGY AND PROCEDURE

Original research

The original study titled "The Impact of Alzheimer's Disease on Family Caregivers" was funded by the National Institute of Mental Health, #NIMH 2R0141766, to Clare Collins, R.N., Ph.D., F.A.A.N., Principal Investigator. It was a four-year longitudinal study of community residents. The subjects were family caregivers for a family member with Alzheimer's Disease or related dementia. The purpose of the study was to examine caregiver reactions to providing care for persons with a dementing disease over time. Caregiver reactions were studied following the transitions of institutionalization and death.

The sample subjects were solicited through local chapters of the Alzheimer's Association, Michigan Association of Adult Day Care Centers and health-care agencies in Southwest Michigan. Caregivers interested in becoming a study participant returned a postcard to the principal investigator. Trained interviewers screened the caregivers to determine eligibility for entry into the study.

A convenience sample (n = 338) of family, self-identified caregivers, providing the most care to a relative with dementia was selected to meet the following criteria: 1) 55 years of age or older; 2) dependent in at least one basic activity of daily living (ADL) and one instrumental activity of daily living (IADL); 3) diagnosed as having Alzheimer's disease or other irreversible dementia; and 4) a resident in the community at the time of entry into the study. Written informed consent was obtained from each caregiver. Approval for the study was obtained from the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University.

The original study design was to interview respondents every twelve months. Actually, the average time for the second data collection was twenty two months after the first collection, entry into the study, and the third collection time averaged fourteen months later (Collins, 1993).

Design

This research is a non-experimental ex post facto descriptive study. The study purpose is to describe the involvement in ADL care by spouse caregivers after placement of their husbands or wives in a long term care facility.

Research questions

1) With what frequency do spouse caregivers visit with their husbands or wives in a long term care facility?
2) What is the duration of visits by spouse caregivers with their husbands or wives in a long term care facility?
3) What are the frequency and type of each ADL performed by spouses for their husbands or wives in a long term care facility?

Operational definitions

Spouse caregiver:

The spouse of an elderly person in a long term care facility who was the self-identified caregiver providing the most care prior to institutionalization.

Visit frequency:

The number of visits per month as identified by question 2 of the survey instrument.

Visit duration:

The mean number of minutes per visit per month as identified by question 3 of the instrument.

Level of involvement:

The frequency with which spouse caregivers assist their husbands or wives with ADL care per week, identified by questions 4a, 5a, 6a, 7a, 8a, 9a, 10a and 11a in the survey instrument.

(see Appendix A for copy of questionnaire)

Sample

The sample participants for this study are spouse caregivers of dementia patients who institutionalized a husband or wife in a long term care facility during the course of the original study.

Sociodemographic data

The variables presented for examination in this study are age, race, gender and education.

Visitation and ADL involvement

Data for spouse visiting patterns were obtained from responses on the Involvement Scale Items instrument. Participants were asked if they visit their spouse once a month or more. If the response was yes, they were asked the average number of visits and the average number of minutes per visit.

The Involvement Scale Item instrument also identified the institutionalized husband's or wife's need for assistance with ADL care as perceived by the spouse caregiver. Responses for each of the eight basic ADLs were solicited with a five-point Likert scale selection (Given, Keilman, Collins & Given, 1990). This instrument, operationalizing frequency of ADL care, is a modified version of the Cornwell Involvement Inventory (Given, B. & Given, 1985). On the Involvement Scale Item instrument, respondents were asked if their relative needed assistance

with specific ADLs. The 8 ADLs were: 1) eating, 2) dressing, 3) combing hair or shaving, 4) showering or bathing, 5) toileting or using bedpan or commode, 6) walking, 7) getting in or out of bed and 8) moving in bed. A "yes" response led to a second part of that question, a list, requesting customary assistance with the ADL. Five frequency options measuring spouse frequency of involvement in each of the activities included once a week or less, several times a week, once a day, several times a day and I do not help.

Reliability

Reliability is defined as "the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure" (Polit & Hungler, 1991, p. 653). The Involvement Scale Items instrument is a modified version of the Cornwell Involvement Index instrument which measures Activities of Daily Living and Instrumental Activities of Daily Living. The portion of the Cornwell Involvement Index instrument which measures ADLs was analyzed for reliability. The alpha coefficient was 0.89 (Given, B. & Given, 1985).

Protection of human rights

The study data set are stored on diskettes in the College of Nursing at Michigan State University. Approval of human rights protection procedures for this study was

obtained from the University Committee on Research Involving Human Subjects (Appendix B).

Analysis of the data

Sociodemographic data, age, race, gender and education are described in terms of mean and range and percentage. Spouse caregiver visitation with their institutionalized husband or wife is analyzed for frequency and duration with means, range and percentages. Participation in numbers of ADLs by spouse caregivers is shown by percentage of the sample group. A frequency distribution indicating the amount of assistance provided by the spouse caregiver for each of the eight ADLs is utilized.

CHAPTER 4

RESULTS AND DISCUSSION

Sample and background material

A total of 53 spouse caregivers reported placing a husband or wife in a nursing home. Spouse gender was almost equally balanced as 53% (N = 28) were females and 47% (N = 25) were males. The average age was 69 years. The sample was 98% caucasian, and 54.7% possessed some college or professional education. Characteristics of the spouse caregivers are displayed in Table 1.

Table 1
Selected Demographic Caregiver Characteristics (N = 53)

Group	N	%	Mean	Range
Gender				
Male	25	47		
Female	28	53		
Age			69	51-86
Race				
White	52	98		
Black	1	2		
Education				
Grade School	5	9.4		
Some High School	5	9.4		
High School Graduate	14	26.4		
Some College or Professional Education	29	54.7		

The mean age of the institutionalized husband or wife was 71 years with a range of 56 to 84 years. The average length of institutionalization was 11.5 months with a range of 1 to 20 months.

Research question

1. With what frequency do spouse caregivers visit their husbands or wives in a long term care facility?

With the exception of one wife, all spouse caregivers visited their husbands or wives at least monthly. The range of visits was very wide, from 1 to 90 a month, with an average of 26 visits a month. Table 2 displays the visitation pattern.

Table 2
Monthly Visits of Spouse Caregivers to Nursing Home

Number of Visits	Percent of Respondents	N (N = 50)
1	1.9	1
4	5.7	3
7	1.9	1
8	5.7	3
9	1.9	1
10	1.9	1
12	13.2	7
14	1.9	1
15	5.7	3
16	9.4	5
27	3.8	2
28	1.9	1
30	22.6	12
36	1.9	1
48	1.9	1
60	7.5	4
75	1.9	1
90	3.8	2

Research question

2. What is the duration of spouse caregiver visits with their husbands or wives in a long term care facility?

Most caregivers spouses reported visiting either one hour (22.6%) or two (24.5%) hours. A smaller number (13.2%) visited for 3 hours. Two reported visiting for 6 hours. The average visiting time was 1.8 hours (see Table 3).

Table 3
Length of Spouse Caregiver Visits to Nursing Home

Minutes per visit	Percent of Respondents	N (N = 52)
10	1.9	1
30	13.2	7
45	1.9	1
60	22.6	12
75	3.8	2
90	5.7	3
100	1.9	1
120	24.5	13
150	1.9	1
180	13.2	7
240	3.8	2
360	3.8	2

Research question

3. What is the frequency and type of ADLs performed by spouses for their husbands or wives in a long term care facility?

As shown in Table 4, spouse caregivers were involved with all ADLs. Assistance was rendered for the following ADLs: eating, dressing, grooming, bathing, toileting, walking, getting in and out of bed and moving in bed. More

spouse caregivers (66%) assisted with eating than any other ADL. Grooming (52.8%) and walking (33.9%) ranked second and third respectively for spouse participation.

Table 4
Percentage of Spouse Caregivers Involved in ADLs

Activities of Daily Living	Number of Helping Spouse Caregivers (N = 53)	Percent of Sample
Eat	35	66.0
Groom	28	52.8
Walk	18	33.9
Dress	9	17.0
Toilet	8	15.2
In & Out of Bed	5	9.5
Move in Bed	4	7.6
Bath	1	1.9

The need for specific ADL care varied among the institutionalized spouses, and spouse caregiver involvement also varied. Shown in table 5 are the number and percent of institutionalized spouses who needed assistance with ADLs. Also shown are the number and percent of spouse caregivers who provided assistance. Institutionalized spouses

Table 5
Spouse Caregivers Providing Help with ADLs when Needed

Activities of Daily Living	Spouses Needing Help with ADLs	Spouse Caregivers Providing Needed Help
Bath	98.1% N = 51	1.9% N = 1
Groom	96.2% N = 51	54.9% N = 28
Dress	92.5% N = 49	18.4% N = 9
Eat	81.1% N = 43	81.4% N = 35
Bed in & Out	58.5% N = 31	16.1% N = 5
Walk	50.9% N = 27	66.7% N = 18
Toilet	49.1% N = 26	30.1% N = 8
Move in Bed	41.5% N = 22	18.2% N = 4

required the most assistance with bathing (98.1%), grooming (96.2%) and dressing (92.5%). Of the spouse caregivers who provided assistance, 28 (54.9%) helped with grooming, 9 (18.4%) helped with dressing and 1 (1.9%) helped with bathing. Spouse caregivers provided the most assistance with eating (81.4%), walking (66.7%) and grooming (54.9%).

Table 6
Number of ADLs and Number of Spouse Caregivers Providing Assistance (N = 53)

Number of ADLs	Spouse Caregivers	
	N	%
0	10	18.9
1	12	22.7
2	12	22.7
3	10	18.9
4	3	5.7
5	4	5.5
6	2	3.8

Table 6 shows the number of activities of daily living with which spouse caregivers provide assistance. Out of eight activities of daily living 2 spouse caregivers involved themselves in 6 activities, while 10 spouse caregivers were not involved in any activities. Most spouse caregivers were involved in between 2 and 3 activities.

How often spouse caregivers assist with each ADL is illustrated in Table 7. Assistance frequency ranged from once a week to several times a day. It appears that a small number of spouse caregivers were involved in ADLs several times a day.

Discussion

Results of this study indicate spouse caregivers frequently visit their husbands or wives after institutionalization. Caring does not stop with institutionalization. Spouse caregivers average nearly daily visits to nursing homes. The average number of visits by spouse caregivers in this study was 26 times a month. Zarit (1992) found family caregivers (26% daughters, 42% spouses, 32% other relatives) visit on average 4 days a week, while York and Calsyn (1977) found family caregivers (84% children, 16% spouses and other family members) visit 12 times a month or about three times a week. Moss et al. (1993) reported 68% of family caregivers (58% children, 10% spouses, and 32% others) visit at least once a month and 2% never visit. The results of this study disclose, with the exception of one wife, spouse caregivers visit nearly every day, which is more numerous than the visiting frequency reported by researchers for other family members.

The mean visiting time for spouse caregivers in this study was 1.8 hours. This was a longer visiting time than that reported by Moss (1993). She reported family caregivers visit an average time of 1.2 hours. Zarit (1992) reported family caregivers visit an average of 6 hours during the week and 3.5 hours on weekends for a total of 9.5 hours per week. Spouse caregivers in this study spent on average 11.3 hours visiting each week.

Table 7
ADL Involvement by Spouse Caregivers

Activities of Daily Living	Several Times a Day	Once a Day	2-6 Times a Week	Once a Week
Eat n = 35	22.9% n = 8	22.9% n = 8	34.3% n = 12	20.0% n = 7
Groom n = 28	7.1% n = 2	21.4% n = 6	28.6% n = 8	42.9% n = 12
Walk	27.8% n = 5	11.1% n = 2	33.3 % n = 6	27.8% n = 5
Dress n = 9			11.1% n = 1	88.9% n = 8
Toilet n = 8	25.0% n = 2	12.5% n = 1	37.5% n = 3	25.0% n = 2
Bed In & Out n = 5	20.0% n = 1	40.0% n = 2		40.0 % n = 2
Move in Bed n = 4		25.0% n = 1	25.0% n = 1	50.0% n = 2
Bath n = 1			100% n = 1	

There may be several explanations for the frequency of spouse caregivers visits in this study including emotional attachment, ease of commuting and good health. Strong emotional attachments between the spouses may elicit a need to be near their husband or wife. They may have experienced loneliness in the home after institutionalization,

preferring to spend time visiting in the nursing home than being home alone.

Visit frequency may have been influenced by ease of commuting to the nursing homes. Spouse caregivers may have had sufficient travel conditions to facilitate frequent visits to the nursing homes. The nursing home may have been located close to the spouses' residence. Spouse caregivers may have driven their own automobiles and experienced no problems with traffic congestion. If the spouse caregivers did not drive an automobile, convenient and acceptable public transportation may have been available or there may have been an abundant support network of individuals willing to chauffeur spouse caregivers to the nursing home.

The health of spouse caregivers may have permitted their frequent and lengthy visitations. Seven spouse caregivers reported visiting two to three times a day, while the average was almost one daily visit. Four spouse caregivers reported visiting for three to six hours when the average amount of time spent was 1.8 hours. The frequency of visits as well the length of time would require the spouse caregivers to have good physical health to continue spending a long time away from their homes nearly every day.

Spouse caregivers visit their husbands or wives in the nursing home frequently and for long periods of time after placement. These visitation results dispel the stereotype that nursing homes act as "dumping-grounds" for infirm family members.

All institutionalized spouses needed ADL assistance and results showed 81.1% of spouse caregivers provided assistance with ADLs. Most helped with two or three ADLs, but six spouse caregivers were involved to a greater degree in the care of their husbands or wives. These 6 spouse caregivers (11%) visited from 3 hours to 6 hours daily and assisted with up to 6 ADLs. This daily schedule suggested they were fully absorbed in caregiving activities. Long visiting hours combined with high levels of caregiving involvement could be stressful for selected spouse caregivers.

Overall, the greatest amount of involvement of spouse caregivers was with eating, grooming and walking. There may be several different reasons for assistance with eating being performed most frequently by spouse caregivers. Assistance with eating may be a pleasant experience for spouse caregivers. Or, the spouse caregiver may believe the nursing home staff does not assist their husband or wife skillfully, timely or courteously and the spouse feels obligated to fill a need. Also, it is not unusual for nursing home staff to encourage spouse caregivers to help when eating assistance is needed and this may prompt more spouse caregiving involvement. The last explanation for the high frequency of spouse caregiver involvement is that opportunities exist more than three times each day for assistance with eating.

More than half of involved spouse caregivers reported participation in grooming. Grooming is described as combing hair or shaving. Spouse caregivers possibly assist with grooming to fill a personalized need of their husband or wife. Hair care done by nursing home staff tends to be standardized. Spouse caregivers may want to see their husbands or wives with their own individualized hair style. Because shaving is time consuming, nursing home staff may encourage spouse caregivers to perform the shaving task for them. Overall, spouse caregivers may experience a good feeling from seeing positive effects of their personalized care and are likely to persevere in individualized grooming care.

Of the involved spouse caregivers, 18 helped their spouse with walking. This may be explained by ample opportunity for participation and the pleasure of the activity. In addition, exercise is often a part of the nursing plan and the staff tend to support spouse caregivers' walks with their husbands or wives. Encouragement from staff, ample opportunities and probable feelings of accomplishment are plausible reasons for spouse caregiver's frequent participation in walking.

Fewer numbers of spouse caregivers provided needed help with toileting, dressing, move in bed, in and out of bed, and bathing. Despite nearly all institutionalized spouses needing help with bathing, only one spouse caregiver furnished assistance. The possible reasons are lack of

opportunity and lack of physical ability. The need for performing some of the activities may not have existed during the time the spouse was visiting. As a group, spouse caregivers whose mean age was 69 years may not have sufficient strength for assisting with all of the above activities. It is possible that those were the activities spouse caregivers were unable to perform at home. The lack of ability to assist their spouse with toileting, dressing, moving in and out of bed and bathing may have prompted placement in the nursing home.

This study was conducted utilizing Bower's theory of family caregiving as a theoretical framework. It examined ADL caregiving by spouse caregivers, classified as Instrumental care in Bower's theory. Assistance with all of the ADLs (bathing, eating, dressing, grooming, walking, toileting, getting in and out of bed and moving in bed) was reported by spouse caregivers.

According to Bower's theory activities performed by family caregivers have specific purposes and there may be several reasons for a caregiver's single act. This study reveals spouse caregivers involve themselves in ADL activities which are typically performed by nursing home staff. This might suggest the activity is being performed for reasons other than to actually accomplish a task. The reasons for the spouse caregivers' behaviors in this study may be similar to those proposed by Bower. She suggests family caregivers perform tasks in the nursing home for

several reasons: to preserve their family member's dignity, to demonstrate and teach the staff personalized techniques, and to let the staff know their family care-recipient is a person who is loved.

The majority of the sample spouse caregivers were well educated as 54.7% possessed college or professional education. Spouse caregivers' formal education combined with knowledge from caregiving experiences was probably equal to or exceeded caregiving knowledge possessed by nursing home staff workers who provided ADL basic care. They may have felt the staff needed more education about caring for their husbands and wives. They might have expected a higher quality of care than was being provided in the nursing home and they possibly participated in selective ADLs to enhance caregiving quality for their husbands or wives.

Bower's theory of family caregivers' actions having more than one purpose could also be supported by other researchers by implication. Several researchers discovered families spend time teaching the nursing home staff about their care-recipient resident. Chenoweth (1986) found family caregivers frequently act to teach institutional staff about how to care for dementia relatives. Family caregivers felt strongly about the care of their family member and spend time demonstrating their expectations of care to the staff (Hasselkus, 1988; Townsend et al., 1989). Family member caregivers also attempt to become more socially and emotionally involved with the staff so that the staff will

react more positively toward their institutionalized family member (Duncan & Morgan, 1994). Spouse caregivers in this study who involved themselves with ADL tasks may have been acting to teach the staff about their husbands or wives.

Several previous studies of family caregivers in the nursing home reveal both family and staff claim responsibility for providing personal care (Rubin & Shuttlesworth, 1983; Schwartz & Vogel, 1990; Shuttlesworth et al., 1982). It would appear from this work that spouse caregivers perform personal care for their husbands or wives, giving support to those studies.

York and Calsyn's (1977) research revealed family caregivers express a lack of anything to do during their visits and that families want to become involved in activities in the nursing home. After institutionalization, residents tend to become immobile and sit for hours doing nothing (Spasoff et al., 1978). Walking is an activity spouse caregivers probably use to occupy their time as well as to provide therapy. Spouse caregivers in this study (67%), in addition to eating and grooming, were involved with walking their husbands or wives. Eighty one percent of all spouse caregivers in this study assisted with ADL care. These results appear to support York's findings that families desire involvement in the nursing home.

Although the framework for this study is the model from Bower's theory of family caregiving, a more realistic description of spouse caregivers in the nursing home is

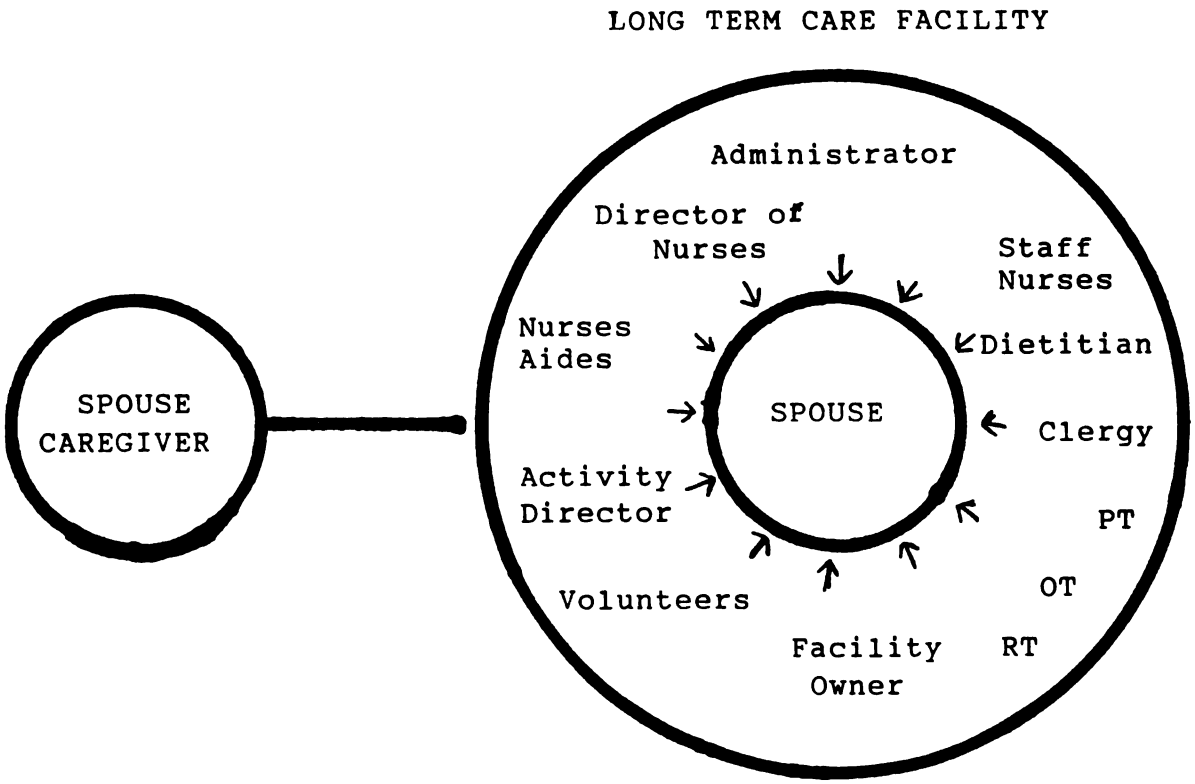
depicted in Figure 2. Research about spouse caregivers of institutionalized family members combined with results of this study indicate spouse caregiver involvement is not an integral component of care within nursing homes. Although spouse caregivers provide ADLs care almost daily in the nursing home, their assistance is not routinely integrated into the plan of care designed by nursing home staff. Spouse caregivers are viewed as separate or apart from their spouse and not essential in the caregiving process.

The model from Bower's theory (Figure 1) shows a picture of spouse caregiving from the perspective of family caregivers continuation of care for their spouse after placement in a long term care facility. Spouse caregivers seek involvement. Figure 2 represents reality in nursing homes. It diagrams the position of spouse caregivers as it actually relates to the formal organization of the long term care business.

Summary

More than 98% of spouse caregivers visit their spouses. Of visiting spouse caregivers, 81% were actively involved with one or more ADLs. These findings generally support other research indicating family caregivers continue to provide care after institutionalization of their spouses, however, the results of this study add clarity to the spouse caregiver role after institutionalization of their spouse.

Figure 2. Spouse Caregiving Involvement in the Nursing Home/Long Term Care Facility



CHAPTER 5

SUMMARY AND CONCLUSIONS

Overview

In this descriptive study spouse caregiver visitation and involvement in ADLs in the nursing home was analyzed for frequency. In this chapter study limitations, existing literature, future research, implications for advanced nursing practice and for education of healthcare providers at all levels will be discussed.

Limitations

The retrospective design of this work is a major limiting factor for this study. Although Bower's theory of family caregivers guided the study it was possible to analyze only a portion of the theory, Instrumental caregiving. The questionnaire used to measure instrumental care reported spouse caregiving involvement in eight ADLs. Investigation of these activities constitute only one part of Bower's theory and did not examine the other four care categories. In addition to categorizing types of care performed by family caregivers, Bower's theory describes family caregivers as having specific purposes for caregiving

acts. This study did not examine spouse caregivers' purposes in caregiving acts.

Another limitation of the study is the small number of participants in the sample (n = 53). A small sample size decreases the possibility of the sample being a true estimate of the population (Polit & Hungler, 1991). The volunteers in this sample were predominately caucasian and well educated. Their responses may not represent the populations of those who are non-volunteers, non-caucasian, and less educated. All were caregivers of dementia patients who might receive more direct care from their spouse caregivers than would cognitively intact patients by virtue of their "helplessness". These conditions would prevent generalization to a larger population.

The instrument used in the study was a self-report with closed-end questions. Data gathered from fixed-alternative limit the responses. It may not offer all the responses the subjects may select. Thus the data may not reflect all of the possible responses from the sample.

Discrepancies in institutionalization time of the sample subjects may be another study limitation. Spouse caregivers who recently placed their husbands or wives in a nursing home may react differently from those of longer time placements. Time requirements for each spouse caregiver's adaptation to their husband's or wife's placement in the nursing home may have influenced their responses.

Implications for advanced nursing practice

This study has many implications for Advanced Practice Nurses (APNs) serving the elderly, particularly those within institutions of long term care. The application of Bower's theory in this study provides guidelines and useful concepts by which the APN may view the caregiving role of spouses within the institution.

As a clinician in primary care, the APN assesses the capabilities, needs and goals of spouse caregivers and may identify activities within Bower's instrumental care category which would be beneficial to spouse caregivers. These activities may meet the social, mental and physical needs of spouse caregivers. In this process the APN would be alert for spouse caregivers who becomes overly involved in caregiving, to the detriment of their own health. Health management of spouse caregivers is holistic, it includes emotional, spiritual and physical elements which may impact health. This means that caregiver spouses should ideally be offered primary care services in the nursing home along with their institutionalized spouse. Assessment and development of health care plans which include spouse caregivers' personal goals as well as goals for their husbands or wives is an important aspect of the APN role.

Whenever particular activities are identified as appropriate in the role of spouse caregivers within the institution access to necessary materials and staff cooperation must be assured. The APN, as an advocate, guides

this process with support and encouragement by welcoming spouses presence and involvement in the nursing home. Through regular evaluations the APN makes timely plan modifications so that progress toward the spouse caregivers' goals are maintained.

APNs working within nursing homes should support shared caregiving by spouse caregivers. They should find out the desires of spouse caregivers and help them achieve their goals. In order to assure spouse caregiver success, APNs must educate nursing home personnel about the importance of spouse caregivers' participation in caregiving activities. APNs should also encourage spouse caregivers to join together to support each other in their caregiving roles. Belonging to a support group may assist spouse caregivers in times of stress. Spouse caregiver support groups should be encouraged, respected and function within nursing homes.

Potential travel difficulties for visiting should also be explored. The resolution of problems which spouse caregivers may experience commuting to visit their spouse should be a consideration of health care providers, APNs and nursing home staff.

APNs in primary care have opportunities as well as the responsibilities for changing spouse caregiver status by speaking on behalf of spouse caregivers in the nursing home so that they are viewed as an integral component in the care of their husbands or wives. The lack of a clear definition of a spouse caregiver role in the institution as

well as ambiguity of family/staff caregiving task responsibility has been reported in several research projects. Providing theory based caregiving knowledge might clarify the roles of spouse caregivers. Clarification of share caregiving in the institution, resulting in a more clear definition of responsibilities, may reduce job overlap and spouse conflict with the staff.

As an educator the APN may provide in-service education programs to nursing home personnel based upon Bower's theory of family caregiving. Although all health care workers with the elderly population should benefit, the target groups for this information would be nursing aides and Licensed Practical Nurses (LPNs). Burgio et al. (1990), in a study in a teaching nursing home, demonstrated LPNs and nurses aides in long term care workers have the most frequent contact with residents. By association, nurses aides are in frequent contact with the residents' families. Research shows families confrontations with staff regarding poor quality of resident care are quite frequent and that residents' wives are shown to be the most orally aggressive toward the staff (Vinton & Mazza, 1994). If health care workers had more knowledge about the importance of spouse caregivers' role within the institution, conflicts between family caregivers and the institutional staff may be reduced. Education might promote staff cooperation and thus clarify the role performance of the spouse caregiver in the nursing home.

Not only is there a role for APNs within long term care facilities, there is also a role outside as a consultant. Through consultation, APNs may assist the facility personnel in recognizing the need for the development and implementation of an acceptable and responsible position for spouse caregivers. The APN may provide information about the role of spouse caregivers to those charged with making decisions in long term care. Once the position is legitimized by recognition by the administration, the process of shared caregiving between spouse caregiver and staff might be achieved through a system of mutual respect and common goals. This would provide more continuity of care from the home to the institution.

Implications for existing literature

Research studies in the literature relating to spouse caregiving in institutions of long term care are limited. Typically, spouse caregiver participation is within the context of the larger family group. This study looked at spouses only and described the visiting and ADL care performed by spouse caregivers. It should add clarity to the role of the spouse caregiver in the nursing home. The findings of this work contribute research information about visiting patterns and ADL care performed by spouse caregivers for their husbands or wives who are institutionalized in long term care facilities.

Recommendations for further research

The retrospective design of this research project provides only limited opportunity to utilize Bower's four categories of family caregiving. Theory categories of preservative care, preventative care and anticipatory should be examined. Bower (1987) has shown these categories of care to be of great importance to family caregivers. A research design containing all five of Bower's family caregiver care categories as well as purpose of the caregiving acts would increase research knowledge about spouse caregiver activities after institutionalization of their husband or wife.

A longitudinal study to examine spouse caregiver health, involvement in ADLs and satisfaction at three months, six months and one year after institutionalization is recommended. The transition from home care to nursing home care usually requires a great deal of adjustment. Six weeks to three months is the average length of time for adaptation, but some residents never adapt (Greenfield, 1984). Collections of data over a long period of time after institutionalization may indicate changes in the behavior of spouse caregiving involvement in ADL care.

Length of marriage and spouse caregiver age are additional variables for future investigations. There may be significant differences in spouse caregiving based upon age classifications of young-old, old-old and oldest-old. Length of years married may also impact spouse caregiving

involvement. Future investigations of spouse caregivers visiting their husbands or wives in nursing homes might examine various factors which may influence the frequency of visits by the spouse caregiver to the nursing home. Existing research suggests mileage as one factor influencing visiting frequency for all visitors, relatives and non-relatives (Hook et al., 1982). More information about travel distance as well as other transportation problems may add knowledge about the frequency of spouse caregivers visits to the nursing home.

The present study described spouse caregivers, but it did not distinguish between spouses by gender. Women and men may be involved in different caregiving activities and with differing frequency. Thus gender may have an influence on performance of specific caregiving activities and is an area worthy of more inquiry.

The attitude of the nursing home staff may also influence spouse caregiving in the institution. Future studies may examine spouse caregiver role from the perspective of the staff. The study should elicit attitude information from all departments in the nursing home. Such a study might discover attitudes on the part of the staff that have important bearing upon the caregiving behaviors of spouse caregivers. Researchers of spouse caregivers in long term care facilities find there is no defined role for spouse and often describe conflicts between spouse

caregivers and the staff of nursing homes. An attitudinal study may provide insight for solving of this problem.

Summary

Limitations of the study were presented. Implications for advanced nursing practice were discussed. Contributions to current literature regarding spouse caregiving activities in nursing homes were discussed as well as recommendations for future research.

APPENDIX A

APPENDIX A

MODIFIED VERSION OF THE CORNWELL INVOLVEMENT INVENTORY

(Listed below are the questionnaire items used in this study.)

1. Now that your relative is living in a different care setting, do you still visit him/her once a month or more?

___ YES (1) (Go to question #2)
___ NO (2) (Go to question #12)

2. If YES, how many times per month (on the average)? (WRITE IN NUMBER)

___ (Number of times/month)

3. How long do you usually stay each time you visit? (WRITE IN NUMBER)

___ (Average number of minutes per visit)

4. Does your relative need help with eating?

___ NO (2) (Go to question #5)
___ YES (1) (Go to question #4a)

4a. If YES, how often do you help your relative with eating?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

5. Does your relative need help with dressing?

___ NO (2) (Go to question #6)
___ YES (1) (Go to question 5a)

5a. IF YES, how often do you help your relative with dressing?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

6. Does your relative need help with grooming such as combing hair or shaving?

___ NO (2) (Go to question #7)
___ YES (1) (Go to question #6a)

6a. If YES, how often do you help your relative with grooming such as combing hair or shaving?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

7. Does your relative need help with taking a shower or bath?

___ NO (2) (Go to question #8)
___ YES (1) (Go to question #7a)

7a. If YES, how often do you help your relative with taking a shower or bath?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

8. Does your relative need help with using toilet, bedpan or commode?

___ NO (2) (Go to question #9)
___ YES (1) (Go to question #8a)
___ Not applicable, relative has catheter/used diapers/is incontinent (3) (Go to question #9)

8a. IF YES, how often do you help your relative to use toilet or commode?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

9. Does your relative need help with walking?

___ NO (2) (Go to question #9a)
___ YES (1) (Go to question #10)
___ Not applicable, relative does not walk (3) (Go to question #10)

9a. If YES, how often do you help your relative with walking?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help (5)

10. Does your relative need help with getting in and out of bed?

___ NO (2) (Go to question #10a)
___ YES (1) (Go to question #11)
___ Not applicable, relative does not get out of bed (3)
(Go to question #11)

10a. If YES, how often do you help your relative with getting in and out of bed?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

11. Does your relative need help with moving in bed?

___ NO (2) (Go to question #11a)
___ YES (1) (Go to question #12)

11a. If YES, how often do you help your relative move in bed?

___ Once a week or less than once a week. (1)
___ Several times a week (2-6). (2)
___ Once a day. (3)
___ Several times a day. (4)
___ I do not help. (5)

APPENDIX B

APPENDIX B

MICHIGAN STATE
UNIVERSITY

March 21, 1995

TO: Frances L. Markley
4444 S. Bagley
Ithaca, Mi 48847

RE: IRB#: 95-140
TITLE: SPOUSAL CAREGIVING INVOLVEMENT IN THE NURSING HOME
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: 03/20/95

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

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)336-1171.

Sincerely,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Carla L. Barnes

OFFICE OF
RESEARCH AND GRADUATE STUDIES

University Committee on Research Involving Human Subjects (UCRIHS)

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

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