

THE LIVED EXPERIENCES OF EMPLOYED ADULTS WITH DEPENDENT
ADULT CAREGIVING RESPONSIBILITIES

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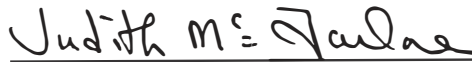
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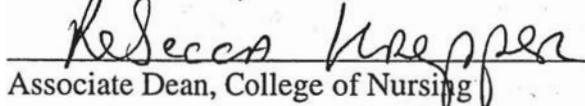
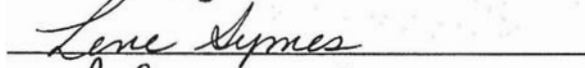
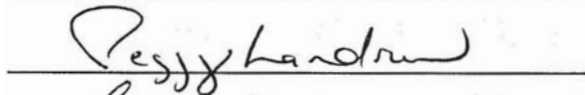
I am submitting herewith a dissertation written by Cheryl Novak Lindy entitled "The Lived Experiences of Employed Adults with Dependent Adult Caregiving Responsibilities." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing.



Judith McFarlane, DrPH, Major Professor,

Major Professor

We have read this dissertation and recommend its acceptance:



Associate Dean, College of Nursing

Accepted:



Dean of the Graduate School

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DEDICATION

To my supportive husband, my beautiful daughters, my loving parents, and to those who are employed and willingly provide many hours of unpaid caregiving.

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I would like to acknowledge all those individuals who have offered encouragement and support during my pursuit of greater knowledge and understanding. I want to thank my dissertation chairperson, Dr. Judith McFarlane, who has skillfully guided me through the process providing encouragement and direction. Many thanks for the time and guidance given by my dissertation committee members, Dr. Peggy Landrum and Dr. Lena Symes as this study evolved.

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ABSTRACT

CHERYL NOVAK LINDY

THE LIVED EXPERIENCES OF EMPLOYED ADULTS WITH DEPENDENT ADULT CAREGIVING RESPONSIBILITIES

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It is estimated that about 21% of the adult population provide unpaid care to a family member or friend annually who is chronically ill, disabled, or aged. Fifty nine percent of these adults are employed either full time or part time. With employment and informal caregiving, there may be competing demands on the person's physical, psychological, social and fiscal resources, depending on support at work and at home. The purpose of this phenomenological qualitative study was to explore the lived experiences of people who combine compensated employment and caregiving responsibilities. The research question addressed by this study was: What are the lived experiences of employed adults with dependent adult caregiving responsibilities? The participants' perceived benefits and negative aspects of caregiving responsibilities when combined with compensated employment were examined.

Few studies were found that described the positive and negative experiences of people combining employment and caregiving. Eleven women who in the past 12 months had provided care to a relative with a chronic physical or mental illness and were employed participated in this study. Through semi-structured interviews, the women

talked about their experiences. The interview transcripts were analyzed using Colaizzi (1978) qualitative phenomenological method. Using the participants' own words, seven themes were identified that included 1) doing what you have to do, 2) exhausted, 3) depression and frustration, 4) isolation, 5) personal rewards, 6) feeling torn, and 7) care coordinator and work flexibility. This study found that there are both positive and negative aspects of combining compensated employment and caregiving responsibilities. Implications for practice include: 1) assessment of the caregiver for signs and symptoms of exhaustion and depression with appropriate referrals, 2) identification of resources needed by caregiver with appropriate referrals, 3) flexible work schedules, and 4) employer benefits to include assistance with care coordination, respite, and financial planning.

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CHAPTER I

INTRODUCTION

It is estimated that over 44.4 million adults provide unpaid care to a family member or friend annually who is chronically ill, disabled, or aged. This represents about 21% of the adult population. Forty-eight percent of these adults are employed full time while an additional 11% are employed part-time. The majority of the caregivers are female (61%) (National Alliance For Caregiving & AARP, 2004).

Numerous studies have been conducted that have found serving as a caregiver for a person who is chronically ill, disabled, or aged has led to strain (Starrels, Ingersoll-Dayton, Dowler, & Neal, 1997), depression (Cannuscio et al., 2002; Clark, 2002), caregiver burden (Clark et al., 2004; Foster & Chaboyer, 2003; Kramer & Lambert, 1999; Stull, Kosloski, & Kercher, 1994; Zarit, Stephens, Townsend, & Greene, 1998), and fatigue (Clark, 2002; Kespichayawattana & VanLandingham, 2003; Nijboer et al., 2000; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). Employment has been found to increase caregiver stress (Ettner, 1995; Marks, 1998; Scott, Hwang, & Rogers, 2006; Stull, Bowman, & Smerglia, 1994). Studies have identified negative consequences of combining employment and caregiving responsibilities. Some of these negative aspects have been the need to reduce work schedules (Starrels, Ingersoll-Dayton, Neal, & Yamada, 1995), increased absenteeism (Barling, MacEwen, Kelloway, & Higginbottom, 1994; Burggraff, 1998; Scharlach, 1994), and the inability to work overtime or accept promotions (Dunham & Dietz, 2003; Metropolitan Life Insurance Company, 1999).

There has been limited evidence that combining compensated employment with caregiving responsibilities can lead to potentially advantageous results (Marks, 1998; Scharlach, 1994). Caregivers have reported increased self-efficacy, satisfaction in providing care, and a sense of purpose (Scharlach, 1994). When comparing employed caregivers and unemployed caregivers, depression scores were lower in the employed group (Burggraft, 1998). Employment has been viewed as a break from caregiving responsibilities and a means for social interaction as well as a source of increased financial resources (Dunham & Dietz, 2003; Scharlach, 1994).

Problem of Study

Currently, over 21 million employed adults in the United States are engaged in unpaid informal caregiving for a person with chronic physical or mental illness or disability. With employment and informal caregiving, there may be competing demands on the person's physical, psychological, social and fiscal resources, depending on person's support at work and at home. When caring for a loved one, an individual makes choices to manage responsibilities in their lives (Gates, 2000).

The purpose of this qualitative study was to explore the lived experiences of people who combine compensated employment and caregiving responsibilities. The participants' perceived benefits and negative aspects of caregiving responsibilities when combined with compensated employment were examined and described.

Rationale for the Study

In reviewing the literature, several quantitative studies have identified the negative aspects of combining employment and caregiving responsibilities (Marks, 1998;

Scharlach, 1994; Starrels et al., 1997; Stull, Bowman et al., 1994). Pohl, Collins and Given (1998) combined qualitative and quantitative methods to examine the employment decisions of women engaged in informal caregiving for a parent and found increased stress and burden among the women. Only two qualitative studies were found that described the experiences of people combining employment and caregiving responsibilities (Dunham & Dietz, 2003; Scharlach, 1994). Positive aspects of combining employment and caregiving responsibilities were noted. One out of five Americans provides care to a relative or friend annually. Fifty-nine percent of these people are employed either full time or part-time (National Alliance For Caregiving & AARP, 2004).

When informal caregivers seek health care for their care recipients with chronic physical or mental illness or disability, nurses should assess the experiences of the informal caregivers. Based on the assessment, nurses as advocates could assist informal caregivers to fulfill dual roles as caregiver and employee. This could include the identification of resources and assistance in the community and the workplace. It is important for employers to understand the experiences of employees in the dual role of informal caregiver and employee. Employers may be able to implement programs that will support these employees in the dual roles of caregiving and employee, which could lead to increased productivity and retention of a stable workforce.

Philosophical Orientation

Phenomenology enables understanding of the essence of an individual's experience (Merleau-Ponty, 1962/1999). The philosophy of Maurice Merleau-Ponty provided the philosophical underpinnings for this phenomenological study of lived experiences. According to Merleau-Ponty (1962/1999), knowledge of the world is derived from each individual's point of view. The individual's perception of lived experiences is an essential tenet of his philosophy (Thomas, 2005). Every action associated with an experience is a result of the individual's perception. Knowledge and meaning comes from an individual's perception, which is learned from the events and physical interaction with one's environment. Speech is the mechanism in which individual perceptions are expressed in order for others to know and understand the experiences of the individual (Merleau-Ponty, 1964/1967).

Intentionality, or the interconnectedness between people and their world, is another tenet of Merleau-Ponty's philosophy (Thomas, 2005). Individuals are not passive in the world, but rather actively involved in the events surrounding them. Individuals may have contradictory perceptions of the same event (Merleau-Ponty, 1964/1967). To understand the meaning of an experience to an individual, the person's worldview must be described.

Merleau-Ponty disavowed Cartesian dualism or the separation of the mind and the body. He believed an individual is a thinking body in the world (Merleau-Ponty, 1964/1967). The lived body is the unification of the mind and body. From this belief, embodiment is the third tenet of the philosophy, meaning the body is vital for perception,

thought, and interaction with the world (Thomas, 2005). How the body moves through time and space leads the individual to know the world (Wilde, 2003). Time is another principle of the philosophy with a focus on the present (Thomas, 2005). Subjective experiences make one aware of time.

Merleau-Ponty viewed the human experience as sacred (Thomas, 2005). This directs the investigator to be a learner with interest in understanding the human experience when approaching a study participant. The investigator seeks to understand the complex relationship between the body and the world. Using the philosophy of Merleau-Ponty, the investigator focused on the lived experiences of employed adults who have caregiving responsibilities to a dependent adult (Davidson, 2000).

Assumptions

The study was based on the following assumptions:

- There is interdependence between the employment and informal caregiving responsibilities.
- Study participants would be able to share their perceptions of their experiences with the investigator.
- Study participants would discuss their experiences openly and honestly.
- The experiences of the participants could be analyzed to identify common experiences among the participants.

Research Question

The research question addressed by this study was:

What are the lived experiences of employed adults with dependent adult caregiving responsibilities?

Definition of Terms

The terms used in this study are defined as follows:

1. Lived experiences are the described experiences of the study participants as related to their dual employment and informal caregiving responsibilities.
2. Employed adult is a person at least 18 years of age who receives monetary compensation for work performed.
3. Dependent adult is an individual requiring assistance in performing activities of daily living (ADL) or instrumental activities of daily living (IADL) due to a chronic mental or physical illness or disability.
4. Caregiving is attending to the physical needs of another person because that person is unable to do so themselves as a result of a chronic mental or physical illness or disability.
5. Caregiver is an individual who provides direct care to a dependent adult.

Limitations

The following were the limitations of this study:

- The sample was limited to one study site.
- The participants in the study self-selected to participate.

- Although the study site organization was culturally diverse, the participants were limited to those persons who were English speaking.

Summary

It is estimated over 21 million employed adults provide informal caregiving to adults with chronic physical or mental illness or disability. This study was designed to explore the lived experiences of people who function in the dual roles of compensated employment and caregiving responsibilities. Numerous studies have found negative consequences associated with informal caregiving. Few studies have identified outcomes of combining employment and informal caregiving responsibilities. Only two studies have examined the experiences of individuals having the dual responsibilities of employment and informal caregiving.

The orientation of this phenomenological study was based on the philosophy of Maurice Merleau-Ponty. The major tenet of his philosophy is that the meaning of experiences is derived from the individual's perception of the experience. Therefore, the investigator focused on understanding the relationship between the dual roles of employment and informal caregiving experiences.

The study was limited by the use of a single study site. It was further limited because participants were required to understand and speak English and self-select to participate.

CHAPTER II

REVIEW OF LITERATURE

There has been limited evidence that combining compensated employment with caregiving responsibilities can lead to potentially advantageous results (Marks, 1998; Scharlach, 1994). Caregivers have reported increased self-efficacy, satisfaction in providing care, and a sense of purpose (Scharlach, 1994). Employment has been viewed as a break from caregiving responsibilities and a means for social interaction as well as a source of increased financial resources.

The purpose of this qualitative study was to explore the lived experiences of employed adults with dependent adult caregiving responsibilities. The participants' perceived benefits and negative aspects of combining compensated employment with caregiving responsibilities were examined.

Existing Models

A review of the literature began by searching two databases, CINAHL and JSTOR. The key words of "caregiving" and "employment" were used. This resulted in the retrieval of 93 and 271 citations respectively. Upon reviewing the journal articles, those that were specific to childcare, care receiver experiences, political and legal issues, interventional studies, duplicate study reports, and non-research articles were eliminated. An additional 60 articles were eliminated because "employment status" was one of the characteristics captured on the demographics of study participants, but was not addressed in the findings of the studies. Thirty-four articles and one dissertation examined the

relationship between employment and informal caregiving. In addition, a research report by the National alliance for Caregiving and AARP (2004) was found on the Internet.

Nurses conducted four of these studies.

Frameworks

In a meta-analysis of published studies through 1996 on informal caregiving conducted by Kramer (1997), only 29 studies were found. Of these studies, 13 identified the theoretical framework used that included role theory, resiliency model of family stress adaptation, and stress/adaptation. Of twenty-eight studies published after the meta-analysis, the theoretical or conceptual frameworks were identified in 14. Stress theory was used in eight of the studies. Experiential finding meaning was used in two studies (Ayres, 2000; Farran, Miller, Kaufman, Donner, & Fogg, 1999). Two studies used grounded theory (Boland & Sims, 1996; Yates, Tennstedt, & Chang, 1999). One study found used Parse's human becoming theory to guide a phenomenological study of the experiences of caring for an elderly relative (Gates, 2000).

No meta-analysis was found on studies conducted to examine the relationship between employment and informal caregiving. Of the 35 studies retrieved for this study, only 13 investigators identified the theoretical or conceptual framework used in the study.

Exchange theory and cultural variant model were used by Bullock, Crawford, and Tennstedt (2003) to study the effect of the relationship between caregiver and care receiver and employment status. The major components of exchange theory are reinforcement patterns, social rewards, and costs. These components are thought to be

significant in the decisions and choice people make. The cultural variant model was used to explore the family functions in the African American families in the study.

Ettner (1995) used the standard labor leisure choice model to examine the effect of eldercare on labor supply decisions. In this model, a person chooses how time is spent. If one has a sense of obligation to provide informal care to a relative or friend, there will be less time to spend on other activities including leisure.

Role theory was used in five of the studies. Gender differences between employed caregivers was analyzed using role theory to demonstrate the role demands from family and career (Fredriksen, 1996). Using role theory to illustrate caregiving as a role, the effects of work family conflicts and caregiving on the well-being of caregivers was examined (Marks, 1998). The effects of role satisfaction and role involvement on the well-being of caregivers was studied by Martire, Stephens, and Atienza (1997). Role theory and the associated gender role demands were used by Neal, Ingersoll-Dayton, and Starrels (1997) to examine the differences in caregiving based on gender and relationship of caregiver to care receiver. The multiple roles of female caregivers and stress buffering effects were analyzed by Stephens and Townsend (1997) with role theory providing the framework.

Intergenerational solidarity was used as the conceptual framework to evaluate the stress effects of eldercare on employed sons and daughters (Starrels et al., 1995). To test elements of parent-child cohesion, intergenerational solidarity has been used. Several types of solidarity have been identified, which include association, affection, consensus,

function, family orientation, and structure. In this study, workplace factors were studied to determine the effect on solidarity among family members by gender.

To examine family care responsibilities among employees, a resource demand conceptual framework was used by Fredriksen and Scharlach (1999). The resource demand conceptual framework incorporates concepts from stress and coping theories as well as the concepts of resources and demands from role theory. This provided a framework to study the dynamic relationship between caregiving and employment.

Kramer and Kipnis (1995) used Pearlin's conceptual model of caregivers' stress to study gender differences in tasks, role strain, and use of resources. This model provides a context to study stress, caregiving tasks, role strains, resources available, and outcomes of the stress.

The socialist feminist perspective provided the conceptual framework for Keefe and Medjuck (1997). The purpose of their study was to determine if the strain in employed caregivers can be predicted based on employment, caregiving and economic factors. The impact on the roles and obligations of women as a result of the relationship between capitalism and patriarchy is the focus of the socialist feminist perspective.

Work-family role strain theory was used to study the effects of the care receiver's impairments on the stress of the employed caregiver (Starrels et al., 1997). The relationship among caregiving demands, stresses, and resources was tested using this theory.

The theoretical model of interrole conflict was used to examine factors that differentiate conflict experienced by women fulfilling several roles and to study

caregiving stress of women experiencing conflict between caregiver role and other roles (Stephens, Townsend, Martire, & Druley, 2001). The model has been used to determine ways stress in one role can affect other roles of an individual.

Methodology

Of the studies that examined the relationship between employment and informal caregiving, 10 studies were based on data found in various databases. The databases used included the 1992 Nurses' Health Study (Cannuscio et al., 2002), the 1988 Panel Study of Income Dynamics (Couch, Daly, & Wolf, 1999), the 1989 National Long Term Care Study and Informal Caregiver Survey (Doty, Jackson, & Crown, 1998), the 1986-1988 Survey of Income and Program Participation collected by the Census Bureau (Ettner, 1995), the 1988 National Survey of Families and Households (Farkas & Himes, 1997; Jenkins, 1997; Voydanoff & Donnelly, 1999; Wolf & Soldo, 1994), the 1992-1994 National Survey of Families and Households (Voydanoff & Donnelly, 1999), the 1992-1993 Wisconsin Longitudinal Study (Marks, 1998), and the 1984 and 1987 Waves of the National Longitudinal Survey of Mature Women (Pavalko & Artis, 1997). The investigators identified sub-samples of the data being analyzed based on demographics, employment status, and provision of informal caregiving. Sub-sample sizes ranged from 317 to 61,383 survey participants.

In the 1992 Nurses' Health Study, respondents self reported caregiving time and employment. The study sample of 61,383 respondents was derived from the original cohort of 121,700 nurses. These respondents provided information on caregiving responsibilities, were married or widowed, and had not been diagnosed with heart

disease, cancer or stroke. The survey incorporated several instruments. The investigators chose Mental Health Inventory to determine degree of depression and the Berkman-Symes Social Network Index to identify social ties. The goal was to examine if the interaction between social ties mediated the effects of depression resulting from informal caregiving (Cannuscio et al., 2002).

The 1988 Panel Study of Income Dynamics collected data about family labor in and out of the home, money transferred to parents, and living arrangements. The original sample was 4,711 households. However, households with a parent in an institutional setting were eliminated from the study resulting in a final sample of 4,328 households (Couch et al., 1999). The purpose of the study was to determine how families allocate their time between work, parents, and housework.

Doty, Jackson, and Crown (1998) used the 1989 National Long Term Care Study and Informal Caregiver Survey for their study. In these two databases, detailed data were available regarding individuals providing informal care as well as descriptions of the activities of daily living (ADL) and the instrumental activities of daily living (IADL). Based on exclusion criteria, the 4,463 respondent sample was narrowed to 587. The purpose of the study was to determine the impact of employment on the amount of time women were able to engage in informal caregiving.

The pooled data from the 1986, 1987, and 1988 panels of the Survey of Income and Program Participation collected by the Census Bureau were used to examine the effects of eldercare on the labor supply (Ettner, 1995). After men, women under 35 and over 64 years of age, women with more than two jobs, and women living in a group

setting were eliminated, the sample size was 11,486 women with 7,563 employed.

Employment demographics data and hours of caregiving for a disabled elderly were analyzed.

Several investigators used the 1988 National Survey of Families and Households (NSFH) that included responses from 13,017 people. The impact of employment and caregiving responsibilities for an ill or disabled relative or friend on voluntary activities was studied on 7,808 survey participants (Farkas & Himes, 1997). Jenkins (1997) divided the 7,790 women survey respondents into four non-exclusive comparison groups. The groups were women (n=7,790), working women (n=4,240), working women with at least one child under 18 co-residing with the woman (n=2,194), and working women with at least one child under 18 and responsible for providing care to someone with a serious illness or disability (n=317). The time spent in the labor market and the time spent in providing care were compared with the results of the self-administered Center for Epidemiological Studies Depression (CES-D) scale. The allocation of time between employment and caring for a parent was studied on the 1,717 married women that participated in the 1988 NSFH (Wolf & Soldo, 1994).

In 1992-1994, the 12,224 interviews for the second wave of the NSFH were conducted. A sub-sample of 2290 respondents was identified for this study. These respondents had at least one child living at home and they provided informal care to a parent. Hours spent in providing care, time with spouse, and work hours were compared with degree of psychological distress using the CES-D scale and marital happiness (Voydanoff & Donnelly, 1999).

The 1992-1993 Wisconsin Longitudinal Study included 6,875 respondents. A sub-sample of 5,782 employed respondents was identified for this study that examined the effects of work and caregiving on the well-being of caregivers (Marks, 1998). The CES-D scale was used to measure well-being. Two surveys were used to measure type of caregiving and to identify mediators of conflict.

There were 22 quantitative studies and 2 qualitative studies. One study combined both qualitative and quantitative methods in data collection. All studies had convenient samples that ranged in size from eight participants to 1888 participants. These studies used one of three purpose statements.

The first and most prevalent purpose of the studies was to examine the association of caregiving and employment with depression (Burggraff, 1998; Canning, Dew, & Davidson, 1996; Edwards, Zarit, Stephens, & Townsend, 2002; Martire et al., 1997; Stephens & Townsend, 1997; Stephens et al., 2001; Stull, Bowman et al., 1994), burden (Burggraff, 1998; Canning et al., 1996; Edwards et al., 2002; Kneipp, Castleman, & Gailor, 2004; Martire et al., 1997), strain (Barling et al., 1994; Canning et al., 1996; Fredriksen & Scharlach, 1999; Keefe & Medjuck, 1997; Scott et al., 2006; Starrels et al., 1997; Stephens & Townsend, 1997; Stephens et al., 2001), and/or fatigue (Scott et al., 2006). The CES-D scale was used to measure depression in four of the studies (Burggraff, 1998; Edwards et al., 2002; Kneipp et al., 2004; Martire et al., 1997; Stull, Bowman et al., 1994). The Zarit Caregiver Burden Inventory was administered to determine the degree of burden being experienced in three of the studies (Burggraff, 1998; Edwards et al., 2002; Kneipp et al., 2004). The Level of Burden Index was used in

the study by the National Alliance for Caregiving and AARP (2004) to determine burden as a result of ADL and IADL performed by the caregiver. Canning, Dew, and Davidson (1996) administered the Symptom Checklist 90 to evaluate psychological distress. Several investigators used structured interviews to identify depression, caregiving demands, and personal resources (Barling et al., 1994; Canning et al., 1996; Fredriksen & Scharlach, 1999; Keefe & Medjuck, 1997; Starrels et al., 1997; Stephens & Townsend, 1997; Stephens et al., 2001). Scott, Hwang, and Rogers (2006) studied the effect of caregiving on fatigue, stress, and work errors using daily logbooks. Participants self-reported hours worked, fatigue, alertness, stress, and work errors.

To study the relationship between employment and caregiving was the second most frequent purpose statement. This relationship was studied using investigator developed questionnaires or surveys (Barnes, Given, & Given, 1995; Bullock et al., 2003; Pohl et al., 1998; Scharlach, 1994; Starrels et al., 1995; Stoller, 1983). Three studies used qualitative methodology that included a semi-structured interview guide to examine the relationship between employment and caregiving (Dunham & Dietz, 2003; Pohl et al., 1998; Scharlach, 1994).

The third most frequent purpose statement was to identify gender differences between employed caregivers. Investigator developed instruments were used to collect data on demands, resources, burden and stress (Fredriksen, 1996; Ingersoll-Dayton, Starrels, & Dowler, 1996; Kramer & Kipnis, 1995; Neal et al., 1997; Starrels et al., 1995).

Findings

When comparing employed and unemployed caregivers, those employed experienced more depression, burden, and physical health problems (Canning et al., 1996). In contrast, although the burden was the same in both groups, Burgraff (1998) found less depression and physical problems in those employed versus those unemployed. Edwards, Zarit, and Stephens (2002) found no differences between employed and unemployed caregivers in relationship to the amount of depression, burden and strain experienced. In a national survey, 58% of 1,247 respondents were working either full-time or part-time (National Alliance For Caregiving & AARP, 2004). The Level of Burden Index for 31% of the employed respondents was at level 4 or 5. Level 4 respondents provided on average 33 hours of care per week and performed 5.2 IADL and 2.9 ADL. Level 5 respondents provided about 87 hours of care per week with 5.9 IADL and 4.2 ADL performed. Increased strain was identified by Barnes, Given, and Given (1995) when the informal caregiver terminated employment to engage in informal caregiving. Two studies identified that as the caregiving time commitment increased, the risk of depression increased (Cannuscio et al., 2002; Voydanoff & Donnelly, 1999). This may be attributed to the decreased time for social ties. However, a study examining the participation of employed caregivers in voluntary activities found participation did not decrease as caregiving responsibilities and time increased (Farkas & Himes, 1997).

Physical fatigue and emotional strain were associated with combining caregiving and employment (Fredriksen, 1996; Fredriksen & Scharlach, 1999). Eight percent of the employed participants in the National Alliance for Caregiving and AARP (2004) Survey

reported physical health status as fair to poor with 9% reporting emotional strain. This was similar to the results of the unemployed respondents. Scott et al. (2006) found nurses with informal caregiving responsibilities had higher levels of fatigue, sleep deprivation, and stress than those without caregiving responsibilities. It was also found the informal caregivers worked more hours which was attributed to the financial burden of caregiving.

Other costs of combining employment and caregiving were identified, including interruption of career path, leaving a job to be closer to care receiver, retiring earlier, and taking a lower paid job to reduce the amount of work related stress (Dunham & Dietz, 2003). Employment was found to negatively affect the relationship between the caregiver and the care receiver (Scharlach, 1994). Paid work was not found to buffer the effects of caregiving (Voydanoff & Donnelly, 1999). Working caregivers were found to have more conflict on the job related to work responsibilities rather than their caregiving responsibilities (Edwards et al., 2002). The incidence of work related errors was 2.5 times higher in the caregivers of elderly care recipients (Scott et al., 2006).

Several rewards have been identified when combining employment and caregiving. Work becomes a refuge from the caregiving demands (Dunham & Dietz, 2003). An individual may have a sense of accomplishment being able to manage work and caregiving responsibilities (Dunham & Dietz, 2003; Martire et al., 1997). Employment provides resources including salary, health benefits and counseling (Dunham & Dietz, 2003). As income increased, there was a decrease in strain (Keefe & Medjuck, 1997). Support from co-workers, improved job performance, and higher self-

esteem were viewed as positive aspects of combining employment and caregiving (Scharlach, 1994).

When conflict existed between employment role and caregiving role, absenteeism could be predicted (Barling et al., 1994; Scharlach, 1994). Burggraf (1998) found 21.6% of the 62 employed participants in the study had not missed a single day of work in the past 6 months. However, 13.7% had been absent more than two weeks in the past 6 months. Other negative aspects identified were reduced productivity at work and reduced energy to manage caregiving responsibilities (Scharlach, 1994). A correlation was found between the amount of caregiving tasks performed and the need to take time off from work (Starrels et al., 1997). One study reported that 96% of the study participants (n=278) experienced conflict between employment and caregiving roles with the greatest conflict occurring in the caregiving role (Stephens et al., 2001). However, Doty, Jackson, and Crown (1998) found only a minority of caregivers experienced conflict between employment and caregiving. It was found that a majority of those employed full-time did not change their work schedules while those working part-time did make changes in their schedules (Pohl et al., 1998). Burggraf (1998) identified that 16% of the 62 unemployed study participants had recently quit their jobs due to their caregiving responsibilities. Kneipp, Castleman, and Gailor (2004) found 30% of their study participants lost their jobs due to care giving responsibilities. In the National Alliance for Caregiving and AARP (2004) survey, 57% of the respondents reported taking time off to meet caregiving demands, 10% reduced work hours, 6% lost jobs, and 4% declined promotions.

With regards to gender differences in employed caregivers, females were found to provide more care (Gerstel & Gallagher, 1994; Ingersoll-Dayton et al., 1996; Jenkins, 1997; National Alliance For Caregiving & AARP, 2004; Neal et al., 1997; Stoller, 1983). However, no difference was identified regarding health care management (Ingersoll-Dayton et al., 1996). Men working in high professional status jobs provided less care than men working in lower professional status jobs. No difference was found between the amount of care provided by women in high and lower professional status jobs (Starrels et al., 1995). Women were found to reduce work schedule, take uncompensated leave or terminate employment more often than men to met caregiving responsibilities (Fredriksen, 1996; Jenkins, 1997). Fredriksen and Scharlach (1999) found women experienced more physical fatigue, more emotional strain, and more financial strain than men. Women were more likely to decline promotions and extra assignments than men.

Gaps in Nursing Science

Based on the literature review, only four nursing studies examined the relationship between employment and informal caregiving (Burggraaf, 1998; Kneipp et al., 2004; Pohl et al., 1998; Scott et al., 2006). As noted in the literature, one out of five people provide informal care to someone who is seriously ill or disabled. Dunham and Dietz (2003) indicated practitioners need to assist caregivers in developing skills not only to provide care, but also on how to negotiate with their employers for more family friendly environments. However, the nursing literature has not addressed the needs of these informal caregivers.

Further research should be conducted to determine what resources, services, and support employed caregivers need in order to continue in both roles (Barnes et al., 1995; Bullock et al., 2003; Ettner, 1995). More research is needed to understand the complexities of combining employment and informal caregiving (Canning et al., 1996; Farkas & Himes, 1997; Jenkins, 1997; Scott et al., 2006).

Summary

In the review of the literature, 35 studies were identified that investigated combining employment with caregiving responsibilities. Various theoretical and conceptual frameworks have been used to study the topic. Several studies examined the degree of depression, burden, and/or strain experienced by employed informal caregivers. Some investigators have explored the relationship between employment and caregiving. Others have studied the gender differences in combining employment with informal caregiving. Investigators have identified both positive and negative outcomes. However, the literature is not conclusive regarding the effects of the dual responsibilities toward employment and informal caregiving.

CHAPTER III

PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

This qualitative phenomenological study was conducted to explore the lived experiences of people who combine compensated employment and caregiving responsibilities. The participants' perceived benefits and negative aspects of compensated employment and caregiving responsibilities were examined.

Setting

Employees of a tertiary hospital in Southeast Texas were recruited as study participants. This employer has approximately 4,500 full time and part-time employees. The organization's intranet and weekly newsletter was used to recruit participants.

Population and Sample

Purposeful sampling was used to select English-speaking participants who were at least 18 years of age for this phenomenological qualitative study. Inclusion criteria for a study participant were a person who in the past 12 months had provided care to a relative or friend with a chronic physical or mental illness or disability, for at least 30 consecutive days for a minimum of 1 hour each day, and was employed a minimum of 20 hours a week. The employment was financially compensated. Sampling continued until saturation or when no new information was obtained from participants, but rather repetition of the same important points occurred.

Protection of Human Subjects

To assure protection of human subjects, the research protocols of the study site Investigational Review Board (IRB) were followed. A proposal was submitted to receive IRB approval from the study site. Once approval was received, a request for exempt review was submitted to the chair of the TWU IRB Committee for the Houston campus. A copy of the study site approval letter was submitted with the request.

Instruments

The investigator developed semi-structured interview questions. A series of questions were asked to assess the activities the caregiver performs for the care recipient. These included activities of daily living (ADL) as well as instrumental activities of daily living (IADL) such as communication, transportation, meal preparation, and safety. The study participants were asked to describe the experiences they have had in providing informal care and being employed using the following questions:

1. How do you feel when offering this caregiving to (name of recipient)?
2. How has the caregiving affected your relationship with (name of recipient)?
3. How has the caregiving affected you?
 - Probe regarding physical, social, emotional, and financial impact.
4. How has the caregiving you offer affected your employment?
5. How has your employment affected you caregiving?
6. How has combining employment and caregiving changed your life?
7. What are the positive aspects of combining your caregiving responsibilities with your employment responsibilities?

8. What are the negative aspects of combining your caregiving role with your employment responsibilities?
9. When doing both caregiving and employment, what resources are needed?

Data Collection

Information regarding the study was provided to each study participant. Each participant was asked to sign an informed consent to participate in the study. After signing the consent form, the participant was asked demographic questions about self and the care recipient as well as activities of daily living (ADL) and instrumental activities of daily living (IADL) facilitated by the caregiver. A private setting was used to conduct the personal interview. All interviews were audio taped. In addition to the recording of the interviews, the investigator recorded field notes during each interview.

Pilot Study

A pilot study conducted involved the interview of four participants. All were female, with two providing care to adult children and two providing care to aging parents. The participants' ages ranged from 49 to 55. The care recipients were ages 18, 26, 77, 79, and 80. All the participants were employed full time in health care. At the time of the interview, two care recipients resided in the caregiver's home, two had been placed in nursing homes, and one was deceased. Two caregivers were married and two were divorced. All caregivers provided varying degrees of assistance with ADL and IADL.

Open-ended questions enabled the participants to share their experiences in providing informal caregiving and working. The questions were:

How do you feel when offering this caregiving to (name of recipient)?

How has the caregiving affected your relationship?

How has the caregiving affected you?

How has the caregiving you offer affected your employment?

When do both caregiving and employment, what resources are needed?

The audiotapes were transcribed. Using a coding scheme developed on the review of the literature, the transcripts were analyzed to identify similar experiences among the participants.

Findings

From the responses to the questions, nine common themes emerged with an overarching theme of arranging life to meet responsibilities. Each participant discussed her view of reality and what experiences she valued. As each participant recalled her day-to-day routine of informal caregiving and employment, ten themes emerged.

Responsibility towards care recipient. Each participant discussed the responsibility they felt towards the care recipient. One participant described the responsibility of caring for her son as “That’s what parents do.” Another participant was providing care to her mother-in-law and she questioned, “I wonder if I was generous enough, she was always generous to me.” Another related her responsibility to care for her mother as, “I did it because she took care of me when I was little when I needed care.”

Responsibility to work. In performing the dual role of employee and informal caregiver, participants expressed a sense of responsibility towards work. One woman

stated, “There are days he feels bad, but I have to get up and go.” Another said, “I got a family leave for him, but still I hate to miss. It is very hard.”

Fatigue and other physical ailments. These participants describe the impact of informal caregiving and employment as resulting in fatigue and other physical ailments.

One participant stated:

I stay exhausted all the time because I care give at work and I care give at home. I feel like I never get any rest. I can be asleep and he will come and wake me up.

Another caring for her son said:

I’m a lot more stressed than I would be without it (caregiving and employment).

I’m not able to exercise or to do the things I need to do better for myself. I’m really tired.

Impact on relationships. The women expressed that informal caregiving and employment has had a negative impact on social and close relationships. One participant indicated she was “very isolated socially. We have some friends, but it makes it very hard to plan.” Another woman discussed the impact the caregiving has had on her relationship with her daughter. “He’s dark and frightening. My daughters are afraid of him. That’s why my youngest daughter doesn’t live there.” Another shared the caregiving and employment “has caused an adverse effect on our marriage. Our relationship feels like it is on hold.”

Emotional stress/frustration. The stress and frustration was expressed regarding informal caregiving and not with regards to work. One woman shared an incident that portrays the stress and frustration she was experiencing with the caregiving. She said:

There was one day, I had to lay him on the floor. He was unconscious, it was the Friday after Thanksgiving last year. (*Husband's name*) had gone to get some tool on sale that Friday morning. Dad did that thing first thing that morning. Dad was unconscious and vomiting. But he was so big, I couldn't get him up when he started to come to. But I don't think that would have been a good idea. I had to keep him on his side until (*husband's name*) came home from the store. It was probably only 45 minutes. I had to wait for him. If you looked around the living room, here we are, Dad's lying there not acting okay, vomit on the hard wood floors and it had hit the walls. It was like that show *This Is My Life*. I thought what has this come to?

Another woman caring for her mother discussed her frustration:

There were days that I would get tired. But I think that was because she would be feisty with me. She wouldn't want to take a shower...I wanted her to be clean. So her and I would have problems with that issue. But she would drain me out. As it is I'm working all day long with one day off. And I have to do this. And now she gives me a hard time. Just do it and sit. But she wouldn't do it. Sometime I feel like I'm being drained.

Seeking and securing resources. In addition to the caregiving responsibilities, participants discussed the need to seek and secure resources to help with the financial costs of informal caregiving. One woman stated:

He's on a program from Medicaid. And that I got because I got in touch with my state representative. See you learn how the world operates and boy that makes you very empowered. People need that kind of empowerment.

Another woman described her experience trying to get resources in order to keep her mother at her home. She said:

I couldn't afford to keep her full time with somebody at home because the government wouldn't pay me to keep her at home, but they would pay me 24 hours coverage at the nursing home. Which to me, that doesn't make sense...because at home all they would have needed to pay me was \$900 to \$1000 to have somebody to come in while I'm at work...versus paying \$3000 in the nursing home.

Support from colleagues. Each woman shared how work colleagues have supported her. One participant shared how her employer had changed the work schedule without any consideration for the employees. Due to her caregiving responsibilities, she said:

There were people who actually volunteered. I would not ask anyone to cover for me. But people came forth and said you know, we think it is going to be hard for her. And it is like, we'll come help you. We will do our turn and her turn too.

Another participant discussed in her work group, several colleagues are experiencing informal caregiving and working full time as well. She said, "The group I work with is a very solid group that way. We help each other emotionally."

Supportive environment. When discussing what resources one needs when working and providing informal caregiving, a supportive environment offering flexibility was identified as very important. One woman stated, “You will find that other people I know are really loyal to a company that supports them with benefits and allowing some flexibility.” Another offered, “I would like to say it would be nice if employers would let their employees in that situation give them something that they could work out of their home.”

Help from others. Another resource needed when working and providing informal caregiving is help from others. One woman stated, “When you live it, it really gives you insight into why it is that people need help. And the major lesson is that you can’t do it yourself.” Another thought due to the complexities of the dual role, “I felt a need for a case manager.”

Arranging life to meet responsibilities. Although only one participant stated that she had arranged her life to meet her responsibilities of caregiving and employment, the other participants gave examples of how each of them had arranged their lives to meet their responsibilities. Each discussed how they arranged to have someone be with their care recipient while they were at work. Arrangements at work were made to change their work hours. One participant found it necessary to become a per diem employee in order to be assured she would have the time off to take her mother to many doctors appointments.

Discussion

The participants in the pilot study experienced stress related to their dual responsibilities toward caregiving and employment. Each participant experienced conflict in their dual roles and the responsibility they felt towards each role. Despite the conflict, each participant had clarified the meaning of her dual role experiences. Each participant made choices based on personal values. The participants made choices about arranging their life to meet caregiving and employment responsibilities. As explained by one participant, “This experience has forced me to look at the big picture, weigh my options, and chose the ones best for my family.”

The findings of the pilot study support the findings of Ettner (1995), Marks (1998), and Stull et al. (1994) that employment increases caregiver stress. The need to alter work schedules was also identified which is consistent with a study conducted by Starrels et al. (1997)

The positive aspects of caregiving reported in earlier research such as an increased self-efficacy, a satisfaction in providing care, and a sense of purpose (Scharlach, 1994) was discussed by two of the participants. One participant explained, “I have seen emotional up lifting in myself, self satisfaction.” Previous research has found employment as a break from caregiving responsibilities, a means for social interaction, and a source of increased financial resources. The participants in the pilot study did not articulate these positive aspects. However, they did discuss the importance of support from work colleagues which has not been documented in the literature.

Revisions Based on Results of the Pilot Study

In the pilot study, the interview questions did not aid the investigator in gaining insight into the complexities of combining the employment role with the informal caregiving role. The interview questions were revised to ask the participants to describe how the experience has changed the caregiver's life. Additional questions were added to gain insight into what the participants' viewed as the negative and positive aspects of combining employment and caregiving.

Treatment of Data

The recordings were transcribed verbatim within 2 days of the interview to assure changes were made before additional interviews were conducted. The transcripts were read to identify statements each participant used to depict experiences of informal caregiving and employment (Creswell, 1998). The meaning of the each statement was determined. Similar statements of participants were grouped together into themes or common experiences between the participants (Morse, 1994).

Actions were taken to demonstrate the trustworthiness of the data. The themes identified were validated with the participants to determine if the themes were consistent with their experience to assure credibility of the data (Polit & Beck, 2004).

To assure confirmability, records and field notes were retained. Notes were made that described the analysis of the data and the development of the themes. Comments made during the validation review by the participants were documented. If changes were made to the identified themes based on the validation, these changes were documented to assure the dependability element was achieved.

The data were analyzed using the Colaizzi qualitative phenomenological method (Colaizzi, 1978). This method enables the investigator to find the lived experiences of the participants. The steps in this approach are as follows:

1. Read the protocols or participant's descriptions of the phenomenon.
2. Identify significant statements or phrases that reflect the phenomenon.
3. Determine the meaning of each statement or phrase.
4. Arrange meanings into themes.
5. Develop comprehensive descriptions of the phenomenon.
6. Validate the findings with the participants.

Summary

In this chapter, the methodology used in this qualitative phenomenological study was described. The setting, population and purposeful sampling for this study were discussed as well as measures taken to protect human subjects. Data collection procedures were described. The findings of a pilot study were presented. Based on the pilot study, the revisions made to the interview questions are discussed. The treatment of the data was explained.

CHAPTER IV

ANALYSIS OF DATA

The purpose of this qualitative study was to explore the lived experiences of people who combine compensated employment and caregiving responsibilities. The participants' perceived benefits and negative aspects of caregiving responsibilities when combined with compensated employment were examined. The research question addressed by this study was:

What are the lived experiences of employed adults with dependent adult caregiving responsibilities?

This chapter describes the sample group, documents the participants' responses, and groups the study findings into thematic categories with supportive quotes from study participants.

Description of the Sample

This purposive sample consisted of 11 female participants providing care to 15 adults with chronic or terminal illnesses. Four potential participants contacted the primary investigator (PI) following the notice in the study site newsletter. Of these four, only one completed the interview and validation interview. This information is found in Figure 1. Seventeen potential participants were identified by others and made known to the investigator. Of these potential participants, 10 completed the interviews and validation interviews. This information is found in Figure 2.

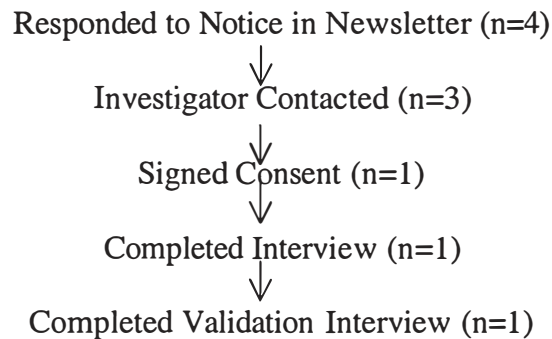


Figure 1. Participant Response to Newsletter.

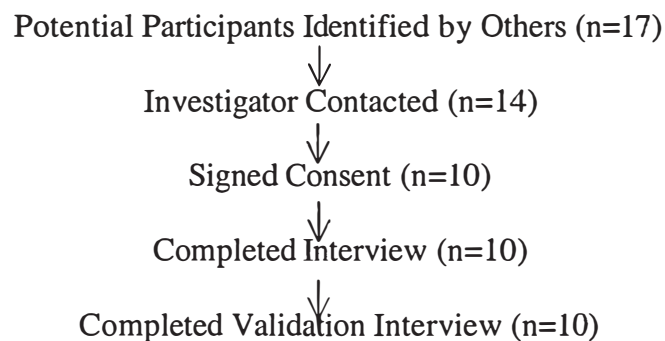


Figure 2. Participant Response to Contact by Investigator

Of the 11 participants, two reported caring for two adults and one reported providing care to three adults. Seven participants were informal caregivers for their aging mothers. One participant was the primary caregiver for her mother-in-law. Two were providing care for both parents. Two were providing care to their spouses. One participant was providing care to an adult child. The participants ranged in age from 37 to 59. The care recipient age ranged from 18 to 88. At the time of the interview, three care recipients lived in their own homes, 2 lived in assisted living facilities, one was deceased, and the others lived with the informal caregiver. Seven participants were married. The

remaining four participants were single due to divorce, separation, widowhood, or never being married. Seven participants were Caucasian and four were African American. The participants provided varying degrees of assistance with ADL and IADL.

All the participants were employed in health care. All but two of the participants worked 36 to 40 hours per week. Those two worked 20 hours per week.

Findings

Each transcript was read to identify the participant's description of the phenomenon. Using the coding scheme developed and revised during the pilot study, words and phrases that appeared to be significant were highlighted. Constant comparative analysis of the transcripts was made to systematically identify similar experiences among participants. As in the pilot study, 10 themes emerged. However, after close examination, it was determined that some of the themes could be combined. This resulted in seven themes. Using the participants' own words, the seven themes were: 1) doing what you have to do, 2) exhausted, 3) depression and frustration, 4) isolation, 5) personal rewards, 6) feeling torn, and 7) care coordinator and work flexibility. The conceptual descriptions of the themes are found in Table 1.

Table 1

Conceptual Descriptions of Themes

Themes	Conceptual Descriptions
Doing what you have to do	Responsibility towards care recipient resulting from relationship to care recipient; a sense of obligation and commitment to the role

Exhausted	The physical outcome of caregiving with limited time to care for self
Depression and frustration	The emotional outcomes of caregiving including stress and resentment
Isolation	The social outcome of caregiving impacting relationships with family members and friends
Personal rewards	The positive outcomes of combining caregiving and employment
Feeling torn	The negative outcomes of combining caregiving and employment
Care coordinator and work flexibility	The perceived resources needed by caregivers when combining caregiving and employment

Doing What You Have to Do

A major theme in each of the interviews was doing what you have to do. This can be conceptually defined as the sense of responsibility the caregiver has towards the care recipient. Participants discussed being caregivers as an obligation towards family. One participant stated, “You just do what you have to do.” A participant who is the primary caregiver for her mother said, “I have no question that’s (caregiving) my priority...I am honored to serve.” As one participant discussed how she became the primary caregiver for her mother said, “I feel like that is what families should do.” Another response was, “My parents took care of me when I was small...I knew one day it was going to come.” Another said that she was the only family member in the area.

Some participants discussed providing the care as a result of the love they feel towards the recipient. One said, “I feel it is the love that makes me want to do it.”

Another participant stated, “I love being with my parents and that’s nice. That part of it I actually feel grateful to be with them a little longer.” Another said, “It’s you know, I love them. We’ve arranged our lives in such a way that we can take care for them.”

Some participants indicated daughters are expected to provide care to aging parents. This expectation came from the participants themselves or other family members. When asked how she became the primary caregiver, one participant responded, “I’m her daughter.” “I am the oldest daughter,” was the response of another participant. Another stated, “They (other family members) depend on me to take care of mom.” One participant attributed her family’s expectation of her being the primary caregiver because she is a nurse.

The participants who were registered nurses indicated their sense of responsibility came from being a nurse. As one participant described how she became the primary caregiver for her mother, she said, “When she was very sick, I became the nurse. And I felt good that I could help her.” Another stated, “Being a nurse, I guess I always thought it was going to be me.” When asked why she became the primary caregiver for her husband, she said, “Because I am the nurse.” The response was the same when one participant was asked why she became the caregiver for her mother-in-law.

Exhausted

Exhausted can be conceptually defined as the physical outcome of caregiving with limited time to care for self. One participant described her experience as “I was tired because she would get up in the night and I was worried something was wrong.” When asked about the physical effects of caregiving, one participant said,

It is so exhausting that usually if I can do it for 12 hours, I need somebody else for the other 12 hours. I have turn him every two hours...The exhaustion and not taking care of myself... It becomes an issue of being even more tired because I'm trying to squeeze in extra hours or doing shifts nobody else wants to do just to get the hours in.

Another said, "I was exhausted. If I got free time, I didn't want to see anybody. I didn't want to do anything. I just wanted to lay there and watch TV. I was tired a lot."

When another participant was asked why she was so tired, she responded,

I am working at home and I work here...Nursing is a physical job and sometimes you are just exhausted. And then, going home and having to do the same stuff at home...And some days, it is God, I just don't want to see another sick person.

Several voiced that the exhaustion and not taking care of themselves resulted in increased physical illnesses. Two participants indicated their arthritis had worsened. One had experienced a lupus crisis. Another participant stated, "I was in so much pain from lifting, stooping, and bending." Another reported increased neck and shoulder pain in addition to swelling in her jaw. When she went to an oral surgeon, she was told she was grinding her teeth as a result of her fatigue.

Four participants indicated they had gained weight since they had become the primary caregiver. This was a result of eating poorly and not being able to exercise. Three participants indicated they had experienced increased difficulty controlling their own diabetes. They also attributed the uncontrolled diabetes to their food intake and lack of exercise.

Two participants stated that they didn't have time to get sick. However, one had just had pneumonia that had resulted from a delay in seeking treatment for an upper respiratory infection. The other had recently experienced unexplained vertigo.

One participant had not taken a vacation in the four years. All her paid time off had been taken to meet caregiving responsibilities for her three care recipients.

Depression and Frustration

The emotional outcomes of caregiving including stress and resentment are the conceptual definition of depression and frustration. Those experiencing depression talked about being sad or crying. One participant stated, "I think I'm more depressed and more disorganized and so I become more stressed...It is real frustrating." Another participant describing her depression said,

I just want to hide in my house and have no one call me, no one bother me. I just don't have the capacity to enjoy myself. It is too much work...I just want to go to bed. I don't want to be around anybody...It's like Marilyn Monroe. People always ask why would she kill herself? She had everything. But if you don't feel that way, it doesn't matter what you have.

Another participant discussed that on her days off work from work, she didn't even get dressed. She felt even if she had some place to go she would have to stay home with her mother.

Some participants described how frustration has resulted in resentment towards the care recipient. One participant described her feelings of resentment when her mother calls in the middle of the night. She feels her life is not her own. She said, "It makes me

resentful...My first reaction is to stomp my feet...I feel guilty that I'm resentful."

Another participant stated, "I have to nag her because she can't remember and some things are not a big deal and others are...I begin to feel a little resentful."

Other participants indicated their resentment has come from their frustration with the situation. One participant indicated she resented having to pay for home health aids knowing that on her time off she is providing the same care without any financial compensation. Another participant was frustrated and resentful due to the health insurance didn't pay for certain drugs to control chemotherapy-induced nausea and vomiting. Another participant described her situation as,

I go through depression and am resentful. I ask God, why me? Why are you putting all of this on me? How do you let me bear all this? When can I have some time for me without worrying or stressing about my parents?

Some participants experienced resentment and frustration towards siblings. One stated, "I feel resentment towards the situation and resentful towards my siblings. I think I got treated wrong by my siblings." One participant discussed not having the freedom to things. She expressed anger and frustration that she and her sister "don't do things evenly."

All the participants described the stress and strain they have experienced as a result of the frustration associated with caregiving. One participant stated, "It is very stressful. It is like a roller coaster." Another participant described the stress as follows:

The hardest thing is making decisions...I have her life in my hands. I have been so stressed every second, every time the phone rings. Thinking it will be

something I will have to make a decision about. I dream all the time that I'm lying on a cement slab and there is one right on top of me. That's how it feels.

Some participants described how the stress and frustration have decreased their tolerance. One stated, "My tolerance is really low. I have zero tolerance. I can't take nonsense from my husband. I can't take nonsense from her (referring to her care recipient) or nonsense at work. I just want to retreat."

Isolation

Isolation can be conceptually defined as the social outcome of caregiving impacting relationships with family members and friends. All the participants described some isolation that has occurred as a result of caregiving. One participant described her isolation resulting from caregiving as "taking a vacation from your life." Another participant stated that she had "put the social life to the side." Others reported the inability to go out with friends for dinner or other social events.

Some participants discussed the strain the caregiving has had on their marriages. One participant stated, "I don't think my husband has been fully understanding." Another participant stated the caregiving has strained the relationship she has with her husband. When discussing the caregiving she provides her mother-in-law, one participant expressed a concern that her husband does not get involved with the care unless she gets "a little mean."

Several participants discussed how caregiving has negatively affected their relationships with their siblings. One participant described a time she was trying to tell her brother what was happening with their mother. The brother would not listen and tried

to give advice without comprehending the situation. The participant's response was, "Stop, never mind." Since that time, she has not talked with her brother about their mother. Another expressed a concern that the caregiving has strained the relationship she had with her sister. When describing her siblings' involvement with the caregiving for their mother, another participant stated, "They don't take an active role because it is not pleasant. They like to do the pleasant things. That makes me seem a little grumpy... I think it is affecting relationships among my brothers and sisters."

Personal Rewards

The conceptual definition of personal rewards is the positive outcomes of combining caregiving and employment. There were three positive outcomes identified that included 1) satisfaction with the ability to provide the care and work, 2) support of co-workers, and 3) work providing a break from caregiving responsibilities.

All the participants discussed the satisfaction they have in providing care and continuing to work. One woman stated, "It is a challenge, but also rewarding. People that have to manage that kind of life have a lot to bring an employer in terms of multitasking, productivity, knowing how to get things done, and knowing how to negotiate systems." Another described as, "The personal rewards knowing my mother is being taken care of and knowing that I can do both."

Another personal reward was the support from co-workers. Participants discussed the benefit of working with others who have caregiving responsibilities. One woman indicated that she shares her experiences with others resulting in an exchange of ideas regarding how to handle certain situations. When describing how she has combined work

and caregiving responsibilities, one participant stated, “You have a support system at work. People ask how’s your mom? So it helps to talk to people who have been there or done that...It helps to validate that you’re not crazy or you are doing the right thing.”

As a personal reward, employment provided a break from caregiving responsibilities. One participant said, “Having work and being in the real world is positive. It is a benefit.” Another participant described work as an “outlet” and provided an opportunity not to think about caregiving responsibilities. Another participant referred to work as a time to forget about the caregiving and focus on the work. Three participants referred to work as an “escape” from caregiver duties. One participant said, “I actually need the time away. I’m really happy to come to work. I’m happy to do the work... It is my time to do what I like to do.” Several participants indicated that they thought it would be very difficult to be a full time caregiver. One participant said, “If I had to sit at home and not have employment, I don’t think I would be as good a caregiver. It would grate on my nerves.”

Feeling Torn

Feeling torn can be defined as the negative outcomes of combining caregiving and employment. The participants reported a sense of conflict between the responsibility towards caregiving and the responsibility towards employment. When describing work and caregiving responsibilities, one participant said, “I feel very torn. I mean I have no question that caregiving is my priority...but when I call and say I can’t come to work, it feels like an excuse.” Another participant stated, “You get that pull between how much do I work and how much do I take off.” One participant explained how it is necessary to

arrange her work in order to meet her caregiving responsibilities said, “I’m trying to balance work and home, but everything I do has to revolve around how it is going to affect my mom.” Another described the arranging her work schedule as “working around it (caregiving).”

Some participants discussed concern regarding being distracted at work due to their caregiving responsibilities. One participant described a time when her mother was not doing well. She said, “I worked hard to try to either not put myself in a position of doing a critical thing or triple checking myself. Your attentions are divided. Your attention is not there...It affects the job.” Another participant stated, “Sometimes I feel that I don’t perform 100%, but I get the work done. I look back and wonder how did I do it? I don’t know if I’m coming or going.”

Feeling torn was evident when some participants discussed of not accepting promotions due to caregiving responsibilities. One participant said, “I passed up a management position...It was tough because I had to decide what to do. I decided to continue to do what I was doing because it would cause Mom a lot of angst...I felt depressed and left out.”

Care Coordinator and Work Flexibility

The conceptual definition of care coordinator and work flexibility is the perceived resources needed by caregivers when combining caregiving and employment. When participants were asked what resources were needed, several discussed the need to have help from others. Several suggested a care coordinator to help coordinate care and to identify available community resources. Participants wanted assistance in securing

Medicare, Medicaid, and other financial assistance programs, arranging transportation, identifying support groups, and accessing respite programs. One participant said, “You can easily get an attorney or a plumber, but you can’t get someone to help coordinate the care...someone to coordinate the resources and to help navigate the system.”

Another resource identified by the participants was work flexibility to be able to meet caregiving demands. Work flexibility was needed to take care recipient to doctor’s appointments and to accommodate schedule changes to enable the caregiver to meet caregiving demands. One participant said, “I need to have some choice and flexibility so I can make a plan and have some control over it. If the schedule is too rigid, something’s going to give. I have to be able to work around doing both.”

Additional Finding

Approximately a quarter of the participants reported caregiving was affecting them financially. This was a result of the care recipient having little or no health insurance to cover the cost of care. The health care expenses were being paid by the caregiver.

Summary of Findings

The purpose of this qualitative study was to explore the lived experiences of people who combine compensated employment and caregiving responsibilities. The participants’ perceived benefits and negative aspects of caregiving responsibilities when combined with compensated employment were examined. The sample consisted of 11 female participants providing care to 15 adults with chronic or terminal illnesses.

Seven themes emerged. Using the participants' own words, the seven themes were: 1) doing what you have to do, 2) exhausted, 3) depression and frustration, 4) isolation, 5) personal rewards, 6) feeling torn, and 7) care coordinator and work flexibility.

Doing what you have to do refers to the sense of responsibility the caregiver has towards the care recipient. The responsibility may be based on an obligation towards family, as a result of love felt for the care recipient, or due to expectations of the caregiver or other family members. Those participants who were registered nurses indicated their responsibility came from being a nurse.

Exhausted is defined as the physical outcome of caregiving with limited time to care for self. The exhaustion resulted from working at home and at work. Several participants discussed increased physical illnesses and weight gain resulting from the exhaustion and not taking care of themselves.

Depression and frustration are defined as the emotional outcomes of caregiving. Several participants discussed experiencing depression. Frustration has led to resentment towards the care recipient, the situation, or siblings not involved in the caregiving. Stress and strain have resulted from frustration.

Isolation can be conceptually defined as the social outcome of caring impacting relationships with family members and friends. Participants described the social isolation of not being able to go out with friends. Some participants discussed the strain caregiving has on their marriages. Several participants discussed the negative effect of caregiving on their relationships with their siblings.

The conceptual definition of personal rewards is the positive outcomes of combining caregiving and employment. Three positive outcomes were identified that included 1) satisfaction with the ability to provide the care and work, 2) support of co-workers, and 3) work providing a break from caregiving responsibilities.

Feeling torn can be defined as the negative outcomes of combining caregiving and employment. The participants described a sense of conflict between the caregiving responsibilities and the employment responsibilities. Some participants discussed being distracted at work due to their caregiving responsibilities. Feeling torn was evident when some participants discussed not accepting promotions due to caregiving responsibilities.

The conceptual definition of care coordinator and work flexibility is the perceived resources needed by caregivers when combining caregiving and employment. Participants suggested a need for a care coordinator to help coordinate care and to help identify community resources. Participants wanted assistance in securing financial assistance programs, arranging transportation, identifying support groups, and accessing respite programs. Participants stressed the importance of work flexibility to be able to meet caregiving demands.

Through an analysis of the interviews, the research question can be answered. What are the lived experiences of employed adults with dependent adult caregiving responsibilities?

CHAPTER V

SUMMARY OF THE STUDY

This qualitative study explored the lived experiences of people who combine compensated employment and caregiving responsibilities. The participants' perceived benefits and negative aspects of caregiving responsibilities when combined with compensated employment were examined. The research question addressed by this study was:

What are the lived experiences of employed adults with dependent adult caregiving responsibilities?

In this chapter, the findings of this study are discussed in relation to previous studies conducted to explore the impact of combining compensated employment with informal caregiving. Based on the findings of this study, conclusions are stated as well as implications for nurses and employers. Recommendations for future research to further investigate this phenomenon conclude this chapter.

Summary

The lived experiences of 11 employed female adults with caregiving responsibilities for dependent adults were examined using a phenomenological approach. Employees of a tertiary hospital in Southeast Texas were recruited through the organization's newsletter and through contact by the primary investigator. Inclusion criteria for a study participant were an English speaking person who in the past 12 months had provided care to a relative or friend with a chronic physical or mental illness

or disability, for at least 30 consecutive days for a minimum of 1 hour each day, and was employed a minimum of 20 hours a week. The employment had to be financially compensated.

Approval from Investigational Review Board (IRB) at the study site was obtained. Once approval was received, approval from the chair of the Texas Woman's University IRB committee for exempt review was obtained. Participation in the study was voluntary. A participant signed an informed consent prior to the interviews. To assure confidentiality, a code was assigned to each participant. The code was used on the demographic and interview forms as well as the audiotape. All forms and audiotapes were locked in a file cabinet.

The investigator developed semi-structured interview questions. A series of questions were asked to assess the ADL and IADL performed by the caregiver for the care recipient. The study participants were asked to describe their experiences in providing informal care and being employed. To gain a better understanding of the participants' experiences, the investigator used probe questions and requested examples.

A pilot study was conducted in late 2005 with four participants. The interview questions did not aid the investigator in gaining insight into the complexities of combining employment and caregiving responsibilities. Interview questions were added to ask participants to describe how the experience has changed their lives. Also, questions were added to gain insight into what the participants thought were the negative and positive aspects of combining employment and caregiving responsibilities.

Using the Colaizzi (1978) method, the transcripts of the interviews were analyzed to identify statements that depicted the experiences of the participants. With a coding scheme, the statements were grouped together into themes. Seven themes emerged. Using the participants' own words, the seven themes were: 1) doing what you have to do, 2) exhausted, 3) depression and frustration, 4) isolation, 5) personal rewards, 6) feeling torn, and 7) care coordinator and work flexibility. Doing what you have to do refers to the sense of responsibility the caregiver has towards the care recipient. Exhausted is defined as the physical outcome of caregiving with limited time to care for self. Depression and frustration are defined as the emotional outcomes of caregiving. Isolation refers to the social outcome of caring impacting relationships with family members and friends. Personal rewards refers to the positive outcomes of combining caregiving and employment. Feeling torn refers to the negative outcomes of combining caregiving and employment. Care coordinator and work flexibility refers to the perceived resources needed by caregivers when combining caregiving and employment.

Discussion of the Findings

The phenomenological philosophy of Merleau-Ponty (1962/1999) provided the framework for this study. Using this framework, the investigator reviewed the interview transcripts to identify the individual's perception of the lived experiences. Statements from all the transcripts were compiled into categories to derive meaning from the lived experiences of the participants.

The goal of this study was to explore the lived experiences of people who combine compensated employment and caregiving responsibilities and to identify

perceived positive and negative aspects of the dual responsibilities. All participants voiced a responsibility for their care recipient. They attributed this sense of responsibility to expectations of family, care recipient, and/or self as well as out of love for the individual. Other studies have identified participants having a sense of obligation to meeting the care demands for the care recipient (Dunham & Dietz, 2003; Kramer & Kipnis, 1995).

Exhaustion was identified as the physical outcome of combining caregiving and employment. Participants indicated their exhaustion resulted from the physical nature of caregiving, lack of sleep, and/or limited personal time. In a study conducted by Scharlach (1994), of the 94 employed caregivers participants, 48% reported reduced energy, 21% lack of free time, and 6% physical strain. Fredriksen and Scharlach (1999) found 78% of 1,146 respondents experienced physical fatigue. In addition to finding that fatigue was significantly higher in those providing elder care, Scott et al. (2006) noted 25% of 393 participants had less than 5.75 hours of sleep a day. This was a result of caregiving and employment responsibilities.

Participants in this study reported an increase in physical illnesses and weight changes as a result of not taking time for themselves. In a study examining the association between caregiving and well-being in employed and unemployed women, the employed women had poorer health (Marks, 1998). However, no significant difference was found between the health of employed male caregivers and unemployed caregivers. Canning et al. (1996) estimated one fifth of caregivers have 3 or more physical illnesses soon after the onset of caregiving. They identified employment and physical health as

predictors of emotional distress. Caregivers need to acknowledge the importance of taking care of themselves as a means to reduce the risk of physical effects of caregiving.

The majority of research on caregivers focuses on depression, stress, and/or caregiving burden (Starrels et al., 1997). Depression and frustration were identified as the symptoms of emotional distress in this study. Cannuscio et al. (2004) found that as the amount of time spent in providing care increased, there was an increase in depression. Employment status did not affect depression (Cannuscio et al., 2002; Edwards et al., 2002). Participants in this study described frustration resulting in resentment towards the care recipient, situation, or siblings. This leads to stress. Employment can increase physical stress (Stull, Bowman et al., 1994). Conflict between the caregiving and employment demands is a predictor of psychological stress (Barling et al., 1994). Women report higher levels of role strain than men do (Fredriksen, 1996; Fredriksen & Scharlach, 1999; Kramer & Kipnis, 1995). Marks (1998) found men experience more stress when become caregivers and continue to be employed.

A sense of social isolation can be a result of caregiving and employment. Caregivers often indicate they do not have time to do social activities. Cannuscio et al. (2002) identified that as social interactions decrease, there is an increase in depression. Involvement in volunteer activities is viewed as a way to counterbalance the isolation experienced with caregiving (Farkas & Himes, 1997). One finding in this study that is not in the literature is the effect of caregiving on relationships with friends, siblings, and/or spouses.

One personal reward of combining caregiving and employment is a sense of satisfaction and accomplishment of being able to meet the responsibilities associated with both roles (Dunham & Dietz, 2003; Martire et al., 1997; Scharlach, 1994). Personal rewards include support from co-workers and being involved in meaningful work (Scharlach, 1994). Employment can be viewed as providing balance or a break from caregiving responsibilities (Edwards et al., 2002). Employment has been described as a place for support and an outlet (Pohl et al., 1998).

Negative outcomes described as feeling torn between employment responsibilities and caregiving responsibilities (Pohl et al., 1998). The responsibility towards work is in conflict with the responsibility towards the care recipient (Kramer & Kipnis, 1995). Work needs to be arranged around caregiving demands (Fredriksen & Scharlach, 1999; Pohl et al., 1998). Missing work due to caregiving demands is viewed as another negative outcome (Barling et al., 1994; Ettner, 1995; Fredriksen & Scharlach, 1999; Scharlach, 1994). Caregivers can be distracted at work due to caregiving responsibilities and/or fatigue. This may lead to an increase in errors Scott et al. (2006) or decreased productivity (Scharlach, 1994). Due to caregiving demands, the caregiver may reduce their work schedules or terminate their employment (Dunham & Dietz, 2003; Pavalko & Artis, 1997; Pohl et al., 1998). In addition, Pohl, Collins, and Given (1998) report caregivers stay in the same jobs or decline promotions.

Help from others is needed to coordinate care and access resources to support caregiving activities. Employed caregivers need assistance in meeting the daily needs of the care recipient such as transportation, meal preparation, and hygiene (Kramer &

Kipnis, 1995). A supportive work environment that allows flexibility is the most important benefit an employed caregiver needs (Barnes et al., 1995; Bullock et al., 2003; Dunham & Dietz, 2003; Fredriksen, 1996; Ingersoll-Dayton et al., 1996; Scharlach, 1994; Scott et al., 2006). This enables them to meet the dual responsibilities of caregiving and employment.

Although about 25% of the participants in this study described a negative financial impact of caregiving, other studies have reported a significant impact especially for woman caregivers (Doty et al., 1998). It is reported caregivers are not aware of the long-term financial consequences of caregiving (Keefe & Medjuck, 1997). Worklife lost as a result of time taken to provide care can not be recovered resulting in effects on paid retirement benefits (Pavalko & Artis, 1997)

Conclusions and Implications

The following conclusions were derived from this study:

1. Caregivers have a sense of responsibility towards the care recipient based on a sense of obligation, love for the care recipient, or family expectations.
2. Employed caregivers experience exhaustion from the demands of caregiving and employment. This exhaustion can be manifested in physical illnesses.
3. Employed caregivers experience depression and frustration.
4. Frustration may result in resentment towards the care recipient, the situation, and/or other family members.
5. Stress and strain have been the result of frustration associated with caregiving.

6. Caregivers experience social isolation as a result of the caregiving demands that affect relationships with friends and family members.
7. Employed caregivers experience satisfaction as a result of being able to provide care and work.
8. Co-workers provide support to the employed caregiver.
9. Employment provides a break from caregiving responsibilities.
10. Employed caregivers experience a sense of conflict between their caregiving responsibilities and their work responsibilities.
11. Employed caregivers may experience distractions at work due to caregiving responsibilities.
12. Employed caregivers have not accepted promotions due to caregiving responsibilities.
13. Employed caregivers need assistance in coordinating the care and identifying resources.
14. A supportive work environment providing work flexibility enables caregivers to remain employed while continuing to provide care.

The following are implications generated by the findings of this study for nurses providing care for person with a chronic mental or physical illness and for employers of informal caregivers:

1. The nurse should assess the caregiver for signs and symptoms of exhaustion and depression. Appropriate referrals should be made.

2. The nurse should interview the primary informal caregiver to determine what resources they have available. If the caregiver has limited resources, the nurse should make a referral to a social worker.
3. Employers should review scheduling plans to assure informal caregivers have flexible schedules.
4. Employers should review and revise benefit plans to provide access to care coordinators to help employed informal caregivers coordinate care and to provide assistance in securing financial assistance programs. Financial planning consultants are needed to provide advice as to how to manage the financial aspects of caregiving.
5. Additional benefits should be added to provide support groups and respite programs for employed caregivers.
6. Employers should facilitate access to information regarding community programs and helpful hints when being an informal caregiver.

Recommendations for Further Study

Based on this study, the following recommendations for future research are as follows:

1. This study was limited to one study site. This study should be replicated in other work sites to determine if other employed caregivers have the same experiences.
2. There is some evidence in the literature employed men and employed women approach caregiving differently. Further research is needed to compare the experiences of men and women in caregiving.

3. Although this study included Caucasian and African American women, further investigation should study the effect of culture on caregiving practices and responsibilities.
4. Randomized controlled studies are needed to determine the effect of support groups on depression, frustration, and isolation resulting from caregiving.

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APPENDIX A

Agency Permission for Conducting Study

TEXAS WOMAN'S UNIVERSITY
COLLEGE OF NURSING

AGENCY PERMISSION FOR CONDUCTING STUDY*

The St. Luke's Episcopal Hospital

GRANTS TO Cheryl Novak Lindy

a student enrolled in a program of nursing leading to a Doctoral degree at Texas Woman's University, the privilege of its facilities in order to study the following problem.

What are the lived experiences of employed adults with dependent adult caregiving responsibilities?

The conditions mutually agreed upon are as follows:

1. The agency (**may**/may not) be identified in the final report.
2. The names of consultative or administrative personnel in the agency (**may**/may not) be identified in the final report.
3. The agency (**wants**/does not want) a conference with the student when the report is completed.
4. The agency is **willing**/unwilling) to allow the completed report to be circulated through interlibrary loan.
5. Other _____

Rosemary Leguina
Signature of Agency Personnel

4-11-06

Date

Cheryl Lindy 4/12/06
Signature of Student

Judith M. Jarne 4/12/06
Signature of Faculty Advisor

*Fill out and sign three copies to be distributed as follows: Original—student; copy—agency; copy—TWU college of Nursing.

APPENDIX B

Human Subjects Review Committee Approval

Institutional Review Board
(832) 355-3347
Mail Code 3-288



July 8, 2005

INITIAL APPROVAL DATE JULY 6, 2005

Cheryl Lindy, MS, RN, BC, CNAA-BC
Director, Nursing Education
St. Luke's Episcopal Hospital
6720 Bertner Avenue, MC 4-278
Houston, Texas 77030

Project #2611

"The Lived Experiences of Employed Adults with Dependent Adult Caregiving Responsibilities"

Dear Ms. Lindy:

The above protocol was reviewed and approved at the July 6, 2005 meeting of the Institutional Review Board of St. Luke's Episcopal Hospital.

This letter will serve as verification that the St. Luke's Episcopal Hospital Institutional Review Board operates in accordance with all applicable laws, regulations and guidelines for clinical trials and under Federal Wide Assurance No. FWA00002312, issued April 8, 2002. We maintain compliance with the FDA Code of Federal Regulations, International Conference of Harmonization (ICH) and Good Clinical Practice (GCP) guidelines.

Continued review will be required as follows:

- a. Annually
- b. Prior to any change in protocol
- c. Promptly after unanticipated problems (adverse events)
- d. After any other unusual occurrence
- e.

The method of review will be by written summary.

Cheryl Lindy, MN, RN, BC, CNAA-BC
Page 2

July 8, 2005

The administrative review process of protocols is handled separately from the IRB review. When final administrative approval is granted, you will receive notification from the Department of Research. Should you have any questions regarding administrative approval, please contact Cheryl Fullmer at 832-355-6801.

Sincerely,



Arthur W. Bracey, M.D.
Vice Chair
Institutional Review Board

AWB/jrs

Institutional Review Board
(832) 355-3347
Mail Code 3-288



March 6, 2006

Cheryl Lindy, MS, RN, BC, CNAA-BC
Director, Nursing Education
St. Luke's Episcopal Hospital
6720 Bertner Avenue, MC 4-278
Houston, Texas 77030

Project #2611

"The Lived Experiences of Employed Adults with Dependent Adult Caregiving Responsibilities"

Dear Ms. Lindy:

The St. Luke's Episcopal Hospital Institutional Review Board is pleased to inform you that the amendment (increased enrollment and additional questions on interview) to the above referenced protocol was approved on March 1, 2006 according to institutional guidelines.

Continued review of the study will be required as follows:

- a. Annually
- b. Prior to any change in the protocol
- c. Promptly after unanticipated problems (adverse events)
- d. After any other unusual occurrence

The method of review will be by written summary.

Sincerely,

A handwritten signature in black ink, appearing to read "Frank A. Redmond".

Frank A. Redmond, M.D., Ph.D.
Chair
Institutional Review Board

FAR/jrs

TEXAS WOMAN'S UNIVERSITY

DENTON DALLAS HOUSTON

INSTITUTIONAL REVIEW BOARD

1130 John Freeman Blvd., Houston, Texas 77030 713/794-2074

MEMORANDUM

TO: Judith McFarlane
Cheryl Novak Lindy
Student ID # 0120130

FROM: IRB

DATE: May 4, 2006

SUBJECT: IRB Exempt Application

TITLE: The lived experience of employed adults with dependent adult caregiving responsibilities

This application is **approved**. This approval lasts for 1 year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.


Gretchen Gemeinhardt, Ph.D.
Chairperson

APPENDIX C

Consent Form

INFORMED CONSENT

Protocol Title: **THE LIVED EXPERIENCES OF EMPLOYED ADULTS WITH DEPENDENT
ADULT CAREGIVING RESPONSIBILITIES**

Investigator: Cheryl Lindy, MS, RN

832-355-4458

Advisor: Judith McFarlane, DrPh, RN, FAAN Dissertation Chair 713-794-2138

Introduction

You are being invited to take part in a research project called "The Lived Experiences of Employed Adults With Dependent Adult Caregiving Responsibilities," conducted by Cheryl Lindy. Your decision to take part is voluntary and you may refuse to take part, or choose to stop taking part, at any time. A decision not to take part or to stop being a part of the research project will not change the employment relationship you have with St. Luke's Episcopal Hospital. You may refuse to answer any questions asked or written. This research project has been reviewed by the St. Luke's Episcopal Hospital Institutional Review Board as project # #2611 and Texas Woman's University Office of Research.

Purpose of the Study

The purpose of this study is to determine the experiences of people who are employed a minimum of 20 hours a week and offer informal caregiving to a person with a chronic physical or mental condition or disability for at least 30 consecutive days during the last 12 months. You will be asked to describe your experiences as a caregiver and being employed at the same time.

Description of Research

If you decide to take part, you will be one of up to 25 people in the study. You will be interviewed. The interview will last about one hour in a place that is convenient and comfortable for you. During the interview, you will be asked questions about your experiences in providing care for a relative or friend with a chronic physical or mental illness or disability while being employed. The discussion will be tape-recorded so what we discuss can be studied in detail. There are no right or wrong answers. Three months after the meeting, you will be asked to meet a second time for about an hour with the investigator so we can get a better understanding of what we talked about at the first meeting.

Time Commitment

You will be asked to give a total of about two hours to this project.

RISKS

You may feel uncomfortable talking about past experiences. You may feel hesitant to discuss your experiences honestly with the nurse investigator for fear that your comments may be viewed negatively or your employer will find out information discussed. The nurse investigator will keep the interviews with you strictly confidential.

BENEFITS

There may be no direct benefit to you for participating in this study other than talking about your feelings with a person who is interested in your experiences. However, information gained through this study will increase the understanding of the experiences people have when caring for a relative or friend with a chronic physical or mental illness or disability.

Alternatives

You may choose not to take part in this research study.

Voluntary Participation/Withdrawal from Study

Your decision to take part in this study is voluntary and refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may stop taking part at any time without penalty, or loss of benefits to which you are otherwise entitled.

IN CASE OF INJURY

In the event of injury resulting from this research, St. Luke's Episcopal Hospital or Texas Woman's University will not offer financial compensation nor absorb the costs of medical treatment. However, necessary facilities, emergency treatment and professional services will be available to research subjects just as they are to the community generally. Your signature below acknowledges your voluntary participation in this research project, but in no way releases the investigators, sponsors, institutions or agencies from their professional and ethical responsibility to you. You should report any injury to Cheryl Lindy at 832-355-4458 and the St. Luke's Episcopal Hospital Institutional Review Board at 832-355-3347 and the Texas Woman's University Office of Research at 713-794-2840 or via e-mail at IRB@twu.edu

COSTS, REIMBURSEMENT, AND COMPENSATION

You will not be asked to pay for any expenses related to this study, however, you are expected to provide your own transportation and parking for the meetings. You will receive a \$25 gift certificate at the completion of the interview for taking part in this research project.

CONFIDENTIALITY

A special number will be used to identify you in the study and only the investigator will know your name. This signed informed consent will be maintained in a locked file cabinet with access limited to only the investigator. Your name will not appear in any reports or publications produced from this study. Confidentiality will be protected to the extent of the law.

QUESTIONS

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study, you should ask the investigator or advisor. Their phone numbers are at the top of this form on the first page. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the St. Luke's Episcopal Hospital Institutional Review Board at 832-355-3347 or the Texas Woman's University Office of Research at 713-794-2480.

SIGNATURES

~~I have read this~~ I have read this consent form and all of my questions about this study have been answered. By signing below, I acknowledge that I have read and accept all the above information and agree to participate in this study. I have been provided with a copy of this consent form.

Signature of Participant

Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge of its contents.

Signature of Investigator

Date

Revised Informed Consent
Approved by IRB

Version 7/05/06

Date 7-7-06
Signature [Signature]

APPENDIX D

Demographic Questionnaire

Code # _____

THE LIVED EXPERIENCES OF EMPLOYED ADULTS WITH DEPENDENT ADULT CAREGIVING
RESPONSIBILITIES

Directions: Please complete the following information about you and the recipient of care.

First name of care recipient _____

How did you get involved in providing care? _____

Length of time involved in caregiving _____

Your birth date _____

Date of birth of the care recipient _____

Which of the following group's best
describes you:

Your relationship to the care recipient _____

Gender of the care recipient

African American _____

Female _____

American Indian _____

Male _____

Asian _____

Does the care recipient live with you

Hispanic _____

yes _____ If YES, for how many years _____

White _____

no _____ IF no:

Other (Please describe) _____

How many miles away from you does the person
live? _____

Which of the following group's best
describes you:

About how many minutes does it take to arrive at their
residence? _____

Married/Common Law _____

What activities do you assist or perform for the care
recipient?

Single _____

Walking _____ Yes _____ No _____

Divorced _____

Feeding _____ Yes _____ No _____

Widowed _____

Toileting _____ Yes _____ No _____

Co-habiting _____

Bathing _____ Yes _____ No _____

Other (Please describe) _____

Transporting _____ Yes _____ No _____

Please describe: _____

Dressing _____ Yes _____ No _____

Work activities _____ Yes _____ No _____

(please describe) _____

Communication _____ Yes _____ No _____

(please describe) _____

Writing _____ Yes _____ No _____

(Please describe) _____

Safety _____ Yes _____ No _____

(please describe) _____

Other (please describe) _____

APPENDIX E
Interview Protocol

Code # _____

THE LIVED EXPERIENCES OF EMPLOYED ADULTS WITH DEPENDENT ADULT
CAREGIVING RESPONSIBILITIES

Interview Questions

How do you feel when offering this caregiving to (name of recipient).

Give me an example

How has the caregiving affected your relationship with _____?

(First name of care recipient)?

How has this affected you? Physically, psychologically, socially, financially

Give me an example

How has the caregiving you offer to (first name of care recipient) affected your employment?

Give me an example

How has your employment affected your caregiving?

Give an example

How has combining employment and caregiving changed your life?

Give me an example

What are the positive aspects of combining your caregiving responsibilities with your
employment responsibilities?

Give me an example

What are the negative aspects of combining your caregiving role with your employment
responsibilities?

Give me an example

When doing both caregiving and employment, what resources are needed?