



12-1-2000

The Effects of Eldercare Responsibilities on Employed Caregivers

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THE EFFECTS OF ELDERCARE RESPONSIBILITIES ON EMPLOYED
CAREGIVERS

by

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Bachelor of Science in Nursing, University of North Dakota, 1979

A Thesis

Submitted to the Graduate Faculty

of the

University of North Dakota

in partial fulfillment of the requirements

for the degree of

Master of Science

Grand Forks, North Dakota

December

2000

This thesis, submitted by Nancy Jean McEnroe in partial fulfillment of the requirements for the Degree of Master of Science from the University of North Dakota, has been read by the Faculty Advisory Committee under whom the work has been done and is hereby approved.

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This thesis meets the standards for appearance, conforms to the style and format requirements of the Graduate School of the University of North Dakota, and is hereby approved.

Carl Fox

11-22-00

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ACKNOWLEDGMENTS

I would like to express my sincere gratitude to my advisor and chairperson, Dr. Diane Langemo for her guidance, patience and encouragement throughout my graduate degree process. I would also like to thank the other members of my committee, Dr. Mary Laycock for the wonderful insight I took away from her classes outside of nursing and to Dr. Marcia Gragert for her belief and enthusiasm she sparked in me on my thesis topic.

I would also like to thank Dr. Julie Anderson for her support and belief in me during the entire graduate degree process. Her expert assistance with the statistical analysis and explanations of the data were very helpful and valuable to me. She is a true friend and colleague of mine, and I will cherish this experience and many more.

I would also like to thank my sister Barb Delohery for her gentle persistence and support that she gave me throughout this process. To my family, my husband John, and my two children Brad and Maggie who have given me all the love and encouragement possible.

This thesis is dedicated to my late father, Dr. Frank Hill, who gave me love and courage to be and do whatever I wished in life.

ABSTRACT

The number of people in the older population will continue to grow as the decades progress. The most rapid increase expected would be between the years 2010 and 2030 when the “baby boom” generation reaches 65 years or older. By the year 2030, there will be about 70 million older persons, more than twice the number than for the year 1998.

More and more people will live long enough to experience multiple chronic illnesses, disability, and dependency; in addition there will be more relatives in their fifties and sixties who will be facing the concern and expense of caring for them. Those over the age of 85 years are most likely to need help with activities of daily living such as dressing, bathing, and toileting; and instrumental activities of daily living such as meal preparation, shopping, transportation, and paying bills. Family members such as daughters-in-law, granddaughters, husbands, sons, and nieces and nephews, are the ones who provide the vast majority of help needed by the elderly. Those family members typically find themselves juggling responsibilities of their own work, their children and their elder relatives.

The purpose of the study was to examine the effects of elder caregiving on caregivers employed outside the home and their work. Lazarus’ Stress and Coping Model provided the theoretical framework for this study. An Eldercare Survey Tool was given to employed caregivers to determine what types of caregiving are

provided for the older adult, how many hours are spent on eldercare caregiving per week, and to what extent emotional, physical, or financial burdens are experienced by the caregiver. Descriptive statistics were used to analyze and describe the answers to the questionnaire, including demographic information. The data were analyzed using the Statistical Package for the Social Sciences (SPSS) which labels variables and provides parametric and non-parametric statistical procedures. The open-ended questions were analyzed using content analysis.

The findings of this study suggest that employees who have caregiver responsibilities for older adults outside of work have issues that may affect their work and family life. This study suggests that caregiving does interfere with work life by employees having to go into work late, leaving early or taking time off during the day due to their caregiving responsibilities. The study also suggests that participants feel that they have experienced less time for family and have had to give up hobbies and vacations due to their caregiving responsibilities. The typical caregiver in this study was female, white, married, mid forties, and employed full-time as a professional. The study also suggests that employees with eldercare responsibilities have both difficulties and rewards from their caregiving experience.

CHAPTER I

INTRODUCTION AND REVIEW OF LITERATURE

Introduction

The older population, specifically those individuals 65 years or older, numbered 34.7 million in 2000. The number of older Americans increased by 3.2 million or 10.1% since 1990, compared to an increase of 8.1% for the under 65 year population. In addition, the elderly population itself is getting older. In 1998, the 65-74 year age group was eight times larger than in 1900, the 75-84 year age group was 16 times larger, and the 85+ year age group was 33 times larger (Duncker & Greenberg, 1999).

The number of people in the older population will continue to grow as the decades progress. The most rapid increase expected will be between the years 2010 and 2030 when the “baby boom” generation reaches age 65. By the year 2030, there will be about 70 million older persons, more than twice the number than in the year 1998. People 65 years and older are projected to represent 13% of the population in the year 2000, and an astounding 20% by 2030 (Conklin, 2000; Duncker & Greenberg, 1999). The ramifications of these statistics are most significant.

According to the U.S. Census Bureau (*A Profile of Older Americans*, 1999), more and more people live long enough to experience multiple chronic illnesses, disability, and dependency; concomitantly there will be more relatives in their fifties

and sixties who will be facing the concern and expense of caring for them. Those over the age of 85 years are most likely to need help with activities of daily living (ADL) such as dressing, bathing, and toileting; and instrumental activities of daily living (IADL) such as meal preparation, shopping, transportation, and paying bills. Family members such as daughters, wives, daughters-in-law, granddaughters, husbands, sons, nieces and nephews, are the ones who provide the vast majority of help needed by the elderly (Marosy, 1998), and this is not expected to change.

According to a 1997 survey done by the National Alliance for Caregiving/American Association of Retired Persons, 22.4 million U.S. households are involved in caregiving. The majority (64.2%) of caregivers are employed, while 51.8% are employed full-time. The survey also indicated 14.4 million full and part-time employed caregivers are balancing work with their elder caregiving roles. The demands of combining work and providing caregiving duties to an older family member can create stress, especially for those families who are still raising children and now find themselves faced with caring for an elderly parent at the same time (Anastas, Gibeau, & Larson, 1990). Trying to juggle multiple caregiving responsibilities for both children and older adults can create both work and family conflicts (Wagner & Neal, 1994).

Purpose of the Study

The purpose of this study was to determine the effects of elder caregiving responsibilities on the employed caregiver and their work. This study examined eldercare responsibilities such as what types of caregiving are provided for the older adult; how many hours are spent on eldercare caregiving per week; and to what

extent emotional, physical, and/or financial burdens are experienced by the caregiver. This study addressed the prevalence of such factors as increased absenteeism, lost or missed job opportunities, increased personal phone calls at work, and loss of productivity while at work.

Review and Critique of Related Studies

This study was concerned with factors that impact job performance of employed caregivers with eldercare responsibilities and also the personal effects of caregiving as experienced by the employed caregiver. According to a 1997 joint survey, Family Caregiving in the U.S. by the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) survey, 14.4 million caregivers are employed full or part-time, which requires juggling of personal work schedules and eldercare duties. The survey reported that employed caregivers make or receive more personal phone calls regarding their older relative, come in late, take longer lunch breaks, and leave early. In addition, they must often miss work to take the older adult to an appointment or to deal with a sudden crisis.

Demographic Factors

Demographic changes project that the number of people in the older population will continue to grow as a result of better diagnosis, treatment, and management of illnesses affecting the elderly (Thibodeau, 1993). The demand for caregiving will increase as the elderly population increases and because older adults are likely to have one or more chronic illnesses (The Institute for Health & Aging, 1996). Consequently older adults with chronic conditions are living longer than ever before. According to the U.S. Census Bureau, as older adults are living longer they

will be faced with more chronic illnesses, and these conditions will result in the older adult becoming dependent on others for help in performing the activities of daily living. As the older adult experiences multiple illnesses, the demands on the employed caregiver increase. Employed caregivers who experience few demands on time and energy with eldercare duties view the caring of the elderly as a positive experience. However, as the demands on time and energy increases, the experience becomes increasingly negative (Thibodeau, 1993). Consequently, as the employed caregiver faces problems or role changes in their caregiving experience, family members are directly affected (Brody, 1985). The family is affected by interference with its privacy, life style, socialization, vacations, future plans, and income (Brody, 1985). Each family member feels the affects of the change in balancing the roles and responsibilities of caregiving as it impacts the family dynamics (Brody, 1985). Some of the adaptations made by the employed caregiver as reported by Scharlach (1994) include working longer hours, taking work home, working harder, and obtaining help from co-workers. Consequently this leaves significantly less time for personal time, and adds to the stress of juggling work obligations, caregiving duties, and family responsibilities (Krach & Brooks, 1995).

Characteristics of Caregivers

According to Anastas, Gibeau, and Larson (1990), the characteristic working caregiver in their study was predominately white, married, and middle class. The report indicated that 60 percent of the caregivers were in their 40s, and the majority had one or more children still living at home. The 1997 NAC/AARP study reported the working caregivers surveyed were also predominately female, white, married, in

their 40s, and also had children under the age of 18 years still living at home. Stone, Cafferata, and Sangl (1987) supported these findings in an earlier study of caregivers, where they were primarily women (72%), with adult daughters comprising 29 percent of all caregivers, and wives 23 percent of the population surveyed. The average age of the caregiver in this study was 57 years with 25 percent of them 65 to 74 years of age and 10 percent 75 years of age or older. The 1997 NAC/AARP study reported in their findings the typical caregiver was a 46 year old woman who was employed and also spent around 18 hours per week caring for a relative who lived nearby. In addition, the average duration of caregiving was 4.5 years, while the typical care recipient was a 77-year old woman living alone, who had at least one chronic illness. A 1997 study by the National Family Caregivers Association (NFCA) reported that the family caregivers studied were predominately women (81%) compared to men (18.1%). The average age of the caregiver in the NFCA study was between 36 and 65 years of age and married; over half of the caregivers were employed full time; and 77 percent had children under the age of 18 years living at home. Marosy (1998) suggested that eldercare is primarily provided by women, however as the traditional male-female roles continue to change, a significant number of men are taking on eldercare responsibilities as well.

Caregiver Types

Working caregivers provide different types of caregiving depending on their situations, from anticipatory caregiving in which the caregiver is not providing direct care, but helping plan for future needs with the older adult, to actual instrumental

caregiving which is more direct hands on care (Bowers, 1987; Marosy, 1998).

Bowers (1987, p. 25-28) identifies five categories of caregiving:

1. Anticipatory caregiving includes decisions based on anticipating a possible need of the older adult.
2. Preventive caregiving is providing activities for the purpose of preventing injury, illness, physical, and mental deterioration of the older adult.
3. Supervisory caregiving is active and direct involvement for such things as arranging for, making sure, setting up, and checking up on the older adult.
4. Instrumental caregiving is the direct hands on care which includes assisting and doing for the older adult. This type of caregiving is to maintain the physical aspect and health status of the older adult.
5. Protective caregiving is the caregiver's attempts to protect the older adult from the awareness that he or she is being taken care of.

The type of caregiving and how much time is involved will determine how the working caregiver will juggle work obligations, caregiving duties, and family responsibilities.

Caregiving Tasks

Just as there are different types of caregiving there are also different tasks that accompany each type of caregiving. Those tasks and their intensity can vary from one older adult to another depending on their situation or condition. An older adult's level of disability is frequently categorized based on the amount of assistance required in both activities of daily living and instrumental activities of daily living (The Institute for Health & Aging, 1996). Activities of daily living (ADLs) include

dressing, bathing, eating, mobility, and other personal care activities. Instrumental activities of daily living (IADLs) include shopping, preparing meals, help with use of the telephone, managing money, and other care to help independent living (Institute for Health & Aging, 1996). The 1997 study by the NAC/AARP reported that 98 percent of caregivers surveyed assisted with at least one IADL, and more than four in five assisted with three or more IADLs. The caregiver duties included help with transportation (79%), help with grocery shopping (77%), help with household chores (74%), preparation of meals (60%) and managing the finances for the older adult (56%). The 1997 study by the NFCA reported 61 percent of the caregivers surveyed assisted with one or more IADLs, which included groceries, meals, housework (26.8%), companionship (15.5%), financial management (9.2%), medication management (5.2%), and transportation (4.3%). The 1997 NAC/AARP study reported that just over half (51%) of the caregivers surveyed assisted with at least one ADL, and 29 percent helped with at least three. The caregivers reported assisting with getting the elder in and out of a chair (39%), with dressing (31.4%), with bathing (26.6%), and with toileting (26.2%). The 1997 NFCA study reported that 39 percent of the caregivers surveyed were responsible for assisting with one or more of ADLs. Anastas et al. (1990) reported the most common task working caregivers engaged in was providing emotional support and companionship.

Hours Spent Caregiving

In another study by the National Alliance for Caregiving; *The Caregiving Boom: Baby Boomer Women Giving Care* (1998), the caregivers surveyed reported the time spent giving care was an average of 22 hours per week. Just one year

earlier, the 1997 NFCA study reported that 32.4 percent of caregivers provided 20 hours or less per week on caregiving duties, while 17.4 percent of caregivers surveyed spent 21 to 40 hours a week, 19.5 percent spent over 40 hours a week, and 40.8 percent provided constant care. The average caregiver provides care for 18 hours per week, and one in five caregivers provides at least 40 hours of care per week or constant care (NAC/AARP, 1997). The variation in time as reported by working caregivers depended on the type and intensity of caregiving duties, with some caregivers spending one to five hours a week with less intense care given and other caregivers spending over 20 hours with more intense care being provided.

Physical and Emotional Burden

There are many difficult challenges that working caregivers face while providing caregiving duties to an older adult. Some negative or problematic aspects of caregiving reported by working caregivers include emotional distress, financial hardship, and physical strain (Scharlach, 1994). Working caregivers also reported a variety of health problems such as nervousness, insomnia, headaches, weight changes, and drowsiness (Krach & Brooks, 1995). A majority of caregivers surveyed in the 1997 NFCA study reported experiencing depression (60.6%), while sleeplessness was reported by 50.6%, back pain by 40.8%, stomach problems by 24.2%, headaches by 14.9%, and 11.8% reported colds and flu symptoms. The study also reported the most difficult problems the caregiver faced were the sense of isolation and lack of understanding from others, loss of leisure time, and the sudden responsibility of making major life decisions. Wagner (1997) found that employed caregivers experienced several adverse health effects more frequently than did other

employees, which included headaches, difficulty sleeping, and weight gain or loss. Adult children struggling to balance the demands of work and family can experience increased stress levels when any sudden crisis with an older adult they are providing care for occurs (Bergen, 1994). This is particularly true for women who juggle work, family and eldercare responsibilities, where they often experience high levels of stress as they try to compress increasing numbers of activities into smaller amounts of time (Green, 1991). Women often experience powerful emotional reactions to the demands of caregiving responsibilities, especially to their parents. Emotional reactions include guilt, anger, resentment, embarrassment, and sadness over the unexpected and sudden role as the caregiver (Green, 1991). Brody (1985) found that as adult children meet the increasing demands of caregiving duties for their parents, a shift in their family homeostasis occurs; such shifts can have the potential for stress, especially because this often predicts the increasing dependency in the future.

Financial Burden

Financial hardship may be an issue for the working caregiver as they try to provide eldercare for the older adult, and meeting the cost of caregiving may require combining their own financial resources plus those of the elder, and other family members (Marosy, 1998). The 1997 NAC/AARP study of caregivers reported that only a small percentage stated they experienced a financial hardship, however as the level and intensity of eldercare increases the more out-of-pocket expenses the working caregiver experiences. The study also reported one-fifth of all employed caregivers surveyed gave up work either temporarily or permanently: eleven percent

took a leave of absence, six percent gave up work entirely, and four percent took early retirement. The demands on some caregivers are often overwhelming in that they are forced to leave their jobs to become full-time caregivers (NFCA, 1997). The 1997 NAC/AARP study also reported caregivers were spending out-of-pocket about \$2 billion per month for medicines, groceries, and other support for their older relative. And half of all caregivers surveyed spend an average of \$171 per month of their own money.

Work and the Caregiver

The 1997 NAC/AARP survey found that caring for an older relative seriously affected the employment of one in four survey participants. Ten percent of the study participants had to quit work completely, another eleven percent took a leave of absence, and seven percent moved to a less demanding job or took a cut in hours. Time was reported as the number one need of employed caregivers. Caregivers frequently needed to make adjustments in work schedules (going in late, taking time off during the day or leaving early) to accommodate caregiving responsibilities (Marosy, 1998). Scharlach (1994) found that employed caregivers reported the negative impact of eldercare duties and work was reduced productivity because of tiredness, impaired concentration, and emotional stress associated with caregiving. In another study on chronic care, The Institute for Health & Aging (1996) reported 60 percent of employed caregivers said that caregiving interfered with their work. The study reported that working caregivers were forced to rearrange schedules, take time off from work without pay, work fewer hours, or quit altogether to become a full-time caregiver.

Employers need to be aware of the family work conflicts, and the consequent loss of productivity because of the employed caregiver's multiple roles. Employed caregivers need to identify the kinds of problems they are experiencing while trying to balance work, eldercare, and family and also examine how their place of employment can assist them (Liebig, 1993). As employed caregivers alter their work schedules by coming in late, taking long lunch breaks, leaving early, making or receiving phone calls at work related to their caregiving responsibilities, missing work to take their older relative to an appointment or dealing with a sudden crisis, a financial burden is born by employers as well as employees (NAC/AARP, 1997). According to the 1997 NAC/AARP study the major effects of caregiving on employee productivity fall into five categories: (a) costs due to workday interruptions, (b) absenteeism costs, (c) costs due to partial absenteeism, (d) costs due to eldercare crises, and (e) costs associated with supervising employed caregivers. With employed caregivers adjusting their daily work schedule, it is easy to imagine how fast and extensive business costs can rise due to the loss in productivity. The 1997 NAC/AARP study reported the estimated annual cost of full-time employees, who are caregivers, to U.S. businesses is \$11.4 billion per year. The study also reported the costs would exceed \$29 billion per year if caregivers providing less intense eldercare duties, those working part-time, and those long distance caregivers were included in the calculation. Given these findings it is important that employees and employers work together in mutual support of caregiving needs.

Policy and Program Issues in the Work Setting

Policy issues employers can explore to effectively address and manage caregiving issues which will benefit both the employer and employee are: (a) Employee Assistance Programs (EAP), (b) offering flex time, (c) awareness training on caregiving issue, (d) information and referral on caregiving options and community based service, (e) on-site adult day care programs, (f) support groups for the caregiver; and (g) offering staff an opportunity to donate sick time for elder caregiving activities (NAC/AARP, 1997). These policy issues are ideas that employers and employees can work on together to minimize the emotional, financial, and physical costs of older adult caregiving. According to Denton, Thiessen-Love, and Slate (1990), employees look for programs or benefits from employers that will assist them at many different levels, ranging from decision making when the older adult is independent to providing physical care as the older adult becomes more dependent. Most employers offer benefits that support the caregiver providing eldercare, and tend to be inexpensive programs such as seminars and other information services. The most frequently supplied benefits reported by employers are information services, EAPs, flextime, and leaves of absence (Denton et al., 1990).

Summary

The number of people in the older population will continue to grow, and as more and more people live longer they may experience multiple chronic illnesses that eventually could leave them dependent on family members as their caregivers. From the literature, evidence indicates the typical caregiver is predominately female,

white, married, between their 40s and 50s, and also has children under the age of 18 living at home. The majority of family caregivers are employed full- or part-time, which requires juggling of personal work schedules and eldercare duties.

The type of caregiving, the tasks involved, and the time involved will determine how the working caregiver will balance work obligations, caregiving duties, and family responsibilities. The demands of combining work and providing caregiving duties to an older family member can create stress, especially for those families who are still raising children. Some adaptations made by the employed caregiver such as working longer hours, taking work home, and getting help from coworkers may lead to less time for personal time, adding to the stress of caregiving duties, and family responsibilities.

Significance of Study

As the older population increases and more people live longer, so do the chances of this population experiencing multiple chronic illnesses. As these elders live longer, the chance increases that they will require assistance in daily living, which is most often provided by a family member. Many of these caregivers are employed outside the home. Nurses have a role in educating and assisting the family members of elders, who are also working and taking care of their own children, to become informed caregivers for these older adults. Employers also need to be an active participant in working with their employees to assist maintaining a balance of work, eldercare responsibilities, and other family responsibilities.

Research Questions

This study addressed four research questions:

1. What are the demographic characteristics of an employed caregiver to an elderly person?
2. What factors do employed caregivers with eldercare responsibilities believe influence their job performance at work?
3. What are the personal effects (physical, emotional and/or financial burden) of caregiving as experienced by the employed caregiver?
4. What policies or programs are in place in the work environment for employee's that support caregiving responsibilities for an older adult?

Theoretical Framework

Lazarus' Stress and Coping Model was used as a theoretical framework for this study. Lazarus defines stress as a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his other resources and endangering his or her well-being (Lazarus & Folkman, 1984).

Lazarus also looks at stress as a transaction between the person and an event within a certain environment that focuses on individual differences, rather than events or reactions (Lazarus & Folkman, 1984). This model suggests a person's perception of mental and physical health is related to the ways he or she evaluates and copes with the stresses of living (Polit & Hungler, 1995). Nursing's understanding of the concept of stress and its consequence(s) on individuals is essential when applied in clinical nursing practice in terms of nurses making a positive difference by being in the situation in a caring way (Marriner-Tomey, 1989). Nurses have conducted

research within the context of the Lazarus model, including studies of stress and coping among family members responsible for a nursing home placement, coping and adaptation to chronic illness, and coping effectiveness in postmyocardial infarction patients (Polit & Hungler, 1995).

Lazarus' model explains people's methods of dealing with stress, such as environmental and internal demands that have an impact on a person's resources and endanger his or her well being (Polit & Hungler, 1995). Lazarus' Theory of Stress and Coping emphasizes the continuous, reciprocal nature of the interaction between the person and environment (Lazarus & Folkman, 1984). Stress is also described as the disruption of meanings, and coping is what the person does about the disruption. Both doing something and refraining from doing anything about the particular stressful situation are ways of coping (Marriner-Tomey, 1989). Lazarus believes that coping strategies are learned, deliberate responses to stressors that are used to adapt or change the stressors (Polit & Hungler, 1995).

Lazarus' theory of stress as a transaction is based upon four concepts: (a) demands, (b) primary appraisal of demands, (c) secondary appraisal of demands, and (d) reappraisal of demands. The demand, which is an event within the internal and external environment confronting an individual, comes first followed by the primary appraisal. A primary appraisal is made when an individual makes a conscious evaluation of the demand and decides if it is a harm/loss, a threat or a challenge. In the appraisal of challenge, a person may see an opportunity to prove herself or himself; and is viewed as a pleasant, exciting, and interesting experience. Threat occurs when the person perceives being in danger, and it is experienced when the

person anticipates future harm or loss. In the threat appraisal the person still seeks ways to master the situation and is striving for a positive outcome of the situation in order to gain or restore his or her well being. In the experience of harm/loss, some damage to the person has already occurred, and these damages can include the injury or loss of valued persons, important objects, self-worth or social standing. Instead of trying to master the situation, the person surrenders, overwhelmed by the feelings of helplessness (Lazarus & Folkman, 1984). The secondary appraisal is the next step and is an assessment by an individual of coping mechanisms available for utilization in adapting to a demand. And finally the reappraisal occurs, which is a reevaluation by an individual of the effectiveness of the coping mechanisms utilized to adapt to a demand (Lazarus & Folkman, 1984). Lazarus' theory attempts to look at what factors lead some persons, and not others, to respond effectively to events within a certain environment; why some persons differ in their sensitivity and vulnerability to certain types of events in a certain environment; and why some persons are able to adapt over longer periods than others to events within a certain environment (Lazarus & Folkman, 1984).

Definitions

For the purpose of this study the following definitions were used:

Activities of Daily Living (ADLs): Activities involving personal care, such as eating, bathing, dressing, toileting, and getting in and out of bed.

Caregiving: Providing unpaid assistance to an older relative or friend with the purpose of helping them remain as self-sufficient as possible.

Coping: Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.

Eldercare: Informal caregiving or the process of helping an older relative or friend.

Demographic Characteristics: The characteristics of the study population, which include age, gender, ethnic background, marital status, socio-economic status, and employment status.

Elder/Elderly/Older adult: Persons age 65 years old and older.

Employed Caregiver: Anyone, 18 years of age or older currently providing a degree of informal care to an older relative or friend. For this study, there was no limitation on percentage of time employed.

Instrumental Activities of Daily Living (IADLs): Activities performed to manage one's daily life or maintain a household and live independently; examples include preparing meals, grocery shopping, managing finances, paying bills, and transportation.

Job Performance: How well one is able to do their work.

Personal Effects: Any physical, emotional and/or financial burdens experienced by the caregiver.

Policies/Programs: Any written information in the form of a policy or program that is available to employee's that supports caregiving.

Stress: A particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being.

Assumptions

The underlying assumptions made in this study were:

1. That employees who are also elder caregivers experience some stress on their work lives.
2. That the subjects are employed caregivers with eldercare responsibilities.
3. The tool is valid, reliable, and applicable to a rural ND community.
4. The Eldercare Survey Tool is used in person and not by telephone.

Limitations

The findings of this study are limited by the following factors:

1. Some employed caregivers with eldercare duties may have been unwilling to participate in the study for a variety of reasons.
2. The study involved only employed caregivers of older adults.
3. Employed caregivers who participate are employed varying percentages of time.

CHAPTER II

METHODOLOGY OF STUDY

Included in this chapter are discussions concerning the study population, sample, study design, and the instrument used. The data analysis procedures, as well as the methods used to protect the rights of human subjects are also presented.

Population and Sample

The population for this study was comprised of adult males and females employed outside the home at a regional health care system who have eldercare responsibilities along with work. The adults lived in or around an urban area of 75,000 in a north central area of the U.S. A convenience sample was obtained from multiple settings within one medical complex. Settings included clinics, a hospital, a home care agency, and a health institute. The sample size was 64 subjects who met study criteria.

Study Design

An exploratory, descriptive design was used for this study. An exploratory descriptive study aims to observe, describe, document, and also explore the factors that contribute to the phenomenon (Polit & Hungler, 1995). This study utilized a questionnaire to examine the effects of elder caregiving on employees and their work. The study looked at what types of caregiving are provided for the older adult,

how many hours are spent on elder caregiving per week, and to what extent emotional, physical, or financial burdens are experienced by the caregiver.

Data Collection Methods/Procedures

Human subject joint approval was obtained from the University of North Dakota and the health care system Institutional Review Board. The researcher attended department staff meetings and presented short, clear verbal instructions to employees of the health care system. The researcher made one visit to each department staff meeting to distribute the questionnaires at the meeting, and collect them upon completion. The cover letter included instructions for completion of the questionnaire, that completion and return implied consent, and how the researcher would convey the study findings. The researcher explained the time frame up front, and any questions were answered at that time. The researcher requested that only adult employees with eldercare responsibilities should participate. A wrapped “ballot type” box was used for placement of completed questionnaires.

Instrumentation

The study instrument used to collect data was the Eldercare Survey Questionnaire with modifications added by the researcher. The researcher received permission to use, with modifications, the Eldercare Survey tool from Gail Hunt, Executive Director of National Alliance for Caregivers (NAC). Ms. Hunt was part of the design team from the National Alliance for Caregivers that sponsored and designed the study along with the American Association for Retired Persons. The study was designed as a telephone survey to be used with a nationwide random sample of caregivers aged 18 years and over. The NAC contracted with the

International Communications Research, Inc. (ICR) to conduct the survey, generate the samples, and prepare the report. The survey was conducted between August 13 and September 20, 1996 with respondents capable of answering questions in English by telephone. The questionnaire took 15-20 minutes to complete by phone. A total of 1,509 English speaking family caregivers participated in this telephone survey: 623 Whites, 306 Blacks, 307 Hispanics, 264 Asians, and 9 other. All percentages reported in the findings of the survey referred to proportions of the entire U.S. population of informal caregivers; the findings of the sample of caregivers had been adjusted or weighted to reflect accurately the distribution of U.S. telephone households with a caregiver. In the study when percentages were cited and compared across subgroups, the differences were statistically significant at the .05 level or better. A factor analysis was conducted to determine which variables were most closely associated with the intensity, level of difficulty, or amount of wear and tear involved in informal caregiving. Based on the outcome of the factor analysis, a Level of Care Index consisting of five points was created. This enabled each caregiver to be assigned for analytical purposes to one of the five levels, based on the intensity of caregiving provided. The data collected from this survey has been used in other studies by the National Alliance for Caregivers: (a) The Metlife Study of Employer Costs for Working Caregivers; (b) Comparative Analysis of Caregiver Data for Caregivers to the Elderly 1987 and 1997; (c) The Metlife Juggling Act Study; and (d) The Caregiving Boom: Baby Boomer Women Giving Care. The 35-item tool has four parts: Part I (3 questions) asks information on whether they are or are not an elder caregiver; Part II (9 questions) asks demographic questions about

elder(s) being cared for; Part III (11 questions) asks general questions about caregiving; Part IV (11 questions) include caregiver demographic information and the caregivers' work situation, and one open-ended question soliciting information on what she/he believes the main concerns/issues to be in the care of an elderly person. As part of the modification of the tool, seven questions were added to part III of the questionnaire, one question removed, and three more open-ended questions were added; this brought the total questions on the survey tool to 44. Six questions added to the survey pertained to the personal effects (physical, emotional and/or financial burden) of caregiving as experienced by the employed caregiver. One question added pertained to the employer's attitude toward the demands of eldercare responsibilities by the employed caregiver. The three open-ended questions were added to ascertain the biggest difficulty as well as the greatest reward by the participant in taking care of an older adult. Two experts with advanced degrees and background in research and education reviewed the tool for clarity.

Data Analysis

Descriptive statistics were used to analyze and describe the answers to the questionnaire, including demographic information. The data were analyzed using the Statistical Package for the Social Sciences (SPSS) which labeled variables and provided parametric and non-parametric statistical procedures. Pearson correlation, t-test, and chi-square were used to test for significant relationships as appropriate. The open-ended questions were analyzed using content analysis.

Protection of Human Subjects

Approval of this study was obtained from a joint agreement of the Institutional Review Boards of the University of North Dakota and a health care system. Employees of the health care system complex were participants in this study; the employees participating had eldercare responsibilities. Study subjects were informed by a written introduction, attached to the Eldercare Survey Questionnaire, and completion of the questionnaire indicated consent to participate. Anonymity and confidentiality was assured for all study participants, as the questionnaires did not contain any identifying information. All of the participants had the right to withdraw from the study at any time without repercussion. The risks to participants were expected to be minimal, however, there was a possibility that “stressful feelings” may be experienced while answering the questionnaire. A number for Pastoral Care at the health care system was provided in the cover letter to the participants. To the researcher’s knowledge, no participants availed themselves of this service. Benefits of participating in this study were the knowledge gained from the information the participants provide that may help others in similar situations.

CHAPTER III

PRESENTATION AND ANALYSIS OF DATA

The purpose of this study was to examine the effects of elder caregiving on caregivers employed outside the home and their work. Included in this chapter are discussions of the study population and sample, followed by the analysis of the data collected. The research questions were:

- (1) What are the demographic characteristics of an employed caregiver to the elderly person?
- (2) What factors do employed caregivers with eldercare responsibilities believe influence their job performance at work?
- (3) What are the personal effects (physical, emotional and/or financial burden) of caregiving as experienced by the employed caregiver?
- (4) What policies or programs are in place in the work environment for employee's that support caregiving responsibilities for an older adult?

Quantitative data from this study were analyzed using descriptive statistics; the open-ended questions were analyzed using content analysis.

Description of the Sample

A total of 140 questionnaires were distributed to employed caregivers eighteen years of age and older with eldercare responsibilities outside of work, and a total of 64 were completed and returned to the investigator during a period of one

month. The response rate for this study was 45 percent. On one of the 64 surveys returned, the participant answered just the four open-ended questions. This survey was retained for content analysis only. The investigator, in various staff meetings throughout one health care system, personally handed out the 140 questionnaires. The twenty-nine staff meetings the investigator attended included participants from the laundry department, intensive care unit, medical surgical units, research department, occupational health department, critical care unit, rehabilitation unit, respiratory care, and the family birthing unit. Other areas included: occupational therapy, social work department, nutrition services, human resource department, business office, radiation/oncology unit, surgical critical care unit, plant services, hospice department, home care department, respiratory home care department, surgery department, purchasing department, pediatrics, specialty services department, oncology, main clinic, and cardiac nursing department.

Presentation and Analysis of Data

Research Question 1

What are the demographic characteristics of an employed caregiver to the elderly person?

Demographic characteristics included age, gender, ethnicity, marital status, socio-economic status, and employment status. The majority (82.3%) of study participants were female, with a mean age of 46 years (SD=8.38, range=28-67). The majority (98.4%) of participants were of White/Caucasian background, and also married. Thirty-three percent of the participants have a household income in the \$30,000 to \$49,000; while 32.0% were in the \$50,000 to \$79,000 range. The

participants reported household size as follows: 32.0% had two members, 24.0% four members, 18.0% had three members, and 16.0% had five members in the household. The majority (52.0%) had no children under the age of 18 years dependent on them financially; and 45.0% had no persons over the age of 18 years and less than 60 years dependent upon them financially. Sixty-seven percent of the participants described their work as professional, with the majority (81.0%) working full-time.

The majority (63.5%) of participants reported providing some type of care for a person over the age of 60 years on a continuing basis, including financial, housing, feeding, bathing, transportation, and other. Eighty-seven percent reported that they have provided care within the last five years to a person over the age of 60 years, and 90.0% anticipated providing care to someone over the age of 60 years in the next five years.

Sixty-two percent of participants cared for at least one person over the age of 60 years, 16.7% for two persons, and 7.0% provided cared for three persons over the age of 60 years. The majority (64.5%) of elders over the age of 60 years and receiving care were female, with a mean age of 78 years ($SD=8.48$). The elder being cared for were a mother or father (69.4%), a mother-in-law or father-in-law (35.5%), grandparent (9.7%), or an aunt or uncle (6.5%).

The majority (72.6%) of the elders over the age of 60 years receiving care from the participants lived in their own home, while the others lived in the participant's home or a nursing home. The majority of participants (46.7%) reported providing care for two years to five years, 23.3% for six months to two years, 18.3%

have provided care for more than five years, and 11.7% less than six months. The participants reported the most frequent type of care provided (see table 1) was transportation (66.7%) and the least frequent was personal care (28.6%). Some elders over 60 years of age also received services from outside sources. The additional services provided by outside sources were as follows: 32.5% transportation, 30.0% home repair and nursing services, 20.0% personal care, 15.0% homemaking, 12.5% meals, and 2.5% counseling.

Table 1

Type of Care Provided by Employed Caregiver for an Older Adult

Type of care provided	Frequency	Percent
Transportation	42	66.7
Companionship	40	63.5
Home maintenance	38	60.3
Housekeeping	28	44.4
Meal preparation	23	36.5
Assistance with bill paying	22	34.9
Personal care	18	28.6
Other	15	23.8

The majority (38.3%) of participants reported they spend less than three hours a week providing care, 30.0% spend three to seven hours a week, 20.0% 8 to 14 hours a week, 5.0% spend 15-21 hours a week, and 6.7% spend more than 21 hours a week. Sixty percent of the participants reported the primary caregiver for the

person over the age of 60 years was the participant themselves, 40.0% the participant's spouse, 25.0% another relative, and 7.0% a non-relative is the primary caregiver.

Research Question 2

What factors do employed caregivers with eldercare responsibilities believe influence their job performance at work?

When participants were asked if they felt caregiving responsibilities interfered with their work life, the majority (42.0%) reported sometimes, 32.0% reported seldom, 16.0% reported never, and 10.0% reported frequently. The majority (76%) of participants, as both worker and caregiver, had experienced related to their work going in late, leaving early, or taking time off during the day to provide care. Study participants reported they did not have to take a leave of absence, go from working full-time to part-time, turn down a promotion, lose any job benefits, or take a less demanding job as a result of their caregiving responsibilities. Half (50%) of the participants reported they did not, in an average month, have to spend time away from work because of their caregiving responsibilities, while 43.5% reported spending less than a day, 4.8% one to two days, and 1.6% more than five days.

Research Question 3

What are the personal effects (physical, emotional, and/or financial burden) of caregiving as experienced by the employed caregiver?

Seventy-three percent of participants reported that they did not suffer any physical or mental health problems as a result of caregiving, and 27% reported they

did. Additionally, participants were asked to rate, on a scale of one to five, where one was not at all stressful and five was very stressful, how much stress they experience in terms of physical, emotional, and financial stress or strain in caring for an older adult (see Table 2). Emotional stress was found to be the most stressful for participants with a mean of 3.08 (SD=1.17).

Table 2

Stress Rating in Providing Care for an Older Adult

Stressor	Mean	Standard Deviation
Emotional stress	3.08	1.17
Physical strain	2.16	1.21
Financial hardship	1.59	1.13

When participants were asked the yearly financial support that they provide as part of caregiving, the majority reported no financial obligation to the older adult. Table 3 reports the levels of financial support provided per year to the older adult by study participants.

The majority (61.3%) of the participants reported that as a result of caregiving responsibilities they have spent less time on other family members than before. Sixty-one percent of the participants reported that they have had to give up vacations, hobbies, and other activities due to caregiving responsibilities. The majority (83%) of participants reported they had no difficulty in securing home care

services for the older adult. In addition, nearly the same percent (79%) reported experiencing no difficulty affording home care services.

Table 3

Levels of Financial Support Provided to an Older Adult Per Year as Part of Caregiving

Financial support per year	n	Percent
None	23	36.4
< \$1,000	22	34.9
\$1,000 to \$2,499	10	15.9
\$2,500 to \$4,999	2	3.2
\$5,000 or more	3	4.8
No response	3	4.8

The open-ended item (see Appendix, Item 41) allowed participants to elaborate on the biggest difficulty they face in taking care of an older adult. Four common areas of difficulty participants shared were: time issues, distance away from the older adult, stubbornness of the older adult, and financial concerns. One participant who wrote about the time issue noted, “juggling time” and “scheduling time around work schedule” and another, “they schedule appointments without checking my schedule first so the appointment has to be moved or I have to trade days at work.” Other participants wrote, “Time, fitting their needs into my busy schedule, usually need a full day to help her do her errands” and “rest, self care, private time, time for husband, time for children, relaxation” and “time constraint

with a full time job of 48-52 hours a week.” Others wrote, “ Guilt of not spending enough time with them” and “ finding enough time to get to visit while having four children to care for.” Another wrote, “ Finding time for myself” and “ finding enough time to get everything done that needs to be done in two households.”

Participants wrote about the difficulty regarding the distance issue, “ Emotional guilt of not being closer to help take care of the many little things” and “living in a different town and having to travel three hours to get there,” and another “distance from them and a health care facility and lack of understanding their medical condition.” Others wrote, “ Distance from father” and “ my parents live 120 miles from where I work. When there is a medical crisis, the time involved to get to them is stressful” and “my mother lives 750 miles away, widowed and lives alone, siblings near her have minimal flexibility in their jobs to help her.”

Participants shared that stubbornness by the older adult was a difficulty in caring for them. One participant wrote, “ The adult being stubborn and not wanting to do what is required of them” and another “ their stubbornness, they don't want any outside help from any organizations, they feel they are not in control” and “ stubbornness, thinking it is welfare.” Others wrote, “ My mother insists that she can continue to do all the things she is used to doing, including yard work, yet doing heavy physical labor is very tiring and increases her fatigue and frustration levels” and “getting to make the healthy adult see how much strain on him it is to take care of someone who needs care.”

Financial issues were reported by participants as difficult. One participant wrote, “Uncertain financial future of two of our elders, in health care and in home

needs.” And another wrote, “Wondering how long there will be enough money for my parents to live independently, and the awkwardness in even addressing the questions about money.” Others wrote, “Worries regarding making good choices so she can be financially independent” and “being able to help financially.”

Other difficulties in caring for an older adult expressed by the participants were the following: watching their parents grow older, the older adult thinking they are a bother, declines both physically and mentally, knowing their needs and meeting them, wondering if they are doing enough, and juggling work, family and eldercare responsibilities.

Research Question 4

What policies or programs are in place in the work environment for employee’s that support caregiving responsibilities for an older adult?

When participants were asked to rate their employer’s attitude toward the demands of their caregiving, the majority (83.7%) believed their employer was very understanding, 12.2% somewhat understanding, and 4.0% reported not very understanding. The majority (52.6%) of participants said they had not sought help at work for problems they were having in their caregiving role, while 47.4% had sought assistance. Of the 47.4% of participants who have sought help from the workplace, 38.6% did so from another co-worker, 12.3% called on a supervisor, 8.8% received it from employee assistance, 3.5% from personnel, and 1.8% from employee health.

Family/friends was the most frequent source (68%) for information on caregiving issues for participants, while a large number (41.5%) sought help from the doctor or other health professional. Other sources were government (11.3%),

church (9.4%), 7.5% media, 5.7% internet, and 1.9% employee assistance program. (Participants could check more than one source). Participants were asked to rate how certain following services would be to their caregiving situation. Of those responding, 63.5% (n = 40) felt that flexible work hours would be most helpful to them, followed by educational workshops (61.9%), while 28.6% (n=18) responded that before-tax deductions were least helpful (see Table 4). Participants who responded were most uncertain regarding the helpfulness of adult day care services (n = 26, 41.3%).

The open-ended item (see Appendix, Item 44) allowed participants to elaborate on what they thought the main concerns and issues relating to the care of the older adult are and how the community and workplace could help. One participant wrote in, “ Work should be a place to help employees cope with the new stress of eldercare” and another “the workplace should allow time off for new duties with eldercare without guilt, and time off to deal with stress issues.” Other participants wrote positively of their workplace, “ My workplace has allowed me to adjust my schedule and take what time I need to take care of family responsibility” and another wrote, “ I was fortunate to have a very understanding group of people to work with, as I know a lot of employees don’t, the flexibility was much appreciated.” Education on services and access to services was another common theme the participants shared would be helpful for the workplace and community to look into.

Table 4

Rating of Services in Terms of Helpfulness in the Caregiving of Older Adults

Service	Helpful n(%)	Not Helpful n(%)	Uncertain n(%)
Flexible work hours	40(63.5%)	8(12.7%)	9(14.3%)
Educational workshops	39(61.9%)	8(12.7%)	11(17.5%)
Chore services	34(54.0%)	14(22.2%)	9(14.3%)
Homecare services	34(54.0%)	7(11.1%)	16(25.4%)
Transportation	32(50.8%)	14(22.2%)	11(17.5%)
Home safety	31(49.2%)	12(19.0%)	12(19.0%)
Housing assistance	26(41.3%)	13(20.6%)	17(27.0%)
Respite care	25(39.7%)	12(19.0%)	19(30.2%)
Health assessment	24(38.1%)	11(17.5%)	20(31.7%)
Counseling	23(36.5%)	13(20.6%)	21(33.3%)
Support groups	23(36.5%)	11(17.5%)	23(36.5%)
Extended leave of absence	22(34.9%)	11(17.5%)	23(36.5%)
Adult day care	19(30.2%)	10(15.9%)	26(41.3%)
Tax deduction	18(28.6%)	16(25.4%)	23(36.5%)

n = represents the number of participants answering the question

% = percent of the participants answering the question

One participant wrote, “ What types of services are available, support group for family members, and education, what can I do” and, “access to correct channels of referral, knowledge of what is available, and a support group for the sandwich generation people” and another, “ services and accessing services.”

Other Findings

The open-ended item (see Appendix, Item 42) asked participants what the greatest reward was for them for taking care of an older adult. Five common areas were reported: (1) keeping the older adult out of the nursing home, (2) giving back, (3) knowledge gained, (4) knowing they are cared for and happy, and (5) forming deeper bonds. Keeping them in their own home was a popular response, and one participant wrote, “ To know that my mother is not sitting in a nursing home and is still somewhat active” and another “ that they can be at home and among relatives and friends.” Others wrote, “Being able to meet all needs and keep them in their own home” and “ keeping them out of a nursing home.”

Participants responded that giving something back to the older adult was a great reward. One wrote, “ Knowing that she once took care of me with love and tenderness and now I can repay her with love and tenderness.” Others wrote, “ Being able to give back the caring and support to my mother who helped me when I needed the caring and support” and “ knowing that we are making life easier for there future as they have for us in the past.” Participants wrote, “ The companionship, and being able to give back a little of yourself” and “ my father always helped me out whenever needed, I am glad I can help him out” and another, “ giving back to a parent all that they have given to me as a child.”

Knowledge gained was another popular response among the participants who answered the question. One participant wrote, "Learning about me, my history, learning coping skills of life" and "gaining some of their knowledge like history, quilting and crafts." Others wrote, "Learning more about them, sharing, hearing them and all their wisdom" and "she stays very involved with her grandchildren, and provides us with joy and family history." Other participants wrote, "We gain from their knowledge, experience, love and rich storytelling" and "the elderly have great knowledge and are so fun to listen to, they have great stories, we could learn a great deal from them."

Knowing that the older adult is well taken care of was another reward reported by the participants. One participant wrote, "Knowing she is well cared for, healthy, and safe" and "knowing you've helped brighten someone's day and their quality of life is better because you care." Others wrote the biggest reward, "Meeting their needs," "being able to help," "the smile on her face and the hugs," and another wrote, "Mom appreciates all we do for her and she is truly one of my best friends." Other participants reported, "Knowing that you're helping them and they appreciate your help" and "seeing the piece of mind and comfort I can give them when they are ill and to help them through it by being calm and reassuring."

Other rewards expressed by the participants were showing love to another person, getting the chance to form a deeper bond with parents, satisfaction, and the ability to spend time with parents and keep track of their well being. Participants wrote, "Feeling the satisfaction of doing something for others" and "knowing that we have done our best, the rewards." Another participant wrote, "Being able to

show love, care, compassion for the ones that we are close to, showing God's love to our older adults.”

In another open-ended item (see Appendix, Item 43), participants were asked to pick one word that they personally felt about being a caregiver. Of those participants who responded, 29 were positive words, and 26 were negative words. Some of the positive words were grateful, honored, blessed, love, satisfaction, needed, and joy. Other positive responses included good, willing, content, rewarding, dependable, and special. Some negative responses were torn, frustrated, overwhelmed, tired, stressful, hard, work, sandwich, constant, stuck, unsettled, and concerned.

CHAPTER IV

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

In this chapter there will be a brief summary of this study and a discussion of the results. It also includes recommendations for nursing, education and research.

Summary

More and more people will live long enough to experience multiple chronic illnesses, disability, and dependency; in addition there will be more relatives who will be facing the concern and expense of caring for them. Family members will find themselves balancing responsibilities of their own work, their children and their elder relatives.

The purpose of this study was to determine the effects of elder caregiving responsibilities on the employed caregiver and their work. The study examined eldercare responsibilities such as the types of caregiving provided for the older adult; the hours spent on eldercare caregiving per week; and the extent to which the caregiver experienced emotional, physical, and/or financial burdens.

Lazarus' Stress and Coping Model was used as the theoretical framework for this study. Lazarus defines stress as a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his other resources and endangering his or her well being. This model suggests a person's perception of mental and physical health is related to the ways he or she evaluates

and copes with the stresses of living. The findings in this study were supportive of Lazarus' Stress and Coping Model. Study participants were able to rate their stress level and reported they did not suffer any physical or mental health problems due to their caregiving experience. The study participants reported their biggest difficulties and greatest rewards in caring for an older adult. The findings would tend to support the model where study participants evaluated their caregiving situation and were coping with at least the majority of stress of the experience.

The study was conducted in a Midwestern urban city with a population of approximately 50,000. The researcher distributed questionnaires to employees of one hospital, who were 18 years of age or older, employed at the hospital and had eldercare responsibilities outside of work. There were 64 questionnaires completed, with 63 retained for statistical analysis plus one other retained for content analysis only, as only the open-ended questions were answered. The questionnaire was developed by Gail Hunt, Executive Director of National Alliance for Caregivers (NAC), and permission was received by the researcher to modify and use the tool. The questionnaire consisted of four parts: Part I (3 questions) asks information on whether they are or are not an elder caregiver; Part II (9 questions) has demographic questions about an elder(s) being cared for; Part III (17 questions) asks general questions about caregiving; Part IV (11 questions) includes caregiver demographic information and the caregiver's work situation, and four open-ended questions.

Discussions/Conclusions

In this sample of hospital employee caregivers in a Midwest urban city, the majority of participants were female, white, married, mid-forties, earning between \$30,000 and \$49,000, and employed full-time in a professional-type job. The majority (63.5%) of the participants reported providing care for a person over the age of 60 years of age on a continuous basis. Eighty-seven percent of the participants have provided care within the past five years for a person over the age of 60 years, and 90.0% reported they anticipate in the next five years that they will have to provide care for someone over the age of 60 years.

The majority of the participants reported providing care for one person over the age of 60 years, who most often was a parent. The elder being cared for was primarily a female with a mean age of 78 years living in their own home. The majority of the participants have provided care for two to five years; the most frequent type of care provided was transportation, and the least frequent care provided was personal care. The largest percent (38.3%) of participants spent less than three hours a week providing care, with 30.0% spending three to seven hours a week. The majority of the participants did not have children under the age of 18 years of age dependent upon them financially in their household.

The majority (42%) of the participants felt that caregiving responsibilities sometimes interfered with their work life. Caregiving interfered with work in that they have had to leave early, go in late, and take time off during the day to provide care. Overall, they reported less than a day in an average month this happened.

Research Question 3 investigated the personal effects (physical, emotional, and/or financial burden) of caregiving as experienced by the employed caregiver. The majority of participants reported they did not suffer any physical or mental health problems as a result of their caregiving experience. Participants rated the stress of caregiving as being most difficult emotionally, followed in order by being affected physically and then financially. Over one-third (36.5%) of participants reported having no financial obligation as part of the caregiving responsibility, while 34.9% reported a financial output of less than \$1000/yr. The majority of participants did not feel this is a financial hardship or burden. The biggest difficulties reported in caring for an older adult were in areas of time issues, distance from the older adult, stubbornness of the older adult, and financial concerns.

The majority of participants felt their employer's attitude toward their caregiving situation was very understanding. While the majority of participants reported not seeking help from anyone at work for problems regarding their caregiving role, those who did sought assistance most often from a co-worker or supervisor. Participants reported receiving the majority of information on caregiving issues from family or friends as well as from the doctor or other health care professional. Some information was received by the participants from church, media, internet, the government, and employee assistance. In terms of helpfulness of certain services, participants felt flexible work hours would be the most helpful, while before-tax deductions was rated least helpful. Other areas participants felt would be helpful were educational workshops, chore services, home care services, transportation, home safety, respite care, housing assistance, and counseling.

Participants felt their work environment was supportive, but would like more information on services available and access to those services.

The greatest rewards in caring for an older adult were in five common areas: (1) keeping the older adult out of a nursing home, (2) giving back to the older adult, (3) knowing they are well cared for and happy, (4) knowledge gained and the rich storytelling, and (5) the ability to form deeper bonds. Participants' provided one-word responses to explain how they personally felt taking care of an older adult; the responses were nearly equal with positive and negative responses.

Limitations

One of the limitations of this study was that the questionnaires were collected in one Midwestern city that had a population of predominantly White/Caucasian background, leaving a minimal representation of other ethnic backgrounds in the sample. The questionnaire was distributed to employees at only one health care center, limiting the generalizability of the study results. Another limitation was the ability of the survey to reflect accurately the lived experience of the employed caregiver.

Recommendations for Nursing

Nurses assume a major role in assisting older adults and their family's cope with the changes that come with aging. Family members must be informed that they may be the primary caregiver for the older adult, and that they need to be realistically prepared to face the necessary tradeoffs of balancing sometimes competing demands on their physical, emotional, and financial resources. It is the role of nurses to educate clients and their families that the demands of caregiving may have an effect

on work, family and personal time. Nurses must be advocates for older adults and family members and assist them in addressing a plan of care both long and short term.

Nurses must promote healthy aging, and educate people on the various aspects of aging, both normal and abnormal. Nurses need to promote well-being, such as daily exercise, proper nutrition, and self-education for both the older adult and their family members. Nurses need to give information about the older adult's disease to the family caregiver so that they know what to expect, and how to care for this person with the disease. Nurses should be active as facilitators of support groups for caregivers of older adults. Caregivers need support from other caregivers in similar situations as well as the expertise and knowledge background nurses can provide.

Nurses must understand the concept of stress and its consequence(s) on individuals in situations pertaining to caregiving and the use of their coping skills. Nurses must be familiar with the current research concerning trends in the aging population, and have accurate knowledge concerning issues such as heart disease, cancer, stroke, osteoporosis, dementia, falls prevention, and other aging issues. Nurses could be advocates for working caregivers and help business employers and employees define the needs and demands that come with the caregiving experience.

Recommendations for Education

With the growth of the aging population, there will be an impact of caregiving on business productivity. Businesses would be well advised to take an active role work with their employees, to increase the use of flex-time and job

sharing, to add long-term and tax deductions to their benefit packages, and provide employees with caregiving options and information. There is a dual economic impact of caregiving on both the caregivers themselves and on employers, thus the situation is enhanced when employers and employees work together.

Classes should be offered to all health care professionals addressing caregiver need and the demands caregiving can precipitate. Classes should also be offered to caregivers and potential caregivers that would address how to help balance work, family and caregiving responsibilities. Classes for employers that would outline the potential problems employees are faced in trying to balance the demands of caregiving and work.

Recommendations for Research

More research needs to be done on the subject of stress, particularly family caregivers who are subject to stress from a variety of sources. Stress is a normal part of daily life, yet too much stress can be detrimental to health and well-being. More research in the area of chronic caregiver stress would help to identify the signs and symptoms before a crisis occurs. Nurses can help with education of the warning signs of stress and what to do to relieve the stress. Nurses can play an important role to prevent caregiver burnout that is not only harmful to oneself but their loved ones as well.

Replication of this study is recommended with a larger sample size between two health care facilities as well as one health care facility and a non-health care facility. Theoretically, health care facilities could provide a more nurturing environment for caregivers than a non-health care facility. Health care facilities

should have easy access to information on various aspects of the aging including chronic conditions, diseases, and other issues. Is there a difference in the caregiver experience between caregivers who are employed at a health care facility and those who are employed in a non-health care facility?

More research into the caregiving experience should be done to determine if the caregiver themselves have made future plans for themselves due to this experience. Has this caregiving experience made the caregiver better prepared for the possible needs and demands that might potentially come with aging. Has the caregiving experience opened the lines of communications between other family members such as their spouse, other siblings and the caregiver's own children on various aspects of aging, and if so, in what ways?

APPENDIX

PARTICIPANT LETTER AND QUESTIONNAIRE

APPENDIX

PARTICIPANT'S LETTER

Dear Participant,

You are invited to participate in a study being conducted with Altru Health System employees about the effects of Eldercare responsibilities on employed caregivers. I am a graduate student in the Adult Health Nursing program at the University of North Dakota and also am coordinator of the ElderNet program at Altru Health System. I am conducting this research for my master's thesis.

The purpose of this study is to determine the effects of elder caregiving responsibilities on the employed caregiver and their work. This study will examine eldercare responsibilities such as what types of caregiving are provided for the older adult; how many hours are spent on eldercare caregiving per week; and to what extent emotional, physical, and/or financial burdens are experienced by the caregiver. This study will address the prevalence of such factors as increased absenteeism, lost or missed job opportunities, increased personal phone calls at work, and loss of productivity while at work. The results of this study will be shared with the agency administration. It is hoped that the agency will use the information provided to address changes that can enhance the work environment of employed caregivers.

Please complete the attached questionnaire. It should take approximately fifteen minutes to complete. The questionnaire should only be completed if you are 18 years of age or older, employed at Altru Health System, and have eldercare responsibilities. Your responses will be kept strictly confidential and no one will be able to know who completed each individual questionnaire. You may choose not to participate. Completion and return of this questionnaire will be accepted as your consent to participate. Risks for participating in this survey are minimal; however if filling out this questionnaire causes any stressful feelings to be experienced by you, please feel free to contact the Pastoral Care at Altru Health System, the number is 780- 5300.

Thank you for taking the time to complete this questionnaire if you do choose to participate. If you have any questions about this study or would like a description of the results, please feel free to contact me at home (772-2981) or work (780-5881), e-mail address: nmcenroe@altru.org.

Sincerely,

Nancy McEnroe RN, BSN 2210 Belmont Rd. Grand Forks, ND 58201
Dr. Diane Langemo, Chair, 777-3215

Eldercare Survey Tool

Part I:

1. On a continuing basis, are you providing (e.g., financial, housing, feeding, bathing, transportation, etc.) for a person over the age of 60 years?
 Yes No
2. Within the past 5 years, have you provided care (e.g., financial, housing, feeding, bathing, transportation, etc.) for a person over the age of 60 years?
 Yes No
3. Do you anticipate that in the next five years you will have to provide care (e.g., financial, housing, feeding, bathing, transportation, etc.) for a person over the age of 60 years?
 Yes No

Part II: Information on Specific Care Provided

4. Currently, for how many persons over the age 60 are you providing care?
 Persons
5. In the past five years, for how many persons over age 60 did you provide care, but are no longer?
 Persons
6. What is the relationship to the person(s) for whom you care?
 mother/father wife/husband grandmother/grandfather
 sister/brother aunt/uncle mother-in-law/father-in-law
 other: (specify)
7. What is the gender of the person(s) for whom you care? If more than one person is being cared for by you, put the appropriate number in each category.
 Male Female
8. What is the age of the person(s) for whom you care? If more than one person is being cared for by you, provide ages.
 Age Age
9. What kind of care are you providing that they cannot do themselves?
 (please check all that apply)
 personal care (bathing, toileting, etc.) home maintenance housekeeping
 transportation companionship meal preparation
 assistance with bill paying other (specify)

10. Where does this person(s) live?
 in your home in their own home out of town other (specify)
11. How long have you been providing this care?
 less than 6 months 6 months, but less than 2 years 2-5 years
 more than 5 years
12. Which of the following services does the person receive from an outside individual, firm, or agency? (please check all that apply)
 homemaking chores repairs and home maintenance personal care
 nursing services home delivered meals counseling transportation
 adult day care other (specify)

Part III: General Questions on Caregiving

13. Have you had difficulty finding suitable home care services for your relative?
 Yes No
14. Have you had difficulty affording care or services?
 Yes No
15. Have you had difficulty securing services for your relative?
 Yes No
16. Who is the primary caregiver for your relative(s)?
 self spouse other relative non-relative
17. On the average, how much time do you spend providing care for relatives over 60? (please check **one** only)
 under 3 hours/week 3-7 hours/week 8-14 hours/week
 15-21 hours/week over 21 hours/week
18. The yearly financial support that you provide as part of your caregiving amounts to: (please check one only)
 none under \$1,000/year \$1,000-\$2,499/year
 \$2,500-\$4,999/year \$5,000/year or more
19. Do you feel your caregiving responsibilities interfere with your work life? (please check one only)
 never seldom sometimes frequently very frequently
20. In your experience as both a worker and caregiver, did you ever ..? (please check all that apply)
 have to go in late, leave early, or take time off during the day to provide care
 have to take a leave of absence
 have to go from working full-time to part-time

- have to turn down a promotion
 lose any of your job benefits
 take a less demanding job

21. In an average month, how much time do you spend away from work (being late or absent) because of your caregiving responsibilities?

(please check one only)

- none less than a day 1-2 days 3-5 days more than 5 days

22. How would you rate your employer's attitude toward the demands of your caregiving?

- very understanding somewhat understanding not very understanding

23. From which of the following have you sought help at work for problems you are having in your caregiving role: (please check all that apply)

- employee assistance personnel co-worker employee health
 supervisor no help sought from anyone in the work place other
 (specify) _____

24. There may be other ways in which providing care to an older person that may affect your life. (Two-part question): As a caregiver have you experienced less time for other family members than before?

- Yes No

Have you had to give up vacations, hobbies, or your own activities?

- Yes No

25. Have you suffered any physical or mental health problems yourself as a result of caregiving?

- Yes No

26. On a scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how much of a **physical strain** would you say that caring for an older adult is for you?

____ score

27. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how **emotionally** stressful would you say that caring for an older adult is for you?

____ score

28. Using the same scale from 1 to 5, where 1 is not at all stressful and 5 is very stressful, how much **financial hardship** would you say that caring for an older adult is for you?

___score

29. To date , where have you received most of your information about caregiving issues? (check all that apply) ___government agency ___family/friend ___Internet ___doctor or health care provider ___church ___media ___employee assistance program ___other (specify)

30. Please rate how helpful the following services would be in your caregiving situation. (please circle one number for each item, rate all services)

Not

Helpful Helpful Uncertain

1	2	3	Flexible work hours and flexible leave
1	2	3	Before tax deductions for dependent care
1	2	3	Extended leave of absences (3 mo. or more)
1	2	3	Adult day care services
1	2	3	Week end, evening or occasional relief from caregiving
1	2	3	Home care services, such as home health, personal care, homemaker
1	2	3	Chore services (for errands, home maintenance, housekeeping)
1	2	3	In-home health assessments to help in planning a course of action/care
1	2	3	Transportation available for elders from a residence to medical appointments, essential shopping
1	2	3	Assistance in finding and using adult residential services (e.g. nursing homes, homes for adults, group homes.)
1	2	3	Workshops with information about Medicare/Medicaid, finances, community resources
1	2	3	Counseling
1	2	3	Support groups with other working caregivers that focus on helping you cope
1	2	3	Home safety assessment to ensure the older adult is living in a safe environment

Part IV: General Demographic Information

31. What is your age as of your last birthday? ___Age

32. What is your gender? ___Female ___Male

33. What is your ethnic background? ___ White ___ Black ___ Hispanic ___ Asian
___ Other (Specific)

34. What is your marital status? ___ Married ___ Separated ___ Divorced ___ Never
Married ___ Widowed

35. How many family members currently live in you household? (Please include all
infants, children, and adults related to you by blood or marriage)
_____ People

36. What is the number of children under 18 who are dependent on you for
financial or other care?
_____ Children

37. What is the number of persons over age 18 and under 60 who are dependent
on you for financial or other care?
_____ People

38. What is your annual household income? (include all members of your household)
___ Under \$10,000
___ \$10,000-29,999
___ \$30,000-49,999
___ \$50,000-74,999
___ \$75,000-99,999
___ Above \$100,000

39. How would you best describe your current type of job?
___ Executive ___ Professional ___ Technical ___ Clerical ___ Paraprofessional
___ Skilled labor ___ Unskilled labor ___ Other (Specify)

40. Are you employed: ___ Full-time ___ Part-time

41. What would you say is the biggest difficulty you face in taking care of an older
adult?

42. What would you say is the greatest reward for taking care of an older adult?

43. If you had to pick one word to describe how you personally feel about being a caregiver, what word would you choose? _____ word

44. What do you feel are the main concerns and issues relating to care of the elderly person? How can your community and the workplace help?

Thank you for taking part in this survey.

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