2016

The Nurse as a Family Caregiver: Their Experience, Their Story

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THE NURSE AS A FAMILY CAREGIVER:

THEIR EXPERIENCE, THEIR STORY

BY

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A dissertation submitted in partial fulfillment of the requirements for the degree

Doctor of Philosophy

Major in Nursing

South Dakota State University

2016

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This dissertation is approved as a credible and independent investigation by a candidate for the Doctor of Philosophy degree and is acceptable for meeting the dissertation requirement for this degree. Acceptance of this dissertation does not imply that the conclusions reached by the candidate are necessarily the conclusions of the major department.

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I dedicate this dissertation to my family….

To Dan, who gave me the gift of caring for you, the last five years of your life.

To Jason, Eric, Brian, Matthew, Scott, Kris, Kimberly, Beth, and their families who supported me in the final days of the caregiving experience.

To my sons and their wives Jason & Kristin, Eric & Jennifer, Brian & Cassie, and Matthew & Anna, you are a reminder of purpose in my life.

To my grandchildren, Peyton, Jackson, Christopher, Ellie, Noah, and Macy who teach me about life and love.

To my Hansen children, grandchildren, and great grandchildren who have been such an important part of my life.

And most of all to my *Hawkman* Dan, who with your love, patience, support, and being willing to put our life on *hold* has allowed me to pursue my dream.

I love you all.

ACKNOWLEDGEMENTS

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ABBREVIATIONS

ADLs   Activities of Daily Living

IALDS   Instrumental of Activity of Daily Living

NI   Narrative Inquiry

RN   Registered Nurse

SPM   Stress Process Model

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ABSTRACT

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The purpose of this qualitative narrative research study was to explore and bring more attention to the Registered Nurse in the role of *informal caregiver* to family members. These caregivers are responsible for the care of parents, spouses, and children. The stories shared in this study are not isolated experiences as more and more nurses are placed in the caregiver role outside of their formal professional role. The number of caregiver roles are expected to increase with the increasing numbers of baby boomers and improved life expectancy.

CHAPTER 1: INTRODUCTION AND BACKGROUND

Introduction

Rosalynn Carter (2009) once said, "There are four types of people in this world: those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who will need caregivers" (para.1). Included as caregivers are family members. These individuals are frequently called upon to provide informal care for their ill or dying relatives, through the progression of disease and hospice care. The numbers of informal caregivers are increasing yearly. Estimates recognize that 29% of the adult population in the U.S. or 65.7 million people (National Alliance for Caregiving & AARP, 2012) provide care for family members or friends who are aged, ill, or disabled, reflecting a 31.7 million increase in caregivers from 2008 (Houser, 2008).

Informal caregiving for family members has both positive and negative qualities. In comparison to negative caregiving characteristics, positive aspects have received little attention (Hwang, Fleischmann, Howie-Esquivel, Stotts, & Dracup, 2011). When asked, informal caregivers identified positive experiences are related to companionship, being fulfilled and rewarded, enjoyment, and duty/obligation (Cohen, Colantonio, & Vernich, 2002). Cohen et al., (2002) further identify increasing the positive features of caregiving would support the caregivers' contribution in the experience and reduce the impact of caregiver stress and burden. The quality of the caregiving relationship is central and significant to the positive aspects of the caregiving experience (Boerner, Horowitz, & Schultz, 2004; Carbonneau, Caron, & Desrosiers, 2010).

Positive aspects in the caregiving experience relate to the caregivers' physical and mental health, their general well-being, and role actualization (Carbonneau et al., 2010).

Caregivers with higher levels of self-efficacy experience greater positive viewpoints on caregiving and better coping skills with negative emotions and health consequences (Semiatin & O'Connor, 2012).

Negative aspects of the caregiver role have often been identified as caregiver burden or stress, a multidimensional reaction associated with mental, emotional, social, and financial stresses related to giving care to a family member with chronic health or a disease process (Nguyen, 2009; Sorrell, 2014). The increased amount of time an individual contributes to caregiving and lack of resources corresponds to the increased level of burden or stress (Cox Curry, Walker, Moore, & Hogstel, 2010).

Registered nurses (RNs) are a health profession group who may serve as family members providing informal care. Although RNs provide family caregiving, there is limited information and studies available recognizing the double duty role of a health professional, specifically the experiences of those who become informal caregivers (Boumans & Dorant, 2013). Serving in the informal caregiving role may place individuals at increased risk to experience caregiver burden, stress, and role overload in addition to compassion fatigue or caregiver burnout (Honea et al., 2008; Nguyen, 2009; Whitebird et al., 2012). From the increased risk areas, mental and/or physical issues evolve, creating a compromised well-being in addition to quality of life and work concerns (Honea et al., 2008; Zarit, Femia, Kim, & Whitlatch, 2010).

Additional segments of life may also be affected for the RN as the informal family caregiver. RNs who continue with employment and have a caregiving role outside of the hospital, or a duo duty role, may experience an increased burden or stress, and an imbalance with their professional and personal lives. Combining the family caregiver role

with employment can frequently be difficult with role conflicts and opposing needs (Scott, Hwang, & Rogers, 2006). The demands of caring for family members are main reasons nurses reduce employment hours, change their roles within a facility, or leave nursing (Gryzwacz, Frone, Brewer & Kovner, 2006; Rosenfeld, 2007; Scott et al., 2006).

Within the family caregiving role, RNs experience additional responsibilities and stressors in their lives when providing formal care in the hospital setting to their patients and informal care in the home setting for family, a double duty role (Boumans & Dorant, 2013; Ward-Griffin, 2004). Although examples of joy may be connected with the providing of home care for family members, adverse issues related to this experience may emerge. Ward-Griffin, St-Amant, and Brown (2011) identified "the dynamics of caregiving are extremely complex when the family caregiver is a health professional" (p.12).

Initially RNs may accept the additional responsibility of their acquired family caregiving role with a sense of enthusiasm, hope, and idealism. The situation begins to change with the increase of caregiving responsibilities, as the situation complicates family and work roles, ambiguity and blurring of boundaries are created (Ward-Griffin et al., 2011). Distress related to this double duty role, including patient and caregiver complications and inability to say no, contribute to quality of life changes. The potential for the caregiver to experience burden, stress, and role overload in addition to compassion fatigue and/or caregiver burnout is a quality of life concern (Ward-Griffin et al., 2011).

Purpose of the study

An abundance of research and evidence identifying informal caregiving as a stressful and arduous experience for most family members exists. While the general informal caregiver role has been addressed through considerable research, there is limited information and studies available associated with experiences of RNs caring for their own family members. The purpose of this narrative study was to explore the lived experience of registered nurses who are or have provided care as the informal family member caregiver in the home setting.

The study provided an opportunity to hear the voices and stories of this caregiver group. The perceptions and viewpoints were seen through the eyes of those who have lived the caregiving role, including physical, psychological, and interpersonal experiences.

Research Question

The research question for the study: What is the meaning of the lived experience of the RN in the family member caregiving role?

Significance of Research to Nursing

Caregiving dynamics are complex when the family caregivers are also health professionals (Ward-Griffin, et al., 2011). As additional responsibility in caregiving evolves, nurses may begin to view the situation in which they have been placed with increasing ambiguity. Caregiving is known to be a stressful and arduous experience for most family members, but little has been recognized regarding the RN who becomes an informal caregiver to their family member.

Providing informal care, especially for the nurse in a family member role, is a growing phenomenon that deserves careful attention and systematic research. This caregiver role affects nurses outside of their private life through the shaping and influence of their professional practice (Mills & Aubeeluck, 2006). The informal caregiver role also affects the quality of life of the caregiver, threatened by the continuous exposure to psychological, physiological, and financial burdens (Haley et al., 2002).

There are higher rates of morbidity among caregivers who provide care both at work and at home to family and they are less likely to see a physician and have preventative screenings (O'Brien, Whitehead, Jack, & Mitchell, 2012). Nurses who provide care in this double duty setting are at an even higher risk for developing physical and mental symptoms overload (Boumans & Dorant, 2013).

Emotionally, individuals who give up their personal time to provide care have higher levels of stress than those able to have healthy social relationships (McCurry & Hunter Revell, 2015). These caregivers often identify their experience to be lonely and isolating (McCurry, 2013). The well-being of the family caregiver is often decreased when there is an increase in the emotional and physical demands of caregiving (O'Brien et al., 2012).

Caregiving Statistics. Not only are the caregiving roles evolving, but the number of individuals who provide care for family members is increasing. The Pew Research Center identified the number of family caregivers increased from 30% in 2010 to 39% in 2012 (Desilver, 2013). Caregivers who provide care for a relative are at 86%, including

36% caring for a parent and 14% caring for a child (National Alliance for Caregiving, 2009a).

The average age of a caregiver is 48 years (Alpert, 2104) and the duration of a caregiver's acquired role is 4.6 years. More than half of family caregivers provide an average 20 plus hours of care every week, an increase from eight hours in 2004; one in five provide care more than 40 hours per week (National Alliance for Caregiving, 2009a). Weekly, family caregivers average 43 hours of care whereas, those in spousal care may devote 100 hours, with women spending more time than men in the caregiving role (Alpert, 2014; Wolff, Dy, Frick, & Kasper, 2007). When caregivers were asked if they had a choice in the decision to take on the caregiving role and responsibilities, 49% indicated they felt there were no other options (National Alliance for Caregiving and AARP, 2015).

The increased number of family members in the informal caregiving role, along with an increase in the amount of their invested time, establishes the importance to understand the experiences of family member caregivers, specifically RNs whose caregiving role is significantly extended. The RNs family member caregiver role is multidimensional, changing their lives with increased demands and stresses, economically, emotionally and physically. These caregiver role changes have furthermore been associated with shaping and influencing their professional practice (Mills & Aubeeluck, 2006).

Earlier research on family caregiving concentrated on specific areas of the physical aspects and disease processes within the caregiving role. Recent research and literature are expanding to include additional understanding of the general caregiver role

comprised of physiological, psychological, and relational dimensions. When RNs are informal caregivers they provide care both at work and in the home setting. These nurses involved with informal caregiving acquire double duty responsibilities and blurred boundaries. This blurring of boundaries and continual negotiation between family and professional caregiving predispose caregivers to adverse health consequences (Ward-Griffin et al., 2011).

Registered nurses within the role of duo duty caregiving experience a lack of resources, both personal and professional, in addition to facing an increase of familial care expectations. This decrease in resources and the increase of expectations may dispose the providers to negative consequences. Informal caregiver RNs place high levels of expectations on themselves, internally and externally, decreasing the boundaries between the formal and informal settings (St-Amant et al., 2014). The added responsibilities of providing care in the work and home setting generates a double duty responsibility. These increasing familial care expectations predispose the providers to negative consequences (Ward-Griffin et al., 2011).

Previous research on the informal caregiver role include Boyle's (2009), qualitative study of the experiences of the caregiving spouse and Gattuso and Bevan's (2000) exploration of adult daughter caregivers and their aging mothers. Various caregiving experiences may be similar to double duty caregiver roles, but existing research is deficient specifically to the needs and concerns of RNs who do not have an opportunity for respite going between the formal to informal caregiver roles.

Registered nurses in the informal caregiver role may differ from other professions as their opportunity for respite from providing hands on care is absent or limited. Nurses

in the caregiving role are continually on duty with their role as a formal caregiver competing with the informal caregiving role. This competition may produce mental and physical fatigue. Caregiving fatigue or burden can adversely affect their informal and formal caregiving roles (Scott et al., 2006). Caregiving without respite has been equated to job responsibility 24 hours a day and seven days a week (Sawatzky & Fowler-Kerry, 2003). Even during the night hours, the caregiver is on call for emergencies that might arise.

Hearing the experiences of nurses providing informal family care offers insight to the caregiving experiences while examining the needs and issues faced by RNs in the family member caregiver role. In the beginning of their newly acquired family caregiving role, some RNs may accept their added responsibility without reservation. While in similar situations other RNs may feel a resistance to being in the caregiver role, but are unable to verbalize their lack of willingness to provide care to family members and implement what the family expects because they are a nurse (Scott et al., 2006; Ward-Griffin, 2004; Ward-Griffin, Brown, Vandervoort, McNair, & Dashnay, 2005).

Approximately three-fourths of caregivers are employed. Individuals taking care of family members devote an average of four hours a day or an average of 28 hours per week to their informal caregiving while maintaining full-time employment (Family Caregiver Alliance, 2009). In this shared role of employment and care provision, many caregivers are required to make employment adjustments. Seventy percent of working caregivers have made some job change to accommodate their caregiving role. Of these working caregivers, 12% reduced work hours or took a less demanding job, while 9%

gave up work entirely, compared to three percent who took an early retirement choosing caregiving over work (National Alliance for Caregiving, 2009b).

Work-related difficulties are found in 70% of working caregivers due to the double duty caregiving roles (National Alliance for Caregiving and AARP, 2009). Informal caregivers are mostly women (66%) and their average age is 48 (National Alliance for Caregiving, 2012). Among these working caregivers, 69% report having to change their work schedule, decrease hours, take unpaid leave, turn down a promotion, or quit work entirely (Feinberg, Reinhard, Houser, & Choula, R. (2011). Not only are there implications for the individual's professional career, but the labor force and employers are also impacted by the RN in the informal caregiving role. The National Workforce Survey of 3,998,416 RNs specify that 93% of practicing RNs are female and at an average age of 50 years. A recent survey of RNs identified 53% are still employed (Budden, Zhong, Moulton, & Cimiotti, 2013).

Caregiving may deteriorate the caregiver's health, leading to a higher rate of illnesses and stress related conditions. In the double duty care role, RNs experience greater fatigue in the formal care environment than those who are not providing informal care (St-Amant, et al., 2014). According to the National Alliance for Caregiving and Evercare (2006), caregivers have indicated they do not take time for their own healthcare, such as going in to the physician (67%), or they put the care receiver's needs over their own (57%). Of those who say their health has declined, 53% report that declining health has made it harder to support their loved ones. Half (53%) of caregivers who said their health had gotten worse due to caregiving also said the decline in their health has affected their ability to provide care.

Additionally, 29% of caregivers report having difficulty in finding time for themselves, managing physical stress, and family responsibilities. Further, over half of the caregivers (51%) said they do not have time to take care of themselves and 49% of these individuals identified they are too tired to do so (National Alliance for Caregiving and AARP, 2004).

Personal Caregiving Role

Narrative research often will be interconnected or share a significance to a personal experience of the researcher. The experiences of the nurse as a family caregiver have a significant meaning to me as I experienced the double duty caregiver role. It wasn't until I cared for my terminally ill husband that I discovered the pressures and stress related to informal care giving for a family member while working fulltime. I investigated resources related to this role experience and found very little information, which reassured me my experiences and feelings were a normal reaction to being an informal caregiver while also working in a formal role.

Because I was a RN, caregiver expectations placed on me by my husband's healthcare providers and family members, were at times overwhelming and insurmountable. These expectations included doing treatments, procedures, and providing healthcare support along with the expectations of providing spousal support. I felt unable to say no to those asking me to provide nursing care in the informal care setting, including hospice cares. My husband also looked to me for doing his cares to avoid visits to the health care setting. Through this experience I felt alone without support, resources, and overlooked my health care needs, not having time for preventative care. Before his death, I looked into options to take a leave from my employment, feeling not able to

continue the duo duty role. Many times throughout this experience I wanted to be seen as a spouse and not as a nurse. This feeling of being in a duo duty caregiving role with blurring boundaries had me researching for others in a similar experience, looking for possible support and solutions to the situation. The lack of double duty caregiving experiences available as a resource during my experiences have prompted this narrative research to hear the voices of those in the double duty caregiving role. I am removed over seven years from my experience in the informal family member caregiving role and my previous experiences did not influence the results of this study.

Definition of Study Terms

The following definitions were identified for purposes of the study:

Caregiving. The activity provided by an individual (caregiver) to another person assisting with one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs). ADLs include bathing, grooming, and dressing while IADLs are comprised of preparing meals, housework, and taking medications correctly. Caregivers provide an average 20 plus hours of care every week with an average duration of 4.6 years (National Alliance for Caregiving, 2009b).

Caregiver. A person who provides direct care for children, older adults, or the chronically ill (Merriam-Webster, 2012).

Caregiver Burden. Also known as *Caregiver Stress*, is used to describe what occurs when the emotional or physical health of caregivers is compromised or when the demands of care outweigh available resources (Honea et al., 2008).

Duo Duty Caregiving. Also known as *Dual Duty or Double Duty,* non-ceasing caregiving equal to working shift after shift without respite (Ward-Griffin, 2013).

Individuals who are practicing health professionals providing unpaid informal care in the home setting while continuing to work in healthcare positions (Ward-Griffin et al., 2009).

Family (Informal) Caregiver. A family member, who aids, supervises, or contributes to care and is involved in the daily cares and responsibilities of the weak, ill, or disabled person in a nonpaid role and home setting (Legal Definitions.com, 2012). Generally, *family caregiver* refers to a person who provides care that is a more than response to an illness or functional impairment provided by families (Schumacher, Beidler, Beeber, & Gambino, 2006).

Formal Caregivers. A caregiver associated with a formal service system, a paid worker (Family Caregiver Alliance, 2016).

Home Setting. One's place of residence: domicile: house: the social unit formed by a family living together, the manner, position, or direction in which something is set (Merriam-Webster, 2012).

Nurse as Family Member Caregiver. For purposes of this study, the nurse is recognized as a registered nurse. The caregiver role is providing unpaid assistance and support, including physical and emotional, to family members who have psychological, physical, or developmental needs (Drentea, 2007).

Registered Nurse. A nurse who has more preparation and knowledge than a licensed practical nurse and has passed a specified examination (Merriam-Webster, 2012).

Chapter Summary

This narrative study sought to recognize the stories of RNs who are or have provided care as informal family member caregivers through their lived experiences. The

perceptions and viewpoints of the RN as family caregivers provided an understanding

through the eyes of those who have lived the caregiving role experience.

CHAPTER 2: REVIEW OF LITERATURE

Introduction

The purpose of this narrative study was to explore the experiences of RNs who are or have been a caregiver for their own family member. To guide the study, a review of literature was completed to identify the existing body of information and knowledge gaps related to the study topic. Information from this review provided a foundation for the study by identifying the context of current knowledge related to caregiving.

A two-step process was completed in the review of literature. First, the two subject areas investigated were informal family caregiving and RNs in the family member caregiver role. Second, positive and challenging aspects related to informal caregiving were explored. Positive influences of the nurse in a family member caregiving role included a positive carryover effect to their professional role. Adverse aspects recognized in the literature review were caregiver burden, duo duty roles, and blurred boundaries.

Databases utilized in the literature search include Cumulative Index to Nursing and Allied Health Literature (CINAHL) plus with full text, Medscape, MEDLINE Ovid and PubMed, EBSCOhost, PsycINFO, ProQuest, and Google Scholar. The time frame of the search was January 2000 to August 2016. Key words and phrases utilized in this review of literature were: *registered nurses caring for own family members,* and *informal caregiving, family member caregiving, duo duty caregiving, family caregiving experience, nurses* and *blurred boundaries.*

The initial review of literature identified limited existing information related to RNs caring for their own family member. In contrast, a substantial amount of knowledge

and studies were identified associated with general family members in the informal

caregiver role. Both literature related to the nurse as a family member caregiver and

informal family caregiver are included in this review.

Nurses as the family member caregiver

Nurses' professional health knowledge, training, and experience set them apart

from the non-nurse informal caregiver. Ward-Griffin (2004) and Mills and Aubeeluck

(2006) acknowledge that nursing knowledge, including an understanding of health

organizations, can be beneficial to provide family member care. Even though nurses have

experience working and caring for patients and their families, little has been investigated

how these practices contribute or influence the experiences of providing care for their

own family members.

Nurses in the family member caregiver role face situations only witnessed

previously in working with clients and their families (Cicchelli & McLeod, 2012). The

experience of *knowing* information is different when related to a family member and may

cause panic, fear, and anxiety in the nurse (Salmond, 2011). Ward-Griffin's (2004)

qualitative study found nurses worry about losing objectivity and have a clouded

judgment when working with their family members. Participants in this study viewed

family member caregiving as a normal extension of their nursing duties and felt obligated

to use nursing knowledge in the provision of care.

Research also revealed unrealistic expectations and feelings of inadequacy may

create stress and burden for nurses providing family member care. Olivet and Harris

(1991) indicated nurse family caregivers may face uncertainty in their family caregiving

role. Family members frequently place unrealistic expectations on their family nurses,

expecting them to be an expert with procedures and treatments even if they differ from the nurse's expertise areas. Additionally, these expectations may cause the nurse to feel professionally inadequate as a family caregiver (Mills & Aubeeluck, 2006). Family expectations may create feelings of stress, confusion, and overload within the nurse family caregiver (Mills & Aubeeluck, 2006; Olivet & Harris, 1991).

The added burden of nurse informal caregiving may lead to relationship difficulties, personality changes, and create restrictions on the nurse's personal and professional life. Family nurse caregivers equate the experience to living on the edge (Mills & Aubeeluck, 2006). The participants in the Mills and Aubeeluck study acknowledged the consequence of providing care caused them to experience a negative impact on their quality of life. It was further noted that the burden of care can lead to relationship and intimacy difficulties, personality changes, and limitations on the caregiver's life.

Summary

Nurses in the role of family member caregiver may place upon themselves unrealistic expectations including having feelings of inadequacy when caring for their loved ones. Since nurses are professional caregivers, family members may also expect them to be knowledgeable and experienced with treatments and procedures outside their expertise area. These unrealistic expectations from family members and self may lead the nurse to experience relationship difficulties and burden of care.

Duo duty caregiving roles. This literature focused on difficulties nurses in the family caregiver role face, primarily issues with duo roles of care. Scott et al. (2006) acknowledged while nurses with knowledge and skills will contribute to family member

care, these caregivers also experience challenges not faced by non-nursing family members. Without sufficient respite time many nurse caregivers will become distressed due to the opposing commitments between work and caring demands. Struggling between caregiving roles can generate physical and mental exhaustion which adversely affects both roles in the areas of productivity and performance (Scott et al., 2006).

Ward-Griffin (2004) found nurses viewed family caregiving as expected extensions of their profession and felt obligated to assume additional caregiving roles. Several studies revealed nurses in the family caregiving role struggled with the duo role intertwining and intersecting, leading to inseparability of personal and professional role identity. As these roles intertwine, the lines of nurse and family member are blurred. The *nurse in them comes first* and the caregiver is unable to separate roles to be a family member (Cicchelli & McLeod, 2012; Salmond, 2011). St-Amant et al., (2014) further identified that many nurses felt their paid and unpaid care seemed *endless* as informal and professional caregiving were intertwined and overlapping.

Nurses assuming duo roles as informal and formal caregivers may be at higher risk for stress, reduced life satisfaction, and poor physical and/or mental health (Schumacher et al., 2008). Additional studies identified nurses in professional and informal caregiving roles have needs related to their duo roles of family caregiver and nurse. These nurses are at higher risk for distress due to conflicting obligations and commitments (Mills & Aubeeluck, 2006; Ward-Griffin et al., 2005).

A focus group study approach by Gattuso and Bevan (2000) identified duo role blurring in nurses' experiences and practice models of care created high levels of stress. This stress was linked to conflicts in balancing caring and productivity demands in the

insider-outsider dual caring role dilemmas. These dilemmas involve conflicts between caring roles and/or between being an insider with expert knowledge and a family member of the patient receiving care. If nurses' conflicts and issues are not acknowledged, both recipients of care and the caregiver are impaired by emotional labor and loss of energy necessary to sustain them.

Ward-Griffin et al. (2011) investigated experiences of women in nursing and other health professions who provided care to relatives. Female health care professionals who assumed caregiving roles frequently negotiate boundaries between professional and personal care. Women in the study identified feelings of fatigue, isolation, and tension due to blurring of roles and boundaries. In addition, feelings of fear, anxiety, and helplessness were identified in the health professional's caregiver role (Cooper & Barnett, 2005).

Not all experiences of the nurse in a duo duty role were identified as challenging. An interpretative phenomenological analysis by Mills and Aubeeluck (2006) identified positive features of the duo duty role. Participants identified the family caregiving experience as touching and influencing their professional care practice. Additionally, the caregivers' nursing skills contributed to aspects of the family members' care.

Summary

Although the review identified positive aspects of caregiving as influencing and touching the nurses' practice, the majority of literature reflected undesirable aspects. Unrealistic expectations and feelings of inadequacy were identified as challenging areas associated with nurses providing family member care. In addition, the shifting between

professional and personal caregiving roles or duo duty roles, is an area that can create a higher risk of stress and poor physical and/or mental health difficulties.

Family (Informal) Caregivers

A plethora of literature is focused on the family caregiver. The family caregiver, or informal volunteer caregiver, is one of the oldest types of caring arrangements (Lindqvist, Hakansson, & Petresson, 2004). Boyle (2009) identified expectations that family members will provide care and support. These expectations significantly impact the caregiver causing needs and anxieties similar to their family members receiving the care.

Qualitative studies identify family members frequently assume the caregiving experience leaving the caregiver worried about the care receiver's safety and health. Frequently the assumption of caregiving happens with little or no understanding of what the experience will involve, support needed, or advanced training required to provide satisfactory care (Sawatzky & Fowler-Kerry, 2003; Schumacher et al., 2006). This caregiving situation further prompts the caregiver to struggle with feelings of inadequacy, apprehension, and guilt (Boyle, 2009; Schumacher et al., 2006, Stoltz, Udén, & Willman, 2004; van Campen, de Boer, & Iedema, 2012).

Summary

Family or informal caregivers may be expected to assume the provision of care with little or no training or support. The caregiver in this situation struggles with feelings of inadequacy, guilt, and apprehension. Anxiety created over caregiving creates needs for the caregiver similar to the care receiver.

Positive aspects of family caregiving. To better appreciate the complete caregiver experience, it is important that positive aspects be addressed. The literature review revealed most family caregiving studies address the caregiver experiences negatively and little focus is given to the positive experiences. It has been identified more attention needs to be given to positive aspects of caregiving to understand and assist family members in their experiences (Hunt, 2003; Rapp & Chao, 2000; Sebern, 2005).

Positive aspects in caregiving were identified in a conceptual framework as not being at the opposite ends of the caregiving spectrum from caregiver burdens, but rather they are both separate experiences (Carbonneau et al. 2010). Lundh's (1999) research identified caregiver stress factors and satisfaction can coexist in different areas of caregiving. Furthermore, the quality of the caregiving relationships and importance of the experience to the caregiver are reflected in feelings of accomplishment and may buffer stress and burden. Positive aspects in caregiving increase the caregivers' well-being including physical and mental health. Additional family caregivers identified a coexistence of positive and negative reactions in the caregiving experience. These perceptions were identified as satisfaction and burden, relating to different aspects of the caregivers' situation and experiences (Andrén & Elmståhl, 2005). Literature further supports that the higher level of caregiver self-efficacy, the more likely experiences will be viewed as positive (Semiatin & O'Connor, 2012) including the aspects of feeling good, satisfied with self, and increased confidence (Hunt, 2003). Caregivers who identify positive aspects of caregiving are also more protected from negative effects as are their care receivers (Cohen et al., 2002).

The difference in experiences can be related to the types of caregivers and their motivation for care as examined in a quantitative study conducted by Broese van Groenou, de Boer, and Iedema (2013). Their analysis identified that external support and motivations, strong personal bonds, and the ability to prevent placement in a residential care facility contributed to positive caregiver experience. The study further indicated spouses may find caregiving as a more positive and rewarding experience than other family members due to their commitment and motivation to keep the care receiver in the home.

Summary

Even though the majority of literature regarding caregiving experiences represents negative circumstances, positive aspects do exist. Positive and negative characteristics of care are not on opposite ends of the caregiving spectrum, but are separate situations and may conceivably coexist. The caregiver's role in the family and motivation for providing care will determine how the experience is viewed. Commitment to keep a family member in the home may influence the caregiver to view their role as more rewarding and positive.

Challenges of family caregiving

Complexity of caregiver roles. A descriptive/narrative naturalistic research study by Sawatzky and Fowler-Kerry (2003) described caregiving experiences as consuming and life changing for the caregiver. The study found new caregiving roles often develop quickly, leaving family members little or no alternatives and with minimal understanding of the reality and long-term commitment of caregiving. Their acceptance to the commitment to provide care is frequently made through a sense of responsibility and

love. The study further established a caregiver experiences significant changes in their lifestyle. Change in employment, loss of control and privacy, and relationship changes with the care receiver often occur leaving the caregiver to experience social isolation and loneliness.

McCurry (2013) examined the decision making of informal caregivers caring for individuals with multiple sclerosis. In this exploratory study, family caregivers frequently recognized the experience of caregiving to be lonely and isolating. Feelings of loneliness were often attributed to loss of activities and limitations to their lives. These limitations and lack of freedom can lead caregivers to feel like they no longer have a life further escalating to social isolation (Boykin & Winland-Brown, 1995).

Changes in family roles and relationships can create significant challenges for family caregivers. Dickson, O'Brien, Ward, Allan, and O'Carroll (2010) completed an interpretative phenomenological analysis of the spouse's experience in the caregiver role. This analysis identified couple dynamics shift in the caregiving/caregiver roles, increasing relationship strain. This shift happened when the partner/caregiver sacrificed their identity to focus on the marriage. An interruption in the spousal/family role was created, leading to an alteration in the relationship and identity of the caregiver. Further analysis revealed caregivers will sacrifice their own identity to fulfil the caregiver role.

A qualitative study of informal caregivers by Sawatzky and Fowler-Kerry (2003) identified role changes associated with caregivers providing personal cares for their spouses. As the caregiving transpired, the role of the wife shifted and emerged as nurse or caregiving. It was further noted in some caregivers their family role changed from wife/lover to a mother symbol, creating an absence of support within the relationship.

This shifting of roles led to the caregivers putting their lives on hold along with experiencing loss of control and emotional distress over their past.

Summary

Caregiving roles may develop rapidly leaving family members lacking an accurate understanding of commitment to care and the future life changes. Changes within family roles and relationships can prove to be challenging for caregivers. Wives caring for their spouses may see their role change from wife to nurse or mother symbol. These changes create a loss of control and emotional distress over their previous spousal role.

Caregiver burden. In a study by Werner, Mittelman, Goldstein, and Heinik (2012), caregiver burden was recognized as a negative effect of caregiving. The response includes physical, social, psychological, emotional, and/or financial health concerns experienced by the caregiver in their caregiving role. Lack of care knowledge, and time commitments along with increased obligations create burdens on family caregivers. Chappell and Reid (2002) additionally examined the responses of caregivers and life satisfaction. The study identified an increase in informal caregiving hours led to the caregiver experiencing greater burden and a change in life satisfaction.

The experience of caregiver burden is situational and varies with caregivers perceived demands and resources related to their experience (Chou, 2000). In a review of literature, Nguyen (2009) identified caregiver burden as an experience different for each caregiver, dependent on their coping with the stress and demands of their role. Savundranayagam, Montgomery, and Koloski (2011) performed a dimensional analysis of spouse/partner and adult children caregivers for individuals with chronic illnesses. The

analysis recognized caregiver burden as a predictor for the caregivers' poor health and an outcome of the caregiving experience.

Several studies further specify caregiver burden as a unique concept associated with caregiving, specific to the caregiver's role, frequently identified as a sacrifice of the caregivers' time, job, role, and energy (Chappell, Dujela, and Smith, 2014; Nguyen, 2009; Schubart, Kinzie, and Farace, 2008). Chappell et al., (2014) examined family member differences in experiencing caregiving burdens. The study identified specific disease disorders were not the indicating factor to an increase in caregiver burdens. Gauthier et al., (2007) further determined the functional decline of the care receiver's health condition to be most predictive of caregiver burden.

Davis et al. (2014) examined an analysis of spousal caregiver interviews and the connection of caregiver burden to the caregivers' personality traits. Traits such as optimism, hardiness, and resiliency were noted to have assisted caregivers through challenging aspects of caregiving. The caregivers' perceived burden of their experience was found to be significant in their response to the caregiving role. Through a systematic database review of caregiving for older relatives, del-Pino-Casado, Frias-Osuna, Palomino-Moral, and Pancorbo-Hidalgo (2011) identified the caregiver's perception of the caregiving experience was frequently associated with anxiety and depression versus satisfaction.

Caregiver burden is further differentiated as subjective and/or objective burdens (Chappell et al., 2014; Davis et al., 2014; Hunt, 2003) dependent on the circumstances emanating from the caregiving experience. Identification of these burdens along with monitoring informal caregivers remain important actions for those at risk for caregiver

burden related obstacles. Schultz and Beach's (1999) prospective population based cohort recognized caregivers who live with the care recipients experience higher levels of burdens and stress. Further it was noted the burden from caregiving was a risk factor for mortality among elderly spousal caregivers.

Davis et al.'s (2014) analysis of spouses in the caregiving role identified objective burdens emanating from characteristics of the care received, which often is attributed to home cares physical demands. These demands include activities of daily living such as bathing, feeding, toileting, (Davis et al., 2014) and time spent on caregiving tasks such as laundry, financial duties, and taking the care recipient to health care visits (NJA van Exel, WBF Brouwer, B van den Berg, MA Koopmanschap, and GAM van de Bos, 2004). Objective burden was further identified by Hunt (2003) in a caregiver burden concept review as noticeable, concrete, and a tangible cost to a caregiver from their family member's illness. In an additional analysis, Chou (2000) further acknowledged this burden as verifiable and an apparent disruption of family life.

Chappell et al. (2014) completed a comparison study of spouse and adult children caregivers identifying subjective burden as a psychological and emotional strain placed upon the caregivers. This burden involves the caregivers' feelings, attitudes, or emotional reactions (Chou, 2000) to the caregiving experience. NJA van Exel et al.'s (2004) research identified subjective burden as providing physical, psychological, social, and/or emotional care in caregiving. The researchers further acknowledged although this burden may exist, the caregiver may not perceive it as happening to their lives.

Subjective burden places caregivers at higher risk for development of negative health consequences (Hunt, 2003; Sisk, 2000). A cross sectional systematic review by

del-Pino-Casado et al. (2011) linked subjective burden with caregiver anxiety (Cooper, Balamurali, & Livingston, 2007) depression (Schultz & Rössler, 2005) and physical health issues (Carretero, Garcés, Ródenas, & Sanj*o*śe, 2009). Research findings identify it is crucial to provide caregivers with support strategies and resources to alleviate or reduce subjective burden (Chappell et al., 2014; Davis et al., 2014; and NJA van Exel et al., 2004).

Summary

Caregiver burden is a multidimensional response to negative effects of caregiving. This burden is situational and varies with the caregivers' experiences and perception of demands and resources. Caregiver burden has also been associated with the caregiver's role, time, job, and energy. Caregiver burden is not linked to a care receiver's disease, but rather the rate of the individual's health decline.

Caregiver health outcomes. Family caregivers' physical and emotional health is frequently diminished related to stressors and burdens of their caregiving role. Caregiving demands often cause individuals to overlook their own physical and emotional needs, creating issues that lead to undesirable health consequences (Angelo, Egan, & Reid, 2013; Carretero et al. 2009; O'Brien et al., 2012). Furthermore, many caregivers may not seek medical care as they don't identify their health symptoms related to medical issues (Alpert, 2014). Through a focus group, Angelo et al., (2013) noted caregivers frequently ignored and failed to seek medical care for one or more physical symptoms, not addressing their own health and welfare.

Several studies acknowledged caregivers are at a higher risk of chronic illnesses due to their caregiver role. Scott (2013) identified caregivers limiting time for health

prevention including physician visits, exercise, and healthy diets due to time committed to caregiving. Caregivers increased use of over-the-counter medication treatments and alcohol were also noted in the study. Health conditions including heart disease, diabetes, weight loss, fatigue, heartburn headaches, arthritis, and sleep problems (Chappell et al., 2014; Sawatzky, Fowler-Kerry, 2003; Sorrell, 2014) were identified to have been experienced by caregivers.

Several studies compared the health of caregivers to non-caregivers. In a meta-analysis regarding mental and physical health of caregivers, Pinquart and Sörensen (2003) identified studies of health impairments in caregivers versus non-caregivers. Through this analysis caregivers' psychosomatic complaints including pain (joints), heart complaints (palpitations), and exhaustion (weariness) were noted over minimal health complaints of non-caregivers. A cross-sectional study by Borg and Hallberg (2006) found frequent caregivers were found to have significant poorer health and a noted decline of health with age when compared to non-caregivers.

In an additional review of studies related to caregiver stress and health, Alpert (2014) identified that stress brought on by unalleviated caregiving burden commonly includes symptoms of gastrointestinal complaints, fatigue, depression, and insomnia. It was further noted unrelieved stress can further impact the caregiver's physical health and immune and neuroendocrine systems leading to high blood pressure and diabetes. Epel et al. (2004) detected caregiver stress as a factor in the rapid cell aging process and organ failure. Consequently, this stress leads to a premature aging, wrinkles, and shorter life expectancy of up to ten years. Current research has supported findings of accelerated

aging with a shorter cell life, resulting in major depression, a common psychological symptom of caregiver burden (Verhoeven, et al., 2013).

Pinquart and Sörensen (2003) recognized the mental health issue of depression and its related symptoms as significantly affecting caregivers. Additionally, individuals caring for dementia patients were affected at a higher rate for emotional and physical issues. Through descriptive/narrative research caregivers identified caregiving as placing an emotional stress on each one of them. The caregivers further shared feelings of being overwhelmed, anger, worry, guilt, frustration, emotionally drained and a loss of self in the caregiving role (Sawatzky & Fowler-Kerry, 2003).

Summary

The demands of caregiving may cause the caregiver to overlook their physical and emotional needs including taking time for preventive or medical care for health issues. A comparison of frequent caregivers to non-caregivers identified the caregivers to have poorer health and a significant decline in health with age. Health issues arising from caregiving include depression, anxiety, exhaustion, sleep disturbances, heartburn, diabetes, joint pain and other chronic health issues.

Caregiver Employment. In addition to the concerns associated with duo duty caregivers, challenges also occur with informal caregivers and employment. Burton, Chen, Conti, Pransky, and Edington (2004) examined informal caregivers' loss of employment productivity and increased health risks. Researchers identified increased demands in caregiving had a significant increase in work limitations. Employment distractions such as work schedule conflicts, absenteeism, and performance concerns were identified as stemming from caregiver responsibilities. Caregivers were also found

to engage in a less healthy lifestyle and were identified as having stress-related symptoms and behaviors.

Several studies indicated family caregivers with employment outside the home are susceptible to increased stress from juggling and balancing work with household demands (Angelo et al., 2013; Gaugler et al., 2008; McDaniel & Allen, 2012). According to McDaniel and Allen (2012) the responsibilities of an employed caregiver require more time than usual family responsibilities. The literature review found work conflict associated with negative outcomes for the caregiver and their work performance, including increased alcohol usage, absenteeism and partial absenteeism, work dissatisfaction, turnovers, and poor job performance. Caregiver stress was also found to be intensified when individuals balanced work with caregiving.

Individual, semi-structured caregiver interviews by Swanberg (2006) identified demands from employment may also create added strain for employed caregivers. The environment of the employment setting can intensify or mediate the stress associated with caregiving. Work hours, colleague and supervisor relationships, and job schedules are influencing factors for the caregiver and their ability to work.

Through participant interviews, Scharlach (1994) addressed complementary and competing roles of employment and caregiving. Research further acknowledged positive influences of caregivers' employment. Data analysis identified individuals profited from breaks in the caregiving role, were more sensitive to coworkers and customers, benefitted from coworker support, and positive feelings assisted in their working more effectively. Caregivers recognized negative aspects with caregiving and employment as absenteeism

for the family member's needs, decreased productivity, poor concentration at work, decreased delivery of quality care, and increase of caregiving stress.

In Eldh and Carlsson's (2011) narrative study related to the phenomenon of caring for an ageing parent it was established caregivers seek life balances between caregiving and work. Employment can provide the caregiver stability through providing caregiver satisfaction and a refuge from caregiving. Study participants further identified support and acknowledgment by others enables them to provide family care and work.

Summary

The body of information related to informal caregivers and employment addressed increased caregiver stress related to employment. A significant increase in caregiver demands was found to be related to similar increases in work limitations. Caregivers employed outside of the home are at increased risk of negative outcomes including increased alcohol usage, work dissatisfaction, absenteeism, and poor job performance. The employment environment can mediate or intensify stress for caregivers. Positive effects of caregiving and employment identified included the caregiver benefitting from breaks in caregiving, being more sensitive to fellow employees, and profiting from coworker support.

Literature Gaps

Researchers from various disciplines have researched and provided information regarding the informal family caregiver's efforts in providing care. What is not found within literature is an abundance of research, especially narrative, to understand the RNs involvement in the caregiving experience of their own family members. Narrative

research provides the opportunity for participants to in their own words provide meaning and understanding related to the caring experience on their lives.

The RN role in their own family caregiving was found to be underrepresented in caregiver scholarship. Mills and Aubeeluck (2006) identified the paucity of research relating to the experiences of nurses in the dual caregiving role. It was further recognized support for nurses and additional research is needed for information related to nurses caring for their loved ones.

Further it was recognized that unpaid caregivers who are paid for the same work in their profession have been seldom examined in literature (St-Amant et al., 2014). St-Amant et al., (2014) continued, "Little is known about how nurses respond to their double-duty caregiving role and it they employ certain strategies that may lead to the attainment of additional resources and/or recognition for doing this unpaid care working the family domain" (p. 119).

Summary

The literature review uncovered an abundance of informal caregiving research with limited studies related to the nurse as family member caregiver. In order to provide support to this caregiver group additional research and information needs to be completed.

Conceptual Framework

Stress Process Model. The Stress Process Model (SPM) (Pearlin, Mullan, Semple, and Skaff, 1990) guided this narrative study through exploring the experience of RNs who have provided care as the informal family member caregiver. The SPM has been utilized in various studies of caregiver stress (Bainbridge, Krueger, Lohfeld, &

Brazil, 2009; Brazil, Brainbridge, & Rodriguez, 2010; Brosese van Groenou et al., 2013; Chappell & Reid, (2002); Gonyea, Paris, & de Saxe Zerden, 2008; Zarit et al., 2010). The model was further utilized in the development of national standards related to family caregiver research and practice (Family Caregiver Alliance, 2006).

The SPM is based on the concept that caregiving is a stressful experience of multiple interrelated circumstances. These different experiences are not stagnant, but flexing and changing over time (Brazil et al., 2010; Broese van Groenou et al., 2013). The SPM is not only focused on identification of the circumstances related to stress, but attempts to understand how stressful situations occur and by what means they are associated to each other (Pearlin et al., 1990). Five domains comprise the SPM: background and social context, primary stressors, secondary stressors, mediators, and outcomes (Pearlin et al., 1990).

Background and context of caregiving. The contextual domain of caregiving describes the condition or environment in which caregiving takes place. Within the environment of a caregiving relationship, individuals have specific characteristics that influence the caregiving experience and their stress responses in the caregiver role (Pearlin et al., 1990). The characteristics or domain variables typically are subjective and established characteristics of the caregiver. Variables include age, gender, family composition, education, availability of assistance programs, income, and relationship of caregiver to care recipient (Hilgeman, et al., 2009; Pearlin et al., 1990; Zarit, Todd, & Zarit, 1986).

Ethnic and racial variables are not included in the SPM context domain of caregiving due to perceived differences of stressors, use of coping strategies, and

resources to caregivers (Hilgeman et al., 2009; Pinquart & Sörenson, 2005).

Furthermore, the variables within the context of caregiving may be used to identify at risk

caregivers for increased stress and health issues (Pearlin et al., 1990). See Figure 1.

   Stressors. According to Pearlin et al. (1990) stressors are problematic

experiences, conditions, and activities detrimental to caregivers. Stressors have been

further recognized as difficult circumstances experienced by caregivers, which prevent or

reduce the caregivers' capacity to adapt to the caregiving situation (Gonyea et al., 2008).

Pearlin (2010) identified stressors as appearing as either a disruptive event or persistent

hardship. Caregivers exposed to one stressor, an event or hardship, may over time have

an exposure of clusters of stressors or secondary stressors. Caregiving stressors that

persist could lead the caregiver to experience cumulative adversity (O'Rand, 1996).

   At the same time, caregivers exposed to comparable stressors do not necessarily

cumulate stress or suffer similar consequences due to individual resources, belief

systems, self-esteem, and social support (Pearlin, 2010). The SPM's primary and

secondary stressors are not categorized on value or significance, but their association to

an illness. The model further suggests that one set of stressors may lead to the other, such

as primary stressors will lead to secondary stressors (Pearlin et al., 1990).

   Primary stressors. The SPM links primary stressors directly to the care receiver's

disease or disability (Pearlin et al., 1990; Rania et al., 2004). Primary objective stressors

including cognitive status, dependence, and problematic behaviors are indicators of

poorer caregiving outcomes. (Mausbach, et al., 2012; Pearlin et al., 1990; Zarit et al.,

2010). Primary stressors are often measured through delivery of ADLs and/or IADLs and

the length of caregiving time on which care receivers are dependent on the caregiver

(Pearlin et al., 1990).

The primary stressors comprised of greater receiver care needs pose larger

responsibilities and higher strain for the caregiver often leading to secondary stressors.

Burden effects such as depression and physical health are recognized as secondary

stressors (Chappell & Reid, 2002; Pearlin, et al., 1990).

Figure 1. The Stress Process Model
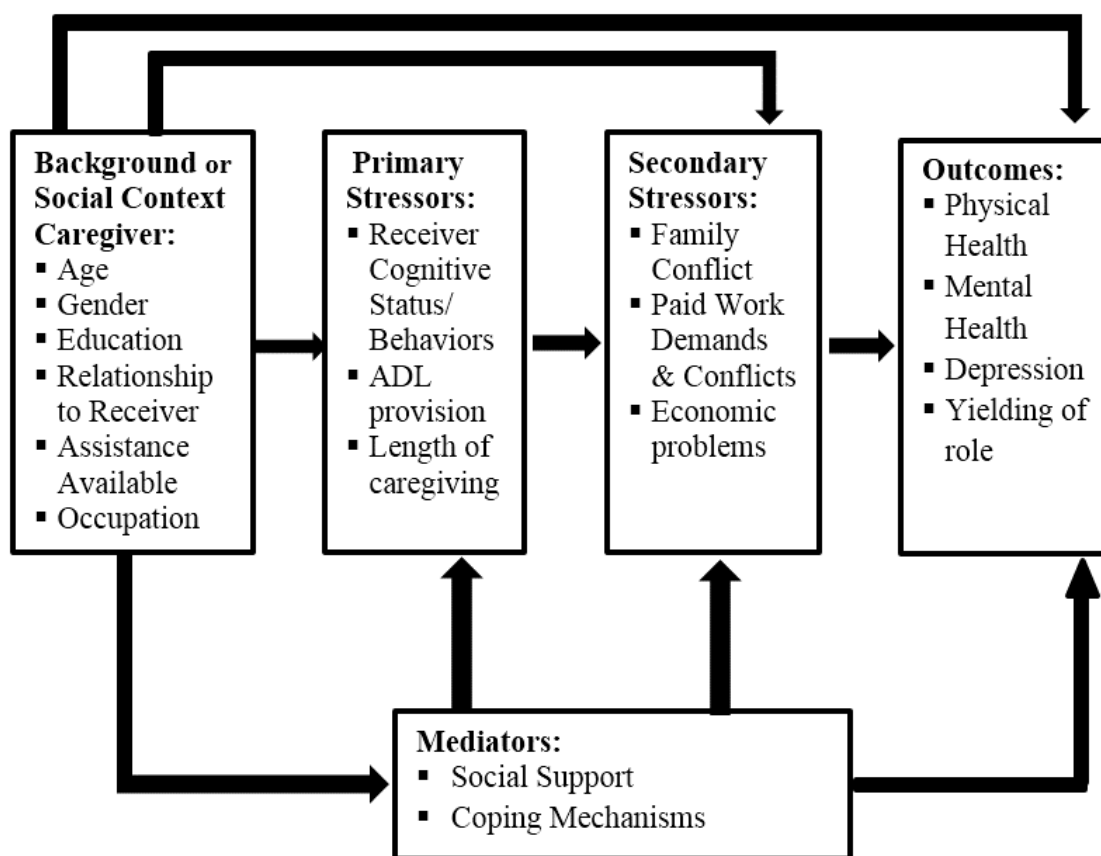
Note. Adapted from Pearlin et al. (1990), p. 586

Mediators. Mediators can influence the relationship between caregiver stressors

and outcomes. They are also the reasons why caregivers may experience similar stressors,

but the mediating factors may influence stressors differently, lessening the outcomes associated with stressors (Gonyea et al., 2008; Pearlin et al., 1990).

Aneskensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) recognized mediators consist of social, self, or formal resources that alter the relation between stressors and outcomes causing variations in burdened caregivers outcomes. Two mediators, social support and coping mechanisms are two distinct phenomena, but have similar functions in stress. Further they can intervene at different times throughout the SPM and are identified as mediating the stressor outcomes (Pearlin et al., 1981; Pearlin et al., 1990).

Outcomes. Outcomes in the SPM refer to the effects from stressors and caregiving experiences on the caregiver's physical and mental well-being (Pearlin et al., 1990, Rania et al., 2004; Pearlin et al., 1981). It was further identified mediators such as social supports and coping mechanisms will influence caregiver outcomes. Outcomes manifested in caregivers relate to their experiences and ability to sustain their social role (Rania et al., 2004). Positive and/or negative outcomes additionally will be dependent on the relationship between the caregiver and receiver and available mediating resources (Broese van Groenou et al. 2013).

Summary

SPM is a multidimensional and comprehensive framework used in caregiver research. This model examines the relationship between five domains: background or social context of the caregiver, primary stressors, secondary stressors, mediators, and outcomes. The principal concept of the model is not only the identification of situations leading to caregiver stress, but how the domains interrelate. SPM further provides an

understanding of how caregivers may experience similar stresses and not experience comparable outcomes.

The SPM was a suitable theory for guiding this study. The model provided a framework for the researcher to examine the caregiving role and link the context of care provision with primary and secondary stressors to explain caregiver outcomes. The model also provides an understanding of how caregiving stress may be similar and yet produce different caregiver outcomes including physical health issues and/or depression (Mausbach et al., 2012). The SPM has been applied in several studies of caregiver stress (Bainbridge et al., 2009; Brazil et al., 2010; Brosese van Groenou et al., 2013; Chappell & Reid, (2002); Gonyea et al., 2008; Zarit et al., 2010) and was further utilized in the development of national standards related to family caregiver research and practice (Family Caregiver Alliance, 2006).

Chapter Summary

Chapter two examined the understanding in current literature concerning the nurse as family caregiver and family caregivers. Literature including nurses in the family caregiver role is deficient. Some caregiving experiences may be similar to those of investigated dual caregivers who are not nurses. However, current research that explores the needs and issues of nurses who find themselves as informal caregivers is very limited. More research is required to explore the needs and issues faced by nurses in caregiving situations.

CHAPTER 3: RESEARCH METHODOLOGY

Introduction

Chapter Three includes the methodology of the study, narrative inquiry (NI). Additionally, this chapter describes the study participants, sample and setting information, data collection methods, research questions, data analysis, rigor and trustworthiness.

Research Methodology

Narrative inquiry (NI) was used for this study as an appropriate approach for gaining a deeper understanding of the nurse caregiver role in caring for their own family member. Narrative inquiry was chosen over a quantitative research method for a greater understanding of the study participants' experiences from their perspective without reducing their experiences to statistics (Taylor & Bogdan, 1998).

The general aim of NI is to illicit accounts of how experiences and events are directly experienced by those involved (Gregory, 2010). Munhall (2012) identifies qualitative methods such as NI as freeing researchers from preconceptions while searching for meaning from the study participants' perspective, relating to their experience. This study method is an appropriate approach when limited knowledge exists related to a phenomenon (Creswell, 2007). Creswell states qualitative research methods report the views of the participant in a natural setting.

NI provides an understanding of an event or situation in an individual's personal and social life as told from their perspective (Clandinin & Connelly, 2000; Munhall, 2012). This research design contributed to the exploration of RNs experiences as caregivers for family members as told through their stories and personal accounts.

Clandinin and Connelly (2000) recommend narrative inquiry should begin by examining and investigating of the aspects of the experience in place of comparing and analyzing theoretical concepts. The authors identified the focus of the inquiry should be on the story itself and understanding the experience, not to prove facts or the accuracy of information. NI ascertains the individuality of the individual's experience and firsthand descriptions (Gregory, 2010).

The initial NI interview provided an opportunity for the participants' personal perspective, in-depth understanding, and the personal context of the experience of caregiving. Interviews were also well suited to research that requires an understanding of deeply ingrained or delicate personal experiences of the participants, since it allows for the chance of a detailed understanding of the experience (Mc Donald, 2005).

According to Munhall (2012), follow-up interviews may be necessary for participant clarification. Additionally, this interview may provide an opportunity to add aspects to the told experience, fill in the story gaps, and check interpretations or meanings of what was originally provided. The participants' experiences may be additionally expressed with the use of artifacts. The use of personal-family-social artifacts can help assemble stories and records of the individual's life experiences (Creswell, 2013).

NI data collection was completed and the meaning of the stories was the research focus. Munhall (2012) identifies potential data collection procedures within NI as:

- Conducting the initial interview.

- Completing the follow-up interview for clarification as indicated.

- Participants bringing alternative forms of expression artifacts including artwork, pictures, photographs, or other mementos, as appropriate

- Examining additional forms of cultural expression, as appropriate.

Study Participant

The sample size was six participants. The sample included RNs who are currently informal caregivers or have provided direct physical or emotional care for family members including, but not limited to children, spouse, and parents who have been diagnosed with various terminal or disabling disease processes. Family member relationship to the caregiver was determined through birth, marriage, or other long-term relationship. The study participants were English-speaking and reading, RNs who are employed or have been employed in a healthcare setting.

The participant's age, gender, race, marital status, ethnicity, and employment status was collected on a demographic survey at the time of the interview. Additionally, the care receivers' age, sex, ethnicity, and relationship to the caregiver was also identified in the survey (See Appendix A). In review of statistical caregiver data (Budden et al., 2013; National Alliance for Caregiving and AARP, 2015; Scott et al., 2006) the sample was reflective of middle-age, female, educated, middle class RNs. Throughout the study the identity of the participants and care receiver remained confidential.

Study Setting

The interviews were conducted in various geographical locations throughout the United States. The participants chose the setting for the interview, either over the internet via a secure Adobe Connect room or an in person interview. Participants who chose an internet interview were sent a link for the Adobe room site through their personal e-mail account. Interviews conducted via Adobe Connect were audiotaped and/or videotaped.

For the in person interviews, the investigator traveled to the participant's city and met with them at the location of their choice. The participant selection of the interview setting allowed the interviewee to share the caregiving experiences in a comfortable and safe environment without the worry of having to travel or arrange care for their care receiver. Interviews conducted in person were audiotaped. The participants determined the day, time, and location of all study interviews.

Study Procedure

Recruitment of participants was through a nonrandom sampling technique of snowballing also known as nominated sampling. Snowball sampling involved individuals who have been suggested to the researcher for the study, including study participants recruiting individuals who they think may be appropriate for the study. The potential participant was provided with information concerning the study and could volunteer to participate (Polit & Beck, 2012; Streeton, Cooke, & Campbell, 2004). This means of recruitment can be advantageous when participants are in a position to recommend individuals knowledgeable on the topic and who can provide a well-informed interview (Mazurek Melnyk & Fineout-Overholt, 2015).

Individuals interested in contributing to the study were emailed, per their personal account, a cover/information letter that inquired about their willingness to participate in the study (See Appendix C). Study participants who informed the researcher of possible caregivers were provided the researcher's phone and email contact information for the potential participants to contact for study information.

Upon their willingness to partake in the study, participants were further screened via a telephone call to determine their eligibility for the study based on the established

inclusion criteria. Contact by phone also served as a means to describe the study and study questions, provided assurance of confidentiality for the participants, and answered questions. Upon agreement to participate in the study, demographic information was collected. The researcher, with participant request, arranged the meeting date, time, and place for interviews.

Study participants were added until the study capacity was met. According to Kleiman (2004), six to eight caregivers with a maximum of 10 provides saturation. Polit and Beck (2012) identify saturation is likely to be reached with 10 study participants; however, in qualitative studies saturation can occur with any number of participants. The data collection continued until overload or saturation was achieved. Morse and Richards (2002) describe the saturation of data as the time when the investigator "has the sense of having heard or seen it all" (p. 174). If the data collected is replicated in several cases, verification of the phenomenon has occurred. During a Qualitative Analysis workshop, this NI was discussed and the conference consultant suggested using six participants for the study (M. Sandelowski, personal communication, 2016).

Data collection

Data collection was accomplished through the internet via a secure Adobe Connect room or an in person audio-taped interview. Adobe Connect recorded information included the caregiver's nonverbal movements and any interview interruptions. Recordings of Adobe Connect and in person interviews with transcript verification for accuracy facilitated the credibility of data collection. Following the appointment, the researcher recorded pertinent notes in a journal. Independent information recorded following the interview was comprised of alias names for the

participant and their care receiver, the family member's relationship, and care receiver's diagnosis.

The semi-structured interviews included several open-ended questions. Interviews lasted approximately 30 - 60 minutes in duration. Semi-structured interviews allowed the participant to discuss and provide more in-depth information on their caregiving experience. This type of interview also provided a flexible focus without constraints and was open for the participant (Kvale & Brinkman, 2008; Munhall, 2012). Riessman (1993) identified the narrative interview emphasis should be placed on the way the individual perceives the events that have occurred. Interview questions asked during the interview included:

1. What are your thoughts and feelings related to the caregiving experience?

2. What impact, if any, did providing care to a family member have on your life?

3. How did your role in the family change with becoming the caregiver?

4. What are different challenges you faced in caring for your family member?

5. What else would you want to share that is relevant to the caregiving experience?

Caregiver participants had the opportunity to freely share their thoughts and emotions by being allowed to tell their story with no time limitations. During the interview this researcher gave full attention to the participant and allowed time for question responses. An environment of trust and openness was provided to allow for the story of caregiving to emerge.

Ethics of data collection

Study approval was obtained from the South Dakota State University Institutional

Review Board of Human Subjects Committee (IRB) (See Appendix B). An explanatory

letter was provided to participants regarding the study (See Appendix C). After receiving

a voluntary consent, study participants signed an informed consent at the time of the

interview (See Appendix D).

Participants provided both written and verbal informed consent to participate in

the study. Adobe Connect participants were emailed a consent form that were

electronically signed and returned per email. Participants interviewed in person were

provided the informed consent for completion and provided a verbal consent before the

start of the interview.

Data collection confidentiality was guaranteed through private interview settings.

Files including transcriptions and interview recordings, demographic information and

memos created throughout the process were stored in a locked safe in the researcher's

private home office. Only the researcher had access to the office or records. According to

South Dakota State University College of Nursing policy, data will be held for three

years and destroyed. Pseudonyms were used in the transcripts to protect participant

confidentiality.

Being over seven years removed from a family caregiving experience was an

important factor in this researcher further distancing herself from personal feelings in

interpreting participants' experiences and analyzing the interviews in an accurate and

meaningful way. In addition, anticipation of possible outcomes of the interview was an

obligation of the researcher. As a nurse of over 30 years, dealing with numerous difficult

situations over the years and having lived the experience of a family caregiver, this researcher understood living the experience through NI could evoke and trigger painful memories for the participant. Participants were informed they would be at no risk of physical harm through this study. Munhall (2012) cautions NI researchers that they are not therapists and may deal with sensitive information. In the situations where the participant became emotional during telling of their caregiving experience, they were asked if they wanted to stop the interview. In this case, the participant had the right to withdraw from the study at any time with referral to counseling as needed at the participant's expense. The IRB addressed potential participant harm in additional detail (See Appendix A).

Rigor and Trustworthiness

In qualitative research, rigor and trustworthiness is established through an accurate representation of the participant's experiences (Speziale & Carpenter, 2007). In this study rigor and trustworthiness was established through transparency with member checking and audit trail, and triangulation. To maintain study rigor, it was also important researchers are aware of their subjectivity with the participants and collected data (Burns & Grove, 2011).

Member checking allowed participants an opportunity to provide feedback by reading their interview transcripts to confirm accuracy. Additionally, this allowed study participants to audit the events, influences, and interpretive choices of the researcher. An audit trail furthermore provided clear and accurate documented information about data evidence and decisions leading to a study conclusion and its defense (Creswell, 2007; Houser, 2012). This study's audit trail included ample documentation reflecting on

how decisions were made in the study progression relating to the research purpose, sample selection, and data collection, data analysis and interpretation. The audit trail supports the trustworthiness and dependability of the study through the recording of the theoretic, methodological, and analytic choices made by the researcher (Houser, 2012; Rolfe, 2006).

Triangulation was also utilized to ensure study credibility. Transcripts were verified to be accurate through cross-checking participant transcripts and researcher notes, which were made for completeness and conformability of the phenomenon and clarification of emerging themes (Creswell, 2007; Lincoln & Guba, 1985). Transferability was achieved through a complete description of the setting and sample used in the study. The inclusiveness of the descriptions was crucial to transferability so others can decide if the research results are applicable to their settings and participants.

Truthfulness in NI is the participant's understanding of the phenomena and that it cannot be tested or measured. NI researchers listen and live alongside the participants as they tell their stories, becoming a part of an ongoing space or partner (Clandinin, 2013). The truth in a NI was not measured by the participant's accuracy of the event, but by the participant's meaning and personal account of the situation.

Data Analysis

Research analysis is the sorting of large amounts of data and finding ideas of significance among them (Creswell, 2013). The analysis process involved total immersion for as long as was necessary to ensure a pure and thorough description of the phenomenon. Analysis continued until all interviews were examined and the theme lists for all participants elicited (Phillips-Pula, Strunk, & Pickler, 2011). Thematic analysis

was utilized for the analysis of data. This analysis approach is frequently used in nursing studies and is based on categorizing aspects of the stories that were told (Riessman, 2008; Vaismoradi, Turunen, & Bondas, 2013). Thematic analysis delivers a qualitative, comprehensive, and distinctive account of the collected data (Braun & Clarke, 2006).

In thematic analysis the researcher searches for and identifies common themes or threads, which extend through the interview or set of interviews (DeSantia & Noel Ugarriza, 2000). The insight and viewpoint of the individual's experience is recognized through identified themes (Brown, 2012). This analysis process involves an evaluation of assembled stories through the development of themes and re-storying of the stories (Creswell, 2013).

Upon each interview completion the video/audio recording was transcribed verbatim including any pauses or emotion responses such as crying, laughing, or sighing. A hired transcriptionist company, Verba-Link, provided a confidentiality agreement (See Appendix E) and completed the transcription process. The accuracy of the transcription was verified, with the researcher listening to the recording while following along with the transcript. Following the transcript verification, analysis began.

Riessman (2008) and Sandelowski (1996) guidelines for data analysis encompassing the identification of common themes and areas in the participant interviews included:

- Reading all the transcripts.
- Identifying and highlighting common phrases or words that relate to the phenomena.
- Rereading transcripts to identify larger concepts related to phenomena.

- Creating categories to assist in the identification of themes.

- Locate overlapping words or phrases to identify new story development.

- Analysis will be complete when information redundancy is met.

Information redundancy occurs with consistent phrases or words appearing in the

thematic analysis without the addition of new phrases or words (Sandelowski, 1996;

Sandelowski, 1991).

Once the themes were developed, re-storying or developing of a new story by the

researcher occurred (Creswell, 2013). The new stories were told from the participant's

point of view, reconstructed and guided from the themes and retold. The retold narratives

functioned as the study results.

This researcher attended a four-day qualitative analysis training conference to

learn and become proficient in narrative/thematic data analysis. Professor and researcher,

Dr. Margarete Sandelowski, PhD, RN, FAAN, an expert in qualitative analysis conducted

the analysis conference. The software, Dedoose was recommended by researchers in

attendance and was utilized for analysis of this study's qualitative themes.

Dedoose (2016), Version 7.5.9, product of Socio-cultural Research Consultants,

LLC, is a computer-assisted analysis software which facilitates coding in qualitative

research. The software allows transcripts, audio, or video recordings to be uploaded,

highlights passages, and codes them with researcher identified terms. Areas of data can

be analyzed, marked and listed separately; and need not be coded in passage order to be

identified as significant. The highlighting and code levels are shown in different colors to

support the researcher in comprehension and organization of data. Coded segments can

be then organized and major themes will emerge to identify a higher-level of categorization in the research.

Identified interview codes were imported into the Dedoose (2016) software by the researcher. Codes which were similar or related were then organized into broader colored categories. Once the transcripts were uploaded into the program they were further analyzed to identify the codes within the dialogues and subsequent themes emerged.

In addition to utilizing software for data analysis, the researcher studied the transcripts, identifying and highlighting common themes that developed from the interviews. The interview themes found in this analysis findings were consistent with Dedoose results.

Chapter Summary

Chapter three discussed the research methodology and design incorporated to explore the experiences of registered nurses who have been in the family member caregiver role. In addition, information related to the study sample, setting, data, collection process, analysis, and study rigor and trustworthiness were discussed. Thematic analysis was completed with the utilization of Dedoose software.

CHAPTER 4: RESULTS and DATA ANALYSIS

Introduction

This chapter reports the results and data analysis of the research study. The information for analysis was identified from the interviews with RNs who are caring or have cared for their own family members. The overall caring experience of each participant was first identified through individual interviews followed by thematic analysis.

Codes and themes were identified in the analysis process with the use of Dedoose software. This software aided identification of key common themes of RN caregiver experiences from the interview transcriptions. To ensure academic rigor, following the software analysis, a final review of the interviews and the themes were studied.

Participant Characteristics

Each participant was assigned a pseudonym to maintain confidentiality. All six participants were Caucasian, female, RNs. No male RNs volunteered for the study. Their ages ranged from 38-69. Four of the caregivers were employed at the start of the experience (see Table 4.1). One caregiver was retired and one became employed during the caregiving experience.

Three participants were married and three were widowed. One participant cared for a son, two for a parent, and three for spouses. All provided care in the home setting and the years spent providing care ranged from two to nine years. Four of the participants provided care in their home and two were caregivers in their parent's home (see Table 4.1).

Table 4.1 Participant Characteristics

Sample (n=6) Caregiver Pseudonym	Age/ Gender	Ethnicity	Marital status	Relationship to care recipient
Diane	69 Female	Caucasian	Married	Spouse
Lynn	61 Female	Caucasian	Widow	Spouse
Cheryl	55 Female	Caucasian	Widow	Mother
Tessa	48 Female	Caucasian	Widow	Spouse
Debbie	38 Female	Caucasian	Married	Daughter
Susan	38 Female	Caucasian	Married	Daughter

The care recipients were female and male, Caucasian, and ranged in age from birth to 76 years old (see Table 4.2). The identified receivers' diagnoses included cancer, neurological, and chromosomal health conditions.

Geographically, the participants lived in Eastern, Southern, and Midwestern states. Three caregivers lived in an urban setting and three lived in a rural location. (see Table 4.2).

Table 4.2 Care Recipients Characteristics

Sample (n=6) Caregiver Pseudonym	Recipients age at start of care/ Gender	Ethnicity	Health Condition	Years Receiving Care	Setting
Diane	74 Male	Caucasian	Neurological	2 years	Urban
Lynn	62 Male	Caucasian	Cancer	2.5 years	Rural
Cheryl	Birth Male	Caucasian	Chromosomal	9 years	Urban
Tessa	58 Male	Caucasian	Neurological	5 years	Rural
Debbie	70 Female	Caucasian	Neurological	8 years	Rural
Susan	76 Male	Caucasian	Neurological	6 years	Urban

Interviews

Five interviews were conducted and audio recorded via the secure Adobe Connect Room online connection and one interview was audio recorded in person. Each participant was asked to share about their caregiving experience and the interview continued with the researcher asking the five related caregiving questions. The participants' responses were clarified and summarized. Themes were developed as result

of identification of the interrelating threads or topics extending across the study interviews (DeSantia & Noel Ugarriza, 2000).

Participant Narratives

Even though the study participants share a commonality as RNs providing care to a family member in the home setting, each has a unique situation and their individual stories are reported. The following are summaries based upon narrative interview transcriptions with quotes representing the participants' own words. These summaries provide the reader a greater understanding of the participant's story related to their caregiving experiences. The caregiver names used are the assigned pseudonyms.

Caregiver Diane.

I am now a fulltime caregiver. Caring for my husband 24/7 made it impossible for me to work outside of the home. Our lives have totally changed from independence and going on trips to dependence and staying home. Even though we have long-term care insurance so I have occasional daily help, it is still up to me to supervise and be on call.

Even when he is in the hospital I still remain vigilant to make sure he won't get bedsores and that he has clean bedding. He's on so many medications, 20-30 a day, that I can't trust just anyone to make sure things were taken care of. I am going to make sure he will get the best care that I can give him.

He became ill so suddenly that things I never did before such as bill paying and household maintenance became my responsibility. All of a sudden I had to take on the tasks he had previously done, not knowing when things needed to be completed or paid. In the beginning he had problems communicating with

anyone and I didn't know what to do first. I thought I was going to jail because I forgot to pay the taxes. It was so much work to find out what needed to be done, I had to dig through everything and of course we each had different filing systems. I had to organize this in addition to taking care of him and myself still being on chemotherapy treatments.

Decisions had to be made. For example, we had five vehicles and now only one driver. I sold the cars, pickup, and motorhome and bought a handicap van. I had never written out a check for the amount of the van before and it took a couple of attempts to get it right with the dealer's help. Over two years later my husband is still upset at me for selling the pickup without his consent. I told him when he can drive again we will buy a new one, but that isn't going to happen. Then I had to sell the golf cart and trailer, but I let him help with that decision and it took two years for him to agree to sell them. I feel like everything is a fight to do what needs to be done.

Our home environment has changed with people coming and going throughout the day. My personal space and privacy do not exist. After two years it is still hard to accept people in my house, so my bedroom became my sanctuary to go and be. I go into my bedroom, shut the door and watch TV for my time. It drives me… you know, there's no privacy. I had to get over the fact that in the morning, when they come, if I am in my pajamas, I am in my pajamas. The house physically had to be completely transformed from new floors to a wheel chair accessible shower, more changes in my life. Even though we have an accessible house and my husband has a power wheelchair, I can only let him use

it outside because we wouldn't have anything left inside. He has left-sided neglect and has a loss of perception and control.

It's been a frustrating and hard experience to deal with my husband's care as he won't do therapy or what the doctors say so there can be improvement. He sees me as a pain for a wife because I need to see everything is done right in his caregiving while getting him to do what he is supposed to do.

For the past two years my health was affected from the stress and conflicts dealing with my husband. For the past six months I have decided to try and take my life back. It's only little things at a time, like church activities or playing mah-jongg, but they are things that are making me feel healthier than I was.

Caregiver Lynn.

Looking back on the caregiving experience, it is easier to talk about it now, over two years have passed since my husband's death. In review, my experience was a blessing and a privilege to provide care. My nursing knowledge helped me navigate the system, but in being a wife caregiver, I never set my RN role aside.

Overall, the caregiving experience was exhausting and a challenge. My employer verbally encouraged me to spend time with my husband, but when I returned to the job my work was waiting for me, exhausting. Often times I had to bring work with me to his treatments and doctor appointments. I was not always present in the way I would have like to have been as a working caregiver, but I wouldn't change it, and am really glad I was able to do what I did.

My caregiving experience was totally different than when I cared for other family members, my parents and aunt. The difference was related to the relationship between husband and wife, but my role changed in giving care. Sometimes I just wanted to be a wife and not think of all the implications of caregiving. In my caregiving role I felt a lot of responsibility to make sure everything was right. I questioned was he getting what was needed, the right medications, and etc. The RN caregiving type role was never set aside it was always present, always there.

When my husband's health further failed, I also had to make more decisions on the business and non-business side of our lives. Our family looked to my husband as long as we could, but then gradually things went more to me. Some of the decisions and responsibilities were things I didn't want and in my caregiving role duties fell into my lap. Some of the decisions I made were hard, but in the end they brought our family closer together.

Guilt is a challenge that I faced in caring for my husband. I think back as a nurse, did I ask enough questions, did I explore enough options, could there have been a different outcome? My kids would ask questions, making me second-guess myself so I brought a notebook to appointments for questions to ask and take notes.

Another challenge was balancing the caregiving work and my personal needs, personal needs went straight out the window. The first thing that happened when providing care was forgetting me. Doctors and nurses should do a better job in asking the caregiver how they are doing and referring them to appropriate

resources. I know my city had caregiver support groups, but no one referred me to them or provided information.

I don't think of myself as a strong person, but I must be. I can't image caring for a family member without an RN background to manage the healthcare aspect. Being an RN gave me a lot of skills to do a good job providing care, but just because I was a nurse didn't mean I knew everything. For that reason, I wanted to be looked at as the wife. I didn't feel providers talked down to me as a nurse, but who I wanted to be was the wife and not the nurse.

Overall my husband appreciated my caregiving and made it rewarding. This appreciation also made me a stronger individual. The hardest time was before he died and he was out of character and crabby. I was strong and approached this change in his behavior and we were able to talk about how he was treating me. Identifying this behavior also gave us permission to talk about death and dying. Would I do a similar caregiving situation again? I would like to think I could.

Caregiver Cheryl.

The overall feeling, I had caring for my son was exasperation, frustration, and failure. His disease was rare and his health continued to decline until death. My son's care took precedence taking up most of my time. It took precedence over my husband, the other children, and job. The impact of caregiving was really significant and if I had to do it over again I would probably do a better job with delegation and being less fearful.

My son was smaller from birth, but for the first two years he seemed to gain weight and do better. It was after the first two years that he started to show signs of problems with weight loss, bruising, and petechiae, enough so others were concerned sufficiently that they told me to take him into the doctor. Having been told to take my child to the doctor was a mortifying experience. The local doctor then referred my son to a specialist after the blood counts came back low, but with limited finances driving to another city was a hardship.

Life was hard, we had no money, and adding a life-threatening situation made it so much harder and it changed everything completely that day. All my focus went to the sick child. It was determined he needed a bone marrow transplant and I went into a patient advocate role, doing a lot of research to inform the insurance company and plead for them to approve the treatment. We had a perfect match to another family member; it was just a process to get it approved.

Not only did my mother role with my ill child transform to become his advocate, but my role with the other children also changed as I couldn't be multiple places at once, so others became in charge of my other children. Being an advocate for my son was crucial.

It bothered me when I had to relinquish control of my other children to additional people because I couldn't be everywhere at once. For example, cutting my daughter's hair was done without my knowledge and cut the way I wouldn't have had it cut and felt betrayed, not having control of my children anymore. I think about my other children growing up with a mother that felt frustrated and fearful all the time…how much it took away from them.

After the bone marrow procedure, it was constant blood counts through the Hickman line. I remember watching how the health care workers completed the procedure and accessed the central line. Usually they did things correctly, but for example, one time the nurse took a phone call while she using sterile procedure and injecting into the central line. I thought, oh my gosh, you know how contaminated the phone is. I think she thought she was so important she just had to take that phone call. This was difficult for me, knowing what I knew. I just didn't think he was getting good care and so yeah, I was a watchdog.

Overall you want to have a good relationship with people caring for your child, but it's frustrating to see health providers not doing what they should and what is done in other institutions. So, there's a lot of going back and forth between feeling guilty, rundown and tired, a lot of feeling pure exhaustion. You're not the most understanding to others feeling that way.

Even with my working as a nurse in a nationally known clinical site, I had great difficulty with my son's medical care and follow through. For example, one physician wanted to take over my son's primary care and to gain my trust said he was present at the transplant, but in reality he confused my son with another child with a similar name. So again my trust was just …. I realized I could never take anything for granted. And so it was, I pretty much felt desperate all the time. I wish I could tell you a happier story, but my caregiving didn't happen that way.

Caregiver Tessa.

Never in my life did I expect to become a caregiver to my spouse, especially at my age, 48 years old. The caregiving experience to me started out

more a gift I could give to my husband. As time went forward and support from family decreased, emotionally with work and never getting respite it was 24/7, the experience became a stressful and frustrating. The experience was so stressful that towards the end, I just wanted it to end and just be done with it, the guilt from thinking that way haunts me. We didn't have long-term care insurance so the option for respite or home health wasn't available.

My husband was in denial most of the time and tried to remain independent at all costs, not following doctor's orders or instructions. He tried to do his own thing, whether or not it put him and others at risk, such as driving when he was not supposed to or trying to ambulate without his wheelchair and falling. This made the caregiving experience a fight to make sure safety was a priority.

The medical community also proved to be a source of frustration. The specialty physicians didn't work together in the care and would often change medications affecting the other's orders. I found that my caregiving role included becoming an active voice and advocate. For example, my husband had a rash and the nurse told him to quit all his medications and go back on them one at a time every week. Luckily, he told me of the nurse's advice and I called the physician, as my husband was on 14 different medications from cardiac to endocrine, to neurological to kidney medications and couldn't live without or quit them abruptly. The physician was appalled that the rash was approached this way.

I thought during the hospitalizations I could have trusted the care and had a respite, but this wasn't to be. Even when he was hospitalized I monitored what

was happening closely, making sure the insulin was given before a meal and the other medications were given on time, especially after insulin was given two hours late causing a reaction. My role as a nurse was 24/7. I knew what his deficits were and what was needed for care, making sure he received the best care possible. I often assisted with ADLs and changed his bedding in the hospital setting.

I was an advocate when physicians wanted to try experimental treatments and tests. I had to step in and question painful procedures and just keep track of everything that was related to the medical care, this in addition to my work, home, and children responsibilities. The advocate role was essential, but a stress producing situation.

It was like my life stopped and everything revolved around my husband. There were many times that fatigue was so overwhelming and little things, snowballed into big situations. When I got home from work he wanted to go, so no matter how tired I was it was loading him and the wheelchair in the van and going. We had to be careful of where we went as he was cognitively inappropriate, blurting out comments and berating me and others. So, yes, caregiving did have a direct impact on my life.

My role as wife definitely changed. Even my husband made a comment on how I was not his wife, but more like a mother and a nurse. This was true, I had his daily ADLs to complete and was always checking to see if medications, home treatments, and therapies were done. So definitely toward the middle and end of the caregiving experience I was a nurse first.

My healthcare was a challenge. I no longer went to wellness checks for medical and dental care. My health declined and I should have taken time for myself, but the time wasn't there. I experienced utter exhaustion and stress from trying to juggle all the aspects of life.

Looking back, caring for my husband is something I would have done again if needed. It wasn't all negative, but it is the negative things that seem to be remembered most clearly. It gave me a new respect for others caring for family members and was definitely a journey.

Caregiver Debbie.

My caregiving experience was a gift. Not a lot of people can or want to physically take care of someone they love. In addition, not everyone can do caregiving because it is so physically and emotionally draining. Caregiving did impact the rest of my life through the experiences involved in the care.

The overall time spent with my mother and the quality time I had with the rest of my siblings was a gift in which I was blessed. Although I felt blessed, caregiving was hard on my husband and children. I didn't think they were impacted while I was providing care, but now looking back I see it. When I came home I was exhausted and it was hard, but it's a paradox.

My roles as a daughter and a nurse would blur when taking care of my mother's ADLs and taking her to medical appointments. The changing of roles just occurs; the *hats* change in different situations. You don't intentionally do that, but it just happens and that really blurs the boundaries which can be definitely hard.

Overall my role in caring for my mother was definitely a nurse first. I was always asking nursing questions to my mother such as did you get your pills on time or did you get what you needed? The role just *bounces* back and forth. Once the nursing issues were taken care of I could go back and be the daughter for a while.

The challenge of taking care of my mother was being exhausted. I need sleep and would feel physically ill. When your caregiving it's a 24/7 around the clock job and is a huge challenge when you add work onto it. It is so different from working as a nurse, when your shift is done you're done. When you are caregiving and are exhausted everything snowballs. It's exhausting; so caregiving as a nurse and as a daughter, you're just exhausted.

Another challenge is knowing too much because you know what the disease progression will be. I think a lot of times, ignorance, when you don't know what is coming is better. Then as a nurse I think because you've seen this before, you start comparing. That's hard because you shouldn't be thinking about what's going to happen tomorrow and need to enjoy your time today.

Caregiver Susan.

As a nurse, I found the caregiving experience for my own family member as very difficult in comparison to caring for patients in the healthcare setting. When my dad became ill and I needed to provide to his care, there were a lot of complications and things I needed to manage. When you are dealing with the situation on the other side of the bed, suddenly you realize there is a lack of communication between healthcare providers and the caregiver.

I felt my primary role was a go-between with different healthcare providers so they knew what each one was doing. The specialists were so focused on their area that they forgot to connect the dots with the other specialists. At this point my primary role became an advocate for my father.

The lack of compassion in the healthcare community was in their looking at me not as a daughter but a nurse. A couple physicians said well, you're a nurse and know the end result, this showed such a lack of empathy. After that I realized how beneficial it is for the care recipients to have a nurse advocate for them at the bedside.

Caregiving was tough, there was never enough time in a day and I was trying to do all the right things. Then the emotional factor of caregiving was added to the mix. The patient was my dad and his role of taking care of me had flipped. As the daughter caregiver, you are trying and needing to be more in control, but your parents don't want to lose their control.

In addition, it was emotionally difficult to handle that I was losing him while trying to make it the best experience possible for him while helping my mom too. It was the nursing standpoint of trying to look objectively as possible at what was happening; it was really difficult. I have a new found respect for nurses who care for their family members and until someone experiences it, no one has an idea of how hard it is to do family caregiving.

My experience was even more difficult since my mom and sister are nurses. It was also hard because my mom and dad wanted to keep fighting and to continue with treatments which his heart couldn't tolerate. My mom really pushed

back at us and wouldn't accept anyone coming in to help such as hospice. This situation created heated arguments. My sister and mom just really butt heads and tended not to communicate with each other. Emotions were high and they would argue you're a nurse, you know this. Of course this didn't help the situation because we were sad, angry, and frustrated, and then they lashed out at each other. I then experienced frustration and anger while trying to be the peacemaker and the go between with my mom and sister.

To add to the experience, my mom couldn't provide much care for my dad as she has a chronic debilitating disease and doesn't get around well. The emotional and physical toll on her created the situation where I had to be involved in the whole caregiving process. It was necessary for me to spend several weeks at a time with my dad, so my husband had to take over with our children and other responsibilities. He was a single parent most of the time. That was hard, having a young family, going between Mom, Dad and the family, working, and trying to balance it all. My family, my husband, and I stuck together, but it was just all stress and having feelings of anxiety all the time.

In looking back, during caregiving I was on autopilot and didn't realize how crazy and dysfunctional things were, it's like, I can't believe that we made it through all of that. It was hard holding our lives together, trying to do the right thing on both sides, and being positive in front of dad. My dad was an optimistic person and didn't like fighting; I just wanted my dad to have a peaceful end.

The stress of the experience wasn't fun, but thank goodness I was there for Dad. I appreciate being able to do all of those things for him and I felt like I was

giving back. I would do it again in a heartbeat and will do the same thing for my mom.

Analysis of Themes

Three main themes emerged from the narratives of RN's caring for their own family members. The themes include *RN caregivers are advocates, RN caregivers experienced their life changing,* and *RN caregivers experienced emotional burdens.*

RN family member caregivers are advocates. Several study participants discussed their RN skills and knowledge as beneficial in the confidence level for family member caregiving. Their knowledge of the healthcare system provided an understanding of standards of care. Their RN background also provided the caregivers with the ability to say *no* when they did not have the competency to provide a treatment or procedure, and their preparation in the advocacy role enabled them to advocate for appropriate care for their family member.

Diane identified advocacy for the care receiver as essential because the patient cannot or will not continually be able to advocate for themselves. She continued it was good she had a nursing background and recognized what standard of care should be expected in a healthcare environment. "I had to be a patient advocate from his ADLs to the procedures and treatments completed. As a nurse, I knew how things should be done and recognized what was going on, making sure my husband received satisfactory care".

Cheryl recalled her role as her son's advocate. "One of my roles as caregiver was patient advocate, so my child didn't suffer some negative consequences when providers didn't carry out the proper procedure." She identified negative consequences her child experienced before she stepped into the advocacy role and identified herself as his

watchdog. Stepping into the advocacy role for her son created a conundrum in her family life as she needed to relinquish control of her other children to family members because she couldn't be multiple places at once. Cheryl's ability to advocate for her son extended to insurance companies as she researched and built a case for treatment approval.

Participants identified how important the advocacy role was from the other side of the bed. Susan identified that as a family member caregiver she witnessed the lack of communication between healthcare providers, an area that wasn't observed in her professional nursing role. Being a care advocate for her parent became her primary role, she shared:

I realized the lack of communication between healthcare providers and just how much advocating you have to do…just that go-between and making sure that this healthcare provider knew exactly what the other healthcare provider was planning. But I tell you what, it is beneficial for that individual that's going through whatever is happening to have a nurse as an advocate in a family situation, to make sure they get the care needed.

Some participants felt that their advocacy role was taken more seriously by the healthcare community since they were RNs. One recalled when caring for mother, physicians' ears perked up when they found out she was a nurse and was there to advocate for her parent's care.

Participants identified their advocacy role not only existed when their family member was in the home setting, but extended to healthcare facilities. Several mentioned they thought there would be relief from the caregiving when their loved one was an

inpatient, but quickly realized they needed to continue to provide care in the role of advocacy. Tessa recalled:

> I thought his hospitalization would provide a much needed break for me, but I quickly found that I still needed to be there as an advocate. It was a challenge because I felt I always needed to be there, observing to make sure he received his treatments, pain and scheduled medications on time. For instance, one morning the nurse came in to give his insulin three hours after breakfast. If I hadn't been there my husband would have received his insulin injection and had a reaction.

Summary

In summary, participants provided examples related to the importance of being a patient advocate for their family member. The RNs' success in advocacy was frequently attributed to having nursing knowledge, healthcare contacts, and individual experiences from their professional background. Participants shared that understanding how to navigate the healthcare system increased their confidence in working with the system, saved time in their success as an advocate, and enabled them to ensure quality care to their loved one.

RN family member caregivers experienced their life changing. Although their professional experiences as a RN provided them strength to provide care, participants identified their lives as ever-changing and shifting during the caregiving experience. Some RN participants juggled family caregiving demands with family and work responsibilities while others could not work outside of the home. This life changing, caregiving experience was highlighted by three areas, the caregivers' struggle for life balance, changing family roles, and health consequences.

Struggle for life balance. Even though all participants identified assuming the caregiving role for their family member without hesitation, they did verbalize struggling to find a balance between the caregiving role and their personal and work life. Tessa illustrated her juggling the caregiving experience as comparable to a scale with her personal life on one side of the balance and caregiving on the other. The scale was rarely balanced. She continued:

> Caregiving impacted my life in many ways. I lost my independence. My time was limited with the kids, I missed their activities and not able to attend functions after work. The last six months was the worse. I couldn't trust him alone in the house and couldn't get groceries on my own. Where I went my husband did, unless one of the kids could sit and watch TV with him.

Debbie reflected on the caregiving experience for her parent. "Caregiving did impact the rest of my life and the quality time I was able to spend with my own family. I can't get that time back to spend with my kids".

Tessa and Debbie's statements were echoed in the other participants' stories related to their personal life and the loss of time with family members and work activities. As voiced by Susan:

> You are kind of on autopilot and you don't think about how crazy and dysfunctional things are until you look back. It's like, my God, I can't believe that we made it through all of that. My husband and I stuck together, the kids were okay. The toughest thing I experienced with caregiving is being in two settings: for my own family and for my parents, you just try to go between and then with working, trying to balance it all, there's not enough time in a day.

Susan acknowledged that even though caring for her Dad and dividing time between her parents and home was difficult, she developed a newfound respect for family members who care for their loved ones.

Lynn identified similar concerns with balancing her personal life and further communicated how she had challenges in the work setting. She recalled:

Work became a challenge even before my husband went into hospice. Even though verbally work was supportive of what I needed to do and encouraged me to take the time I needed to be with him, that encouragement was there. The challenge probably was my workload really didn't change. So even though I was able to take the time off, nobody did my work while I was gone. When I returned, I still had all the work from while I was gone to accomplish. I wouldn't change giving care, I'm really glad that I was able to do it.

After realizing work would be waiting for her, Lyn's attempt to balance employment and caregiving was taking work to her husband's treatments and doctor appointments. She expressed the life unbalance still existed as she wasn't able to fully engage with her husband's physicians or care with work needing to be accomplished.

One participant recognized the need to cut back on work hours and an additional caregiver found it necessary to leave employment to provide care for their family members. Some caregivers acknowledged needing to have individuals on call to check the care recipients when they didn't answer the phone. Although the balance between work and caregiving was challenging, the participants reported their professional practice and self was enriched as a result of providing care to their family members.

Several participants identified the need of being involved in support groups and

being provided available resources when providing care to family members. The spouse caregivers identified support groups would have positively influenced their caregiving experience and decreased their burden of stress, but they weren't offered as an option or based on the diagnosis don't exist.

Diane identified her community needs a support group related to her husband's diagnosis. She shared her view as:

It is really important to have someone to share with so that you are …you know not alone in your frustrations. And it is important for my husband to be with others suffering with the same issues. I just think it would be really helpful…it is dual support for the couple.

Lynn also recognized the importance of doctors asking how the caregiver is or offering support groups and resources to make the caregiving a better experience, but this support wasn't provided or offered. She shared:

To my memory, never once did a physician ask how I was. I know there is support out there. But never once was I asked. So I don't know that we, as the healthcare community, have an assumption because I'm a nurse, I'm the healthcare provider. I don't know if there's an assumption by doctors' offices that he or she is okay and they'll ask for help, and I don't need to have follow-up with support…I was never asked, how are you or can we refer you to a support group, and so on.

One participant caring for her mother identified that a support group was diagnosis related offered to her mother, but no group existed related to caregiving. Several participants felt that being a nurse with a healthcare background inclined

physicians and others not to provide additional support opportunities, as the assumption was made that the caregiver should be aware of available community support options.

Overall, the experiences of caring for a family member had a direct impact on the RN caregivers' life, both professional and personal. Struggling for balance in their life included issues such as taking time away from family, losing their independence and themselves, and having to quit, reduce hours or bring their work home with them. Support was identified as necessary for the caregiver to aid in the reduction of their stress to make a positive outcome to the caregiving experience. One caregiver provided a quote to summarize her feelings toward support, "Sometimes asking for help is the most meaningful example of self-reliance" (Author Unknown).

Changing family roles. All six study participants shared how their roles in the family transformed when they were the caregiver. All participants recognized that their role as mother, child, or spouse changed to an RN role in the delivery of care for their loved one. Along with being in the RN role, daughters identified going into a parental role while two of the spouses identified going into a mothering role during the caregiving experience. In some instances, it was narrated that the care recipients identified the role switch and commented on the change, but even still in these instances the caregiver found it necessary to remain in the RN role.

The participants described how they weren't able to set aside their RN role in the caregiving of a family member. As Lynn pointed out, "You never set aside your RN role, you can't. Being a registered nurse is just so much a part of you. Sometimes I just wanted to be a wife and not think about all the implications related to caregiving".

Diane further described her family role change as not only primarily going from wife into the RN role, but taking over her husband's previous role of head of household and decision maker. She explained this as:

> Along with caregiving, I've had to take control of everything instead of my husband doing it as he always did before. I have to make all the decisions, so that role has changed. A lot of times, he's probably not happy with it, but it is the way it needs to be. Sometimes I need to pull away from him to take over my roles.

Similarly, Lynn shared taking over her spouse's decision-making role was something she didn't necessarily want to do, but was required to as his health failed.

Tessa shared in providing care to her spouse she not only took on the RN, but also a mothering role.

> Did my family role change? Definitely. And even my husband said that I wasn't his wife anymore, but a nurse and mother. This was true, it had to be done. In order to keep his health so he could stay at home longer I became his mother and nurse. I was the nurse first, mother second, and finally his wife. As his illness progressed I no longer felt like a wife.

Tessa further identified this role shift continued through the progression of her spouse's illness even when he was in palliative and hospice care.

Through the care of her son, Cheryl not only identified a role change to being a nurse, but handing over her mother role for her other children. She described this as:

> I definitely went into a RN, patient advocacy role. I just wanted to be a mom, but caring for my son became my primary role. It took precedence over my relationship with my husband, my other children, and my job. It was really

significant…I had this baby that I had been breastfeeding who now had to stay with Grandma, so I had to wean her…another role change for me was relinquishing control of my other children. I think of my children growing up, you know, how much it took away from them.

Even though wanting to continue to be the child, RNs taking care of parents took on a parental role in addition to their nursing role. Both participants in this situation described their role switch as uncomfortable and just wanted to be the child again. As Debbie explained:

I just wanted to be the daughter and not have to worry about, well is the nurse caregiving not being done or what's not being done as the nurse right now because of the circumstances of the event. It's hard because mom expected me to be a nurse first and at times and that wasn't my role. My role was definitely the nurse first.

Similarly, Susan shared the role as daughter changed when caring for her parent. "Just all of the sudden the roles change and you are trying to be in control of decisions. It was really uncomfortable. I wanted to be the daughter again". She further identified the importance of having a conversation with aging parents before the role switch happens to guide RNs placed in a caregiving situation.

In summary, the changing of roles from a family member to an RN role occurred with each of the participants. All indicated they wished for their role in the family not to change, but understood the important role of the RN to provide the best care possible and support for their loved one.

Health consequences. Health changes were identified by several of the participants, and all expressed fatigue and exhaustion associated with their caregiving role. The stress of the situations and hours in the role of caregiver affected their ability to rest and maintain their ability to cover all the bases of their demanding lives.

The beginning of the RNs' caregiving experiences were recounted as approached with positive expectations of caring for a family member. It was noted the longer the caregiver role was necessary, the participants' health declined. The caregivers attributed the decline in health to increased stress, decreased sleep, and lack of time to monitor their own health.

The topic of health was approached by Tessa as:

My health was a challenge for me. I was in an utter state of exhaustion for most of the caregiving experience, especially towards the end getting up every two hours to provide cares, 24/7. I gave up my prevention checkups, medical and dental. I went three years without dental care and two years behind on my mammograms. I only went to the doctor for myself when I absolutely had to, such as a cardiac workup for palpitations identified related to stress. I had an increase in migraines, gained a significant amount of weight and had increased reflux during this timeframe.

Tessa's reported health improved once the caregiving role ended when she was able to get rest and reduce her stress level.

Diane was in a different situation with her health, already compromised from being in the process of chemotherapy treatments and having rheumatoid arthritis when she started the caregiving experience. She noted that her exhaustion from her treatments

in addition to her caregiving created utter fatigue and exhaustion. At the time of the interview, Diane shared she was beginning to feel healthier than in the beginning of taking care of her husband, but exhaustion and stress continue to affect her.

The other participants identified going back and forth between feelings of rundown, general fatigue, and being in a state of pure exhaustion. Even with exhaustion, participants still complained of insomnia issues. Gastrointestinal complaints such as increased reflux and food intolerances were included in the analysis of health issues. Back, neck, and joint discomfort were concerns with caregivers doing increased lifting and weight bearing activities. There was also a participant who had an increase in blood pressure and had to go on mediation.

Summary

RN family member caregivers experience their life changing. The participants interviewed identified their lives as changing and shifting during the caregiving experience. Three themes addressed in relationship to the caregivers' experiences included the struggle for life balance, changing of family roles, and health consequences.

RN family member caregivers experienced emotional burdens. The caregiving experience was often identified as being difficult to handle and a toll emotionally. Specific emotions identified as influencing the caregiver were anger and frustration, guilt, and grief. Even though specific emotions were identified in the narratives, several addressed a general emotional detachment and suspension between the caregiver and receiver.

The detachment and suspension of emotions were identified as related to the stressful situation, demands of caregiving, or a coping mechanism for the upcoming loss of a loved one. Tessa described the emotional suspension and detachment as:

As the caregiving experience and stress continued, we had put off to withdraw any emotional connection to each other. We lost the relationship of a husband and wife. There was a total loss of connection. I missed the holding of hands and our closeness. Instead of kissing me goodnight he would pat me on the head…sometimes I wondered if he thought he was contagious. Then as time went on, I withdrew emotionally to protect myself. He wanted his wife back then, but I had to separate my love from the care I needed to provide…I had to be the nurse and was handling the situation, detaching as a professional nurse.

Tessa further indicated she has wished since the loss of her spouse that their relationship would have remained as a couple. Looking back at the caregiving time, she felt her emotional detachment would protect her from any additional pain with the impending death of her husband.

To protect herself, Lynn also identified withdrawing her emotions so she could make decisions and provide support to other family members. It was easier to withdraw than become emotionally drained. Lynn expressed "I feel like I am pulling away more and more, but I'm getting me back. I'm not as emotionally involved".

Frustration and Anger. Another shared emotional theme participants identified was frustration and anger. These feelings emerged from the actual experience of caregiving and when their family members didn't get the care from the medical community that RN caregivers knew should be the standard of care. Cheryl identified her

overall caregiving experience for her son as having a basic feeling of frustration and anger. Several times throughout her interview she identified having feelings of frustration and anger often related to the lack of understanding of the medical community to her son's diagnosis and care. Cheryl furthered shared how these emotions may have affected her other children, "I think about my children growing up with a mother that felt frustrated and angry all the time. It probably took much away from them".

Conflicts in her family related to caregiving provided a stressful and frustrating situation for Susan. She stated "I had so much anger and frustration and having a lot of time just to stuff it. You just have to stuff it down and go on giving dad good care".

Lynn discussed having to work through a lot of frustration and anger alone when her husband became ill as did Tessa. The lack of understanding related to the diagnosis by other family members and the overall emotional toll of their situation led to these emotions.

Guilt. Four of the caregivers communicated feelings of guilt in caring for their loved one. They shared there was much going back and forth between guilt and frustration during the caregiving experience. The caregivers, due to exhaustion and frustration, also felt guilt for negative thoughts and comments they made toward the care receivers. One participant identified guilt for wishing the caregiving experience would end.

The participants identified feeling guilty if they didn't have the knowledge others or meet the expectations others anticipated to be accomplished in providing cares. Diane recognized her guilt as:

> If you are a nurse and you have knowledge, you feel guilty if you don't know. If
> something would go wrong, you'd feel really guilty. Because you missed it or you
> didn't do enough, or didn't see to it that something was taken care of or better,
> because you should have known better. The expectations are higher for a RN
> caring for a family member.

Lynn also shared similar comments related to guilt:

> Guilt was a challenge in caregiving that I can see now. Guilt when I look back
> and think, I am a nurse. I didn't ask enough questions. I didn't explore things
> enough. If I would have done X, Y, Z different, maybe there would have been a
> different outcome.

These feelings would especially surface when other family members would question what was happening or what was decided in her husband's care.

Other guilt producing situations were identified as the RN having feelings of wanting the caregiving experience to end and to go back to their previous life. Guilt was noted with the questioning of God to why this was happening to their family and at this time in life.

Grief. Grief was identified specifically as an emotion by participants related to loss of past lifestyle and future plans or a loss of what was and what could have been. Participants also mentioned grief in the loss of a couple relationship, loss of self, or the family member's loss of function and mobility.

During the experience of caregiving, grief can be identified to loss of intimacy, independence, control, friendship and family roles. Grief was often associated with the

caregivers' feelings of anger, isolation, and relinquishment of family role or caregiving duties.

For a participant, the grief identified experienced in the caregiving role was acknowledged as different than the grief experienced with the spouse's death. As long as her husband was alive there was still hope, not making the grief as intense as what was experienced with death.

Another RN caregiver identified her grief as being ambiguous. Her spouse suffered from a cognitive impairment and the brief periods that he was lucid, then reverting to a confused state caused frustration and grief.

Summary

The RN family member caregivers shared many emotions related to their experience. These emotions ranged from being emotionally withdrawn and overwhelmed, to a profound sense of thankfulness for being able to participate in care providing.

The common thread identified related to caregiver emotions were frustration and anger, guilt, and grief in their role. In order to make sound decisions and as a coping mechanism withdrawal of emotions may occur.

Chapter summary

In summary, study participants provided numerous instances of the benefits related to having the knowledge connected to their RN background. All participants expressed an emotional connection for their family care receiver.

Through the analysis of the interviews told by RNs caring for their parents and one spouse, the experience was identified as overall positive, they were giving back care from the love they received over time. Even though the experience was not always

positive, they expressed caregiving as a blessing and gift they could provide to a family member.

Two RN caregiver spouses and a mother who cared for family members saw this experience as a challenging event in their lives. They also had a longer period of providing care. Even when the caregiving experience was stressful, distressing, or challenging all participants said they would provide and partake in being a family member caregiver again should ever the need arise.

Chapter 5: Discussion and Implications

Introduction

This dissertation used narrative inquiry (NI) as an appropriate approach for gaining a deeper understanding of the nurse caregiver role in caring for their own family member. The study design allowed RNs to share their stories of what they faced in their professional and personal life during the caregiving experience. Riessman (2008) identified the narrative interview provides an emphasis on the way the individual perceives the events that have occurred.

The study provides additional information into the RNs informal family caregiving role. As identified through an August 2016 literature search, the informal caregiving role has been extensively researched, however the studies of RNs caring for their own family member in the home setting is limited.

Through the NI study interviews, six caregiver participants had the opportunity to freely share stories related to their personal experiences as a nurse in the family member caregiving role. Interview questions included:

1. What are your thoughts and feelings related to the caregiving experience?

2. What impact, if any, did providing care to a family member have on your life?

3. How did your role in the family change with becoming the caregiver?

4. What are different challenges you faced in caring for your family member?

5. What else would you want to share that is relevant to the caregiving experience?

Study findings offer an understanding into the lives and caregiving issues experienced by RNs in the role of caring for their own family members. The caregiving

experiences for each RN shared were unique and individual to their experience, through analysis, analogous themes were recognized.

Findings

This study offers additional support that RNs providing family member care is an experience that impacts the caregiver in several ways. Three themes emerged from this study: *RN caregivers are advocates, RN caregivers experienced their life changing,* and *RN caregivers experienced emotional burdens.* The identified themes correlate with previous research findings.

Related to the first theme, researchers have determined that *RN caregivers are advocates* for their family members with or without collaboration in the healthcare setting (Mitchell, 2007; Salmond, 2010; St-Amant et al., 2014; Ward-Griffin et al., 2005). Advocacy is especially crucial when the family care recipient is unable to participate in decisions related to his/her own care. It is important that caregiver recipients receive encouragement to advocate for self when possible. (St-Amant et al., 2014; Ward-Griffin et al., 2005).

This study identified the RN family caregiver as stepping into the advocate role for their care recipient. Advocacy insured quality care was provided to their family member. In addition, the RN caregiver protected their family member from inappropriate cares and treatments which may have further endangered health and recovery.

Caregivers also verbalized they were being the *voice* for the care recipient. The RN caregivers were able to obtain medical information and request necessary resources, medications, and cares for their loved one.

Knowledge of the healthcare system enabled the caregiver to navigate and collaborate with other healthcare members. Navigation of the healthcare system and knowing which specialist would better deal with their family member's health concern insured appropriate care. Several participants indicated a perception of improved care related to the caregiver's education as an RN.

The study's second identified theme was *RN caregivers experienced their lives changing*. The life transforming events were defined further as struggling for life balance, change in family roles, and experiencing health consequences throughout the caregiving experiences.

Study participants identified struggling for a life balance and dealing with health concerns became more problematic as the caregiver role stretched over a longer time period. In addition, the RNs identified the lack of support and resources as increasing the imbalance in the caregiver's life and decreasing ability to cope. Curry et al. (2010) also found that caregiving that extended over a prolonged period and a lack of resources corresponded to an increased level of burden or stress.

All participants communicated health issues related to their caregiving role, including gastrointestinal, cardiac, and/or musculoskeletal concerns. The RNs also indicated that they experienced overwhelming exhaustion and stress related to their 24/7 responsibilities. The caregivers recognized their personal lack of preventive health care and failure to seek medical treatment contributed to poorer health.

The nurse's experiences in the family caregiver role have been described as having a negative impact on their quality of life and health. Studies identified nurses who have taken on the dual role of professional and family caregiver experience blurring of

professional and personal boundaries. This experience places the caregiver at higher levels of stress, fatigue, sleep disturbances, tension, ill health, and mental exhaustion (Carretero et al., 2009; Chappell et al., 2014; Mills & Aubeeluck, 2006; Scott et al., 2006; Ward-Griffin et al., 2005).

As acknowledged in literature, the family role changes for the RN participants were difficult and created challenges. The role changes in family member caregiving are frequently made through a sense of responsibility, obligation, and love (McCurry, 2013; Sawatzky & Fowler-Kerry, 2003). Dickson et al. (2010) work identified a spousal dynamics shift in the caregiving/caregiver roles, which increased relationship strain. This spousal shift occurred with the partner/caregiver sacrificing their original family role to take over the RN role.

The RN study participants recognized their role in the family as shifting and changing through the caregiving experience. Participants indicated roles of spouse, mother, or child were intertwined and blurred with their role of nurse. Some family caregiver roles changed due to obligations or responsibilities the RN caregiver acquired from taking on the family decision maker role. In addition, there were changes from child to parent and wife to mother roles.

In literature findings, adult-child caregivers recognized the experience as more burdensome than spousal family members (Andrén & Elmståhl, 2007; Chappell et al., 2014; Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010). A dissimilar response in this study was revealed. Both daughters interviewed viewed the care experience and caregiving role as a gift that they could give back to their parents for

their care through the years and two of the spouses experienced high burdens in the caregiving roles.

Theme three, *RN caregivers experienced an emotional burden*, was also recognized in the literature (Cho, Zarit, & Chiribaga, 2009; Chou, 2000; Mills & Aubeeluck, 2006). Specific emotions identified in the study that influenced the caregiver were anger and frustration, guilt, and grief. Two spousal caregivers addressed a general emotional detachment and suspension between the caregiver and care recipient.

In this study, caregivers expressed the demands of the caregiving experience influenced their emotional health. O'Brien et al. (2012) recognized the well-being of the family caregiver is often decreased when there is an increase in the emotional and physical demands of caregiving. It was further identified that often the emotional health of caregivers is compromised with the perceived demands of caregiving (Chappell et al., 2014; Honea et al., 2008; Werner et al., 2012).

Guilt in caregiving experiences was related to the caregivers wondering if they could have done more or feeling inadequate to what was expected. Additionally, participants indicated feelings of guilt related to their desire for the role of caregiver to lessen or end. Studies have identified guilt in caregiving when a caregiver feels a choice needs to be made, which will place their family or job over the care recipient (Eldh & Carlsson, 2011; Hashizume, 2010, Schulz et al., 2012).

In a study of nurse caregivers for relatives, Ward-Griffin (2004) identified guilt as related to nurses feeling they were expected to assume too much responsibility, especially where they lacked knowledge and skills. Further guilt was felt when caregivers made

inadequate clinical decisions given their professional background. Consequently, guilt was identified as a negative impact to the caregivers' health.

Several participants identified their need for support from others and failure to be provided with support group and resource information. The spouse caregivers indicated support groups would have positively influenced their caregiving experience and decreased their burden of stress, but they weren't offered the support options or resources.

Two participants voiced receiving emotional support from close friends and colleagues who were willing to share their own experiences and concerns as important to their caregiving experience. Studies have recognized social support, the relationship between the contributor and recipient, as protecting a caregiver's well-being and health. This relationship is crucial for the caregiver to face issues resistant to their own coping mechanisms (Kondrat, Swanke, Littlewood & Strozier, 2014; Robinson & Steele, 1995; Røthing, Malterud, & Frich, 2015).

According to St-Amant et al. (2014), community resources and support groups need to provide support to nurses providing family care. The appropriateness and availability of provided support forms the caregivers' dissatisfaction or satisfaction in the caregiving experience. Caregivers being unsupported in their role may lead to feelings of guilt, helplessness, frustration and damage their wellbeing and health (Mills & Aubeeluck, 2006; Ward-Griffin, 2015).

In the current study two participants mentioned employment in their interviews. The participants admitted workplace support would have been beneficial in their caregiving experience. Literature supports the need for support in the workplace to assist

in the balance of home and work responsibilities (Eldh & Carlsson, 2011; Kim, Ingersoll-Dayton, Kwak, 2011; Scott et al., 2006).

The intertwining of their RN and family member roles creates distinctive experiences for the nurse, blending professional and private lives together. While the themes identified represent the experiences of study participants, similar themes have been identified through literature as influencing the role of a nurse as a family member caregiver.

Aligning Conceptual Framework to Research

Caregiving, as identified by Pearlin et al. (1990), "is not a unitary experience, but a mix of circumstances, experiences, responses and resources that vary considerably among caregivers and that consequently vary in their impact on caregiver health and behavior" (p. 591). The SPM is not simply interested in outcomes of caregiving, but the how the components of caregiver stress are interrelated.

The conceptual framework of SPM (Pearlin et al., 1990) provided direction and guidance to this NI research. A modified framework is proposed from the study results from the Pearlin et al.'s conceptual framework (See figure 5.1).

Background and/or Social Context. The background or contextual domain describes the environment in which caregiving experience took place. This domain, or the caregivers' characteristics, potentially influence the caregiving experience and its outcome (Pearlin et al., 1990).

The background or social context variables are stable and not flexible. These variables are significant to the caregivers' responsibilities and are threaded throughout the SPM and can influence primary and secondary stressors along with the overall

outcome. Within the perspective of caregiving, the variables can also be used to identify those caregivers who may be at increased risk for health concerns or increased stress (Pearlin et al.,1990).

In this study, the RN family member caregivers' background and social context variables were identified from the study information and demographics. These variables included the caregivers' age, gender, relationship to the care recipient, occupation, and home residence, areas in which the caregivers have little control (See Figure 5.1).

Primary Stressors. Primary stressors originate directly from the care recipients and their greater needs of care (Pearlin, et al., 1990). These stressors are entwined with the caregivers' background and social context characteristics, posing larger responsibilities and higher stress producing levels for caregivers.

Primary stressors identified in this study included the necessary delivery of cares comprising of ADLs and/or IADLs. Recipient dependence on the caregiver, cognitive deterioration and problematic behaviors were likewise identified as creating more work and close observation for the caregivers.

Studies have linked care recipient's level of dependence with caregivers' burdens and poorer health (McPherson, Pentland, & McNaughton, 2000; Newens, Forster, & Kay, 1995) as was identified in my study results. Study participants identified their caregiving role as a 24/7 job. The additional responsibilities and work were noted as leading to a frustrating experience and negative outcomes. Interview analysis additionally identified health consequences and emotional burdens were more common with the older caregivers.

An association was also identified between the length of caregiving and health consequences and emotional burdens. Caregivers attributed their decline in health to longer time in the caregiving role with increased stress, decreased sleep, and lack of time to monitor their own health. Accordingly, the longer caregiving role was also related with the increased emotional burdens.

Primary stressors can directly impact the caregiving outcomes. The caregiving outcomes are identified as caregivers are advocates, the caregiver's life, and emotional burden. Further, primary stressors can indirectly influence additional caregiving concerns leading to secondary stressors (See Figure 5.1).

Secondary Stressors. As result of the primary stressors being durable and strengthening over the caregiving time frame, secondary stressors are established (Pearlin, et al., 1990). Secondary stressors originate from the influence of caregiving stressors into areas directly and/or indirectly affecting the caregiving outcomes. The stressors are established as result of the caregivers' interactions with others connected to the caregiving situation, such as family members.

The secondary stressors in this study included family conflict dynamics, work conflicts, multiple roles, and family demands (See Figure 5.1). Previous studies support current study conclusions. Nurses assuming duo roles as informal and formal caregivers may be at higher risk for stress, reduced life satisfaction, and poor physical and/or mental health outcomes. These nurses are at higher risk for distress due to conflicting obligations and commitments (Mills & Aubeeluck, 2006; Schumacher et al., 2008; Ward-Griffin et al., 2005).

In this NI study a study participant identified work conflict related to her employment outside of the home. The participant acknowledged she was unable to quit her employment after considering the needed health insurance and income. The increasing needs of her spouse made it necessary for the caregiver to identify alternative options for her caregiver role, leading to a secondary stressor.

Another participant identified how the family conflict led to an unfavorable caregiving outcome. When her father's health declined and more care was needed, there was conflict between the RN caregiver and other family members to allow hospice care into the home. This situation not only affected the overall caregiving experience, but had negative aspects related to the family relationship.

Mediators. Social support and resources are considered to be mediators between caregiving outcomes and decreasing caregiver stress. In this study several participants acknowledged not receiving adequate support or resources had a negative influence on their caregiving experience outcomes. They further predicted support would have improved the outcomes and decreased the stress levels associated with providing care.

Studies recognize social relationships as resources from which caregivers can find support and assist them in facing problems related to their caregiving role. Perceived social support is positively and directly related to caregivers' well-being (Chappell & Reid, 2002; Pearlin & Skaff, 1996). This was the situation described by two study participants who received support from close friends or colleagues. The participants recognized the support from friends and colleagues as uplifting their emotional well-being and caregiving experiences. The influence of or lack of mediators can influence the caregiving experience outcomes positively or negatively (See Figure 5.1).

Outcomes. Pearlin and Skaff (1996) recognized individuals exposed to the same stress such as caregiving events will have different outcomes due to different exposures of primary and secondary stressors. They further identified the differences in outcomes will be affected by inconsistencies within moderating resources such as coping and resources.

This study's outcomes were identified from the caregiving experience themes; *advocate, life changes, and emotional burden*. Within the theme of *life changes*, *physical health consequences* and the theme *emotional burdens* and were directly related to increased stress in the caregiving experience. This study showed a greater number of negative outcomes occurred in connection with greater time participants were involved within the caregiving role.

From the study themes, *advocate* and *life changes*, including *life balance and changing family roles*, caregiving outcomes were related to necessities in the caregivers' life circumstances. In addition, these areas were not directly identified as stress related, but stress did impact the caregivers in the mentioned areas (See Figure 5.1).
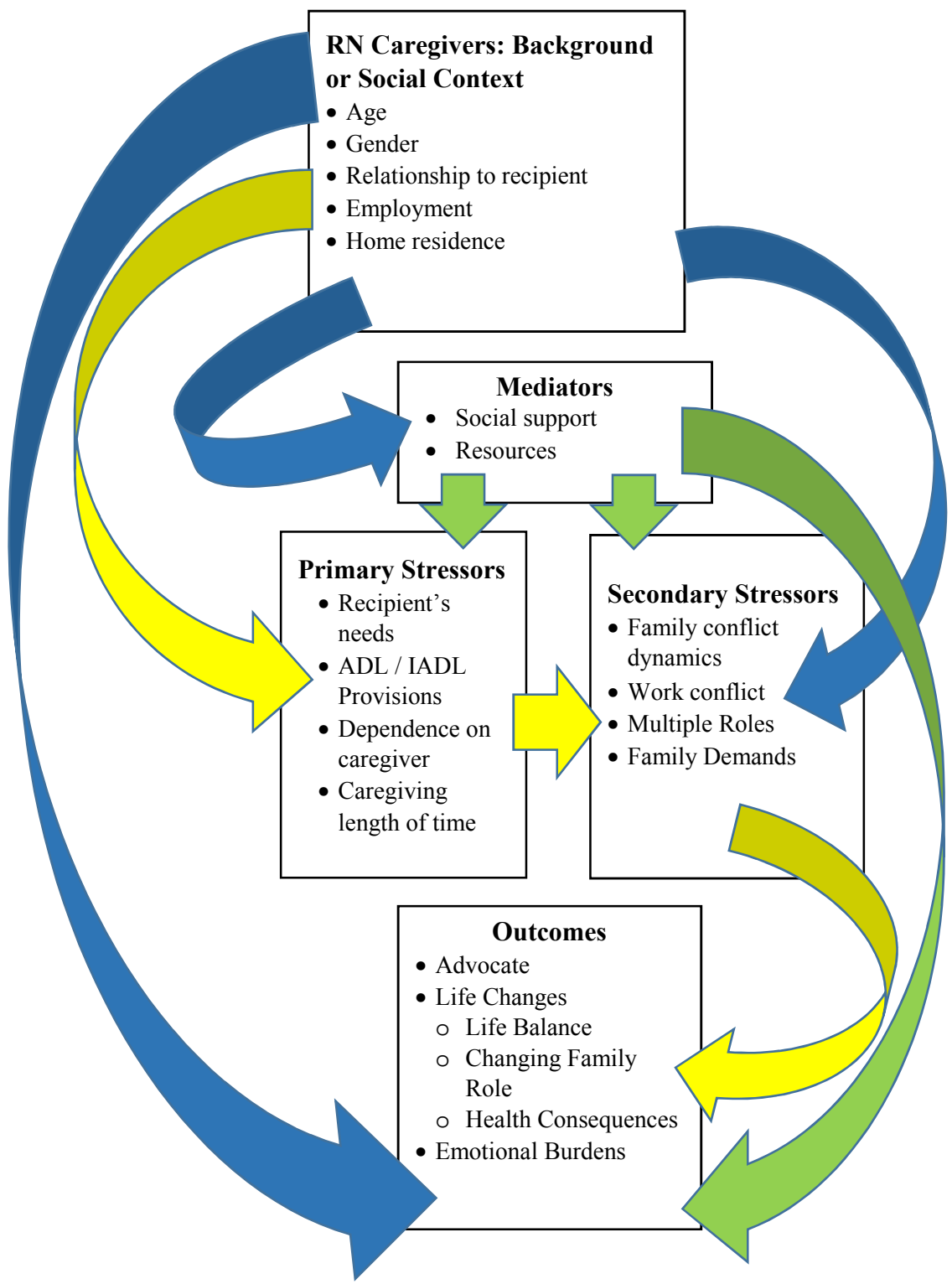
Figure 5.1 Modified conceptual framework

Note. Adapted from Pearlin et al. (1990), p.586

Limitations

Research limitations should be taken into consideration when interpreting the study outcomes. NI methodology seeks stories from the participants. These stories represent recalled events and may vary from how caregiving occurred. The stories may also vary each time the story is told. Furthermore, questions used for clarification may affect the way the participant tells their stories.

Additionally, the narratives provided for this study were reflective of RNs who volunteered for the study, and may not be a representation of other RNs who did not participate. Participants in the study were a small homogenous group, all Caucasian and female, which may limit the variation of caregiving stories told. A male perspective and diverse ethnic backgrounds may have different insights with the caregiving of a family member.

Participants were offered the opportunity to do member checking or review their interview transcripts for accuracy. No participants accepted the invitation to do so.

The study may have been influenced in some way by researcher bias, as this researcher has also lived the experience of an RN caring for a family member. However, this researcher is seven years removed from the caregiving experience and distanced herself from personal feelings in interpreting participants' experiences and analyzing the interviews.

Implications

This study has implications for the nurse as family caregiver as well as the healthcare community. The strength of this NI study lies in the analysis of RNs who are caregivers for their family members. As indicated in the literature review much research

has been done in regards to informal family members caregiving, but limited studies focus on the RNs in the caregiving role.

This study further addresses and provides the opportunity for caregivers to share their personal experiences. These shared experiences deepen the understanding of family caregiving and expands implications related to the RN caregiving role.

The SPM indicates that background and social context are important aspects to stress. Support falls into the category of mediator and is an important factor for RNs in the family caregiving role. Participants told stories how support would have decreased their burdens and enriched their caregiving experience. Two participants indicated the support from colleagues had a positive effect on their caregiving role.

The healthcare community, including primary physicians, should have a better understanding of the life challenges including roles, health and emotional burdens experienced as RNs face in providing care to their family members. It ought not be assumed RNs will ask for support as they care for their family members. The caregiver should be asked if they need assistance and provided with resources.

Understanding the RNs home and professional caregiving role needs to be recognized so caregivers can continue to function in both environments. In nursing practice, managers and directors should be informed of the consequences and increased burdens associated with RNs in the family caregiving role.

Support from management and other colleagues would be useful as caregivers strive to balance their lives. In addition, improved support in the work environment could help to decrease caregiver burdens and increase work efficiency and workplace safety.

In nursing and medical education learners, would benefit from instruction related to healthcare professionals caring for family members. Students should be instructed on the importance and methods of support to family members especially those who have a healthcare background. It is incorrect to assume healthcare caregivers will be adequately prepared to provide care for their family member.

There are also implications for the RN in the family caregiver role. It is important caregivers understand the benefits of reducing life and emotional burdens and the need of self-care. Without a sense of life balance between personal and professional caregiving roles an, RN's physical and emotional health can be negatively influenced.

While in the caregiving environment, nurses need to be cognizant of their health and emotional needs. It is crucial strategies be established to enhance individual resources and health-promotion behaviors for multiple role caregivers.

Recommendations for future research

Information gained from this study has provided a base to further recognize the needs of RNs caring for their own family members. Future research on RN family caregivers would enhance knowledge related to the RN in the caregiving role for their own family members. While this study focused on RNs caring for any family member, questions remain related to specific family dyads, such as RNs caring for specifically their parent, sibling, spouse, or child groups.

Future studies related to exploring the caregiving role between specific family member groups would provide additional input regarding the relationships and response to caregiving within different family relationships. A comparison between caring for

close family members to extended family members, to identify there any differences in the caregiver's health and emotional outcomes.

Examining the RN caregiving within a specific family role, would increase understanding the experiences nurses' faces caring for different family member groups. A further exploration into family roles related to caregiving would additionally identify if family role changes is an expectation within the role of caregiving.

Studies directed towards RN family members caring for family members with a specific disease process would provide better understanding of the caregiver burden and its impact associated to related disease health concerns. This information would lend toward an understanding of the RNs psychological stress and distress in caring for family members with debilitating, chronic, or life-threatening illnesses.

Study comparisons between female and male RNs providing care to family members would help to identify if their different perspectives and needs the different genders face in the caregiving role. The relationship of support groups and resources provided in the caregiving between genders to identify if either group found this assistance impacted their experience.

Other topics for future research were identified from the study themes. These recognized areas of study include outcomes related to the RN in the caregiving role and their life balance, influence of support within the caregiving experience, health outcomes and/or emotional affects related to caregiving, and caregivers' outcomes with workplace support.

Conclusion

Narrative inquiry provided an opportunity not only to hear the stories of RNs in the family caregiving role. The shared experiences provide more than data; they provide the caregiver with an opportunity to *open the door* and giving depth to the caregiving experience.

The results from this study highlighted life situations, the challenging and positive endeavors, from the perspective of the individual providing care for their loved one. Even though all participants said it was an experience they would take on again if necessary, the findings suggest this caregiving experience created a change in the caregivers' lives.

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Appendix A: Demographic Instrument for Background Data

1. Participant age

2. Gender
   - Male
   - Female

3. Marital status
   - Single, never married
   - Married
   - Divorced
   - Separated
   - Widowed
   - In a relationship, but not married

4. Ethnicity
   - White
   - Native American
   - Hispanic
   - Asian
   - African American
   - Other

5. Employment

6. Relationship to care receiver

7. Length of time in caregiving role

8. Care receiver's age when care was provided by RN family member

9. Care receiver gender
   - Male
   - Female

10. Ethnicity
    - White
    - Native American
    - Hispanic
    - Asian
    - African American
    - Other

11. Rural or Urban Setting

Appendix B: South Dakota State University Institutional Review Board
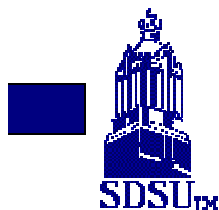
South Dakota State University

Office of Research/Human Subjects Committee
SAD Room 124
Box 2201 SDSU
Brookings, SD 57007

To: Julie Hansen, College of Nursing

Date: May 10, 2016

Project Title: The Nurse as a Family Caregiver: Their Experiences, Their Story

Approval #:   IRB-1605003-EXM

Thank you for taking such care in completion of the request and research protocol. This activity is approved as exempt human subjects research. The basis for its exempt status from 45 CFR 46.101 (b) is:

(2) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior, unless:
(i) information obtained is recorded in such a manner that human subjects can be identified, directly or through identifiers linked to the subjects; and (ii) any disclosure of the human subjects' responses outside the research could reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, or reputation.

If there are any unanticipated problems involving risks to subjects or others please contact the SDSU Research Compliance Coordinator. At the end of the project please inform the committee that your project is complete.

If I can be of any further assistance, don't hesitate to let me know.

Sincerely,
Norm
Norman O. Braaten
SDSU Research Compliance Coordinator

Appendix C: Cover Letter/Information Sheet

Cover letter/Information Sheet
Participation in a Research Project
South Dakota State University
Brookings, SD 57007

Department of Nursing

Project Director Julie Hansen   Phone No. 605-351-7634

E-mail julie.hansen@jacks.sdstate.edu   Date   May 5, 2016

Please read (listen to) the following information:

1. This is an invitation for you as a nurse caregiver to participate in a research project
   under the direction of Julie Hansen at South Dakota State University.

2. The project is entitled: The Registered Nurse as Family Member Caregiver:
   Their Experiences, Their Stories.

3. The purpose of this narrative study is to explore the lived experience of registered
   nurses who are or have provided care as the informal family member caregiver.
   An abundance of research and evidence related to informal caregiving, but while the
   general informal caregiver is addressed through much research, there is limited
   information and studies available associated with experiences of RNs caring for their
   own family members. This study will provide an opportunity to hear the voices and
   stories of the nurse caregiver group. The perceptions and viewpoints will be seen
   through the eyes of those who have experienced the caregiving role.

4. If you consent to participate, you will be involved in the following process, which will
   take about 90 minutes of your time: receive a copy of the questions you will be asked,
   followed by a scheduled interview in a mutually agreed upon place.

5. Participation in this project is voluntary. You have the right to withdraw at any time
   without penalty. If you have any questions, you may contact the project director at the
   number listed above.

6. There are no known risks to your participation in the study. If questions evoke strong
   emotion, referral to Counseling Center or a therapist will be provided. The researcher
   will provide a list of counselors and their phone numbers if necessary; however,
   counseling will be at the participant's expense.

7. There are no direct benefits to participation, but there may be value in sharing a story about experiences in the family member caregiving role.

8. There is no compensation for your participation in this study.

9. Your responses are strictly confidential. When the data and analysis are presented, you will not be linked to the data by your name, title or any other identifying item.

10. As a research participant, I have read the above and have had any questions answered. I will receive a copy of this information sheet to keep.

If you have any questions regarding this study you may contact the Project Director. If you have questions regarding your rights as a participant, you can contact the SDSU Research Compliance Coordinator at (605) 688-6975 or SDSU.IRB@sdstate.edu.

This project has been approved by the SDSU Institutional Review Board, Approval No.: IRB-1605003-EXM

Appendix D: Human Subjects Form

Participant Consent Form
Participation in a Research Project
South Dakota State University
Brookings, SD 57007

Department of Nursing

Project Director <u>Julie Hansen</u>   Phone No. <u>605-351-7634</u>

E-mail <u>julie.hansen@jacks.sdstate.edu</u>   Date   <u>May 5, 2016</u>

Please read (listen to) the following information:

1. This is an invitation for you as a nurse caregiver to participate in a research project under the direction of Julie Hansen at South Dakota State University.

2. The project is entitled: The Registered Nurse as Family Member Caregiver: Their Experiences, Their Stories.

3. The purpose of this narrative study is to explore the lived experience of registered nurses who are or have provided care as the informal family member caregiver. An abundance of research and evidence related to informal caregiving, but while the general informal caregiver is addressed through much research, there is limited information and studies available associated with experiences of RNs caring for their own family members. This study will provide an opportunity to hear the voices and stories of the nurse caregiver group. The perceptions and viewpoints will be seen through the eyes of those who have experienced the caregiving role.

4. If you consent to participate, you will be involved in the following process, which will take about 90 minutes of your time: receive a copy of the questions you will be asked, followed by a scheduled interview in a mutually agreed upon place.

5. Participation in this project is voluntary. You have the right to withdraw at any time without penalty. If you have any questions, you may contact the project director at the number listed above.

6. There are no known risks to your participation in the study. If questions evoke strong emotion, referral to Counseling Center or a therapist will be provided.

7. There are no direct benefits to participation in this study.

8. There is no compensation for your participation in this study.

9. Your responses are strictly confidential. When the data and analysis are presented, you
   will not be linked to the data by your name, title or any other identifying item.

As a research participant, I have read the above, have had any questions answered, and
agree to participate in the research project. I will receive a copy of this form for my
information.

Participant's Signature _____ Date _____

Project Director's Signature _____ Date _____

   If you have any questions regarding this study you may contact the Project Director.
   If you have questions regarding your rights as a participant, you can contact the
   SDSU Research Compliance Coordinator at (605) 688-6975 or
   SDSU.IRB@sdstate.edu.

This project has been approved by the SDSU Institutional Review Board, Approval No.:
IRB-1605003-EXM

Appendix E: Transcriptionist's Consent to Confidentiality

CONFIDENTIALITY AGREEMENT

Date: 05/25/2016
"Verbal Ink": Outskirts, Inc. dba Verbal Ink
"Client": Julie Hansen

This Confidentiality Agreement ("**Agreement**") is entered into by and between Client and Verbal Ink as of the above date in connection with discussions between the parties with respect to Verbal Ink performing transcription services for Client ("**Services**"). Whereas Client intends to provide Verbal Ink with certain confidential and proprietary information regarding Client and/or its business for transcription purposes and Verbal Ink intends to maintain the confidentiality of such information, now, therefore, in consideration of the disclosure of such information, and other good and valuable consideration, the parties agree as follows:

1. The parties acknowledge that related to any Services provided by Verbal Ink to Client, Client may make available to Verbal Ink certain information and materials: (i) in writing, by email, by audio tape or other tangible electronic storage medium clearly marked and identified by Client as "Confidential" or "Proprietary" or (ii) that, by the nature of the information and circumstances surrounding their disclosure ought to, in good faith, be treated as proprietary and/or confidential (hereafter referred to as "**Confidential Information**"). Excluded from Confidential Information are: (i) information which is known to Verbal Ink prior to entering into this Agreement, (ii) information which becomes known to Verbal Ink from a third party who is not subject to a confidentiality agreement with Client, (iii) information which is required to be disclosed as a matter of law, and (iv) information which is generally known to the public.

2. Verbal Ink acknowledges that all Confidential Information furnished to it is considered proprietary and is a matter of strict confidentiality. Verbal Ink further acknowledges that the unauthorized use or disclosure of any Confidential Information may cause irreparable harm to Client. Accordingly, Verbal Ink agrees that Client will be entitled to seek equitable relief including injunctive relief and specific performance, in addition to all other remedies available at law or in equity for any breach of this Agreement. In the event of any dispute under this Agreement, each party and its managers', officers', directors', executives', owners', members', shareholders', employees', affiliates', agents', advisors', representatives', and, in the case of Verbal Ink, its transcriptionists, ("**Representatives**") monetary liability to the other party and its Representatives for all claims related to this Agreement will be limited to direct and proven damages. Neither party (nor its Representatives) will be liable for or entitled to any indirect, incidental, reliance, special, punitive, exemplary or consequential damages arising out of its performance or non-performance under this Agreement, whether or not they had been advised of the possibility of such damages. In the event of any dispute related to this Agreement, each party (and its Representatives) shall pay its own attorneys' fees and other litigation costs.

3. Verbal Ink agrees that, except to its Representatives to the extent necessary to permit them to assist in the performance of the Services, it will not distribute, disclose or convey to third parties any of Client's Confidential Information without Client's prior written consent. All transcriptionists working with Verbal Ink are subject to and must pass criminal background checks before starting work with Verbal Ink. Confidential Information shall not be distributed, disclosed or conveyed to any Representative unless such Representative is advised of this Agreement and agrees to be subject to the terms hereof or a similar agreement.

4. Verbal Ink agrees that all Confidential Information received from Client shall at all times remain the sole property of Client and upon completion of the Services shall be either: (i) returned to Client, if Client has made such prior written request, or (ii) deleted from Verbal Ink's files such destruction certified to the client. Notwithstanding the immediately proceeding sentence, Verbal Ink may (but shall not be obligated to) retain one copy of Confidential Information in its files for legal or regulatory requirements only (subject to the confidentiality requirements hereof). No rights or licenses, express or implied, are granted by Client to Verbal Ink under any patents, copyrights, trademarks, service marks, or trade secrets owned by Client as a result of, or related to, this Agreement.

5. This Agreement is effective upon the date first written above. This Agreement shall remain in full force and effect for three (3) years from the above date.

6. This Agreement is binding on the parties and their successors and assigns, and its provisions may only be waived by written agreement of the parties.

7. This is a binding agreement that contains all of the agreements and understandings of the parties and any amendments to this Agreement must be in writing. This Agreement and any claim related directly or indirectly to this Agreement shall be governed and construed in accordance with the laws of the State of California (without giving regard to the conflicts of law provisions thereof). No such claim shall be commenced, prosecuted or continued in any forum other than the courts of the State of California located in the City and County of Los Angeles or in the United States District Court for the Central District of California, and each of the parties hereby submits to the jurisdiction of such courts. Each of the parties hereby waives on behalf of itself and its Representatives, successors and assigns any and all right to argue that the choice of forum provision is or has become unreasonable in any legal proceeding. This Agreement may be executed in counterparts by facsimile.

READ, AGREED AND ACCEPTED:

By: _____

Its: _____

Outskirts, Inc. dba Verbal Ink

By: _____

Its: *Account Executive*

Alec Wetherington