THE EXPERIENCES OF NURSES AS DOUBLE DUTY CAREGIVERS FOR A FAMILY MEMBER AT THE END OF LIFE: INTERPRETIVE DESCRIPTION

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THE EXPERIENCES OF NURSES AS

DOUBLE DUTY CAREGIVERS FOR A FAMILY MEMBER

AT THE END OF LIFE: INTERPRETIVE DESCRIPTION

BY

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A DISSERTATION SUBMITTED IN PARTIAL FULFILLMENT OF THE
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ABSTRACT

This study explored the experiences of nurses providing end-of-life care for family members while continuing to work as a nurse. As the delivery of healthcare changes in our country, we are seeing a transition to community-based client care. As a result, there are more people with complex, advanced illnesses being cared for in the home by family members and friends. Family caregivers are the primary source of support for older adults with chronic illness and disability. These family caregivers take on many responsibilities, and often experience physical, emotional, psychological, and social distress because of the demands placed on them. A unique subset of this population are nurses who find themselves providing care in both their family lives and in their work, a phenomenon known as “double-duty caregiving”.

There has been an extensive amount of empirical work done exploring informal caregiving and end-of-life care. However, little research has been done to look at informal caregiving at the end-of life when the family caregiver is a nurse. Therefore, this study was conducted to better understand the experience of double-duty caregivers and to contribute to nursing practice knowledge. A qualitative design, using interpretive description, was chosen. Semi-structured, in-depth interviews, using responsive interviewing were conducted with 10 nurses who had previously provided end-of-life care for a family member.

Four themes emerged from the data: It Takes a Village, Driving the Bus, Juggling Many Hats, and Moving Through and Looking Back. The village was intended to capture those components of a support system that were essential in allowing the double-duty caregiver to do this difficult and demanding work. This support system included both the
necessary assistance to care for their family member and the emotional support needed to be able to provide that care as a double-duty caregiver. Driving the bus was related to expectations that were placed upon the double-duty caregivers to care for their family member, because they were the nurse in the family. The bus refers to the care provided, and the driver refers to the expectations placed on the double-duty caregiver which influenced the caregiving experience. These expectations came from themselves as the nurse in the family, family members, the care recipient, hospice nurses, and physicians.

Juggling many hats refers to the double-duty caregivers relentless need to balance multiple roles, or juggle many hats, which caused substantial distress. It was not possible for them to only be the family member and spend time with their loved one. The need to provide and oversee care constantly weighed on the participants. The last theme, moving through and looking back, encompassed the participants’ description of the impact of double duty caregiving both during the experiences and over time after the family member’s death.

Implications for education, clinical practice, and research are identified. The importance of developing open lines of communication between the double duty caregiver and the healthcare team is essential. Clarity of role and mutual respect between the double duty caregiver and the health care team is vital in determining how the double duty caregiver wants to be involved in care. The identification of educational and support needs is essential. Recommendations include further qualitative studies with diverse populations including non-Caucasian and male double duty caregivers, providing end of life care in the United States. There is also a need to explore the impact of double duty caregiving on professional practice.
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Without the nurses who were willing to share their stories with me, this study would not have been possible. Their willingness to discuss such an emotional and difficult time in their lives, was an inspiration. For many it was a tearful and heartwrenching discussion. However, they wanted to help other nurses who would have to live through the same experience. They wanted their stories to guide the development of strategies to better support their nursing colleagues who might find themselves caring for family members at the end-of-life. It was an honor to be allowed to hear their story. To them, I am extremely grateful.

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Chapter One

Introduction

As the delivery of care changes in our country, we are seeing a transition to community-based care. As a result, there are more people with complex, advanced illnesses being cared for in the home by family and friends. Therefore, informal caregiving has become the foundation of long-term care at home for those age 65 and over in the United States. At least 90% of persons receiving help with daily activities at home receive some form of informal care (Spillman et al., 2014). In 2020, 47.9 million Americans provided unpaid care to a family member or close friend in the past year (National Alliance for Caregiving and American Association of Retired Persons [NAC & AARP], 2020). In 2011, 18 million informal caregivers in the United States provided 1.3 billion hours of care monthly to more than 9 million older adults (Spillman et al., 2014). Research has shown that the physical, psychosocial, emotional, and financial demands on the informal caregiver can be high and that the resulting stress or burden can threaten the ability of the caregiver to continue providing care (Brazil et al., 2012; Garlo et al., 2010; Sautter et al., 2014; Schulz, 2020; Spillman et al., 2014; Spillman et al., 2020). Collectively, informal caregivers provide 75% to 80% of total care hours for these older Americans. This is a substantial amount of care that would need to be provided elsewhere in their absence (Spillman et al., 2014). Schulz (2020) noted:

Caregiving is not a new role for family members. What has changed in the past three decades is the number of individuals who take on this role, the duration and intensity of the care provided, and the complexity of the care delivered. The aging
of the population, increased longevity of older adults with significant chronic disease and disability, and an underfunded and fragmented health and social support system have all contributed to placing the major burden on family members. Caregivers provide a valued service to family members and society, but sometimes at a great cost to themselves. (p. 636)

There is growing concern that with the aging of the baby boomer population (Americans born between 1946 and 1964) and the decline in childbearing in America, along with other demographic factors, that these care needs will not be able to be met causing a care gap (Spillman et al., 2020).

Family caregiving has primarily been the responsibility of women. Women dominate the health care workforce and nurses account for the highest number of these workers. Approximately 2.4 million healthcare workers are nurses (U.S. Census Bureau, 2021). Considering the current demographic data from the National Alliance on Caregiving and the American Association of Retired Persons (2020) and the current description of the nursing workforce from the American Nurses Association (cited in Schnur, 2020), it is safe to assume that a large percentage of informal caregivers for a family member at home are nurses. Remarkably, there has been very little research that has examined the experiences of nurses as family caregivers.

**Area of Interest**

My interest in the experience of the nurse providing end-of-life (EOL) care to a family member, while working as a professional nurse, has emerged from personal experience and the stories of many of my colleagues. As a registered nurse, I had the
precarious privilege of being an informal caregiver for each of my parents as they battled cancer. My mother died from pancreatic cancer and more recently my father died from metastatic renal cell cancer. There are still many aspects of these experiences that trouble me. When I speak with colleagues about my area of interest, they often want to share the stories of their own experiences. This has led me to wonder, what it is about this family caregiving experience that made it so difficult for myself and many of my nurse colleagues?

When my mother became ill with pancreatic cancer, I was working in a small community hospital, with my hours being split as a charge nurse on a medical-surgical unit and a staff nurse in the outpatient oncology clinic. My mother had been experiencing vague symptoms for several months and testing was inconclusive. One morning, while working on the medical-surgical unit, her physician reported to me very matter of fact, as if we were discussing any patient on the unit, that her most recent CT scan revealed a small mass on her pancreas. I immediately knew my mother had pancreatic cancer and a probable eight-month prognosis. I felt like I had been run over by a truck, and still had several hours left to work. He told me about the diagnosis before telling my parents, with no time to prepare myself for this type of news, and in the middle of my workday. That is when I knew I was the nurse and not the daughter.

I quickly assumed responsibility for educating and translating complex medical information for my mother. I often found myself explaining the diagnosis, prognosis, testing, and treatment options. Her physicians often spoke to me, so I could explain things to my mother. I think this was just easier for them, but these were very difficult conversations for me to have. I found myself monitoring the care my mother was
receiving and repeatedly advocating for her. Her care was complex, but this was not an issue, because I had the clinical skills to manage all the necessary care. It was just exhausting. I was glad that I could be there to care for my mother. I knew she appreciated my help and certainly was happy for fewer trips to the oncology clinic for care. However, when problems arose, I would blame myself. I could not help feeling like I did something wrong. I needed someone to reassure me that this was not the case, but no one did.

When my mother needed to be admitted to the hospital to manage symptoms of her illness or the treatments, she would be admitted to the medical-surgical unit I worked on. She felt safe and trusted that I would watch over her. She also did not want to be far from home and her friends and family. I would stay with her after my shift was over. The nurses were very kind to my mother and provided excellent care, but I was always the charge nurse sitting at her bedside, not her daughter. The nurses never sat and talked with me. They never held my hand or asked if I needed anything. I was always “on duty.”

My mother wanted to be treated in the small community hospital she was familiar with, by a staff she trusted. So, we administered chemotherapy to my mother during the day in our outpatient clinic, and I helped her manage the side effects at her home in the evenings. At the time, it was not difficult; it was what I did. However, after my mother passed away, I had a very difficult time working in the clinic and caring for women in their early sixties with cancer. I had to leave that job because it became too difficult.

Ten years later, my father was diagnosed with metastatic renal cell cancer. After doing well for several years after his diagnosis and a nephrectomy, he received the news of the metastasis. In many ways, the experience of caring for my father was like my previous experience of caring for my mother. It was also different, because my father had
his own needs and expectations; he had a different way of coping with his illness. I was responsible for all things that were medically related. I helped navigate the healthcare system, I attended all appointments and helped make all decisions.

My father received his treatment in the same oncology clinic that my mother went to and that I previously worked in. It was our first visit to meet his oncologist and plan his treatment, and I was approached to come back and work in the oncology clinic on a per diem basis. I could feel it starting all over again. My father thought this was a great opportunity, because now I could take care of him when he came to the clinic.

I had learned some things from caring for my mother and requested nursing and social work assistance right away. Initially my father received palliative care and then transitioned to hospice care when appropriate. It seemed so much harder this time. The added responsibility of managing his household affairs in addition to his medical care was daunting. There were more family involved, but they had very minimal responsibilities in my father’s care, per his directions. I now had the added responsibility to keep everyone informed about his condition. When my mother was sick, I just worked with her and my father, and she wanted to be informed and make her own decisions. This time, my father counted on me to make the right decisions, and I had to be sure that the entire family was kept appraised of what was happening.

As my father got closer to his death he became intermittently confused, weaker, and more dependent. He was confined to his bed and his bedside chair. I stayed with him all night and napped on the couch near his bed, ever vigilant that he did not climb out of bed and get hurt. My family made it known that they needed to know when his death was imminent so they could be there. What a responsibility! However, I can remember when
he did get very close to death; I called the family, and everyone was able to visit him one last time. The next day he had a burst of energy and was walking around the house, and then in the yard, with our help. He was also seeing a friend, who had recently died, walking down the street, I knew he wanted to go with him. I knew what these events meant; I had seen it all too often in my practice. The hospice nurse came and reprimanded me. She said I was not medicating him sufficiently and that is why he was restless and anxious, and that “I should know better.” So, I became very vigilant, and I mechanically made him take his medication every two hours until he did become calmer and slept. He died that evening. I was left pondering the question, ‘did I hasten his death with the opioids?’

These difficult experiences have left me reflecting on the events over the years. As I entered my first course in the doctoral program, I was advised to choose something to investigate that I was passionate about, something that was meaningful to me as well as to nursing practice. As I discussed my choice with colleagues, many felt it was an important phenomenon to explore, and many offered to share their own stories. A review of the literature revealed that although there is a plethora of research on informal caregiving, and caregiver distress, there is a lack of research on the experience of end-of-life caregiving when the informal caregiver is a nurse.

**Double-Duty Caregiving**

The phenomenon of a nurse providing informal care for a family member while also working as a nurse has been termed double-duty caregiving (DDC) by Ward-Griffin (2004). Ward-Griffin’s research has shown that there is an expectation that nurses provide competent nursing care while functioning in the role of family caregiver.
According to Ward-Griffin (2004) nurses feel obliged to apply their nursing knowledge when providing care to a family member, yet their expertise was rarely acknowledged. Consequently, many expressed feelings of helplessness, inadequacy, and guilt, which had a negative impact on their health. These feelings are also seen in other family caregivers, but for different reasons (Ward-Griffin, 2004). Nurses who assume familial responsibilities continually negotiate the boundaries between their professional and personal caring work. Despite using a variety of strategies to manage the DDC demands, many female nurses experienced dramatic blurring of these boundaries, resulting in feelings of isolation, tension, and extreme physical and mental exhaustion (Ward-Griffin et al., 2005). The purpose of this study was to explore the experiences of registered nurses providing care to a family member at end-of-life (EOL) while continuing to work and to explore the continued effects after the death of the family member.

**Significance and Relevance**

A majority of family caregivers are female (72-81%) with an average age of 57 to 62 years. Fifty percent of family caregivers are currently working and 50 to 62% have attended college (Brazil et al., 2012; Garlo et al., 2010; Sautter et al., 2014). According to the Human Resources and Services Administration (HRSA), 91.4% of registered nurses (RNs) in the United States (U.S.) are female. These demographics support an assumption that some portion of these family caregivers could be nurses. Nurse family caregiver average age is 48 to 50 years, with almost half being over 50 years old (cited in Schnur, 2020). They are at a time in their lives where they may find themselves caring for aging parents, and possibly other family members or a life partner with a terminal illness. Nurses come to the family caregiving experience with the ability and knowledge to care
for people with advanced illness. With this in mind, the expectations placed upon them may be different than other family caregivers.

It has been reported in the literature that DDC is related to an increase in the physical and emotional burden on the caregiver (Mills & Aubeeluck, 2006; Ward-Griffin et al., 2011a; Ward-Griffin et al., 2011b; Wohlgemuth, 2015). There is evidence that nurses who provide DDC experience increased levels of stress and a negative impact on their physical and mental health (Scott et al., 2006). With the aging of the baby boomer generation and the push towards community-based care, it is safe to assume that DDC will continue to increase. In addition to physical and emotional distress, nurses have also reported an impact on the workplace because of DDC (Scott et al., 2006).

According to the American Nurses Association (ANA), there are nearly four million RNs in the U.S., making nursing this country’s largest healthcare profession (cited in Schnur, 2020). DDC can take a personal and professional toll on the nurse. Due to the physical and emotional exhaustion of DDC, nurses are more likely to reduce their work hours, change their work patterns, or turn down a job offer or promotion. This could have a detrimental effect on the nursing workforce. In addition, double-duty caregivers experience an increased risk for making medication errors in the workplace, decreased work productivity, and an inability to provide high quality patient care (Ward-Griffin, 2004).

**Biases and Assumptions**

Qualitative researchers must be constantly aware of their own biases and assumptions and make a conscious effort to ensure these factors do not influence the
gathering of data or the analysis of that data. Previous personal and professional experiences of this researcher have led to the formation of certain biases and assumptions about informal caregiving, DDC and EOL care. These assumptions include that informal caregiving is stressful and that many informal caregivers are nurses. However, the sources of burden and subsequent stress for the double-duty caregiver are different than the sources of burden and stress for the lay person. It is also assumed that if the sources of burden and stress can be identified, appropriate interventions could be developed to minimize the negative effects of the caregiving experience.

Informal caregivers provide care for elderly family members with varying levels of care needs. Assumptions of this researcher also include that end-of-life care is more complex and burdensome, and therefore results in more severe stress and negative physical and emotional outcomes for the informal caregiver. However, a good death may be possible with the proper care, so adequate interventions are needed to support the double-duty caregiver in the provision of EOL care. Currently, appropriate support and assistance is not readily available for the double-duty caregiver providing EOL care. Health care providers, including hospice personnel, are not always prepared to work with nurses who are also family members providing EOL care. There may be indecisiveness around the role each person will take, and the needs of the double-duty caregiver. This can affect the care provided, as well as the physical and emotional well-being of the double-duty caregiver at the time of care as well as long after the family member has died.
Summary

This introductory chapter provided a brief description of the prevalence of informal caregiving and the potential consequences when the family caregiver is a nurse. This researcher’s personal experiences, as well as biases and assumptions were also discussed.

The next chapter begins with a discussion of informal or family caregiving in the United States. This will be followed by a discussion of informal caregiving at end-of-life. The latter part of the chapter will review the literature on DDC, and the gaps found in this body of literature.
Chapter 2
Literature Review

The present literature search was conducted using CINAHL, PubMed, and Google Scholar. Initial keywords included “informal caregiver”, “family caregiver”, “end-of-life”, “terminal”, and “older adult”. This search revealed thousands of potential articles. Therefore, the search was limited to the last 10 years and to studies conducted in the United States. These restrictions were appropriate as this study was designed to explore contemporary issues in informal caregiving in the United States (U.S.). When “nurse” was added to the keywords, the focus of the literature changed to include the paid work nurses do to provide end-of-life (EOL) care. No studies were found that investigated the experience of nurse as informal caregivers for elderly family members. It was not until a consultant from Washington University recommended the work of Catherine Ward-Griffin, that the term “double-duty caregiver” was discovered. When “double-duty caregiver” was added to the keywords, a small body of literature that addressed the nurse as the informal caregiver was found.

There are three sections to this chapter. This literature review begins with a brief discussion of the status of informal caregiving in the U.S. and informal caregiving at the end-of-life. The final section presents a comprehensive review of the limited literature on double-duty caregiving (DDC).

Informal Caregiving in the United States

According to several authors, the term informal caregiving refers to unpaid care to family members or friends (Campione & Zebrak, 2020; NAC & AARP, 2020; Roth et al.
Schulz et al. (2020) describes the informal caregiver as, “relatives, friends, partners, or neighbors who provide assistance, typically unpaid, to someone who has limitations in their physical, mental, or cognitive functioning” (p. 636). This caregiving includes, but is not limited to, supportive care including household tasks and personal care; self-management activities such as interacting with providers, helping to navigate the healthcare system, managing prescribed medications and financial activities (ie., paying bills, insurance claims); and medically oriented tasks (Spillman et al., 2014).

Informal caregiving is the foundation for long term care for the older population (NAC, 2021; Spillman et al., 2014).

There has been a significant increase in the number of informal family caregivers in the U.S. of 9.5 million from 2015-2020. Currently there are approximately 47.9 million family caregivers in the U.S. (NAC & AARP, 2020). A number of reasons have been identified that have caused this alarming increase: Increasing age of the baby boomer generation who require more assistance with more complex and chronic health conditions; workforce shortages in health care and long-term services and supports; and increased efforts by states to move care to home and community-based services due to rising costs of healthcare (NAC & AARP, 2020).

Data from an online survey using a nationally representative, probability-based online panel with more than 1,700 caregivers who were age 18 years or older generated significant up to date information about informal caregivers (NAC & AARP, 2020). The main source of informal caregiving in the U.S. are family members. Caregivers come from all generations, ethnic/racial groups, income and educational levels, family types and gender identities and sexual orientations. However, they are predominantly middle-
aged daughters and spouses with 61% being female (NAC & AARP, 2020; Spillman et al., 2014). On the average, caregivers provide 23.7 hours of care per week often without adequate supports and services in place. Only 31% of caregivers reported using professional services, such as certified nursing assistants. Sixty-three percent of care recipients have long term physical conditions, 27% have emotional or mental health issues, and 32% have memory problems (NAC & AARP, 2020). A large number of care recipients and caregivers live together or in close proximity.

Description of the informal caregiver’s experience has mainly focused on the negative or burdensome aspects of providing care. Positive benefits of caregiving that have been identified in the literature include satisfaction, a closer relationship with the care recipient, enjoying being with the care recipient, and personal growth (Pristavec, 2019; Walker et al., 2016). Also, 51% of caregivers in the NAC and AARP (2020) survey indicated that the caregiving role gave them a sense of purpose and meaning. However, this co-existed with feelings of physical, emotional and/or financial strain.

The impact of caregiving is very individualized and can affect the caregiver’s physical, psychological, social, and financial well-being (Cohen et al., 2017; Roth et al., 2015; Schultz et al., 2020; Willert & Minnotte, 2021). Twenty-three percent of the caregivers who competed the survey found it difficult to care for their own health and 23% stated that caregiving made their own health worse (NAC & AARP, 2020). According to Spillman et al. (2014) “informal caregivers who regularly provide high intensity help (greater hours of care and assistance with activities of daily living) are more likely to experience burden and stress” (p. 4). As the caregiving demands increase, caregivers felt more isolated and alone. The financial costs borne by informal caregivers
has been very difficult to determine. Loss of days at work, delay of schooling or career advancement, food, transportation, caregiver health costs, and medications are only a few of the costs incurred by informal caregivers (NAC, 2021).

Do et al. (2014) note that the relationship between informal caregiving and health outcomes differs by race and ethnicity and socioeconomic status. However, there is very little data that specifically addresses the impact of caregiving on culturally diverse populations (Willert & Minnotte, 2021). One study by Willert & Minnotte (2021) reported that White female caregivers experienced more emotional strain that non-White females. This finding may be related to the presence of stronger bonds with extended family among non-White females.

A number of factors affecting the caregiving experience have been discussed in the literature. These factors include the type and severity of the care recipients’ health conditions, the type and intensity of the care giving tasks, the relationship between the caregiver and care recipient, and co-existing work and childcare responsibilities (Schulz et al., 2020).

Given the escalating numbers of informal caregivers, the need for assessing caregiver needs and caregiver burden and developing support systems has been given increased attention (Campione & Zebrak, 2020; NAC, 2021). The U.S. has fallen behind other countries in finding solutions to address this significant national issue. However, in 2017 the RAISE Family Caregiver Act was passed to provide essential support to informal caregivers which is a hopeful sign. A detailed description of policy initiatives is now available (NAC, 2021).
Informal Caregiving at the End-of-Life

End of life refers to the final period (hours, days, weeks, months) in a person’s life in which it is medically obvious that death is imminent (Free Dictionary, 2011). Typically, the length of time does not exceed a period of six months which is consistent with hospice guidelines. As the person’s disease progresses and death approaches, the family is often directly involved in providing care. In fact, informal caregivers provide the vast majority of care for people at EOL rather than health professionals (Engbers, 2019; McCaffrey et al., 2015; Ornstein et al., 2017; Wolff et al., 2007).

Although there is some discussion in the literature that this type of caregiving can provide a sense of meaning for the informal caregiver (Anderson & White, 2018; Wolff et al., 2007), the burden of caregiving has received much more attention. As the care recipient approaches the EOL, care becomes increasingly complex and much more time consuming. The informal caregiver is challenged with providing more demanding physical care, addressing pain and distressing symptoms, and engaging in difficult decisions regarding treatment options, hiring paid caregivers, place of death, and final wishes (Given & Reinhard, 2017; Ornstein et al., 2017). According to Given and Reinhard (2017), “making the decision to stop curative care and change to comfort and supportive care is one of the most difficult for patients, family caregivers and health care professionals” (p. 51).

Given the increasing complexity of needs and high intensity care of patients at the end of life, it is not surprising that informal caregivers frequently experience physical, psycho-social, emotional and/or financial stressors (Anderson & White, 2018; Grande et al., 2009; Ornstein et al., 2017; Roth et al., 2015; Wan et al, 2022). More specifically,
Clinically significant levels of anxiety and depression occur (Pottie et al., 2014). As the amount of time required to provide care significantly increases, the caregiver may become more isolated at a time when increased support is needed (Given & Reinhard, 2017). Poorer health outcomes and decreased quality of life have also been identified in the literature (Pottie et al., 2014). Sleep disturbances, gastrointestinal disorders, fatigue, weight loss, loss of strength, and exacerbation of chronic illnesses such as diabetes, heart failure and hypertension are commonly seen (Given & Reinhard, 2017).

The importance of providing support and education to informal caregivers of family members who are dying has been highlighted in the literature (Candy et al., 2011; Hudson et al., 2004; Lowey, 2008). Specifically, education related to interpreting patients’ signs and symptoms, pain management (Chi & Demiris, 2017), skills needed to provide physical care, and emotional preparation for the patient’s death have been identified as essential needs of informal caregivers (Perrault et al., 2004). This intervention requires that health care professionals such as hospice nurses, continuously assess the informal caregivers’ changing informational needs over time. Another major consideration is the caregivers’ ability to absorb information given their level of stress and problems with adequate sleep. Utilizing a variety of educational tools, including written information is strongly recommended by Hudson and colleagues (2004).

Developing interventions to support informal caregivers providing care to a family member at end of life has been identified as a critical need (Candy et al., 2011; Engbers, 2019; Lei et al., 2021; Wan et al., 2022). Wan et al. (2022), in a recent scoping review of support for informal caregivers in Canada discussed a number of possible interventions. Psychoeducational programs which include health checkups for informal
caregivers, peer support and group counseling, and symptom management strategies to alleviate the family members’ distress did demonstrate some benefits for the caregivers.

The economic cost of informal caregiving at the EOL is another major area of concern as the need for complex end of life care in the home continues to heighten (Gardiner et al., 2019; Gardiner et al., 2020). Although Medicare costs in the U.S. for hospice care are available in the literature, costs to the informal caregiver are extremely difficult to determine or even estimate. Some of the financial burden for informal caregivers include, but are not limited to, transportation, food, medications not covered by Medicare or other insurance, the caregivers’ health, amount of caregiving time, and delay in education or career advancement (Gardiner et al., 2020). Since women are the primary informal caregivers, their lifetime earnings can be severely impacted.

**Double-Duty Caregiving**

Although there is an abundance of literature that addresses the needs of informal caregivers and growing investigation regarding the needs of informal caregivers who also work outside the home, little is known about nurses who provide care both at home and at work. It can be argued that the experiences of all employed informal caregivers may be similar, such as juggling multiple roles, and using management strategies to cope with the stress of engaging in paid and unpaid work. However, some authors have argued that the unique knowledge and skills that nurses have strongly influences their experience as a double-duty caregivers (Jones et al., 2021; Ward-Griffin, 2008).

There is limited research on the experiences of the nurse as family caregiver with most studies being conducted outside the U.S. In the late 1990’s studies of the unpaid work by nurses included domestic duties and care of the spouse, children, and aging
family members. Three studies were found that examined nurses providing paid and unpaid care (Gottlieb et al., 1996; Ross et al., 1996; Walters et al., 1996). In these studies researchers focused only on how the nurses balanced personal and professional roles. Although care of the aging family member was included as part of the nurses’ personal role, this was not a focus of these studies. The family members’ functional and health status was not known. In addition, the unique knowledge and skills that nurses possess were not even mentioned. However, researchers in these early studies did report the high levels of stress associated with caregiving in their personal and professional lives. In Ross et al.’s (1996) Canadian study, the participants reported feeling burdened by having too many people depend on them but felt obligated to care for both their families and their patients. They used the phrase “torn between two worlds.” The participants in this study also reported positive outcomes including increased household income, and opportunities for personal growth and self-fulfillment. Although participants in Gottlieb et al.’s (1996) Canadian study reported increased conflict and stress, care of aging relatives did not predict any of the outcomes. The participants in this study also reported an increase in their job satisfaction when coworkers were supportive, and employers were responsive to their family care demands. In contrast to Gottlieb et al., Walters and colleagues (1996) did report increased health problems in Canadian younger women caring for a dependent aging relative. Health problems showed an inverse relationship to job satisfaction. Consistent with Gottlieb’s findings, supervisor support increased job satisfaction.

During this same period of time, also in Canada, Catherine Ward-Griffin and associates began to focus specifically on the experiences of employed nurses who were also informal caregivers of aging relatives. Throughout their work, Ward-Griffin and
colleagues acknowledged that the unique education, experiences, knowledge, and skills that nurses possess strongly impact their familial and professional caregiving. They term double-duty caregivers was used to refer to “women who provide care in both their work and their family lives” (Ward-Griffin, 2004, p.93). Ward-Griffin has used a socialist-feminist perspective to explore DDC. This research focused on the care of elder relatives, with varying degrees of required care. Participants were nurses, and other health care professionals, who were actively providing care for family members and were also employed as a healthcare professional during the studies. In addition to the individual impact of DDC, research studies focused on the effect of DDC on the healthcare workforce with the ultimate goal of effecting work, professional, and socio-political policy (St. Amant et al., 2014; Ward-Griffin, 2004; Ward-Griffin et al., 2005; Ward-Griffin et al., 2009; Ward-Griffin et al., 2011b; Ward-Griffin et al, 2015).

Ward-Griffin’s initial research began in 1992 with a qualitative study to explore “new understandings of the interface of women’s paid and unpaid caring work and to identify possibilities for positive action and change among participants and society” (Ward-Griffin, 2004, p.99). Nurses had to provide at least one hour of care per week to an elderly relative or friend and be employed full time or part time at one of two community healthcare agencies in southwestern Ontario, Canada. A convenience sample of 15 participants was recruited. In-depth interviews were utilized for data collection. Results showed that two dimensions of caring, caring about and caring for, were intricately linked for the double-duty caregiver. There was evidence of caring about and caring for in both family care and nursing care, though in varying degrees. She found that:
the dynamics of care are extremely complex when the family caregiver is a health professional... because of personal and familial expectations, the nurses struggled with the challenges of family caregiving, yet because of their knowledge and “ability to work the system” they could access information and services not normally available to family caregivers. (Ward-Griffin, 2004, p. 108)

The double-duty caregivers in this study viewed their family caregiving as a natural extension of their nursing duties. They felt obliged to use their nursing knowledge to care for their relatives, given the high expectations of themselves as well as the expectations of others, including healthcare providers. They assumed most of the care but expressed concern when they were expected to assume too much responsibility for care of a family member, particularly when they lacked the necessary knowledge and skill. This caused tremendous guilt, especially when the person’s health deteriorated under their care (Ward-Griffin, 2004).

In another study that began in 1999, Ward-Griffin and associates examined the experiences of women in four different health professions (nursing, physiotherapy, medicine, and social work) who provided care to elderly relatives. An exploratory qualitative approach was used. Thirty-seven women from southwestern Ontario, Canada representing the four disciplines, were enrolled. Study findings suggest that “female health professionals who assume familial responsibilities continually negotiate the boundaries between their professional and personal caring work” (Ward-Griffin et al., 2005, p. 379). Despite using a variety of strategies to manage the DDC demands, many women experienced dramatic blurring of these boundaries, resulting in feelings of
isolation, tension, and extreme physical and mental exhaustion (Ward-Griffin et al., 2015).

From this study, a conceptual model of the experience of DDC was developed by Ward-Griffin and colleagues. The model depicted the three closely linked components of DDC: familial care expectations, level of support, and negotiating strategies. These strategies included setting limits, using connections, and delegating care. As expectations increased and support decreased the blurring of the boundaries between professional and personal care increased. As a result, nurses were determined to be “making it work,” “working to manage,” or “living on the edge” (Ward-Griffin et al., 2005; Ward-Griffin, 2008).

Using the data from their 1999 study, Ward-Griffin and associates developed the Double-Duty Caregiving Scale (DDCS) to gain an understanding of DDC which they defined as “the provision of care to elderly relatives by practicing healthcare professionals” (Ward-Griffin et al., 2009, p. 109). The DDCS includes 22 items using a five-point Likert scale (1 = strongly disagree; 5 = strongly agree). The dimensions of the scale include expectations; supports; negotiating strategies which include knowing limits, setting limits, and making connections; and the caregiver interface which includes statements related to the boundaries between professional care and family care. The scale mirrors the components of the conceptual model. Higher scores indicate a greater presence of expectations and supports, an increased use of negotiating strategies, and more blurring at the caregiver interface. Ward-Griffin and associates then designed a study to test the psychometric properties of the scale. The DDCS was administered to an age-stratified sample of female nurses randomly selected from the registry list of the
College of Nurses of Ontario. In a sample of 187 nurses, reliability and construct validity analyses were conducted; The DDCS was found to be a valid tool for the assessment of DDC (Ward-Griffin et al., 2009).

In their next study, Ward-Griffin et al. (2011a) sought to critically examine compassion fatigue amongst those nurse-daughter caregivers who were identified as “living on the edge” from their first two studies. These were nurses who lacked the necessary personal and professional resources to care for their parent, while experiencing high familial care expectations. Compassion fatigue was defined as a condition that affects one’s physical, emotional, and social health and well-being; it was differentiated from burnout. Burnout was described as the inability to cope with job stress and can be experienced in areas other than healthcare. Compassion fatigue is more devastating and is the result of direct exposure to the suffering of the care recipient. Burnout and compassion fatigue can coexist. For this study, 20 nurse-daughter caregivers participated in in-depth interviews. Participants reported that professional education and experience resulted in high expectations of self as well as expectations from family and other health professionals to provide nursing care. Most participants revealed strong feelings of affection for their parents leading to a preoccupation with their parents’ health. They expressed that it was very difficult to provide care when you were so emotionally attached. Consequently, they reported experiencing extreme physical and emotional exhaustion, sleep disturbances, generalized fatigue, hypertensive issues, weight control issues, and feelings of inadequacy and powerlessness. Ward-Griffin et al. (2011a) concluded that, “Being both a nurse and a daughter leads to the dramatic blurring of
boundaries between professional and personal care, which ultimately predisposed these double-duty caregivers to compassion fatigue” (p.1).

In their final study, which was conducted from 2009 to 2011, Ward-Griffin et al. (2011b) employed a two-phased, sequential mixed methods design to examine specific negotiating strategies double-duty caregivers used to provide care to an elderly relative. In phase I a cross-sectional correlational survey design was used to examine the interrelationships of the components of the model they had developed (familial care expectations, supports, setting limits, making connections, and the caregiving interface between the familial and professional domains of caregiving) and the resulting health effects for double-duty caregivers and non-double-duty caregivers. They also wanted to compare the health effects of the three prototypes of caregivers they previously identified (making it work, working to manage, and living on the edge). A total of 1424 nurses completed the survey; 483 identified as double-duty caregivers. It was found that double-duty caregivers that were “making it work” had the best health outcomes compared to the other prototypes and non-double-duty caregivers. Double-duty caregivers that had the most blurring between familial and professional boundaries, those “living on the edge,” reported the worst health outcomes (Ward-Griffin et al., 2011b).

In phase II of the Ward-Griffin et al. (2011b) study an emergent grounded theory approach was used to examine the negotiating strategies utilized by double-duty caregivers: setting limits and making connections. Fifty participants were recruited for phase II, which included two telephone interviews which occurred six to 12 months apart. All 50 participants completed the first interview, and 32 of the 50 participants completed the second interview. Data was only used from the 32 participants that completed both
interviews. It was important to understand how DDC changed over time and how each participant enacted strategies for negotiating care. From this data, Ward-Griffin and associates developed the emergent grounded theory they called Negotiating Professional and Familial Care Boundaries (St. Amant et al., 2014; Ward-Griffin et al., 2011b; Ward-Griffin et al., 2015). Their work was disseminated in several publications.

In one publication, St. Amant et al. (2014) described the professional strategies and resources double-duty care givers used to professionalize familial care. They used practices that were embedded in their professional understanding of care including: assessing, advising, advocating, consulting, collaborating and coordinating. They concluded:

Familial care work by double-duty caregivers parallels closely the work performed within nurses’ professional environment. In fact, the work was at times inseparable. The nurses in this study applied strategies they employed in professional practice to a familial setting. Unfortunately, for many of them, their paid and unpaid care work at times seemed endless. Because familial and professional care work were intertwined and at times overlapping it was difficult for double-duty caregivers to find reprieve from caregiving. (p. 128)

In a subsequent publication, Ward-Griffin et al. (2015) examined another part of the theory, striving for balance, which is the “process that responds to familial care expectations in the midst of available resources and reflects the health experiences of double-duty caregivers” (p.57). They explored the three-prototypes of coping with DDC: making it work, working to manage, and living on the edge. It was found that there were
two subprocesses of striving for balance: reaping the benefits and taking a toll. Reaping the benefits reflected the positive experience when double-duty caregivers were confident and competent that they had the knowledge and resources to care for their family member due to their professional status; usually seen when “making it work.” Taking a toll reflected a state of negative and ambivalent feelings resulting in stress, exhaustion, and self-doubt; usually seen when “living on the edge.”

The body of work from Ward-Griffin and associates, spanning 23 years, laid a solid foundation for examining the experiences of DDC. Their work has been cited in the more current double duty caregiving literature. However, the emerging grounded theory and instrument developed by Ward-Griffin and associates have not been utilized by other researchers to date, which was validated by personal communication with Ward-Griffin (October 25, 2020).

Other researchers have also addressed DDC with most studies conducted in other countries. In the United States, Monahan and Hopkins (2002) explored the impact on work performance in nurses employed in long-term care who also provided eldercare at home. These nurses were providing formal eldercare in the workplace and informal eldercare to their relatives at home. Of the 300 hundred nurses who were employed at the facility over 50% provided eldercare at home. Seventy-four participated in the study and completed a survey instrument. A negative work impact associated with informal eldercare was reported. The largest impact was seen in work absences and decreased productivity (92%). Many considered quitting their job (82%) and reported they were dissatisfied with their eldercare arrangements (80%). Work stress was reported by 65% of the nurse-caregivers.
Mills and Aubeeluck (2006) conducted a qualitative study in the United Kingdom with five nurse participants who had previously or were currently providing care for a family member with a life-threatening illness. This qualitative study used structured interviews to explore the information needs, support systems available, and the impact this experience had on the nurses’ quality of life. All participants reported a negative impact on their quality of life. They needed to make compromises that affected their careers and their relationships. Since they were nurses, they felt that they had to have all the answers and were expected to provide important information to other family members. Members of the health care team assumed that the participants had sufficient knowledge about the illness and treatment which was not always the case. These participants also struggled with not being able to be “just a daughter.” Some dissatisfaction with the care provided by other healthcare professionals and the lack of recognition of their own needs was reported. The participants did not want to appear critical of their colleagues and hesitated to ask for what they needed. The inability to take time off from work added additional stress. Participants also reported possible positive outcomes: their nursing skills provided comfort to their loved one; they also became more reflective in their professional work.

Another study conducted in Canada explored the experiences of nurses as family caregivers when the family was diagnosed with advanced cancer. Cicchelli and McLeod (2012) interviewed five nurses. The predominant finding in this study was the need of double duty caregivers to continuously negotiate the expectations and boundaries of being a family member and a nurse. The participants reported being confident and comfortable providing physical care but sometimes felt inadequate and helpless when
they witnessed the suffering of their family member. Other family members viewed them
as information sources. However, these participants had varying degrees of knowledge
related to the cancer diagnosis and treatment. At times the knowledge they did have
caused fear and stress. The participants also experienced conflict when health care
professionals shared information with them but not the family members leaving them to
decide when and how to share that information. Witnessing the decline and eventual
death of their loved one was very difficult. Although nurses often witness patient decline
and death, it was quite different when the person was a loved one. As the family member
continued to decline decision making also became an expectation.

There are very few research studies that have explored the role of men as double
duty caregivers. Anjos et al. (2012) conducted a qualitative secondary analysis exploring
the gendered expectations and exemptions as well as personal health of male double-duty
caregivers. The sample consisted of 28 male nurses who provided care to a family
member. Most of the participants were in management positions or high-acuity
departments. Social norms and gender were found to shape expectations and exemptions
in providing care. The participants took on the role of nurse instead of family member as
seen in other studies discussed above. Unlike female double duty caregivers, these
participants used their knowledge and skill to educate other family members around tasks
that were perceived as women’s work. They delegated physical tasks such as bathing but
maintained managerial tasks such as organizing care and advocating. In other words, they
made themselves exempt from what is considered female work while maintaining
managerial aspects of care. The family member benefited from their positions and
subsequent connections within the health care system. The participants still experienced
stress as they balanced the dual role and tended to focus on the health of their family member at the cost of their own health. This finding was consistent with other studies presented.

In the Netherlands, Boumans and Dourant (2013) conducted a quantitative study that compared the work-related experiences and personal health status of double-duty caregivers with caregivers that did not care for family members. The caregivers included nurses and other health professionals (n = 328). Of these, 90.2% held a general care function (registered nurse or license practical nurse), 2.5% a paramedical function (physiotherapist, occupational therapist, speech therapist, psychologist, social worker, dietician, spiritual counselor, or nursing home doctor), and 7.3% other functions in home care. Results showed that as double-duty caregivers provided more hours of informal care, their mental and physical health worsened. However, double-duty caregivers appeared to be equally motivated and satisfied with their work as their co-workers. No differences were seen in respect to absenteeism. This study concluded that there was a need for long-term solutions at the organizational and legislative level.

Wohlgemuth et al. (2015) conducted an exploratory qualitative study in the United States examining the dual roles of geriatric professionals, the impact of their expertise on their family caregiving, and the impact of the experience on their professional practice. Participants completed semi-structured interviews and included 16 geriatric health care professionals of which 12 were nurses, three were physicians and one was a social worker. They reported that there were advantages and disadvantages to the dual role. Emotions common to all informal caregivers included emotional
exhaustion, guilt, and stress resulting from the demands of providing and coordinating care. However, they also experienced emotions that seemed specific to their area of expertise: they felt that they were always on call; and that their job extended into their personal lives. Participants described holding back their emotions for the good of their family. They described the strain of being the child and a health care provider and appreciated the healthcare professionals who validated their feelings and opinions. Participants also described the burden of knowing too much and feeling emotionally separate from their families because of understanding the prognosis. Feelings of inadequacy when they did not meet their own expectations or that of the family were described. They often had conflicted emotions and questioned if they made the right decisions. Participants also reported the impact of DDC on their professional practice. As a result of their own family caregiving, they had increased insight and empathy for informal caregivers.

Jones et al. (2021) in the United States, explored the lived experiences of registered nurses as family caregivers during a family member’s episode of care. Semi-structured interviews were conducted with 25 registered nurses. Findings revolved around the dual roles that developed for the registered nurse participants. Consistent with other studies, balancing multiple roles, having insider knowledge, and managing expectations were reported.

Additional studies investigating other types of double-duty caregiving found in the literature were excluded from the present manuscript. These studies included double-duty child care (child care only), double-duty elder care (elder care only), and triple-duty care (child care and elder care) (DePasquale et al., 2016; DePasquale et al., 2018;
DePasquale et al., 2019; Hausler et al., 2017; Drake et al., 2019; Kossek et al., 2019; and Scott et al., 2016). A review of these studies found that introducing childcare issues detracted from the true exploration of double-duty caregiving or the dual role of professional caring and familial caring for those with chronic illness and disability, as well as terminal and end-of-life conditions. Double-duty caregivers used their unique nursing education, experience, knowledge, and skills to navigate this dual role.

The present literature review has revealed multiple gaps in the double-duty caregiving literature. Only three of the identified studies were conducted in the U.S. The remainder of studies were done outside of the U.S. in countries with healthcare systems different from those in the U.S. The studies addressed the care of older adults, but most did not indicate the health or functional status of the family members. Elder care encompasses a continuum of care needs ranging from minimal assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) to complex, high-tech medical tasks. Care recipients in these studies could have had care needs falling anywhere on the continuum. Only two studies specifically indicated that care recipients required a higher level of care: one indicating life threatening illness and one indicating advanced cancer. None of the studies addressed the long-term effects of the double-duty caregiving experience. Considering these gaps, the present study was designed to explore the unique experiences of nurses providing care to a family member at end-of-life, in the U.S., while continuing to work, and the extended consequences of this experience following the family member’s death.
Summary

This chapter contained a review of the literature on informal caregiving and informal caregiving at the end-of-life. This was followed by a comprehensive review of the limited literature on double-duty caregiving. The next chapter will present the research design and methodology used in this study, including participant recruitment, data collection, and data analysis. Implications for insider researcher and issues of trustworthiness are also included.
Chapter Three
Purpose, Design and Methods

The purpose of this study was to explore the experiences of nurses providing care to a family member, at the end-of-life (EOL) in the United States (U.S.), while continuing to work, and to explore the extended consequences of this experience following the family member’s death. Specific research questions guiding this study were:

• What are the experiences of nurses who were double duty caregivers providing care for a family member at the end of life?
• What are these nurses’ perceptions of factors that influenced their experience of double duty caregiving (DDC)?
• How do nurses describe the impact of DDC on their health and well-being following the death of their family member and over time?
• What are interventions that could possibly impact the positive experience of DDC?

Research Design

A qualitative design, using interpretive description, was chosen for this study to better understand the experience of double duty caregivers and to contribute to nursing practice knowledge. The experience of health and illness cannot always be counted or measured. The meaning for an individual needs to be explored. Qualitative research allows for the investigation of a phenomenon in an in-depth and holistic fashion through the collection of rich narrative materials. In this way qualitative research can inform nursing practice (Polit & Beck, 2016).
Interpretive description originated in the discipline of nursing as a pragmatic approach to qualitative research (Thorne, 2008). It acknowledges the rich and complex nature of human experiences, valuing both shared and diverse individual experiences (Burdine et al., 2021; Thorne, 2018). Thorne et al. (1997) states that often such research involves:

- Description of and interpretation about a shared health or illness phenomenon from the perspective of those who live it. Such descriptions can be considered a quintessentially nursing form of science in that they reflect a respect for knowledge about aggregates in a manner that does not render the individual case invisible. (p. 171)

Interpretive description provides an inductive approach appropriate for exploratory research which emphasizes the clinical application of qualitative data (Thorne, 2008). Description and interpretation are combined in the analysis of a phenomenon with the added element of returning the findings to clinical practice (Lywan Ng, 2020). Therefore, interpretive description is an appropriate methodology that can be used across health professions when a study aims to capture the subjective experience of a population and intends to use this knowledge to inform practice (Burdine et al., 2021; Hunt, 2019).

Interpretive description arose from a need for an applied qualitative research approach that could address multifaceted experiential questions frequently arising from clinical practice while producing practical outcomes (Campbell et al., 2020). Historically, nurse scientists located their work within well established and accepted philosophical and methodological guidelines of other disciplines, mainly phenomenology, ethnography and
grounded theory. These social science approaches were dominant even in the culture of nursing. However, these methodological approaches often did not meet the needs of the nursing discipline, which is a practice discipline. In the 1990’s a new generation of nurse scientists began to depart from traditional approaches and examine other possibilities. According to Thorne and colleagues, “Because of the interdisciplinarity inherent in nursing science and the availability of doctoral study in nursing, nurses are less commonly pressed into the disciplinary alliances of those who took their doctorates in philosophy, sociology or anthropology” (Thorne et al., 1997, p. 171). Therefore, they may feel more freedom to examine research questions in the context of the overall objectives of nursing science rather than following the methodological dictates of other disciplines (Thorne et al., 1997). The nature of nursing knowledge has encouraged nurse researchers to depart from the traditional qualitative approaches and pursue methods that are particularly well-matched to answering the kinds of research questions that will advance nursing theory and nursing science. The explicit intention to support clinical practice is a unique feature of interpretive description (Dreher-Hummel et al., 2020).

While interpretive description is a relatively new research methodology, there is a growing body of research using interpretive description, which can act as a guide (Hunt, 2009). Thorne et al. (1997), explains that in contrast to traditional phenomenological inquiry, the design of a study using interpretive description should be based on existing knowledge. This knowledge may come from formal research or clinical experience and should be considered a “foundational forestructure”, representing a beginning point for new inquiry. Although clinical knowledge is useful for providing background for many types of qualitative research, in interpretive description this is made central and explicit”
This foreknowledge provides rationale for anticipated boundaries, theoretical assumptions, biases, and preconceptions that will drive design decisions including sampling, data sources, data analysis, and rigor (Thorne et al., 1997).

**Recruitment**

Following approval of the University of Rhode Island Institutional Review Board (Appendix A), this study began with convenient, purposive sampling, using networking to identify potential participants. This type of sampling has a long developmental history and there are as many views that it is simple and straightforward as there are about its complexity. The reason for purposive sampling is the better matching of the sample to the aims and objectives of the research, thus improving the rigor of the study (Gray et al., 2017; Polit & Beck, 2016).

As participants were identified, snowball sampling was used to identify additional participants for the study. This sampling was purposive, which allowed the use of accessible participants (convenience sampling) but had the added advantage of selecting participants whose experiences were required for the study. Eight participants were selected because they could provide the most relevant information (Bradshaw et al., 2017; Polit & Beck, 2016). Two additional participants were recruited through Sigma Theta Tau, Delta Upsilon at-large Chapter, the professional nurse honor society. A flyer (Appendix B) was distributed through the organization’s listserv to assist in recruitment.

**Participants**

Qualitative samples tend to be small because the emphasis is on the depth and richness of the data and intensive contact with participants, and not on generalizability. There are no fixed rules to establish the most appropriate sample size (Kuzel, 1999). Data
saturation is commonly used in qualitative research to determine sample size. It refers to the point during data collection when no new useful information occurs in the data (Ando et al., 2014; Hennink et al., 2017; Sandelowski, 1995). Researchers have shown that saturation of the data generally occurs within five to 12 interviews and even sooner among homogeneous individuals (Ando et al., 2014; Guest et al., 2006; Hennink et al., 2017). Although this may be a fairly arbitrary range, it is important to recognize that “in the applied health disciplines, it is inherent in the practice mandate that patients theoretically represent infinite variation in relation to their experiences with health care” (Thorne, 2008, p. 98). Therefore, in accordance with Thorne, data saturation may never truly be attainable.

Given the range and practical considerations, a sample size of 12-15 nurses was selected for this study. In this study, nurse refers to registered nurse. Inclusion criteria included: age 18 years and older; the ability to speak and read English; participants, while employed as a professional nurse, also provided informal EOL care for their family member in a home setting; death of the family member; and willingness to participate in a one to 1 ½ hour interview and a shorter follow-up interview. In this study, family members include parents, adult siblings, spouse, or partner. Exclusion criteria included nurses who were providing care for children or family members with dementia since these populations have cognitive and behavioral changes and often a prolonged disease course.

Once potential participants were identified, initial contact was made by this researcher via telephone or email to discuss the study and verify that the participant met the inclusion criteria. If the participant met the inclusion criteria and agreed to participate,
the initial interview was scheduled. The researcher contacted eleven potential participants. One of the potential participants did not reply to any correspondences. The other ten potential participants met the inclusion criteria and agreed to participate in the study. The consent form (Appendix C) and the demographic survey (Appendix D) were mailed to the participant to be completed and returned at the initial interview. Interviews were conducted at a location mutually agreed upon by the interviewer and interviewee. Due to concerns surrounding COVID-19, some participants opted to attend interviews virtually using a Zoom platform (n = 2). All interviews (in-person and virtual) were audio-recorded. Regardless of the platform used, comfort and privacy were paramount.

Data Collection

Data was collected between July and December 2021 using a semi-structured interview guide (Appendix E) and demographic survey. The questions on the interview guide were derived from the research questions. Each participant took part in two interviews. Semi-structured in-depth responsive interviewing based on Rubin and Rubin’s (2012) approach was used with all participants for this study. This method emphasizes the importance of working with interviewees as partners in the research process. Within this approach, researchers develop and maintain relationships with the interviewee, whom they refer to as conversational partners. The basis of the responsive interviewing model is formulating and asking three types of questions: main questions, probes, and follow-up questions. Main questions address the overall research questions and structure. For example, “Can you tell me about your experience caring for your family member at the end-of-life while you continued working?” Probes help guide the conversation and elicit detail. Follow-up questions explore and test ideas that emerge
during the interview. Follow-up questions are critical to responsive interviewing because they create the interaction with the interviewee.

Responsive interviewing involves “choosing interviewees who are knowledgeable about the research problem, listening carefully to what they tell you, and asking additional questions until you really understand them” (Rubin & Rubin, 2012, p. xvi). Interviewers listen to hear the meaning of what interviewees tell them and follow up questions can be used for clarification. According to Rubin and Rubin (2012) responsive interviewing should be used whenever you want to learn about something in depth from another person’s point of view.

A second interview, also using a semi-structured interview guide (Appendix F), was planned to be conducted within a week of the initial interview. Because of the emotional nature of the conversation, and the length of time since the caregiving events, participants may have forgotten important details that they wished they had shared in the first interview. A second interview provided an opportunity for the participant to share any details of their experience that were omitted in the initial interview and allowed the researcher to ask any additional follow up questions. In some cases, due to scheduling difficulties there was a longer time lapse between the first and second interview.

Since talking about life events can be difficult and emotionally taxing for some participants, this second interview also allowed the researcher to check on the well-being of the participants. Most of the participants denied any distress following the interview. However, one participant reported that she had nightmares following the initial interview. She clarified that she expected this to occur, because she always had nightmares after
talking about the experience of caring for her mother. She further stated she has gotten much better at dealing with them, and at the time of the second interview they had ceased, and she was in no distress. Additionally, several participants stated revisiting and discussing their experiences had a positive effect. Following completion of 10 interviews, the data were sufficiently rich providing important insights to indicate the appropriateness of this sample size.

**Data Analysis**

Research questions always guide the research design, inform the development of the interview questions, and provide a reference point for data analysis. In this study, data collection and analysis occurred concurrently each informing the other in an iterative process using a form of constant comparative analysis which had its origins in grounded theory. All of the audio-recordings were transcribed verbatim by a paid transcriptionist. The researcher listened to the audio recordings while reading the transcripts to check for accuracy. Data immersion continued after data transcription through repeated readings of the transcripts to get a sense of the whole, generate initial codes, and write notes on preliminary impressions. Initial codes included relevant words, phrases, sentences, or sections that were labelled throughout the text facilitating early analytical assumptions to be pursued in the ongoing data collection. For example, support, expectations, and balancing multiple roles were found consistently across all interviews.

Two researchers coded the interviews separately, then reviewed and discussed their codes collaboratively until 100% agreement was reached. When more than one researcher codes the data, reliability is enhanced (Polit & Beck, 2016). The codes were then collapsed into categories for the data to be placed within more manageable units.
The process continued with the identification and labelling of themes. The search for themes involved discovering commonalities across interviews but also variations. In the final analytic step, the two researchers reviewed the data once again to determine if the data fit and then the themes were refined as needed.

**Insider Research**

Insider research was a concern during data collection and analysis. The insider researcher has been described as a researcher who conducts research with communities, social groups, organizations, or a culture of which one is a member (Greene, 2014; Kanuha, 2000). The insider researcher has pre-existing knowledge of the context of the research which allows the insider researcher to ask more meaningful questions and read non-verbal cues, as well as provide a more authentic understanding of the group under study. For the insider researcher, the interaction is more natural; they know how to approach the individuals. Participants often welcome the opportunity to discuss issues with someone whom they feel understands. Finally, being a member of the group under study often allows the insider researcher easy access and acceptance. However, insider research does pose potential threats of bias with data collection and analysis that may threaten the credibility of the study (Finefter-Rosenbluh, 2017). To safeguard against potential bias, a personal reflection diary was kept throughout this study and peer debriefing was used to share findings with two committee members allowing this researcher to critically think about the research and to acknowledge any feelings that may affect judgement. For example, this researcher assumed that caregiving at the end-of-life was a stressful, and negative experience. Therefore, peer debriefing prevented this researcher from minimizing the positive aspects shared by participants.
Trustworthiness

Strategies were put in place to ensure rigor and maintain trustworthiness using Lincoln and Guba’s (1985) four criteria: credibility, transferability, dependability, and confirmability. Qualitative research is trustworthy when it accurately represents the experience of the study participants. Credibility refers to the confidence in the truth and interpretation of the data. It is based on the accuracy of the information and whether it matches reality (Amankwaa, 2016; Lincoln & Guba, 1985; Polit & Beck, 2016).

Establishing credibility in this study included investigator triangulation with the coding, analysis, and interpretation of the data among this researcher and her major professors. Prolonged engagement with the data was another way credibility was established (Lincoln & Guba, 1985). This researcher listened to the recordings of the interviews and reviewed corresponding field notes. Transcription of the interviews was completed by a transcriptionist. Once transcribed, transcripts were compared to the recordings for accuracy. All transcripts were summarized, and then initial coding began. Transcripts were read and reread for accuracy. Peer debriefing with at least one of the major professors occurred at least bi-weekly throughout the study. This provided the researcher the opportunity to discuss the interviews, feelings generated in response to the interviews, and initial thoughts and ideas about the content of the interviews.

Transferability refers to the extent to which the findings can be transferred to or have applicability in other settings or for other groups (Polit & Beck, 2016). In this study transferability was addressed by using a purposive sample of registered nurses who provided end-of-life care for a family member while continuing to work as a nurse. In-depth interviews with open ended questions were used to obtain thorough and robust
responses. Thick description and verbatim quotations provided evidence of the participants’ perspective of their experience that may be applicable to other registered nurses across care settings and practices providing care to family members.

Dependability refers to the stability and reliability of data over time and conditions (Polit & Beck, 2016). The questions to ask include: “Would the findings of an inquiry be repeated if it were replicated with the same (or similar) participants in the same (or similar) context?” and “Given the data, would other researchers identify similar themes?” (Polit & Beck, 2016, p. 585). In this study, dependability was achieved through the detailed description of the design, data collection, and data analysis. In addition, dependability was maintained by making the researcher’s central assumptions, perspectives, biases, and values known.

Lastly, confirmability refers to the objectivity, or the agreement between two or more independent people about the data’s accuracy, relevance, or meaning (Polit & Beck, 2016). This reflects the degree to which the findings of a study stem from the characteristics of the participants and the context, and not from the biases, motivations, interests, or perspectives of the researcher (Amankwaa, 2016; Lincoln & Guba, 1985; Polit & Beck, 2016). This researcher and at least one committee member read the interviews separately to ensure objectivity. This researcher kept a journal to detail personal feelings, biases, and values during data collection and analysis. This reflection minimized the effects of these factors on the study findings. Thick description and verbatim quotations also gave evidence of the participants’ perspective of their experiences and was used to support the findings. Confirmability in this study also
included investigator triangulation with the coding, analysis and interpretation of the data between this researcher and one of the major professors.

Summary

This chapter presented the research design, recruitment strategies, data collection, data analysis, and trustworthiness. A discussion of insider research is also included. The next chapter presents the findings from the study. Rich descriptions including participant quotations support the research findings.
Chapter Four

Findings

Each of the ten participants reflected on their experience as a double duty caregiver which provided a window into an extremely personal period of their lives. Although each participant had a unique story, common threads as well as differences were identified. Four major themes were identified: “It Takes a Village”, “Driving the Bus”, “Juggling Many Hats”, and “Moving Through and Looking Back”. A detailed description of each theme with examples from the participants’ voices that illuminate each theme are provided.

Description of Participants

Ten self-identified double-duty caregivers participated in this study, all of the participants were female and white. Approximate ages ranged from 21 to 66 with a mean of 49.3 years. All participants were registered nurses. One participant had an associate degree, three had a bachelor’s degree, four had a master’s degree, and two had a doctoral degree. Approximate years of practice ranged from three to 41 with a mean of 27.6 years. The area of specialization of the caregiver at the time they were providing care, included: Five were psychiatric mental health nurses, one was in nursing education, one was a pediatric nurse, one worked in gerontology, one worked in skilled rehabilitation, and one worked in critical care.

The care recipients included seven mothers, one father, one sister, and one grandmother. At the time of caregiving, five caregivers lived a reasonable distance from the care recipient, three lived in the same household, and two lived 100 miles or more
away. The length of the end-of-life caregiving experience, from the caregiver’s perspective, ranged from six weeks to one year, with a mean of 3.47 months. The amount of time in the caregiving role depended on the specific needs of the care recipient on any given day. For the two participants living 100 miles or more away, care was provided for the entire weekend, every weekend. Nine care recipients died at home and one care recipient died in an inpatient hospice unit due to unmanageable pain. Interestingly, the length of time between the death of the patients and the interviews of the participant ranged from 1.5 years to 26 years, with a mean of 13.5 years.

Themes

Four major themes were identified during the data analysis process. As noted, these included: “It Takes a Village”. “Driving the Bus”, “Juggling Many Hats”, and “Moving Through and Looking Back”. Following is a detailed description of each theme with examples from the participants’ voices that illuminates each one. Participants were assigned fictitious names for the purpose of this discussion.

It Takes a Village

All the participants shared the importance of having “a village” as they journeyed through this experience. The village is intended to capture those components of a support system that were essential in allowing the double-duty caregiver to do this difficult and demanding work. This support system included both the necessary assistance to care for their family member and the emotional support needed to be able to provide that care as a double-duty caregiver. While each participant was able to identify some source of support, some participants had more support than others, and some supports were more effective than others.
This particular theme was dominant throughout all of the participants’ interviews. Familial and work supports, friendship networks, assistance of healthcare professionals, and spirituality set the tone for the experience and laid the foundation for their unfolding stories. Therefore, it seemed best to begin a discussion of this theme by presenting an exemplar scenario, followed by a presentation of each participant’s individual village, allowing for insight into the similarities and differences. This allowed for a truthful presentation of the importance of the support system and the impact of variations.

There was one participant, Kendra, whose story exemplified the ideal scenario of having a cohesive and extensive village. She shared:

So during this time with my mom as I was grieving her diagnosis, and then eventually her impending death and then she died, between my husband and my relationship with my husband, my father, my brothers, and my close girlfriends I had an awesome – and I continue to have – I have a great network. I have a great village. You know that it takes a village.

Kendra identified the most influential and positive factor in her experience as her faith which sustained her throughout this very difficult part of her life. She said:

So my mom was a very, very faith-filled woman, my whole family is. I’m very faith-filled… I think and feel that first and foremost we had, we have a strong faith, and so God has a plan for all of us. We’re just here on Earth which is a dress rehearsal for heaven. That is the frame for my family. So now that I have shared that with you, I would say the most influential factor was our strong faith and knowing that for my mom while we would be here without her physically, that we know she would be with our Lord, Jesus our Savior.
She was one of only two participants who really discussed the impact of faith or spirituality as a source of support during this intense experience. Second only to her faith, Kendra expressed the importance of family, including her husband, her father, and her brothers. She described herself as “having a very cohesive large Italian family.” Right from the start, when her mother was diagnosed with cancer, the approach was “We’re all in this together.” Kendra and her brothers set up a 24-hour schedule for taking care of their mother, and her older brother moved in with their parents to provide overnight care. In addition, Kendra felt incredible support from an extensive network of close friends. She added, “I cried a lot with my brothers, with my husband, with my close girlfriends. I mean my mom was dying, and we went from we thought we were great to we’re dying. Yeah, I was sad.” Kendra’s mother, who was the recipient of care, was also an important emotional support. Kendra stated:

I had such an amazing relationship with my mom… I could talk to my mom about my sadness, about my worries; not every day, but we could talk about that we knew that she was not going to have a lot of time with us, and we could talk about how sad that was for me. And we could talk about, we could talk about it all. We could talk about the joy.

Kendra kept recordings of some of these intimate conversations which continue to keep her close to her mother.

Work supports and the support of healthcare professionals were also an important part of Kendra’s support system. Kendra spoke of having a very flexible and supportive work situation. She stated, “I was also very, very supported by my work environment. So it was really a messaging of ‘Kendra, whatever you need to do, whenever.’ I had no
pressure from my work setting.” In addition, she utilized the professional support from a hospice team. Kendra had assistance from a nurse and a certified nursing assistant (CNA). She noted, “We did use them, and they were wonderful, but I did most of her care.” However, as her mom got weaker and required more assistance, Kendra did rely on the CNA to help her provide the necessary care.

All of the other participants also discussed the important effect of familial support, spousal support, and/or the support of friends. The support that each participant experienced varied, and at times that support was lacking which made the experience more difficult. Carrie had the support of her siblings and her spouse. Paula had the support of her brother, a niece, and a nephew, and stated:

My brother, he lived across the street, and I had two nieces and a nephew, my brother’s kids, all of the five of us trying to take care of her… So it took five of us running for several weeks before she died… She was round-the-clock care. I slept on the floor beside her, and sometimes my brother stayed out in the other room and he slept there. We took turns – everybody else took turns – but I was there the whole time. I was amazed at how much work it was… It was so involved cause it’s much different when you take care of a dying patient or a very sick patient in the hospital cause you do your shift and go home.

Sarah also talked about “recruiting a village” which primarily included her niece, who was a CNA, and a friend who was a registered nurse. She also had multiple friends that helped with her mother’s care, although she reported some were more reliable than others. Sarah’s brothers did not live in the state and her father, who lived with Sarah and her mother, was not a reliable caregiver due to his own limitations. Sarah explained, “I
couldn’t leave my mother alone with my dad because he just couldn’t accept that this was happening… He resisted giving her medication.”

Another participant, Kelly, discussed having had a very supportive spouse and two sisters. Her spouse was able to take on the responsibility of childcare, while she and her sisters cared for their mother. Kelly said, “My older sister and I definitely took more of a role than my younger sister. I think that she just didn’t have the mindset of being able to be in that medical world.” Kelly and her sisters were very close. However, Kelly did feel that her younger sister, having no medical background, needed more support. She shared, “I wanted to be that support for her in her understanding of what was going on every step of the way.” At times, however, this was difficult for Kelly as she noted, “the support coming back the other way wasn’t there because she didn’t know anything.”

Brenda was an only child, so there were no siblings for support with providing care for her dad. Her dad’s brother helped, and her mother did offer some assistance, but this was limited due to her own personal barriers. However, Brenda had an extremely supportive spouse who provided the necessary assistance with childcare and household responsibilities. He was also a tremendous emotional support. Brenda stated, “He kind of grounded me through the whole thing,” and later reiterated, “He certainly is kind of the rock in the background that kind of lets me do what I needed to do during that time... and then steps in where he needs to and when he needs to.”

While Susan provided care to her grandmother, she did get emotional support from her mother, whom she lived with, and who had health challenges of her own. She was not involved in the care of Susan’s grandmother, but as Susan explained it:
She was really that emotional support to just listen to me. It really didn’t take her saying anything to make me feel like there was a weight lifted off my chest. I was able to just talk to her and say, “This is what’s going on. This is why I’m frustrated. This is why I’m sad” and all of that. It was really great support… and after her passing she was right there to support me and be like “You know what, you did everything you could. You tried with the family...You tried your best, that’s all you can ask for.”

Carol, who was the caretaker for her mother, lived with her mother and two children, a daughter who was 11-years-old and a son who was 21-years-old. She tried to protect them from seeing their grandmother deteriorate, but they did help with household chores and shopping, especially her son. She also had four siblings that would visit occasionally but did not participate in their mother’s care. Their lack of knowledge about their mother’s condition and differing opinions about her care led to difficult relationships. Carol was able to run necessary errands while they were visiting, but they resented being left alone with their mother. Carol’s support came from her close friends. She shared, “My friends were wonderful..., ya know. They’d come over and we’d play cards in my mother’s room. She couldn’t play but she’d say, ‘come sit in here so I can hear you, and talk, and stuff’.”

Two participants, Megan and Betty, cared for a family member who lived a long distance away. In these cases, establishing and maintaining that “village” was vitally important. In both cases, these double-duty caregivers would drive to the family member’s home every weekend and depend on others to provide care when they were not there. Megan was an only child, but she had a very supportive spouse who traveled with
her to her mother’s home every weekend. In addition, she said, “I had some wonderful nurse friends who certainly were there for me as well as other sources of support.” She spoke about other sources of support:

Most of my family of origin relatives lived around where she was, and she had an excellent couple who were neighbors so I could call them at any time of day or night and have them check on her which really made it more doable for me. She also had a home health aide… she would pop in every day and check on my mother, so those things were really, I would say, necessary for me to have been able to do what I did.

As her mother declined, over the last several weeks of her life, hospice services were added, and a private home health aide was hired. Megan had to travel to her mother’s home more frequently, and during her mother’s last three weeks of life she stayed with her explaining, “I had some cousins, and her brother and his wife were amazing, but they wouldn’t come in and stay overnight or do, do the things that I felt I would do.”

Betty lived 400 miles from her sister, a six-hour drive, but would drive there to provide care for her sister. Initially she would go every other weekend but as her sister’s condition deteriorated, she would drive down every weekend. When Betty was not there, care would be provided by the care recipient’s friend and her hospice nurse. Betty’s sister had a spouse and a son, but they were not comfortable providing any care. She also had multiple siblings who lived much closer, but they did not help with care and rarely visited. Betty shared:

When I wasn’t there her best friend was the caregiver… the husband and the son really weren’t providing care or giving her medications. And when I would go
there, they would basically be like nonexistent… Between her best friend and I, we were pretty much it. Even my own brothers and sisters who all lived there, including my sister-in-law… my sister-in-law was an RN who lived a half-hour away… didn’t want any part of it… not even sitting with her or going down to see her.

Betty was a single mom with three sons, the oldest was a senior in high school, so she needed to continue working full time. Her ex-husband was supportive and would watch their children when she traveled to her sister’s home on the weekends. However, he was not a source of emotional support. She did have several co-workers that offered some support. Betty found this lack of emotional support from her family distressing. She recalled, “There was never one conversation, not one conversation from anybody, including my own family, not one ever that someone actually said to me, ‘So how are you doing with this? Is there anything I can do for you?’”

Nine of the ten participants described the positive impact of a supportive work environment. One participant, Megan, did have some work stressors. She was starting a private practice and did not feel that she could decrease her workload at the time. However, as her mother declined, she eventually needed to stay with her, noting, “during those last weeks I just put everything work-wise on hold and I stayed there.” Even with a supportive work environment, Carol did change her work shift to accommodate the care of her mother, and then eventually left her work position for medical reasons. She recalled, “They were as supportive as they could be losing a full-time nurse, but they never complained to me about it.” Paula, chose to take a leave to be with her mom, noting, “I took time out of work. I took a leave. I had been there for many many years
and they were good to me. So I didn’t really have to worry about that…. They just said take whatever time you need.”

In contrast, Brenda, chose to terminate one of her two jobs to be able to take care of her loved one. One job involved outpatient counseling, which consisted of more on-call time and a huge investment of herself. The other job was in an in-patient setting, with set hours. She remembered:

Trying to reorganize so that when I did go to work it was punch in, punch out, so that I could be a 100% to family when I needed to be versus really doing therapy during that time which was… I knew I wasn’t gonna be successful and needed to take a giant step back from that.

Brenda also talked about the type of clients she cared for in the outpatient setting. She worked with clients that were parasuicidal and suicidal, and she recalls feeling “completely overwhelmed… I couldn’t be responsible for another person’s death.” She spoke of a “loss of boundary” as an outpatient therapist where you really can be more objective. She stated, “The experience of losing somebody, an impending loss, made me feel like it was a personal responsibility. I mean it is a responsibility as a therapist, but I took it on as like a personal relationship type of commitment.” With just the one inpatient job, Brenda described work as a “reprieve:”

I could go there. I could do a set amount of stuff. I had mastery. I was in control, and I could at least have a place where I felt kind of whole in a way where it wasn’t – everything wasn’t so uncertain.

A number of participants discussed the instrumental support of coworkers during the difficult time of caring for their family members. Sarah explained, “I had a very
lovely staff I worked with, and they were very understanding… I had accumulated a lot of leave and people would cover for me.” Sarah’s schedule was also very flexible allowing her to decide daily if she could go to work or needed to stay home with her mom. Kelly was employed as a nurse providing home care to children and found her colleagues to be very supportive during her mother’s illness. She said, “My work schedule became extremely flexible during that time, and the families that I was working with were very lovely, very supportive. I think that support really helped the whole process.” Susan described her co-workers as very supportive. She explained, “they wouldn’t give me the hardest patient load or the most complex patients, which is tough in an ICU setting… you know the post-surgery people instead of the intubated kind.” She did not make her supervisors aware of her family caregiving responsibilities and did not request any changes in her work schedule. She felt the family would need to make other plans while she was at work. She said:

I gave them (the family) my schedule. I said, “These are the times I’m at work and you’re gonna have to figure it out.” Luckily after very, very much persuading I got them to agree to a CNA for those hours I couldn’t be there.

For all participants, support from healthcare professionals had a significant impact. Nine participants utilized hospice services. However, the impact of these services varied among participants. Several participants deferred certain aspects of care to the hospice nurse, allowing them to be the family member in those moments. Sarah shared:

I used to call on the hospice nurse if my mother needed her foley catheter changed. Although I could have done it, it was something I thought… I’m gonna have them come over and they’re responsible for that. So… just let it go
right?

Brenda recalled, “She (hospice nurse) would take the lead on some of the difficult conversations and just allow me to be the daughter in the room.” Betty had a difficult time listening to her sister discuss her feelings and fears about dying and was able to allow the hospice nurse to be present in these moments. She said:

It is hard here because I didn’t want to talk to her about her dying. I mean when she would start saying stuff I obviously listened but it was very hard for me… and I wanted her to be able to talk to somebody about that, about her wishes… and that’s what I needed the hospice nurse for… When she would start talking about it, it’d be like, “Oh my God.” That was the conflict because the nurse in me would just listen and the sister was like, Oh, I don’t want to even hear this.

Kendra deferred decisions about the dosing of pain medications to the hospice nurse. She shared:

Sometimes the hospice nurse would come in and she’d say, “What do you think about the prn increasing?” And I’d say, “I think what I see in front of me is my – as her daughter, I see my mom in pain but you make the decision about the dose… I’m her daughter. I don’t want to make a decision about morphine now. You make that decision and I’ll do it… I’ll administer it, but you’re in charge of the dosing.” I felt a real supportive and safe space to say, “I’m her daughter not a nurse.”

Even with hospice services, some double-duty caregivers were hesitant to give up the caregiving role. Kelly felt that as a nurse she should be able to care for her mother, and as a result did not get hospice help soon enough. She shared, “I took care of lots of
patients. I’ve taken care of children who have passed away. I’ve taken care of families. I should be able to do this for my own family.” She went on to say:

We really felt like we were on our own. No one really took the helm of resource-providing and that kind of stuff; and I really think we just felt like, ya know, we can do this. We can do this. When you look back, you’re like, no, we probably needed some help.

Even when hospice services were implemented, Kelly and her family never left their mother:

We didn’t take the opportunity to utilize the hospice nurses in the way that I now know about hospice… They were there with us. We did not leave and give ourselves any respite whatsoever.

However, she also felt that there may have been some limitations in the support that was offered because she was a nurse. She spoke of the time when her mother was being started on patient-controlled analgesia (PCA) and the nurses dropped off the equipment and the dosing guidelines but gave very little instruction and support for the use of the equipment. She compared this to the teaching and support that hospice nurses provided in other family situations, “They knew that I was a nurse and so maybe they felt like, ‘Oh well, we don’t have to do as much explaining to them.’”

Another participant, Megan, who lived a distance from her mother, was thankful for the assistance from the hospice team. Unlike Kelly, she felt they did take the time to keep her informed and explain what was happening; and she found this very helpful. However, when she had concerns about her mother’s care, she was often hesitant to
advocate for her mom as she was dependent on the Hospice team’s help and she did not want to jeopardize this relationship. She stated:

I didn’t really feel like I knew them at all…Mother was complaining that she (the home health aide) wreaked of cigarette smoke, and she was rough. And I felt like, I need to somehow voice this to the agency and yet I don’t want to jeopardize anybody else coming in here because I need them.

In contrast, Susan, made it clear that she wanted to be a part of the team, assisting with the treatment plan and sharing her medical expertise. She was pleased with the collaborative relationship established. She explained:

They knew I was like the 24/7 eye. Even when I was not at the house, I knew exactly what was going on. So, I feel that dynamic worked really well just with them respecting that I was a nurse and respecting my perspective as a family member and as a nurse.

Susan also went on to explain an interesting observation she had made being both a nurse and a family caregiver. She described the healthcare professionals and the hospice team as “skating on a thin line.” She noted “some want to be treated as family members, some want to be treated as healthcare professionals. So, you need to read that person and in what aspect they want to be treated as.”

Brenda also found the hospice team extremely supportive, sharing, “We had the most incredible hospice nurse. She was a great advocate for him (her dad) and we were able to get him what he needed toward the end.” She felt the hospice nurses understood the role of family versus the double-duty caregiver being the person who was going to offset what they did, but at the same time they included her in the process. Even with all
the positive support from the hospice team, Brenda recalled instances when non-hospice nurses made visits and did not understand the plan of care for her dad, and described how this resulted in some difficult and painful experiences:

I can remember I was reading a book to my children and the phone rang and I picked it up and it was his doctor screaming at me. “I can’t believe you…you want to take away the DNR…you want him to have all life saving measures…Have you ever seen that? It’s not like ED or whatever that show is. If they do CPR his ribs are gonna break.” He was yelling at me on the phone. And I finally said, after he calmed down, “You will remember I am a nurse. At this moment I am at home with my children, and I do not know what you are talking about.” And then he started to change his tune. Well, apparently our nurse was off that day. They sent somebody who wasn’t a hospice nurse and they wanted to do all kinds of heroic things and were calling the doctor’s office and just didn’t understand the plan of care.

So Brenda, and other participants, recalled negative interactions with the hospice team which made the experience more difficult, and these negative interactions remained vivid after many years.

Paula was convinced by her mother’s physician to get assistance from hospice. He felt she would get more help if her mother was put on hospice care. However, when her mom passed away and Paula called the hospice nurse early that morning, the telephone conversation was very disturbing to Paula. She recalled the nurse saying, “She was already dead. You didn’t need to call me so early.” She remembered feeling bad and thinking, “Well, I’m not used to my mother laying around dead in my house… I don’t
know what you’re supposed to do in that situation cause that’s the first time I’ve had somebody die at home.” Paula then called an elderly neighbor, pleading, “Please come over because I don’t know what to do now…Just come over and be with us for a little while.” Her neighbor did come and stay with Paula.

Carol also used hospice services during the last month of her mother’s life. However, Carol shared, “When she went on hospice they just assumed that I would be taking care of her. They didn’t even offer [any nursing services].” In addition, Carol’s mother preferred Carol to do her personal care rather than strangers; however, Carol did leave the house to do errands while the nurses were in the home. She also felt the nurses took it for granted that she knew what to do because she was a nurse, explaining:

I knew nothing about the hospice philosophy or how it worked or anything, and they just left these meds there and said, “well, ya know, give her the meds when she needs them”… And when I called, she bled out the last night of her life. She was bleeding from everywhere. Everywhere, her ears, it was horrendous. Still the worst death I’ve ever experienced. And I called the hospice nurse and asked them to send someone, that I needed help. And they said, “You’re a nurse. You can handle it.”

Carol also spoke about the lack of spiritual support from the hospice chaplain and her mother’s priest. She commented, “I wasn’t part of the church anymore, so I didn’t need it any more I guess.”

This theme exemplifies the importance of support to the double-duty caregiver. Each participant’s story shows the positive effects of a supportive network of family, friends, and professional caregivers. However, it is also vividly clear that the lack of
support can have serious negative consequences. In the case of professional caregivers, even when they are viewed as helpful and supportive, one inappropriate interaction can have long-term ramifications.

**Driving the Bus**

This theme is related to expectations of the double-duty caregiver that were placed upon them to care for their family member, because they were the nurse in the family. The bus refers to the care provided and the driver refers to the expectations placed on the double-duty caregiver which influenced the caregiving experience. These expectations came from themselves as the nurse in the family, family members, the care recipient, hospice nurses, and physicians.

**Drivers.** All of the participants had expectations of themselves to provide care and to oversee the care provided to their family member because they were a nurse. Paula stated, “Nobody said I had to be there but I couldn’t be anywhere else…and I would not have trusted anybody else.” Carrie felt responsible for her mother’s care and making sure that the best decisions were made. She said, “I felt over-responsible for the whole illness, what was happening with my mom. I constantly questioned, ‘Am I making the right decision? Am I doing the right thing? Am I taking her to enough doctors?… I’m the nurse.’” The need to monitor care that was given was best described by Kelly:

I was like the watchdog, making sure not only things were going OK for my mom from a medical standpoint, but making sure that my sisters, my husband and my sisters’ husbands…like everybody knew what was happening…like I needed to take the helm…probably because of having a nursing background…feeling like I
needed to be the case manager…but I wasn’t the case manager I was her daughter.

Betty provided her own reflection:

You’re just in a different role when you’re a nurse. And I don’t know if it’s the expectations of other people or of it’s the expectations you put on yourself. I don’t know, but you can’t almost have a normal life when you’re the nurse of a family.

As Betty inferred, all care recipients and family members expected the nurse to assume some part of the care, however, those expectations varied considerably. Kendra described that she organized the care and the care delivery was equally provided by her and her two brothers. In Paula’s case, her brother and two nieces looked to Paula for guidance but were willing to help with the care. According to Paula, “I was the boss. I’m the nurse. So they were all looking at me like ‘what are we going to do? How are we going to do this?’ So no one else wanted to take over and they were all willing to help.”

In contrast Susan’s family would stay with their mother but did not provide any physical care. Susan also felt the need to take over other aspects of care, such as giving her the pain medication, because the family was not medicating her properly. Betty received no assistance from family members in the care of her sister. She said:

I think my family felt like, well, I don’t really have to help because she’s the nurse, and she’s the one that can do it… So I think people thought, especially my family, like, well, she does this all the time and, ya know, she’ll be fine. She can just take care of it for us.

Megan felt that her mother expected her to provide her care at home. Although it was never verbalized, Megan said, “It was subtle… she never actually said the words, but
I felt it… She took care of my father …she kept him at home which was his wish. I think she wanted the same thing.” Therefore, Megan drove over 100 miles every weekend to her mother’s home.

Some participants felt that the hospice nurse expected that they would provide care because they were a nurse. Carol stated “When she went on hospice, they just assumed that I would be taking care of her. There were multiple times they didn’t even offer that service (CNA).”

Two participants described the expectations of their family member’s physician in regards to communicating with the family member. As Brenda explained:

As a nurse, you’re always the spokesperson in the room…the one that the doctors’ talk to. It was me who was getting the full story…when decisions need to be made they will also look at you and not treat you like you’re the family member in the room…I think they defer a lot of the responsibility when there is a medical professional in the room…that they’re off the hook…you’re the person that they get to pass this off to, so they can go and take care of other patients. I resent that. I really resent it. Cause you just need to be a daughter.

Carol also discussed that her mother’s physician never shared that she had a terminal illness.

Whenever we went to a doctor’s appointment, they never talked to her. I’d have to encourage them to please talk to my mom. Explain it to my mom…it just never worked out. So I was the one who ended up explaining everything to her… I was the one who told her she was dying, that there was nothing else.
Two participants were the only child in the family system. Megan and Brenda expressed that this was just as strong a driver as being a nurse. They expressed that even if they were not a nurse, being the only child it was assumed they would be the primary informal caregiver.

**The Bus.** The bus refers to the actual caregiving experience of the double-duty caregiver. The expectations placed on the double-duty caregiver, along with the family member’s physical condition and needs, guided the work of the double-duty caregiver. This included physical care, providing support and education to the family, organizing care, advocating, researching alternative treatments, transporting to appointments, communicating with health care providers and collaborating with hospice nurses.

Because of their medical knowledge and familiarity with the healthcare system, participants described their role as a resource to the family, a communicator and an educator, providing information and support to the family. Carrie described having to translate information into terms her mother could understand:

She could make her own decisions but wouldn’t make any decisions until she talked to me and I explained it to her in layman’s terms. So that was a lot of the heaviness…It’s like, ya know, am I explaining it wrong? Am I kinda biased when I’m explaining it?

She went on to say, “She would say to them (her physicians), ‘I want you to talk to my daughter, and then my daughter will explain it to me…I don’t speak your language. She speaks your language.’” Susan spoke of having to teach her family about the physical changes occurring during the dying process:
Knowing everything, or almost everything that was going to happen to her was tough… So when she was going through that final stage of the dying process I was there to be like, “Okay the breaths are gonna slow down… you might not see her breathe for 15 seconds but then she might do an agonal breath which just means she’ll breathe really, really heavy… It’ll sound really awful but she’s okay.”

Betty, who was 400 miles away during the week, felt she needed to be available to the family to answer questions and triage problems when they occurred, even if she wasn’t there at the time. She said:

So even when her friend was there, I became the nurse if there was a problem…and then I had to make decisions. Does she need a visit? Does she need to go to the ER? Then I worry, did I tell them the right thing?

This ability to understand medical terminology and have the knowledge to understand the plan of care, also made the nurse the logical choice to bring the care recipient to medical appointments and bring back information to the family. One participant, Brenda, used the term observer role.

So it’s the professional in the room… so then you become more detached cause you had to have the conversations around healthcare decisions and the translation of it. So you weren’t the daughter there. You stepped out of that role to be the professional in the room.

Carrie shared, “I did allow my sister to take mom to some of her appointments… only if the doctor was willing to call me during the appointment… only if they would get on the phone and talk to me.”
The double-duty caregiver would also organize the care and was often referred to as “the person in charge.” She would collaborate with the hospice nurse and be part of the decision-making process. Kelly shared the need to be in this role. She said, “that feeling like I needed to take the helm… probably because of having the nursing background… feeling like you needed to be the case manager… I wasn’t the case manager. I was her daughter.” Susan felt they were “looking for my medical expertise.” Brenda said, “I definitely was part of that decision-making regarding hospice and… getting the supplies and resources we needed. I was definitely part of that whole process.”

Again, because of the nursing knowledge and skills of the double-duty caregiver, there was an inherent need to monitor care and advocate for the family member when needed. Kelly spoke of a time when her mother was in the hospital, “The nurses on the floor didn’t know how to access her port and they wanted to start an IV. And I’m like ‘No. You get someone who can access it… This isn’t about your convenience it’s about her treatment.’” When Carol’s mother was hospitalized for a surgical procedure, she was having post-op pain and the nurses did not have an order for an analgesic. Carol remembered needing to take on the responsibility of managing her mother’s pain:

She was complaining that she was in pain. So, she had an oncologist, a radiologist. She had a surgeon. She had her PCP, and none of them had gotten back to the nurses with an order for pain med. Here she’s had major surgery and she has nothing for pain… I was nice initially when I went out to the desk. I said, “Please, my mother is in pain, can she have something?” They responded, “Well the doctor hasn’t gotten back to us.” And I said, “Well, you know she does have
four doctors. Let’s try one of the others.” And finally I just flipped out because they weren’t doing anything.

Megan also talked about a need to advocate for her mother. She talked about a time when her mother’s physician was not responding as she thought he should. She said:

My dad died and then she was immediately ill. She had colon cancer, but it took us a while to figure that out because her doctor told her she was grieving and didn’t do…until I sent a registered letter to him saying, ‘Oh my God. If you don’t take care of this there is going to be a price to pay. My mother is ill. She’s not just grieving.’

Kelly and Brenda shared they spent a lot of time researching alternative therapies. Both felt there needed to be more that they could do to help their family member and shared a feeling of helplessness. As Kelly described, “To be perfectly honest, a lot of research looking into new modalities… what else could we do? …looking at homeopathic stuff, seeking out alternative treatments like acupuncture, and ya know, things like that.” Brenda spoke of, “trying to find and read as much as possible for anything alternative… feeling like there needed to be something else I could do because medicine was giving up on him… wanting to find everything and anything to augment and supplement.”

In addition to being an advocate, participants were providing physical care to their family member. However, during the interview process, when asked to describe the caregiving experience, most participants did not include the physical care they provided for the family member. When asked specifically about the physical care, all participants spoke of administering medications, and for six participants this led to a discussion of
pain management. When discussing the care she provided for her sister, Betty shared, “supporting her and getting things in order in the house… especially trying to get her pain under control… never could get it under control. Trying to make sure that medically she was okay… but mainly pain.” They also talked about providing assistance with bathing, toileting and incontinence care, skin care, and turning. Participants spoke of trying to manage the nutritional needs of their family member, including tube feedings. Some family members required oxygen administration and blood glucose monitoring.

When participants were asked why they did not include this physical care in their initial description of the caregiving experience most replied it just came naturally, or it is what nurses do. As Sarah explained:

It may have to do with being nurses. Perhaps it’s just second nature that you wash and turn and do care as well as administer meds and whatever is needed and look out for the other people in the house. So, I never thought of that.

Megan shared, “I guess I just felt like that was part of the whole experience, and I just didn’t really think to speak of it.” She went on to say, “Emotionally it was hard for me. Physically it was not hard for me. Physically I could do it. I knew how to do it. I had the skills to do it. But emotionally… they’re hard to do, They’re hard emotionally.” Paula also said:

I think it’s probably like the physical care is like second nature to us. We know how to do a bed bath and change a bed, and ya know use range of motion and get patients up moving and cough and deep breathing. So that stuff… it’s natural… I think that actually was the easy part… But the emotional part, I mean it’s not easy to lose a parent.
Susan was one participant who did describe the physical care she provided for her grandmother. Her grandmother had nine children, but none of them were willing to provide any physical care for their mother. All of her care was deferred to Susan because she was the nurse. This caused Susan a lot of distress because her grandmother was not getting proper care. Necessary care would be delayed until Susan could get there. Family members did take turns staying with her grandmother, but they would call Susan whenever she needed any personal care. In this instance, despite having a large family, the family provided no support to Susan. Susan shared:

I was always taught we need to maintain the integrity of our patients… My uncle would call me, because she was at that point on 24/7 watch because they didn’t know when she was gonna pass away, and he would call me and say, “she lost control of her bowels and there’s no one here to clean her up,” which was really hard for me because we teach families you need to clean your family member up. You can’t have them sitting in their own feces and urine; and that’s what was happening.

Susan also found the family did not provide medication to her grandmother or prepare her food and feed her properly. Therefore, Susan took over these tasks as well. In addition, the family was not accepting of her grandmother’s prognosis and therefore was not able to make or agree on necessary care decisions. So in the midst of this chaos, Susan felt she needed to find an ally. As her father was deceased, she went to the uncle she felt closest to for support:

It was kind of tough, ya know, trying to get them to make decisions…. Ya know, my father passed away two years prior to my grandmother passing so… ya know,
I didn’t really have him to advocate for her. So, I went to the closest person I knew, and that was my uncle, and he was the eldest boy in the family. So, he kind of talked to the whole family, as a whole, his siblings, and he said, “Listen, we’re just keeping her here for us. That’s the only reason we’re keeping her here.” At that point they started agreeing to things.

**Juggling Many Hats**

This theme strongly emerged from the data of all the participants and is related to how they managed their multiple roles as family caregiver, family member (daughter, grand-daughter, sister, spouse, mother), and nurse. Participants used words like “balancing act”, “juggling”, “dual role”, “walking in two different worlds” and “I’m not a nurse I’m a daughter.” This relentless need to balance these roles caused substantial distress to a majority of the participants. It was not possible for them to only be the family member and spend time with their loved one. The need to provide and oversee care constantly weighed on the participants. Participants felt like they all had a second job. One participant, Brenda, exemplified this struggle stating “How do I be a parent here? How do I be a daughter here? How do I be the professional in the room here? And what hat do I wear at any given time?” Similar sentiments were expressed by all participants. Kelly added, “That dual role was really difficult in juggling… family member and all of the love and support you wanna give to family member… young children…so that role and then also going to work was like very heavy. It was heavy.” Kelly also discussed her concerns being able to continue to give excellent care to her homecare patients while also supporting her family. She said:
Even though I was busy going from one to the other, I did not want to let down my homecare families, but I also did not want to let down my sisters. When they were frightened of something happening I needed to be there for them and for her.

The youngest participant, Susan, described the strain of being a young nurse while providing care for her grandmother. Even though Susan had eight aunts and uncles, none of them were comfortable providing physical care for their mother. For example, they would call Susan to come change her grandmother when she was incontinent. “It was hard to watch this family member (grandmother) and then to care for her as a nurse. It was kind of a double-edged sword for me.”

In addition to this balancing act, participants spoke about the resulting effect on their time. They talked about being on call 24/7, going non-stop, having no down-time, being on autopilot, having a 24-hour schedule, racing time, and dancing as fast as you can. Brenda shared:

I’ve developed a very odd relationship with time. I always felt like it was something that was out to get me…I was racing…it felt that everything had to be done faster and more efficient…and I needed to do more and I think it’s just the helplessness you feel during that process. I’m racing through time to get things done.

Megan provided an example of never being able to have time with her own family. She and her husband planned a three-day respite and she recalled:

Although the relatives were around and the healthcare and whatever…my mother knew we were going. The day we were driving back I got a call from my aunt
saying “Where are you? Where are you? Your mother can’t imagine what happened to you”…and I was like…all I wanted was two days of peace.

A number of participants described strategies they used in an attempt to juggle these roles. Two participants described being able to compartmentalize. For example, Sarah stated, “Once I’m in work, I’m in work…and when I’m home, I’m home.” Some participants intentionally deferred certain aspects of care to other caregivers to preserve time as a family member. Megan convinced her mother, who was the care recipient, to hire outside help so that she could have some time just to be a daughter. She stated “I choose not to come here and spend my time cleaning the toilet, doing the groceries and the laundry. I’d rather sit with you and look at photo albums and reminisce and listen to some music or tell stories.” Other participants requested the hospice nurse to provide certain care. As previously discussed, Sarah requested the hospice nurse change her mother’s foley catheter when needed, Kendra deferred dosage decisions around pain medication to the hospice nurse, and Betty and Brenda looked to the hospice nurse to have the “difficult” conversations with their family members. Brenda recalled, “She (hospice nurse) would take the lead on some of the difficult conversations and just allow me to be the daughter in the room.”

This balancing act and constant demand on the double-duty caregiver’s time proved to be a very difficult situation for most participants, Carrie stated:

I think we have the same feelings that all caregivers have but there’s a whole layer to it, a whole extra layer because we can’t just be the daughter, we have to also be the nurse. And I would cry sometimes about that. I would be like, I just wanna be the daughter.
Betty added, “I don’t want to be the nurse anymore. I wanna be her sister…But I don’t know, sometimes I just couldn’t separate them.” She ended the interview stating, “I would not wish this on anybody to be the nurse of a terminally ill family member. It’s too much.”

Moving Through and Looking Back

Participants shared how being a double-duty caregiver affected them during the caregiving experience and over time after the family member’s death. During the experience, all participants recalled being exhausted, stressed, and overwhelmed. Megan stated, “three-quarters of the time I was in a fog… so stressed out.” Kelly recalled looking back at photos from the time she cared for her mother, and she shared, “Oh my God. I look awful. I look so tired. I don’t remember being that tired,”

Participants also shared the lack of self-care and taking time for themselves while caring for their family member. Kelly talked about not taking good care of herself and not exercising. Susan shared she “was on autopilot” and was not eating right. One participant, Carol, did speak of the physical health effects of caring for her mother:

So at some point, I can’t tell you exactly when, but my health started to suffer. My blood pressure was sky-high. My blood sugars were sky-high, and my doctor put me out of work. So instead of taking care of myself so that I could take better care of her, I just took care of her. All of my efforts went into making her life special cause I knew she had limited time.

Several participants discussed not having the time to process what was happening. Susan stated, “I never, until the day she died, I had never had the opportunity to be emotional and to grieve.” Paula thought that perhaps if she had seen a counselor, or had
someone to talk to, the experience might have been a little easier. However, she stated, “I probably wouldn’t have seen them anyway cause I would have been with my mother.” Brenda echoed this sentiment. She said, “there was clearly, there was no time.”

The dominant emotion experienced by the double-duty caregiver was sadness. Kendra recalled talking to her mom and she said, “we knew she was not going to have a lot of time with us and we talked about how sad that was for me.” She described it as “contextual sadness.” Betty said, “I felt conflicted that I couldn’t be there all the time and just sad that she was so young and just, ya know, just sad.”

Family dynamics did impact the experience for the double-duty caregiver. Frustration and anger did arise when there were strained family relations. Some of these feelings arose when family members would not or could not help in the required care. Susan verbalized a lot of anger and frustration because her grandmother’s children would not clean her up when she was incontinent. They would leave her in urine and feces, waiting for Susan to come and clean her. Susan stated. “So I went home after I had cleaned up my grandmother angry and frustrated…I knew the kind of woman my grandmother was and I wanted to maintain the amount of dignity that she deserved and she was not getting it.” Brenda also experienced anger with her mother for being incapable of helping to care for her father. She said, “For me it was frustration with my mother…she could never stand outside of herself and look at global needs… So I think there were moments when I was incredibly angry with her.” These feelings also arose when there was disagreement around care decisions. Carol was caring for her mother in their home, and her siblings felt she needed to be in a nursing home. She shared:
I loved taking care of her and they insisted she’s going to a rehab. She needs to go there. And I was like “she can have rehab at home. Why take her out of her home?” So we fought a lot about that. Carol finally posed the question to her mother and her mother wanted to stay in her home. Carol said, “They were very angry at me for that.” Susan also was frustrated with her grandmother’s children because they really did not understand the dying process and hospice care, and she felt they were not making the best decisions about her grandmother’s care. She tried to educate them and work with hospice to make sure her grandmother had a good death. Betty had similar issues with her sister’s husband. He wanted her to die at home. However, her pain was unmanageable, and Betty knew she needed to be moved to an in-patient hospice. The hospice nurse was influential in helping with this transition in care. Betty remembers telling her brother-in-law, “I cannot control her symptoms right now. I’ve given her everything I’ve got in this house… I’ve nothing left to give her and she’s not comfortable.” But he refused to move her to in-patient care. She recalled telling the hospice nurse. “He’s really fighting me on it, and I’m not gonna witness this end-of-life horrific death… I just can’t handle that.” The hospice nurse was able to convince the husband to move her to in-patient hospice where she had a peaceful death.

Participants also discussed work-related issues. Although nine of the 10 participants felt their work environment was flexible and supportive, the experience did cause them to alter their work schedule. This involved arriving late, leaving early, or missing a day to provide care to their family member. One participant, Carol, initially changed her shift to accommodate providing care for her mother, and then had to leave
work for medical reasons. Paula took a leave of absence and Brenda left one of her two jobs. Even with reported exhaustion, “being in a fog”, and feeling distracted at work, none of the participants felt that their patient care was affected. It is important to acknowledge that quality of care may have been affected without awareness of the participants. Participant observation may be a valuable approach to collecting this type of data in the future.

Kendra stated:

I became more distracted at work thinking about what was going on with my mom when I wasn’t there… my performance was not impacted at work… I guess I would capture it as intrusive thinking about what is going on with mom right now, how is her pain right now.

Susan also shared, “Fortunately it didn’t affect my patient care… I think I would have called out rather than risking the lives of my patients.”

Participants also talked about some of the lingering effects after the family member had passed away. This time ranged from 1.5 years to 26 years, with a mean time of 13.5 years. The overall sentiment was that it was still very emotional. Most participants did not seek counseling after the experience. They reported talking with their nurse friends. Betty said:

I wish I would have spoken to someone that was not related to me… that was a professional that could get really what was bugging me… I think I was sad for a really long time… It’s almost like you can still function even with grief. And you start to think, well as long as I’m still functioning and able to put food on the table, I don’t really need to go see anybody.
Carol did seek out professional counseling:

    I started seeing her professionally… Having her as a counselor and being able to
    see her once or twice a week was great… I felt, not immediately, but I felt
    comfortable enough with her to cry and sob and yell and stomp my feet and things
    that you need to do. So it felt good to have someplace that was safe to do all that.

Brenda also sought out professional counseling, primarily to deal with the anger toward
her mother:

    After I did, especially to process that anger I mentioned with my mother…
    because how do you continue that relationship when she just never was a healthy
    person… After, processing the grief became something that I needed to do and
    kinda put all those pieces together… and put it into perspective.

Some participants shared more specific long-term effects of the experience. Susan
reported there were still strained relationships between herself and her grandmother’s
children. She also shared that the experiences have affected how she deals with her
hospice patients and their families, stating:

    It opened my eyes to the hospice experience for families... Interacting with
    families is much different now than it was before… I have much more insight on
    what to say to families and how it should happen… I have a whole different
    perspective on how families should be treated, how patients should be treated…
    Just kinda maintaining the patient’s dignity while respecting the family’s wishes.

In addition, Susan shared that her experience thoroughly influenced her career path, and
she was now pursuing an advanced practice degree as a palliative care nurse practitioner.
Carol discussed that it took about a year, but she has mended relationships with her siblings. She also identified changes in her nursing care of hospice clients and their families:

I realized that there’s a lot more going on than just this body that’s dying… Getting the family involved and trying to educate them on what might be needed… If there’s one person that’s the primary caregiver, try to get others to look at the person and offer some support there, not just to the patient.

Betty shared there are two aspects of the experience that she continues to have guilt over. She shared she did not recognize that her sister was experiencing terminal delirium:

The guilt I have as a nurse… that’s the guilt I carry with me… The very last days of her life, I didn’t recognize that it was terminal delirium… She would have went to the hospital sooner. And for some reason, that still carries with me that I did not recognize it.

Betty also expressed regrets that she brought her children to see her sister, and when they arrived her sister was doing very poorly:

Well, that was a big mistake… We walk into the house and as soon as I see her I’m like she is dying. She’s gonna die any day. So, I can’t remember what I did. I don’t remember how I did it… and I said, “These kids need to go back home because I don’t want them seeing her like this.”

Through the interview process, Betty reflected on the experience and when asked what she would have done differently, she responded:
I just don’t think there was anything else I could have done… I should have comfort in that. I should think about that. I should think about, like, what else could I really have done? But I don’t think that way… I don’t go to all I did… Just don’t go to all the good… I don’t know if that’s the nurse in us because I think even as nurses we tend to always focus on what we need to improve… because I think our focus of nursing care is always on the problems. It really is how to fix the problems. So I think it’s hard to go to the good places first.

Participants were asked to think about the experience and to identify what they would do differently if they found themselves in a similar situation. Several participants felt that other than things they had no control over such as the family member getting sick in the first place, being an only child, or being a long distance from their family member they would not change anything. They felt they did the “best they could.” Three participants did say they would take better care of themselves and take more time for themselves. Other comments included asking for help with the grieving process, getting involved with hospice earlier, leaving when hospice was in the home to allow themselves some respite time, and decreasing work responsibilities. Six participants verbalized the importance of the caregiving experience for them personally. As Sarah stated, “I’m just so grateful that we spent that time together… having that rich experience being with her and walking her to the end of her life and reconciling,” Megan shared:

For sure there were positives about it that I had such a close relationship with her… She wrote me a note and left it for me telling me how much she appreciated everything that I had ever been and done for her… I maybe would have done a few things differently but I would have never not done it.
Kendra stated, “There was so much gratitude and honor in taking care of my mom because I was capable to do it.” Paula simply said, “I’m glad I did it.” Carol shared:

It was a pleasure taking care of mom… I was able to talk to her about my horrible adolescent years, ya know, things I tortured her with as I was growing up and resolved those issues between us… I felt like I had no regrets… It really was a blessing having that time with her.

Summary

The findings of this research study describe the unique experiences of the double duty caregiver providing care at end of life to a family member. Direct quotations from the participants, incorporated under each theme, provide rich descriptions of these experiences. The next chapter begins with a discussion of the findings and their relationship with the literature. Limitations and implications for research, nursing practice and nursing education are also presented.
CHAPTER V

Discussion and Implications

The primary purpose of this study was to explore the experiences of nurses as double duty caregivers providing end-of-life care to a family member. Interpretive description was used as the study design. Ten nurses were recruited using purposive and snowball sampling. Data were collected by in-depth individual audio recorded interviews which provided rich descriptions of the nurses’ experiences. Four major themes resulted from the analytic process as discussed in chapter four.

Discussion

It has been reported in the literature that nurses share some commonalities with informal caregivers who provide care for a family member, but they also experience significant differences and challenges (Cicchelli & McLeod, 2012; Jones et al., 2020; Mills & Aubeeluck, 2006). These differences are largely due to their knowledge and experience as a practicing nurse. Nurses assume many different roles when caring for a family member at end-of-life (EOL) including physical care, organizing and monitoring care, communicating with the health care team, educating other family members, advocating, researching alternative treatments, and providing emotional support (Given et al., 2004; Ward-Griffin, 2004; Ward-Griffin et al., 2005). In this study, participants assumed all of these expected roles. However, when describing the care-work they did, physical care was not initially included. Upon probing, participants indicated that this is just what nurses do and it came naturally. As expected, informal caregivers experience a great deal of stress and anxiety when needing to perform nursing tasks including physical care (Bee et al., 2008).
Being an informal caregiver at EOL is stressful and demanding affecting physical and mental well-being (Grande et al., 2009; Jones et al., 2011; Politte et al., 2014; Roth et al., 2015; Wan et al., 2022). For double duty caregivers, balancing multiple roles have been identified as a further source of great stress (Ciccelli & McLeod, 2012; Jones et al., 2020; Mills & Aubeeluck, 2006). The findings from this study support this literature. Participants in this study reported being exhausted and overwhelmed. They were constantly running, being on call 24/7, going nonstop and having no down time. Most participants stated that there were times when they just wanted to be the daughter/sister/granddaughter and not the nurse. As they witnessed their family member declining they experienced great sadness. The emotionality of the experience and sadness persisted even to this day. None of the participants sought professional help during their caregiving experience; rather they relied on their network of friends for emotional support. Two of the participants did seek counseling after the death of their family member. The participants also reported a lack of self-care which has been reported in the literature (Detaille et al., 2020; Miller & Aubeeluck, 2006; Wohlgemuth et al., 2015).

Expectations, both internal and external, placed upon the double duty caregiver are frequently discussed in the literature (Brindley, 2018; Detaille et al., 2020; Jones et al., 2020; Ward-Griffin et al., 2004, 2005, 2015; Wohlgemuth et al., 2015). The findings of this study are consistent with this literature. All participants in this study reported that family members and healthcare professionals had high expectations of them because they were nurses. Some family members expected the double duty caregiver to do all of the physical care, coordinate and organize care, and make difficult decisions.
Some hospice nurses also expected the participants to do the physical care of their family member. The nurses’ work experience can also influence expectations of the self. Some participants felt obligated to be the caregiver because they were nurses and had difficulty relinquishing caregiving.

Providing support to caregivers has been a strong and consistent thread across the literature about informal caregiving, caregiving at EOL and DDC (Candy et al., 2011; Engbers, 2019; Hudson et al., 2004; Lowey, 2008; Wan et al., 2020; Ward-Griffin et al., 2005). In this study, when the participants were asked at the very beginning of the interviews, “tell me about the experience of caring for your family member,” they immediately and spontaneously started to describe the presence or absence of familial supports. This was foremost in their minds. Throughout the interviews it became clear that the amount and type of support strongly influenced their entire experience.

Support includes assistance with actual physical care of the ill family member and meeting the emotional and educational needs of the caregiver. The importance of assessing the informal caregivers’ knowledge and skill in providing care to respond to educational needs has been highlighted in the literature (Candy et al., 2011; Hudson et al., 2004; Lowey, 2008; NAC, 2021). However, when the informal caregiver is a nurse, it is often assumed by family members and health care professionals, they have the knowledge and skill to provide appropriate patient care as well as assume other roles (Jones et al., 2021; Ward-Griffin et al., 2005). Depending on the nurses’ area of specialization and clinical expertise, this may not be the case. Not every nurse knows/feels comfortable with complex care at the end-of-life. In this study, the
participants differed in their level of comfort and desire to participate in different aspects of care.

There is evidence in the literature that the interactions between the double duty caregiver and the healthcare team, including hospice nurses and physicians, play an important role in the caregiver’s experience (Detaille et al., 2020). There needs to be a good relationship and open communication with the health care team regarding mutual expectations. In this study, most participants reported positive and supportive relationships with the healthcare team. However, there were particular instances of poor communication with healthcare providers and lack of mutual respect which was extremely distressing for the caregiver. None of the participants reported the hospice nurse introduced a discussion or assessed the double duty caregivers’ needs and role in the care of their family member. In fact, in this study, five participants initiated the conversation with the hospice nurse with specific requests such as being a collaborative part of the healthcare team, or not wanting to dose medications, insert a foley catheter, or be responsible for difficult discussions with other family members.

Having a supportive work environment, including supportive colleagues and supervisors who are responsive to their family caregiving demands, has been noted in the literature to improve job satisfaction (Boumans & Dourant, 2013; Detaille et al., 2020; Monohan & Hopkins, 2002; cited in Ward-Griffin et al, 2015). According to Ward-Griffin et al. (2015), inflexibility in the work schedule was the main reason that double duty caregivers left their employment. In this study, nine participants reported a positive work environment with supportive colleagues and accommodating managers. As a result, participants reported job satisfaction. However, one participant took a family leave and a
second participant took a medical leave due to medical problems that were exacerbated by the stress of family caregiving. Another participant continued to work but did leave a second job that she had prior to caring for her father. Some authors have suggested that nurses’ paid work can be compromised when they are a double duty caregiver (Ward-Griffin, 2004). Although several participants described being distracted and fatigued at work, they also specifically reported that the quality of patient care was not affected.

Surprisingly, only one participant discussed the economic burden that she experienced as a consequence of her caregiving. Authors have addressed this as well as the need to provide financial renumeration to informal caregivers as well as support (Candy et al., 2011; Gardiner et al., 2020; Orzeck et al., 2014). Earning potential and income are also affected when one engages in double-duty caregiving (DDC) (Orzeck et al., 2014; Wohlgemuth et al., 2015).

Although authors emphasize the burden of double duty caregiving, there is some evidence in the literature that positive experiences do occur. Some double duty caregivers in past studies have described feeling good about being able to provide care and comfort to loved ones, having a sense of fulfillment (Mills & Aubeeluck, 2006), and increased empathy in one’s professional role (Wohlgemuth et al., 2015). In the present study, five participants also discussed some positive outcomes from the experience. Two were able to resolve past conflicts with their family member. One expressed that “it was an honor and a blessing.”

The present study underscores the unique needs of double-duty caregivers providing EOL care to a family member. When a caregiver is a nurse, balancing multiple roles and managing expectations of the family, healthcare professionals, and
oneself adds additional significant burden. Although the average length of time since the
death of the family member was 13.5 years, it is remarkable that when the participants
reflected on their caregiving experience, the type, amount and effectiveness of support
they received was the pivotal factor that shaped their experience. The overwhelming need
for support of the double-duty caregiver is paramount. The notion that the double-duty
caregiver is a nurse, so “he/she can handle it” is not acceptable. Family members and
healthcare professionals should not assume that the double-duty caregiver has the
knowledge or skill to provide the required care. Healthcare professionals should do an
assessment of needs, as they would do with any family caregiver. Even if double-duty
caregivers have the necessary abilities, they still need emotional support during this
stressful and difficult experience. There needs to be mutual respect between the
healthcare professional and the nurse family caregiver, collaboration, and a delineation of
expected roles at the onset of care, and continuously throughout the caregiving
experience as the needs of the care recipient changes.

Limitations

Limitations of this study principally reflect the participant sample. The sample was
very homogenous. All participants were White women from one state on the
northeast coast. This was an educated group of women with six participants having a
graduate degree. Five of the participants were psychiatric mental health nurses. These
participants did not provide physical care to patients in their workplace and had more
flexibility in their scheduling compared with the remaining participants. The psychiatric
mental health nurse participants also had a network of nurse colleagues who were
“counselors” that provided support.
Another potential limitation was that two interviews were conducted on zoom which impacted the ability to observe nonverbal cues. Although facial expressions were observed, observations of general body language was limited. A third limitation concerned the mean length of time since the death of the family member which was 13.5 years. Although some might question the ability to recall details after such a long time period, the majority of participants stated ‘it seems like yesterday.’

**Methodological Implications**

Interpretive description, originated in the discipline of nursing, to provide a research approach that specifically emphasizes the clinical application of qualitative data. This methodological approach provided a meaningful way to explore the experiences of double duty caregivers providing end-of-life care to a family member with the purpose of influencing nursing practice. Despite the challenges imposed by COVID 19, the in-depth guided interviews provided meaningful and rich data. Knowledge gained from this study will add to the literature and has important implications for nursing research, practice and education.

**Implications for Future Research**

Further research is sorely needed with diverse populations who provide double-duty caregiving at EOL care in the United States (U.S.). There is a paucity of literature that specifically examines the experiences of non-white informal caregivers. This is extremely important in order to develop culturally appropriate interventions and policies that address caregiver health. There has also been very little research conducted with male double duty caregivers.
Participants in this study provided care for a family member who died an average of 13.5 years ago. These participants were selected to explore long-term effects of double-duty caregiving. However, given that hospice care has continued to evolve over this time period, it would be extremely beneficial to conduct a study of double duty caregivers whose family members died within the last two years. Exploring the relationships and communication between the hospice nurses and the double duty caregivers is particularly essential.

There is also a need to explore the impact of double duty caregiving on professional practice. There is some evidence in the literature that double duty caregiving can affect the workforce as well as individual work performance. In this study, none of the participants identified any negative impact on the care of their patients in the clinical setting.

**Implications for Nursing Practice and Education**

Nine participants in this study utilized hospice services. However, the impact of the services varied significantly among participants. Hospice philosophy emphasizes family centered care. In order to provide this type of care, collaboration with the double duty caregiver is key. Clarity of role and mutual respect between the double duty caregiver and hospice nurse are vital in determining how the double duty caregiver wants to be involved in care. Given the expected increase in double duty caregivers in the future, all nurses need to be educated about the stressors that exist for double duty caregivers and the importance of identifying the unique needs of each double duty caregiver. Hospice nurses need to be educated about the variation in knowledge
that nurses have based on areas of specialty and experience. The need for the development of interventions for supporting caregivers of family members at end of life has been identified as a priority (Cohen et al., 2011; Wan et al., 2022). Interventions to relieve the caregiver burden of double-duty caregivers need to be individualized and collaborative.
Appendix A

University of Rhode Island Institutional Review Board Approval

THE UNIVERSITY OF RHODE ISLAND
DIVISION OF RESEARCH
AND ECONOMIC DEVELOPMENT

OFFICE OF RESEARCH INTEGRITY
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FWA: 00003132
IRB: 00000599
DATE: July 19, 2021

TO: Susan DeSanto-Madeya
FROM: University of Rhode Island IRB

STUDY TITLE: Nurses as Double Duty Caregivers for Family Members at the end-of-Life: Interpretive Description

IRB REFERENCE #: 1771341-1
LOCAL REFERENCE #: IRB2122-006
SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS
EFFECTIVE DATE: July 16, 2021
REVIEW CATEGORY: Exempt 2(iii)

Thank you for your submission of materials for this research study. The University of Rhode Island IRB has determined this project falls into the EXEMPT REVIEW category according to federal regulations 45 CFR 46. Per URI IRB policy, the project has been reviewed by either the IRB Chair or the IRB Administrator. Approval is valid for the duration of the project.

No changes to procedures involving human subjects may be made without prior IRB review and approval. You must promptly notify the Office of Research Integrity of any problems that occur during the course of your work using Appendix S - Event Reporting.

If you have any general questions, please contact us by email at researchintegrity@etal.uri.edu. For study related questions, please contact us via project mail through IRBNet. Please include your study title and reference number in all correspondence with this office.

Matthew Delmonico, Ph.D., MPH
IRB Chair
Appendix B

Recruitment Flyer

RESEARCH STUDY
CAREGIVERS PROVIDING END-OF-LIFE CARE FOR LOVED ONES

RN\textsuperscript{s}

I am a registered nurse with a background in oncology and palliative care, and a student in a PhD program in the College of Nursing at the University of Rhode Island. I am very interested in learning about the experiences of nurses who have provided end-of-life care for a family member while continuing to work in a paid nursing position. You would be asked to participate in an interview lasting about 45 minutes to an hour at your convenience.

I am looking for RN\textsuperscript{s} who have lost a loved one at least one year ago, to volunteer to be interviewed about their experience.

If you would like to participate in this research study or have any questions about the study please contact me:
Sandra A. Basley RN, PhD(c)
sbasley@uri.edu

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Appendix C

Informed Consent

THE UNIVERSITY OF RHODE ISLAND

IRB Exempt Consent

[Susan DeSanto-Madeya]
[College of Nursing]
[Nurses as Double Duty Caregivers for a Family Member at the End-of-Life]

You are being asked to take part in a research study. The purpose of the research study is to explore the experiences of nurses providing care to a family member at the end-of-life (EOL) while continuing to work, and to explore the extended consequences of this experience following the family member's death. Please read the following before agreeing to be in the study. If you agree to be in this study, you will be asked to participate in two interviews. Both interviews will be recorded and kept confidential. It will take you approximately 60 minutes to complete the first interview and approximately 30 minutes to complete the second interview. Questions will be asked about your experience providing end-of-life care for a family member while continuing to work in your nursing role. There are no known risks, benefits or compensation.

Your responses will be confidential. Interviews will be transcribed and all identifying information will be removed. Transcriptions will be kept in a locked cabinet in the primary investigator’s private office. Access will be limited to members of the research team. The responses may be used in this dissertation and published manuscripts.

The decision to participate in this study is entirely up to you. You may refuse to take part in the study at any time without affecting your relationship with the investigators of this study or the University of Rhode Island (URI). Your decision will not result in any loss of benefits to which you are otherwise entitled. You have the right not to answer any single question, as well as to withdraw completely from the interview at any point during the process; additionally, you have the right to request that the researchers not use any of your responses.

You have the right to ask questions about this research study and to have those questions answered by me before, during or after the research. If you have questions about the study, at any time feel free to contact Susan DeSanto-Madeya from the College of Nursing at the University of Rhode Island at (401) 874-2038.

Additionally, you may contact the URI Institutional Review Board (IRB) if you have questions regarding your rights as a research participant. Also contact the IRB if you have questions, complaints or concerns which you do not feel you can discuss with the investigator. The University of Rhode Island IRB may be reached by phone at (401) 874-4328 or by e-mail at researchintegrity@etal.uri.edu. You may also contact the URI Vice President for Research and Economic Development by phone at (401) 874-4576.
By signing this consent form, I confirm I have read the information in this consent form and have had the opportunity to ask questions. I also confirm that I am over age 18 years. I will be given a signed copy of this consent form. I voluntarily agree to take part in this study.

Printed Name of Participant

Signature of Participant Date

Printed Name of Person Obtaining Consent

Signature of Person Obtaining Consent Date

AUDIO/VIDEO ADDENDUM TO THE CONSENT FORM FOR RESEARCH
By signing this consent form, I confirm that I give my permission for audio or video recording(s) of me, to be used for the purposes listed above, and to be retained for five years. You may still participate in this study if you are not willing to be recorded.

Printed Name of Participant

Signature of Participant Date

Printed Name of Person Obtaining Consent

Signature of Person Obtaining Consent Date
Appendix D

Demographic Form

Demographic Data Collection Sheet

Code Number: _______________

Directions: Please complete this survey based on your status during the caregiving experience.

1. Gender:  □ M  □ F

2. Age (years):  □ 21-25
    □ 26-30
    □ 31-35
    □ 36-40
    □ 41-45
    □ 46-50
    □ 51-55
    □ 56-60
    □ 61-65
    □ 66+

3. Ethnicity:  □ White
    □ Hispanic or Latino
    □ Black or African American
    □ Native American or American Indian
    □ Asian/Pacific Islander
    □ Other: ________________________

4. Caregiver relationship to dying person:
    □ Parent  □ Mother  □ Father
    □ In-law  □ Mother  □ Father
    □ Spouse  □ Wife  □ Husband
    □ Partner
    □ Sibling  □ Sister  □ Brother
    □ Other: ________________________
5. Status of residence at time of caregiving:
   □ Shared same household
   □ Lived independently, but in reasonable distance to provide care
   □ Lived independently, but needed to move to provide care
   □ Other: __________________________

6. Amount of time spent in caregiving role:
   Daily: ________
   Weekly: _______

7. Length of caregiving experience:
   Weeks: ________
   Months: _______
   Years: _______

8. Location of death:
   □ Home    □ Acute care    □ Long term care facility    □ In-patient hospice
   □ Other: __________________________

9. How long ago did your family member die? _________________

10. Level of education:
    □ Diploma
    □ Bachelor’s degree
    □ Master’s degree
    □ PhD

11. Years of nursing practice:
    □ 0-5
    □ 6-10
    □ 11-15
    □ 16-20
    □ 21-25
    □ 26-30
    □ 31-35
    □ 36-40
    □ 41+

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12. Setting of nursing practice:  □ Hospital  □ Skilled nursing facility  □ Long-term care facility  □ In-patient rehabilitation  □ Out-patient rehabilitation  □ Clinic/healthcare provider office  □ Homecare  □ Community

13. Nursing Specialty: ________________________________

14. Role of employment:
   □ Direct care  □ Manager  □ Administrator  □ Educator
   □ Other: ________________________________

This research has been approved by The University of Rhode Island Institutional Review Board.

The University of Rhode Island is an equal opportunity employer committed to the principles of affirmative action.
Appendix E

Interview Guide

Code Number: __________

Opening remarks

First I want to thank you for meeting with me today. As you know, I am interested in learning more about the experiences of nurses who have provided end-of-life care for a family member. I believe it is important to learn about these experiences in order to plan effective interventions to better support nurses – both as clients and caregivers.

*Review the consent form and invite participant to ask any questions. Obtain signature if this has not been previously obtained.*

*Collect Demographic Survey*

This interview will be recorded. Are you okay with that?

Just to remind you, you may pause at any time and at any time you may ask to have the recording stopped. As well, you may stop the interview at any time.

Prompting Questions

1. Please describe what it was like for you to take care of _______ at end of life while also working as a nurse.
2. Please describe any factors that influenced this experience.
3. Please describe how this experience affected your health and well-being, including after the death of ________, and over time.
4. Is there anything that did, or could have, made this a positive experience.
5. Looking back, is there anything you would have done differently?
6. Is there anything else you would like to share about the caregiving experience?

Thank you for sharing your story with me today. I know it can be difficult talking about such an emotional time in your life. Are you feeling okay?

I would like to set up a time for our second interview. This will be a time for you to share any information that you may have not thought about today. It will also give me the opportunity to be sure I have accurately understood the information you have shared, and to ask any follow-up questions I might have. When would it be convenient for you to meet?
Appendix F

Follow-up Interview Guide

Code Number: __________

Opening remarks:

I want to thank you for meeting with me again today. First, I wanted to make sure you were not experiencing any distress after the interview on __________. This interview will also be recorded. Are you okay with that? Just to remind you, you may pause at any time and at anytime you may ask to have the recording stopped. Also, you may stop the interview at anytime.

Prompting Question:

1. Is there anything else you would like to share about your experience caring for __________ at the end of life while also working as a nurse.

   *At this time I would validate my interpretation of information shared in the first interview and ask any clarifying questions.*

Thank you for taking the time to participate in this research project and sharing your story with me. May I contact you if I have any further questions about what you have shared with me?

Further referrals:

Do you have any friends or colleagues that you can think of that might be appropriate for this study?

If so, would you be willing to contact them and ask permission to give me their contact information?
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