

**Double and Triple Duty Caregiving and  
its Effect on Personal Health and Wellbeing:  
A Pilot Project and Sample Funding Proposal**

by  
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## Ethics Statement

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University

or has conducted the research

- c. as a co-investigator, collaborator, or research assistant in a research project approved in advance.

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## **Abstract**

This capstone project examines the effects of double and triple duty caregiving on the personal health and wellbeing of nurses. A mock research grant is proposed for the Canadian Institute of Health Research (CIHR) Project Scheme, based on a critical review of literature and the results of a pilot project. Qualitative interviews were conducted with nine female nurses (aged 45 to 67) living in British Columbia who were providing informal caregiving for a family member. Results from the pilot project indicate that these caregivers experience adverse physical and mental health issues, which in turn compromise their job performance and heightened their family obligations. Caregivers also experience burden differently, depending on their nursing qualifications and support networks. Overall, it is argued that research is needed on this topic to further examine how double and triple duty caregiving places unnecessary strain on both healthcare workers and the health care system.

**Keywords:** double duty caregiving; triple duty caregiving; wellbeing; health; job performance; work-family balance

## **Dedication**

I dedicate this capstone project to my mother, Jane Campbell, the ultimate triple duty caregiver.

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# Chapter 1.

## Introduction

### 1.1. Background and Rationale

In 2012 the Canadian General Social Survey (GSS) reported that eight million Canadians provided care to family members or friends with long-term health conditions, disabilities, or issues associated with the effects of aging. Indeed, 30% of Canadian women reported that they provided care to a family member, and of those between the ages of 45 to 64, approximately half were currently caring for a parent (Sinha, 2012). It is also estimated that 30 to 50% of the working population is providing care to elderly family members (Ward-Griffin et al., 2009). Thus, caregiving constitutes a significant role undertaken by families, especially among women. As our population continues to age, this activity undoubtedly will take on added significance for individuals, communities, and the Canadian health care system.

Although most family caregiving is informal (or unpaid), it is critical to recognize that caregivers may be providing unpaid, paid, or a combination of both types of care. For the purpose of this project, Nicole DePasquale's "double duty" and "triple duty" caregiver terms are used to describe certain types of carers. Health care professionals such as nurses, who provide formal (paid) caregiving, and are also caring for a family member or friend, are hereafter referred to as double duty caregivers. These individuals are further classified as double duty elder caregivers if the individual is providing care for an older adult, or double duty child caregiver if the healthcare professional is providing care for a child. Finally, the term triple duty caregiver can be applied to women employed in the health care field and also caring for an older adult such as their parent(s) or parent(s)-in-law as well as children of various ages (DePasquale, Bangerter, Williams & Almedia, 2016a). However, the structural elements of caregiving relationships described above are not what directly affect a woman's health and wellbeing. Rather, it is what Catherine Ward-Griffin (Ward-Griffin et al., 2009) termed the 'blurred boundaries' of caregiving. Blurred boundaries between paid and unpaid caregiving explain the inability of nurses to separate their paid and unpaid caregiving responsibilities. The overlap

begins to accumulate and the women are cemented into a cycle of constant caregiving with little relief. Therefore this project does not provide a comparison between double and triple duty caregivers as some authors have previously done, but examines the results of the blurred responsibilities between paid and unpaid caregiving among nurses.

According to the Canadian Institute of Health Information (CIHR) (2011), the average age of health care professionals is rising, increasing the likelihood that employed, formal caregivers are also providing informal care to elderly relatives. These individuals are more likely to be women, some of whom may also be caring for children as a part of the so-called “sandwich generation.” The “sandwich generation” is a term used to describe middle-aged women who are in between the acts of caring for their (typically) young adult children, while also balancing the demands of caring for their aging parents (Mitchell, 2014). However, this literature neglects women who are sandwiched between generations and also provide formal caregiving as a nurse or health care professional (Ward-Griffin et al., 2005; DePasquale, Davis, Zarit, Moen, Hammer, & Almeida, 2016b).

According to the GSS, 30% of individuals caring for an older adult reported 5 of 9 possible signs of psychological distress and comprise the largest group of individuals requiring access to health care services. For example, one million Canadian family caregivers consulted a medical professional as a result of a caregiving responsibility, and of that group, 402,000 were caring for a parent. In comparison, approximately 175,000 reported caring for a spouse, and about 120,000 reported caring for a child (Minha, 2012). The financial burden and other hardships associated with caregiving also play a large role; 10% of family caregivers caring for a parent stated that their caregiving duties prevented them from maintaining employment (Minha, 2012).

Falling birth rates, increased participation of women in the work force, higher divorce rates, and greater geographic mobility will persistently limit the availability of informal caregivers (Keefe, Glendinning & Fancey, 2008). Despite these changing demographic trends, the Canadian health care system relies on family members and friends to help care for the rapidly aging population in order to share the burden and cost associated with caregiving. If these caregivers are women who work in the nursing profession, there is often an assumption that they should care for their aging parents (Depasquale, Mogle, Zarit, Okechukwu, Kossek, & Almeida, 2017). However, this aging

population of nurses who are also providing informal caregiving can experience adverse physical and mental health issues, compromised job performance and thus economic status and heightened family and social obligations (Keefe et al., 2008). On a macro-systemic level, this burden can result in a higher rate of workplace accidents and job turnover (DePasquale et al., 2016a), resulting in greater costs for business and government.

## **1.2. Purpose and Research Questions**

Given the pressing and growing significance of the issues previously discussed, the purpose of this capstone project is to develop a grant funding proposal based on the Canadian Institute of Health Research (CIHR) Project Scheme (2018). Specifically, I propose to further examine the effects of double and triple duty caregiving on the personal health and wellbeing of nurses. Additionally, this project examines the impact that negative health and wellbeing can have on job performance and work-family conflict. Chapter 2 will cover the theoretical perspectives that guide the research, while Chapter 3 presents an overview of the existing literature on double and triple duty caregivers. In Chapter 4, I will discuss how a pilot project completed in the fall of 2017 established my thematic areas, in conjunction with providing a rationale for the grant funding proposal. This pilot project addresses the current gaps in research by examining nurses in British Columbia who are double or triple duty caregivers, a population that has previously never been studied. Other research gaps addressed in this pilot project include how different qualifications of nurses, such as whether they are a registered nurse or a licensed practical nurse, may contribute to moderators and/or mediators of stress, which in turn may result in precarious job performance and work-family balance.

While there is a plethora of literature on caregivers' health and wellbeing, as well as the juggling of paid work with familial caregiving duties, few researchers have attempted to study the adverse effects of formal (paid) caregiving. Notably, there is an absence of research focused on health care professionals such as nurses, who also provide informal caregiving (unpaid) to family members or friends. Therefore, this research can help to critically evaluate institutionalized procedures that purportedly support the health and wellbeing of nursing staff, as well as policies used to assist informal caregivers. Additionally, the findings of this project will inform future directions of

research on the detrimental effects that double and triple duty caregiving can have on the health care system, from an operational and economic perspective.

One primary research question and three secondary research questions guide this study:

- Primary Research Question: How does being a double or triple duty caregiver contribute to a woman's personal health and wellbeing?
  - RQ1: How do the responsibilities involved in double or triple duty caregiving contribute to stress and fatigue?
  - RQ2: How does the stress and fatigue involved in double or triple duty caregiving contribute to and/or hinder job performance and work-family balance?
  - RQ3: What moderators and mediators help to prevent stress, fatigue, and work-family conflict amongst double or triple duty caregivers?

## **Chapter 2.**

# **Theoretical Perspectives**

## **Conceptual Framework**

This grant proposal adopts a critical feminist approach, influenced by the work of feminist-gerontologist Nancy Hooyman, combined with Leonard Pearlin's classic stress-process model. This synthesized perspective also includes the novel concept of "role captivity" and the strain it causes in relationship to double and triple duty caregiving. This concept refers to the "quality of being and acting in one role while wanting to be and act elsewhere, yet feeling that there is no easy way to extricate oneself from the role" (Skaff, Pearlin & Mullon, 1996, p. 248).

### **2.1. Critical-feminist Perspective**

Since women were the primary target population within the pilot study and the CIHR grant proposal, it was essential to include their voices and experiences in this qualitative phenomenological research. Phenomenological research is "an action-sensitive understanding method, which finds its beginning and end in the practical acting of everyday life and leads to a practical knowledge of thoughtful action" (Bergum, 1991, pp.55). Within the context of this capstone project, phenomenological research examines the lived experiences of women who occupy multiple caregiving roles to provide insight in the meaning derived from being a double or triple duty caregiver. A critical feminist approach to caregiving explores the unique connection between a woman's socially constructed domestic roles, and other forms of gendered caring work (Baines, 2004; Hooyman & Gonyea, 1999). Further, this lens helps us to critically assess how the public and private domains that women occupy are intertwined and reciprocally dependent on one another.

Women occupy a complex location between the private and public domain when they hold the role of double or triple duty caregiver (Ward-Griffin et al., 2009). Unfortunately this complex location blurs boundaries between their public and private

lives putting women in a vulnerable position. In their public lives women will make less money and receive fewer promotional opportunities and in their private lives they will take time off work to care for their family. Many women will straddle a line between these two roles for the majority of their life, creating a realm of recurrent gender inequality. Catherine Ward-Griffin and colleagues (2005) went beyond gender and included the social positions which women held that shaped these connections between public (work) and private (home-life). This intersectionality lens examines the various ways in which women are oppressed, based on dominating factors such as race, sex and class. While women may use a variety of strategies and resources to address the formal and informal demands of caregiving, it is found that the more time, finances, and other resources a woman possesses allow her to better maintain the boundaries between her paid formal caregiving and unpaid informal caregiving. Unfortunately, many women in double or triple duty caregiving positions do not have the additional time, finances and resources resulting in interlocking forms of oppression. The social positions that nurses occupy situate them in a vulnerable place where the stress and fatigue experienced from paid and unpaid work directly influence their job performance. This puts women at risk of job termination, burn out, or experiencing a work-place injury. Additional factors such as being a single mother, divorced, an immigrant and/or living in a rural area moderates or mediates the stress and fatigue experienced while performing caregiving duties. For example, living in a rural area limits the availability of respite options. Meanwhile, being a single mother without a partner to help with childcare duties exacerbates the stress experienced during triple duty caregiving.

Ward-Griffin et al. (2011) also stressed the importance of moving away from the overly-medicalized approach of reacting to caregiver stress and burnout as a health issue to be treated. Previous literature examining compassion fatigue and burnout put the onus on the individual woman to get help and be responsible for “taking on too much.” Without acknowledging the social context of women providing caregiving, society is continuing to “blame the victim” (Ward-Griffin et al., 2011; Martin-Matthews, 2002). Instead, these researchers emphasized the importance of being proactive, and examining caregiving as a socially constructed phenomenon based on social expectations and role performances. These gendered expectations cause women to be consistently caring for someone else, whether it is a spouse, child, parent, colleague, or friend. This results in women holding the role(s) of double or triple duty caregivers.



Without changing socially constructed gender norms, the health care system continues to rely on women and caregivers to provide and supplement formal caregiving support (Baines, 2004). The proceeding pilot project utilizes the critical-feminist perspective by providing women a platform to share their experiences as caregivers. The pilot project will attempt to explore how the nurses experience inequality in their private and public lives as a result of taking on the assumed caregiver role. Many nurses would explain their caregiver role came as a result of being women; daughters, daughter-in-law's, mothers and wives. Additionally, the pilot project will explore women's opinions on the desired supports which would help combat the inequality experienced. Hooyman and Gonyea (1999) state that instead of viewing the role of a caregiver as a problem, a feminist model should concern itself with systemic change by creating greater societal recognition of the caring work that women do. Therefore, rather than changing the work done by double and triple duty caregivers, how can governments help support these women both in providing choices for them, as well as the recipients of their care, via workplace supports and health care policy?

## **2.2. Stress-process Model**

Pearlin, Millan, Semple, and Skaff's (1990) stress process model examined the relationships among different contexts that lead to personal stress, and how these contexts and conditions change over time. Rather than explaining what these conditions were, this model aimed to examine the relationships between these contexts, and how they influence one another. Pearlin and his colleagues (1990) examined the following four domains and their relationship to one another: the background and context of stress, the stressors, the mediators of stress, and the outcomes/manifestations of stress. The model has been applied to caregiver stress to examine how different stressors influence and build on top of one another. In this paper, it is used to examine how stress experienced by nurses in their work environment is exacerbated by personal stressors resulting from informal caregiving. In addition to recognizing the work double and triple duty caregivers perform, addressing the stress and fatigue experienced by nurses will enhance productive work environments and encourage strong work-family balance. In understanding how double and triple duty caregiving stress is experienced we can mitigate the vulnerable position women occupy within society.

Appendix A shows the stress-process model as it applies to caregiver stress for an individual caring for a family member with Alzheimer's disease. The model starts with the contextual factors, such as socio-economic status, and leads to objective and subjective primary stressors, such as cognitive status. This results in secondary role strains, for example employment-caregiving conflict that ultimately impacts the secondary intrinsic strains. And these strains, like self-esteem, result in outcomes such as depression or anxiety. Mediators that affect all contexts within this model include coping skills and/or social supports. The arrows show how the different contexts are linked to one another, influencing or being influenced by other contextual factors (see page 67).

Depasquale and colleagues (2016b) adapted the stress-process model in order to examine the psychosocial consequences of double and triple duty caregiving. Examining the proliferation of stress involved in the role of being an informal caregiver results in stressors developing in other roles, such as in the workplace. Hence, their conceptualization provided a comprehensive overview of the primary and secondary stressors that double and triple duty caregiver's experience, and how they contribute to positive and/or negative outcomes. The primary stressors included the subjective experiences of perceived stress and psychological distress produced by the informal caregiving role. Physical and emotional strain can become a primary stressor as a result of providing care in both the workplace and within the home. Interestingly, it is suggested that providing childcare, and/or being employed as a nurse, may be seen as an anticipated role. This anticipated role means these duties are expected obligations, and therefore women are more aware of the stressors and less affected by them. Women who work in the nursing field and enter into the role of family caregiver in response to an emergency, or as the needs of their family gradually increase over time, tend to assume this role by default (Skaff et al., 1996). This results in role captivity, and causes distress.

Role captivity is a concept that refers to when an individual unwillingly enacts or feels trapped by their caregiver role (Depasquale et al., 2016b, Skaff et al., 1996). In role captivity cases of informal caregiving, older adults have needs that increase over time, change suddenly, and last for unspecified amounts of time. The authors characterized secondary stressors within the stress-process model as role strains within work and family, which are exacerbated and/or influenced by the primary stressors discussed above. Role strains at work may occur when women experience greater job demands,

for instance being an emergency response nurse rather than a nurse at a private doctor's clinic. Role strains within the family can be created by challenging child-rearing situations, for example having a child with a developmental disability. Primary stressors, such as cognitive status or having familial support can augment or minimize the role strain.

An adaptation of Pearlin et al.'s (1990) stress-process model is in Appendix B (see pg. 68). The model is used to apply the findings of DePasquale et al.'s (2016b) research, comparing double and triple duty caregivers who work as nurses to their non-informal caregiver colleagues. This adapted model informed the development of the interview guide for the pilot project in Chapter 4 and reinforced the direction for the grant proposal in Chapter 5. The first section of the interview guide included questions about physical and emotional strain. These questions addressed the primary stressors and are referred to in research question one. The next section of questions in the interview guide enquired about the nurse's job performance and mood concerning familial obligations and their personal lives. The purposes of these questions were to address the secondary stressors referred to in research question two. Finally, the mediators discussed in the model such as coping skills and social supports, were examined in the final section of the interview guide and are referred to in research question three. To capture these mediators, the nurses were asked which community supports and coping methods they access and utilize.

## Chapter 3.

### Literature Review

The purpose of this literature review is to provide an overview of what is currently known about simultaneously performing formal and informal caregiving roles, and the effect on health and wellbeing. In this chapter, I introduce the profile of a double and triple duty caregiver and examine the stress and fatigue that result from the caregiving burden. Next, the topic of how caregiver stress and fatigue implicitly affects job performance and work-family balance of nurses is explored. Finally, I examine how women are coping with these multiple role domains, and briefly discuss the current policies that exist with regard to caregiving.

According to the 2012 General Social Survey, an estimated 8.1 million Canadians provided care to a chronically ill, disabled, or aging family member or friend in the 12 months preceding the survey. At some point in their lives, almost half of Canadians (47%) will provide some form of care to a family member or friend. Women traditionally perform this role, and in 2012 women made up 54% of the informal caregiver population (Minha, 2012). According to Statistics Canada, most informal caregivers (60%) are gainfully employed in addition to their informal caregiving duties. Women have substantially increased their participation within the formal work environment during the last few decades (Keefe & Fancey, 2002; Pyper, 2006). For example, the employment rate of women aged 15 and over increased from 41.9% in 1976 to 57.9% in 2010 (Galarneau & Carrière, 2011). As the baby-boomer population enters retirement age, there will be a need to maintain a balance between paid employment and informal caregiving. This balance is required as this age group continues to work later, and hold higher expectations of a comfortable retirement with few demands. The increased employment rate of older Canadians, especially women, is evident in the growing number of employed 55-to-59 year olds (64.1 % in 2010). The number of employed women aged 60-64 years old doubled between 1996 and 2010 from 21.5% to 41.4% (Galarneau & Carrière, 2011). Unfortunately, being an informal caregiver for an older adult can lead to changes in personal health that can negatively affect job performance, or the ability to work at all (Pyper, 2006).

While there is substantial literature on caregiving burden (Sims-Gould & Martin-Matthews, 2007) and work-family balance of employees (Grzywac et al., 2006; Keefe & Fancey, 2002), a large gap in the literature exists regarding the individuals who occupy multiple caregiving roles. Specifically, these individuals are women who are often employed in the health care field, such as nurses, and are expected to provide caregiving for family members or friends. There is a need for research on caregiving that examines the impact that aging has on women who work in nursing who are also informal caregivers for an aging family member or friend (Boumans & Dorant, 2015; Ward-Griffin et al., 2009). Double and triple duty caregivers are a vital aspect of our social welfare system, and are relied upon for supplementing the few services currently offered by the health care system. However, the line between caregiving in the formal professional sphere, and caregiving in an informal familial setting, is complicated and interconnected.

While it is expected that health care professionals use their skills and knowledge to care for their family members and friends, these individuals are not allowed to be informally involved in caring for their clients and patients. Figure 1 on page 16 displays how the double duty caregiver is constantly negotiating and re-negotiating these boundaries. The failure to include these individuals in research and literature may jeopardize the health of nurses and other health care professionals. Not including double and triple duty caregivers within research also endangers any persons in their care, including family members, friends, or patients (Ward-Griffin et al., 2015). The nurse's health and wellbeing can be jeopardized and endangered because they lack the proper resources and services to do their job. This situation places the individual nurse, their family members, and their patients at risk for harmful situations (e.g. medication errors) when they are experiencing burn out or fatigue.

### **3.1. Double and Triple Duty Caregiving: Stress and Fatigue**

Nicole DePasquale, an American social gerontologist, is one of a small number of researchers to examine double and triple duty caregivers. Her research team investigated women who worked in nursing homes as either double or triple duty caregivers, and found that they experienced stress and psychological distress

(DePasquale et al., 2016b). However, they also documented how positive effects can occur when balancing multiple caregiving roles, such as women feeling a sense of mastery, personal accomplishment and recognition, self-esteem and personal growth, and/or positive family relationships. The researchers also examine differences between double and triple duty caregivers in an attempt to provide a comparison. Within the double duty caregiving population, women experienced more primary stressors such as physical and emotional strain, as well as family-work conflicts, as compared to their colleagues who were not providing care for a family member. The triple duty caregiving group also experienced the same type of psychosocial stressors, but encounter greater work strain and report poorer relationship quality with their family members (DePasquale et al., 2016b). Both groups were more likely to access acute care medical services in comparison to their work peers who were not providing informal caregiving (DePasquale et al., 2016a). Both double and triple duty caregivers and their work peers, who were not providing informal caregiving, had similar rates of health care visits. However, the increase in acute care visits among double and triple duty caregivers explains their lack of time and commitment to personal health. American and Canadian nursing roles and responsibilities do differ, so this research must be completed within a Canadian context. While the comparison between double and triple duty caregivers provide an interesting distinction between caring for older adults versus children and is briefly mentioned in the literature review and proceeding pilot project, providing a comprehensive comparison between the two groups was beyond the scope of the project and grant proposal. However, the ensuing grant proposal in chapter five does aim to provide a comparison between registered nurses and licensed practical nurses within a sample population of double and triple duty nurses in British Columbia.

Stephens and Druley (2001) found similar results to the DePasquale research in their study of 278 women who simultaneously occupied four roles: mother to children at home, parent care provider, employee, and wife. Their research found that being a caregiver to a parent was the most difficult role, with harmful effects on their psychosocial wellbeing. Common characteristics of this group included having less education, lower socio-economic status, and greater experiences of role conflict, in which their role as a mother was often challenged by the demands of caring for their parent. In Canada, the roles of registered nurses and licensed practical nurses vary in educational requirements and income levels. Therefore, their socio-demographic

characteristics vary, which may affect how they experience stress and fatigue. Further research providing a comparison between the two groups, may explain how stress and fatigue can be experienced differently by nurses due to education, income or familial status.

One reason why multiple duty caregivers experience higher rates of stress and fatigue is because of their longer work hours in comparison to their colleagues (DePasquale et al., 2016b). This is possibly due to continual distractions, or the inability to complete tasks in the same amount of time as their peers (Scott et al., 2006). Triple duty caregivers are also 2.5 times more likely to make errors at work, possibly due to sleep deprivation or sleep loss. That same study by Scott et al., (2006) found that one-quarter of the nurses who were caring for an elderly relative obtained 5.75 hours or less of sleep on workdays. Shift work and overtime is a common occupational characteristic of nursing, despite not being recommended for those occupations where a narrow margin for error exists, employees spend the majority of their shift on their feet, and the workforce includes single parents with young children (Scott, et al., 2006).

Another occupational hazard of nursing work that enhances stress and fatigue among women is the physical and social-spatial environment of the institutions in which nurses are employed. Noise, lighting, technology, insufficient use of space, airflow, and poor ergonomics make patients and clients hard to care for, and create an uncomfortable work environment for the caregiver (Wang & Kuo, 2006; Mroczek, Mikitarian, Viera & Rotarius, 2005; Mahmood, Chaudhury, Gaumont, & Rust, 2012). Noisy hospital equipment such as paging systems, telephones, and multiple conversations has a negative impact on work performance. Noise-induced stress can cause emotional exhaustion, burnout, short-term memory loss, and job strain (Mahmood et al., 2012). A lack of appropriate workspace for nurses causes distractions and interruptions, resulting in fatigue, low morale, lack of efficiency and job satisfaction, and increases work stress (Mahmood et al., 2012; Fancey, Keefe, Stadnyk, Gardnier, & Aubrecht, 2012; Nejati, Shepley & Rodiek, 2016).

### **3.2. Double and Triple Duty Caregiving: Work-Family Conflict & Job Performance**

Work-family conflict is a negative effect of double and triple duty caregiving. In one study on registered nurses in the United States, 92% of the nurses state they experienced work interference with family, and 63% report that they experienced family interference with work (Grzywacz et al., 2006). This work-family conflict contributes to nurses having lower job satisfaction (Boumans & Dorant, 2015; DePasquale et al., 2017) and leads to burnout, sickness, and somatic issues (Grzywacz et al., 2006). Again, this not only impacts the individual's quality of life and wellbeing, but also has larger systematic ramifications on labour costs, workplace accidents, and the quality of work within hospital settings (DePasquale et al., 2016a). In one study, almost half (43%) of informal caregivers who were gainfully employed indicate they had arrived late to work, left early, or took time off during the day to care for their family members or friends (Minha, 2012). Additional research shows that women also report a lack of energy for their informal caregiving role, because of the demands of their paid employment (Keefe & Fancey, 2002).

Interestingly, one study on double duty caregivers in the Netherlands (Boumans & Dorant, 2015) found that women suffered from work-life interferences, poorer health, feelings of emotional exhaustion, and require greater recovery time after a work day, but did not experience higher rates of absenteeism. Rather, they experienced more "presenteeism," which means they attended work more often while sick compared to their nursing colleagues who do not provide informal caregiving. These double duty caregivers may be collecting their sick days for any informal caregiving responsibilities in which they have to take off work. They may also fear for their job security if they do take a sick day.

Other literature (e.g. Mitchell, 2014) found that women in the sandwich generation do not necessarily increase their risk of burden, particularly in terms of providing support to their children, since they tend to have young adult children rather than younger-aged children. Baby boomer women on the other hand, experience the greatest burden, and tend to be caring for older relatives with greater health concerns. Additionally, the duration of caregiving hours based on the severity of specific health



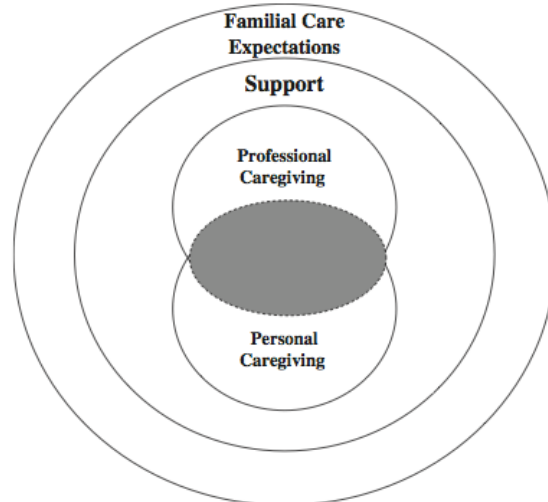
problems can influence the stress and burden levels of the caregiver (Boumans & Dorant, 2015; Pyper, 2006; Stephens & Druley, 2001), as well as possibly interfere with work commitments. Notably, Statistics Canada found that 43% of caregivers who are employed indicate that their caregiving roles affected their ability to work a full day without delays and interruptions; but this increased to 54% when the caregiver provided more than 20 hours of care per week (Minha, 2012).

Therefore, the separation between double and triple duty caregiving is an important one, because caring for older adults, as opposed to children, is usually experienced differently. Researcher Martin-Matthews (2002) encouraged caution when making comparisons between the two groups. While childcare is fairly regularized and follows a predictable pattern, provided that the child is relatively healthy, caring for an older adult can be unpredictable, and varied in the level of support required. Older adults may also have more than one caregiver involved, including friends, siblings, multiple children, whereas children's primary caregivers are typically their parents. Crisis episodes amongst older adults are also not as predictable, and can vary in duration. New, up-to-date research in a Canadian context may provide a stronger analysis of how stress and fatigue affect job performance and work-family balance in the current population of nurses in British Columbia.

### **3.3. Mediators and Moderators on Coping with Role Demands**

Ward-Griffin and colleagues (2009) research on double duty caregiving examined four themes and how they influenced the level of coping managed by nurses who were also providing informal caregiving to a family member. These coping themes included: 1) expectations, 2) supports, 3) negotiating strategies, and 4) the amount of overlap between informal and formal caregiving (refer to Appendix C, pg. 69). The authors arrived at these themes by studying three prototypes of double duty caregivers; those who are making it work, those who are working to manage, and those who are living on the edge. These coping themes can be seen as moderators and mediators, as they directly impact, and strengthen or weaken, the relationship between caregiving and stress, fatigue, work-family conflict, and/or job performance. They also help to explain the relationship between these variables. Firstly, high expectations of oneself, from one's

family, and from within one's profession blur the boundaries between providing formal and informal care. Secondly, the supports available to caregivers came from both personal (emotional) and professional (resources) domains and those who have high levels of support have stricter boundaries and less conflict between their caregiving roles. Finally, negotiating strategies include nurses setting limits on demands, and making connections with resources, in order to moderate the negative impact of double duty caregiving. Setting personal limits decreases the blurred boundaries between roles. Ward-Griffin and colleagues (2009) found their prototypes to be successful in examining the blurred lines between formal and informal caregivers. These blurred lines are what can result in significant, harmful, mental and physical health outcomes for health care professionals.



**Figure 1. Double-duty elder caregiving – based on Ward-Griffin (2009)**

Catherine Ward-Griffin is the only Canadian researcher studying double and triple duty caregivers to date. As mentioned in the introduction, Ward-Griffin (2009) stresses the importance of examining the ramifications of blurred boundaries between paid and unpaid caregiving roles, rather than examining the structure of caregiving relationships. It would be unique to learn how the coping themes discussed within the literature to date may be applied to a group of nurses in British Columbia. The proceeding grant proposal aims to compare different nursing professions (e.g., licensed practical nurses and registered nurses) and how their expectations, supports, negotiating strategies, and the amount of overlap between informal and formal caregiving differ from one another. This may also reinforce which mediators and

moderators help prevent stress and fatigue, such as the expectations of support from their work environment, or the availability of familial support.

### **3.4. Practice and Policy Implications**

The detrimental effects of double and triple duty caregiving on stress, fatigue, job performance, and work-family conflict reinforce the specific workplace and health care policies required to support informal caregivers. These policies act as moderators, and can help combat stress and fatigue (Bainbridge, Krueger, Lohfeld, & Brazil, 2009). The moderators and mediators that prevent stress, fatigue and work-family conflict as addressed in research question three can inform future directions of research in the health care field, from an operational and economic perspective.

Strategies beyond short-term individual coping approaches and counselling are needed in the form of professional, workplace, and government policies, where paid leave without fear of job loss and assistance with childcare is possible (Ward-Griffin, 2008; Ward-Griffin et al., 2011). This may create or reinforce a dichotomy within the work environment, wherein employers are helping staff manage their personal work responsibilities, versus taking a lead role in childcare and eldercare responsibilities. This dilemma poses questions, such as whose responsibility are these dependent individuals? Are they the responsibility of the family, or the responsibility of a collective social welfare system? Regardless, it is economically and politically viable to create sustainable community-based long-term care policies.

The Canadian Nurses Association (CNA) and the Registered Nurses' Association of Ontario (RNAO) published a report in 2010 entitled, "Nurse Fatigue and Patient Safety Report" that provided systemic, organizational, and individual suggestions for mitigating fatigue among nurses. Some systemic recommendations included addressing topics such as workloads, staff shortages, inattention to safe labour practices, research funding to study nurse fatigue, policy initiatives by accreditation bodies and regulatory nursing associations to address the issue of nurse fatigue. Organizational suggestions included creating a culture of safety through policies and programs, increasing nursing educational opportunities, and encouraging the nurses' union to address the work environments that enhanced fatigue. Finally, individual suggestions were made to

encourage nurses to be aware of the signs of fatigue, to be knowledgeable of support policies and procedures, and to work within the ethical guidelines of the Canadian Nurses Association when accepting additional and/or overtime shifts.

Countries with well-established welfare systems are usually those with well-developed caregiver policies. Janice Keefe et al. (2008) outlined four types of systems that provide financial payments for family caregivers. The first system was personal budgets and consumer-directed employment of care assistance, which is currently used in the United Kingdom, Netherlands, parts of Belgium, and the United States. In this system, older adults who need additional support receive a personal budget to purchase care. This approach gives them the ability to decide whether that care is through private nursing, a care agency, or directly employing a personal assistant. Some of these countries, such as the Netherlands, allow this personal assistant to be a family member.

The second system, used in Austria, France, and Germany, included care allowances for older adults. These are direct cash payments made to the older adult, or the individual needing care, with no specification or formalities as to how this person may use this cash, as long as they are using it to acquire care. In Germany, older adults can choose between services, or a lower value of non-taxable cash allowance that may be used for family members or friends who provide the care.

Keefe's third system, which is used in Australia, Canada, Sweden, Norway, and Ireland, entailed care allowances paid directly to the family caregiver. This care allowance is intended to help maintain income for those individuals who may have to interrupt their work schedules, or need to take time off. For example, Canada's employment insurance benefits offer up to 6 weeks of time off to care for a dying relative, called compassionate care benefits. However, this benefit is seen as an entitlement for eligible employees who accumulate 600 hours of paid work in the past year (Canada Revenue Agency, 2017), rather than compensation for care work.

Finally, Keefe recognized that compensating caregivers, instead of formal service provision, as used in some Scandinavian countries, represents a fourth type of system to provide financial payments for caregivers. Under this arrangement, family caregiving is formalized within an employment-type relationship with the state. Thus, the care recipient acts as an employer, and the caregiver acts as the employee (Keefe, et al.,

2008). It is important to note that Canada also has a caregiver credit, where individuals can claim \$2,150 if they are providing caregiving for a dependent with a mental or physical impairment. Prior to 2016, the caregiver credit was available to individuals who support a parent or grandparent over the age of 65 and is living with them. This caregiver credit is no longer available, replaced with the Canada Caregiver Credit (CCC), where the dependent now must still be deemed 'infirm' yet no longer needs to live with the caregiver. This caregiver credit incorporates three previous tax credits: the caregiver amount, the amount for infirm dependents (18 & older), and the family caregiver amount (Canada Revenue Agency, 2018).

The purpose of these financial payments for caregiving services is to maintain income, to help offset the cost of job loss or reduced working hours, to purchase respite, to complement care or to pay for additional services. This is imperative for informal caregivers to maintain a sense of balance within their careers and personal lives. However, these policies might be interpreted as co-modifying caregiving by putting a price on a job that is hard to appraise, blurring the boundary between family care and employment. These financial payments for family caregivers are less compensation than the amount that private care companies would charge, which reinforces the gendered nature of the informal caregiving role, continuing to put women in vulnerable positions.

The health and wellness of double and triple duty caregivers is impacted by the stress and fatigue they experience from both their formal and informal caregiving duties. Physical and emotional strain increasing access to acute care services, difficulty balancing multiple roles and interrupted sleeping schedules affect a nurses job performance and ability to balance paid work with familial responsibilities. This can be seen in high rates of burn out and/or difficulty fulfilling work obligations. Coping mechanisms used by nurses to balance their multiple roles are influenced by the expectations they have of themselves, personal and professional resources they access, and their ability to negotiate caregiving duties. The most important coping mechanism is the social policies currently offered, or lacking, such as the Canadian care allowance, which is paid directly to family caregivers. Again, rarely is this compensation equitable to the time caregivers actually spend providing care. The value of caregivers' unpaid labour must be recognized by national, provincial and territorial governments. Catherine Ward-Griffin suggests this can be done by enhancing double or triple duty caregivers financial means through: top-up's from employers to employees forced to take time off work to

perform caregiving duties, more tax credits for caregivers, providing flexibility in the Canadian Pension Plan and creating a registered caregivers' saving account (Ward-Griffin, *n.d.*).

There is existing research conducted on the stress and fatigue that result from double and triple duty caregiving. This includes heightened stress and psychological distress due to long working hours (DePasquale et al., 2016b), role conflict (Stephens & Druley, 2001), sleep deprivation and sleep loss (Scott et al., 2006) and distracting work environments (Mahood et al., 2012). The experience of work interference with life and vice versa (Grzywacz et al, 2006; Minha 2012) results in lower job satisfaction and burnout (Boumans & Dorant, 2015) which increases labour costs, workplace accidents and quality of work (DePasquale et al., 2016a). Reviewing the current literature on work-family conflict and job performance among double and triple duty caregiving reinforces the need for more empirical studies to ensure work-life balance and job productivity for nurses. However as seen in the changing demographic trends such as increased participation of women in the workforce, higher divorce rates and greater geographic mobility, the historical profile of informal caregivers (womsn, home makers) is changing. Additional changes include the growing number of older adults in Canada, the increasing age of health care professionals and growing demands on informal caregivers will affect women who work in the nursing profession. There is a need for additional research into women who occupy multiple caregiving roles to ensure a healthy workforce of nurses and a comprehensive home care system.

## **Chapter 4.**

### **Pilot Study**

Given the numerous gaps in the literature and the paucity of research on the topic, a pilot study was conducted in order to support the development of a CIHR grant proposal. The purpose of this proposal is to learn more about double and triple duty caregivers, their health and wellbeing and the effect this has on their job performance and work-life balance. This research is important and needs to be further explored because only two investigators have examined double and triple duty caregivers in North America, which includes one study conducted in the United States and one in Ontario, Canada. Examining a population of nurses in British Columbia contributes to provincial health care policy by ensuring a skilled and healthy workforce as well as comprehensive home care system with community services. Ideally, the results of the study will support the need to mitigate the harmful effects of double and triple duty caregiving. Finally, providing a deeper understanding of how double and triple duty caregiving is experienced differently between registered nurses and licensed practical nurses extrapolate those nursing duties that cause greater stress and fatigue.

The following chapter explains the process of how the pilot project is organized, along with the significant findings based on analysis of nine qualitative interviews. As will be demonstrated, this small sample justifies conducting a larger research study where the results are ideally saturated, and can be applied more readily to the larger population of double and triple duty caregivers (Sandelowski, 1995). In short, these findings are used to support a CIHR grant (chapter 5), contributing to a larger, and more impactful study.

#### **4.1. Study Design**

During the fall of 2017, a pilot research study was conducted with nine women between the ages of 45 and 67 who worked as registered nurses or licensed practical nurses in British Columbia. These nurses were also actively providing some form of informal caregiving to a family member. The qualitative study allowed for a thematic

analysis where the investigator was able to further explore topics and delve deeper into some trends that emerged (Bergum, 1991) based on the nurses' experiences. The thematic analysis was used to inform the development of the CIHR grant in chapter five. The themes established in the pilot study provided greater insight into interesting and salient trends, and what further exploration was required in a larger CIHR grant. Later, part of the analysis demonstrates how some nurses experiencing exhaustion and distress were in eminent need of emotional and tangible support. These supports may be established with the results of a CIHR grant.

A semi-structured interview approach was important for this research in order to explore the nuances of multiple caregiving experiences and relationships with family members and friends. Bergum explains how these interview approaches are important within research that takes a critical feminist approach by emphasizing "...the very fact that these women talked about their own experience made a difference in their lives. It raised their own awareness of what they were going through and resulted in reflection that may not have occurred outside the research environment" (1991, p. 67). Pearlin's stress-process model (Appendix A) combined with a critical-feminist perspective was used as a framework to guide the pilot study, including the development of the interview guide. These theories provided a rationale to study the role of stress and fatigue among women in double and triple duty caregiving roles, and how they renegotiate boundaries between their private and public lives.

In this study, an hour-long telephone interview was conducted with the participants. The interview guide is included in Appendix D (pg. 70). After collecting basic demographic information to ensure that the participant met the inclusion criteria, the questionnaire began with questions asking the nurses about how their informal caregiving roles affect their paid work as a nurse. Specific questions about feelings of fatigue, pain, stress and sleeping patterns before, during and after their shifts were included. Questions regarding job performance were subsequently asked in order to learn more about how fatigue, pain, stress and sleeping issues affected their quality of work. The interviewer then explored how the nurses' informal caregiver role was affected by their paid nursing work. The topic of work-family conflict was discussed by asking questions regarding their mood while performing caregiving duties, and how their personal life was impacted. For example, how did their caregiving duties influence the time they have for leisure pursuits and hobbies? Finally, the nurses were asked



questions about their thoughts regarding available community supports, and advice for women in similar situations as their own. These last sets of final questions were asked to determine which mediators and moderators were helpful to the nurses in performing their multiple caregiving roles.

#### **4.1.1. Ethics approval**

Ethics approval for this project was granted by the Simon Fraser University Research Ethics Board and was deemed to have no foreseeable risks or minimal risk for the participants.

### **4.2. Data Collection**

The pilot study research took place over the phone, during a 4-month period between October 2017 and January 2018. The women who participated were registered nurses and licensed practical nurses in various rural and urban settings throughout British Columbia. Potential participants who met the inclusion/exclusion criteria then contacted the researcher who provided the study details. If a potential participant was interested in the study, they were invited to set up a phone call.

All of the nurses scheduled their interviews in advance to work around their shift work, personal appointments, and caregiving work. Phone interviews afforded nurses with the flexibility and anonymity to participate in the study. This method of data collection also allowed the recruitment process to go beyond the Greater Vancouver area. The phone interviews were recorded using a digital recorder, and transcribed using the NVivo (version 11.4.2) statistical software. After the interview data were transcribed, the recordings were deleted as per the ethical guidelines set out by Simon Fraser University, Office of Research Ethics.

### **4.3. Sampling and Recruitment**

The nine nurses participating in this study were recruited using convenience-based methods; mainly snowball sampling and purposive sampling (Sandelowski, 1995; Weil, 2017). Women who were members of online nursing communities such as the

'licensed practical nurses of BC' and 'registered nurses of BC' responded to a post on Facebook. These groups are private, which the investigator needed permission to join, and are used solely as a platform for nurses to openly ask questions or share concerns about their nursing work. This form of sampling is ideal for recruiting pilot study participants, who are members of a relatively homogeneous community. The recruitment poster is shown in Appendix E (see pg. 73). The sample criteria used in this study consisted of women between the ages of 45-67 who are employed as nurses (either part- or full-time), and were providing some informal caregiving within the last 12 months to an adult family member.

According to the Canadian Nurses Association, in 2016 there were 34,674 registered nurses working in British Columbia. The average age of a nurse working in British Columbia was calculated at 44.5 years, and 92% were women. Just over half (55.3%) of these nurses worked full time; 44.6% worked on a part-time or casual basis (Canadian Nurses Association, 2016). According to Statistics Canada (Minha, 2012), 54% of informal caregivers were women, and 60% of these women were a part of the labour market. The sample profile of the nurses in the pilot study is outlined in Table 1.

**Table 1. Sample profile of study participants**

Participant	Marital Status	Household number	DOB	Nursing qualifications	Care recipient
1	Single	6	1967	Registered Nurse (f/t)	Mother
2	Single	4	1963	Licensed Practical Nurse (f/t)	Spouse
3	Common Law	2	1962	Licensed Practical Nurse (f/t)	Father
4	Married	2	1958	Licensed Practical Nurse (p/t)	Mother
5	Single	2	1958	Licensed Practical Nurse (f/t)	Adult Daughter
6	Common Law	4	1961	Licensed Practical Nurse (f/t)	Parents
7	Married	2	1962	Licensed Practical Nurse (f/t)	Parents
8	Single	1	1951	Licensed Practical Nurse (f/t)	Mother
9	Common Law	2	1971	Licensed Practical Nurse (p/t) + f/t Student	Parents, Adult Daughter

Participants expressed no concerns about their conversations being recorded; however, they did express concerns when questions regarding work place errors and accidents were discussed. Some participants stated that they would like to see information about the major themes that the researcher developed after the interviews were finished, in which case permission for their contact information stored in a secure manner was provided. Appendix F (see pg. 74) shows the Informed Consent form.

## 4.4. Data Analysis

As previously mentioned the pilot project data were analyzed using NVivo (version 11.4.2). NVivo statistical software was used for qualitative data analysis to identify and contextualize the major themes expressed in the interview. Transcribing the data allows the researcher to become more familiar with the different themes, to create relationships between concepts, to compare interviews, and to allow identifiers to be replaced with pseudonyms (Weil, 2017). The data is coded into nodes captured through emerging themes that the double and triple duty caregivers discussed (Strauss, 1998). These themes included stress and fatigue, experiences of pain, job performance, work-life balance, team mentality, family dynamics, mediators, and moderators. The data was subsequently disaggregated into smaller nodes; for example, under stress and fatigue, the smaller nodes included sleep and shift work, energy/feelings of exhaustion and self-care. Under the job performance node, data was coded to include nodes such as team mentality, switching shifts, absences and time off. Nodes that were sub-categorized under work-life balance included family dynamics, siblings, and spouses. Some examples of sub nodes that were categorized under mediators and moderators included the health care system, rural versus urban, money and finances, and community supports. Comparisons were made between and across interviews (Strauss, 1998) and particular themes that emerged beyond the review of literature were specified to be points of examination for the CIHR grant proposal.

## 4.5. Findings & Discussion

Five themes emerged from the interviews with double and triple duty caregivers.

1. Feelings of stress and fatigue
2. Experiences of pain
3. Job performance and work-life balance
  - a. Team mentality
4. Family dynamics
5. Moderators and mediators of stress

a. Support from the health care sector

Two particularly noteworthy findings identified in the pilot study that contributed to the development of a CIHR grant were: 1) the differences between nursing qualifications; and 2) the different experiences of double and triple duty caregiving in a rural versus an urban community.

The key overarching theme gathered from this pilot study was rooted in the nurses' feelings of stress, exhaustion and an overall lack of energy. All nine women worked shift work and report they experienced restless sleeps, concerns regarding their self-care and issues with physical pain, with three of the women discussing knee replacements. Interestingly, 8 of the 9 nurses were also routinely taking a sleep aid or a prescribed sleeping medication, some ascribing it to the only way they could function. These feelings of fatigue and discussion around sleep were also embedded in the other themes that emerged, including experiences of pain, job performance and family dynamics. For example, the nurses felt the quality of care they provided to their patients through their formal caregiving work suffered due to exhaustion. Meanwhile, at home they would display a lack of patience for their significant others, children, or parents due to a lack of sleep.

When asked how they balance their multiple competing roles, most referred to 'just making it work', or the power of 'creative scheduling'. Many discussed being distracted from their paid employment because of their informal caregiving duties. However, the team mentality that many women experienced at their job also helped them in balancing caregiving duties. Some alluded to the idea that a predominately all-female work environment is very supportive and understanding when familial issues arise. An interesting, albeit expected theme, is that almost all the nurses said their role as informal caregiver was an assumed responsibility that was never discussed, but was implicit in their role as daughter, wife, and nurse. Expanding on this idea of those women who are providing informal caregiving for a parent, three mentioned how their parent-child responsibilities have gradually shifted and how they find their parents resorting to child-like behaviour. Yet, it is important to note that 8 of the 9 women reported feeling 'blessed' or 'grateful' to be able to provide care for their family member. Indeed, many of them also state that they observed patients within their paid work with no family to take on this role, thereby felt privileged to be able to provide it for their loved ones.

Finally, participants were asked about what helps them mediate stress and fatigue, what exacerbates it, and where they see gaps in supports or services. The majority of the nurses mentioned simple things, like taking a bath, walking their dog, or having a glass of wine to unwind. Unfortunately, some mentioned that they no longer had the energy or time to exercise or perform a particular hobby that once helped them relax. All nine nurses discussed their frustrations with the health care system, and their difficulties with community home health, typically due to the high turnover of nursing aides. Few of the participants referred to community supports, although one nurse discusses a senior's centre her mother accessed. Another nurse spoke about a volunteer position that her parents enjoyed. However, barriers such as the facilities' hours of operation made it difficult to access these services when working 12-hour shifts.

As mentioned earlier, the literature indicates that many women are able to balance simultaneous informal and formal caregiving roles, providing a sense of mastery (Pearlin et al., 1990; Skaff et al., 1996). However, when these roles begin to overlap or 'blur', the women begin to suffer mentally and physically. The majority of the nurses, about four to five of them, fell into the 'working to manage' (Figure 1, pg. 16) group. They were able to set limits for themselves in terms of providing care, and seem to successfully balance their informal and formal care work. Two of the women seemed to be 'living on the edge', since they had high expectations of the type of care they want to provide, which is often complex. They also had little to no family support, and often ended up crying at points within the interview. Lastly, the other women are successfully 'making it work'. They rarely had feelings of frustration, and had family members living with them, who were able to share in their informal caregiving work. It is important to note that these women were less forthcoming with their experiences, and were not quick to discuss items they may considered private family matters. Therefore, 'making it work' may be a façade they felt was necessary to portray.

#### **4.5.1. Stress and fatigue: 'Not all cylinders are firing'**

As previously mentioned, all nine nurses worked shift work and were currently, or recently, working consistent night shifts. All nine experienced 12-hour day and night shifts, and other than two nurses who worked casual/part time, the rest had a schedule that included 2 days, 2 nights, then off for four days. Many of the women specified that they could only endure night shifts by pooling their breaks into a longer prolonged break,

and then using that time to sleep. One woman used her breaks to visit her father who lived in the same town where she worked as a nurse, which was one hour away from her home. Some of the women said that because of where they lived, they had to commute, and working night shift, or working while sleep-deprived, put them in risky situations. “Well, it’s just adds more of a struggle. I am competent, but tired sometimes getting through it, getting through a 12 [hour shift]. Then driving, it’s a danger on me, I often fall asleep driving home” [Participant 3, age 56]. Another individual [Participant 4, age 60] spoke about the commute adding hours onto an already long day.

Yes, I sleep 6 hours at the most. Because I live on an island and have to deal with ferries...a lot of girls will sleep 4-5 hours then have a nap before work, but I could never do that. So 6 hours at the most when I work night shift is all I could handle.

Another interesting theme was that 8 of the 9 participants were taking some type of sleeping aid or medication, which they attributed to working night shift.

I’ve been on sleep aid medication for probably the last 15 years of nursing. Finding with shift work, I absolutely require it. And now I take trazodone on a nightly basis a light dose, 25 mg, but I take zopiclone when I am working night shift, to get me to sleep in the morning if I have another shift, or to switch me over from nights to days. And I’ve been doing that for a long time.” [Participant 3, age 56].

One woman said she recently discussed sleep schedules with other nurses on her floor during a break, “One night shift we were talking, and all 7 of us in the room, all 7 of us who were working were on trazodone or zopiclone.” Further studies need to determine the use of sleeping aids and medications by nurses, as well as to compare between double and triple duty caregivers and their peers who are not providing any type of informal caregiving. One participant said she woke up a lot, and worried about issues regarding her parents. Her reply when asked how many hours of sleep she gets a night:

It varies, anywhere between 6.5 hours, to...if I am on days off I would say 10 hours. Although I am wakeful, I wake up a lot at night. I am not one of those people who are awake for 2 solid hours, but I wake up a lot during night. With my age, I am waking up and starting to worry about stupid things and stay awake. Anxious about my parents, not overly often though. [Participant 6, age 57]

Another important theme that surfaced during the interviews regarding sleep and energy levels was the effect that it had on personal relationships, self-care, and work

performance. The nurses said that they often “snapped” at their spouses due to a lack of sleep and described their behaviours as “cranky” or “short tempered”. One woman described how a lack of sleep affects her day-to-day functioning:

My husband observes it. I got off nights yesterday morning so I know not to plan anything that is going to require my attention to detail, or any focus thinking or anything like that. Because I am not there. My husband calls it my grumpy day, and tries not to engage me. So I am trying to not do that, and be better. I don't mean to be grumpy and short. Not all cylinders are firing though. [Participant 7, age 56]

Consequently, this lack of energy and tiredness affected the quality of care the nurses felt that they could offer their patients:

Honestly, I think it affects me mentally. I just never want to go to work. I just, I learned that I hate working on a medical floor. I'll never work on a medical floor again. I just don't know, I felt exhausted and frustrated. I think a big thing is, ya I am tired already. I am stressed...I can't provide good care. I can't provide the care I actually want to provide. [Participant 9, age 47]

Not only did the exhaustion and sleep deprivation affect their attitude and how they felt about their job, it also had large implications for their work performance and the safety of patients entrusted in their care, “On nights, particularly after 3 in the morning, I ensure any meds I am giving, I am double-checking. And I often find when I go back and read my charting I have to clarify things. I use words I didn't mean to use. I wrote something down different that I didn't mean to use, in my head” [Participant 7, age 56].

#### **4.5.2. Experiences of pain: ‘When my body gives out on me’**

Nurses invariably brought up experiences of muscle and joint pain, but to varying degrees: “Yes. Currently right now, it's my low back. And my shoulders. And I have, also my right Achilles tendon, and I have tendonitis in my left hand” [Participant 6, age 57]. This quote encompasses the physical nature of nursing work and the ramifications it has on women's bodies. Participants acknowledged that a 12-hour shift consisting of lifting, dressing, bathing, and toileting patients is physically demanding work. While it is not surprising that nursing work is a physically demanding job, the women did express that the work was getting harder as they got older. “At my age, everyone keeps asking when I am going to retire. And I say when my body gives out on me or tells me I can't do this anymore” [Participant 6, age 57]. Because the participants have been nursing for 20-30

years, some referred to recurring pain or injuries sustained over the years, “I nursed without these fancy lifts, and ceiling lifts, which are basically new, pretty new. Everything was hands-on” [Participant 2, age 55]. Speaking about her difficulties in dealing with a Workers Compensation Board (WCB) claim, the result of a back injury sustained at work no one had witnessed, one woman said:

Um, my permanent line was on a medical ward when I first started working for a few years. I was constantly getting back injuries. And so, it's interesting because I didn't have a witness to my injury. And it didn't show up until the next day. So when I tried to claim workers comp, it was denied. And my manager never backed me up because they didn't see it as a witness. And there was one time I was off for 3 months and over 3 months they cut off your benefits, so I couldn't even go to physio, I couldn't do anything. I was basically in pain and nothing was covered. You know I am at work; I get injured on the job because it's over capacity and we have aggressive, violent people, elderly who don't understand that they can't pull on me. Right? So yeah, it's very hard to get help, you can't find help to get someone up, so you are doing a lot of unsafe care. [Participant 9, age 47]

The physical nature of nursing work affected the ability to complete routine tasks after work or on days off. The women described how this physical exhaustion affected their ability to function after work, particularly when providing informal care to their family members. As one nurse described,

I don't have to physically caregive for my parents at the moment. Though I have in the past. But I am providing them a lot of support in their life to maintain independence. So I would say the pain does interfere with that because there are some days I maybe not go out there if I was planning to spend the day with them or not spending as much time with them because I am in pain or I have appointments, I have chiropractor appointments. [Participant 6, age 57]

This chronic or intermittent pain also affected their ability to relax and unwind in their free time. Given the limited leisure time they did have, the nurses often did not spend it on self-care. The nurses spoke about having to give up sports or exercise activities, which also affected their social lives. Three of the women brought up knee replacements, an interesting topic to further explore. Is this common amongst all nurses, or is it a common theme amongst individuals in the 45-to-64 age range? Knee replacements have long recovery periods, and would affect an individual's ability to work, as well as their ability to carry on with informal caregiving, in addition to personal errands and activities.



I've had a, well on medical surgical floor it's quite demanding. I have had a left knee replacement, and the right knee can be replaced at any time, when I have the time for it. So my knees quite bother me. [Participant 6, age 57]

Another woman said, "I have a bad knee. I had to take 2 years off work for my other knee, I had a knee replacement" [Participant 5, age 60].

### **4.5.3. Job performance & work-life balance: 'Just make it work'**

#### ***Team mentality: shift work/creative scheduling***

A common theme all women mentioned throughout their interviews is their active strategy of switching shifts. This is a common solution when caregiving duties conflicted with work schedules. Creative scheduling was also the method they used to free up time to bring their family members to medical appointments, which were often scheduled between regular business hours (9am to 5pm). Because of their shift work, switching shifts or scheduling these appointments on their days off allowed them the flexibility to attend these daytime appointments with the care recipient.

I take time off, for sure. I have had to switch shifts. Absolutely switching shifts. I've had to, uh, I don't know if I've called in sick or not, but probably have and would. If anything, I usually try to shift shifts around to accommodate appointments" [Participant 6, age 57].

Another nurse spoke about management playing a large role in women being able to switch shifts. Two women mentioned that management were starting to "crack down" on nurses splitting shifts or switching their scheduled shifts. One nurse who recently went back to school to complete her bachelor's degree in order to become a registered nurse, but still worked casual shifts as an LPN, remembered back to a time when she was working full time:

I never had to take long periods of time off work. Just sick days. Um, but yeah, I can't honestly remember how many sick days I had, but I remember taking up paid sick days trying to take care of her [daughter]. I don't think I got in trouble for this, the manager at the time was easy going. Management had a huge part of it. After I left, there was a new manager, and we used to do a lot of shift swaps. I would do a lot of shift swaps....And yeah, usually it's okay, but now the manager who is there doesn't allow any shift swaps. Which is unheard of. Usually when you get your schedule, when you are permanent you get a schedule for a whole year. And that first week or two everyone is sitting down and every two minutes of free time they have they are going through and trying to switch shifts and being like I need to switch this and this. It's ridiculous. [Participant 9, age 47]

When informal caregiving duties became too strenuous, or care recipients went through a period where they required heavier care, for example a surgery, or were recovering from an accident, many of the nurses had to take a period of time off work. As one nurse recounts,

I would have to just make it work. You know, and I did, at the time, when my dad went to St Paul's I could go with him. I have a great team leader at work and have seniority. So I had banked holiday and banked over-time, so what I try to do is bank as much time as I can, with some insight, over time, so I have a good bank of hours so if I have to take a set of 4 off, I can. [Participant 6, age 56]

This usually meant women were giving up vacation time, or banked days, time that should be spent relaxing and recovering from the demands of their jobs. This same woman, speaking about being off sick from work and instead of focusing on her own health and getting better, said she felt it is serendipitous that she doesn't need to balance her work schedule when her father suddenly fell ill:

Three years ago I was off work for a year, I was quite ill, going through treatment myself. And that was when everything happened with dad [quadruple bypass], and so on. It was worrisome, as long as I am okay to care for him, its okay. But when it isn't, that's what I try to have ready. Life surprises you sometimes, and unfortunate things happen. [Participant 6, age 56]

Another woman who cared for her husband, who had a traumatic brain injury, used her vacation time and days off for the sole purpose of scheduling her husband's appointments and therapies. "And my vacation time is booked when my spouse needs his big brain surgeries. My vacations were spent in different hospitals down in the mainland" [Participant 2, age 55].

When nurses were unable to switch shifts or arrange their days off, they were forced to work 12-hour shifts, often distracted by their duties waiting for them at home.

I gave up a lot of overtime...I am not a 'sick caller' type of person. I always had a large sick-bank. It affects my work as far as concentrating focus. Because I get a lot of calls from home. From one of his workers. From him, about things that were happening at home. So I deal with home emergencies when I was at work. Often I have to rush and do some immediate patient care and I would have to leave my work place and come home and deal with the situation at home, and have to rush back to work, my colleagues would cover for me. And to have to worry about what is going on at home and what was happening now, for the rest of the day. And getting calls, all while dealing with my daughter....And stuff with her...it's a lot of things. [Participant 2, age 55]

The nurses also discussed getting phone calls at work, texting their siblings, or in-laws, or feeling out of the loop when leaving their vulnerable family members in the care of others for long periods of time. “Sometimes my mom will message me when I am at work. Forgetting that I am at work. Sometime like that, or you know, yeah it’s always on my mind” [Participant 6, age 57]. While the nurses did not admit to workplace accidents or feeling unequipped to perform their paid job duties, except for one woman who admitted to having made errors in administering medication, the distractions of their informal caregiving definitely influenced their ability to concentrate.

I find I run out of energy quickly, I am very forgetful after night shifts. Very forgetful. It’s like I’m in a fog sometimes, I don’t sleep well during the day at all. After a couple night shifts I am in this mental fog, and I’ll do stuff, and sometimes I don’t remember where I put things, what I’ve done necessarily. Definitely...” [Participant 6, age 57].

#### **4.5.4. Family dynamics: ‘They all come to me when there is something wrong’**

The nurses spoke a lot about their familial relationships, both positive and negative, and how the relationships were impacted by their informal caregiving duties. All of the women said their informal caregiving duties were an assumed role. It was not a role that was explicitly discussed prior but rather was expected of them as nurses and women. Even if other family members were in the picture, the care recipient often felt most comfortable with their daughter/wife, as the primary caregiver. One participant made it clear that she was still the primary decision-maker despite having a supportive family:

They all come to me when there is something wrong with my mom. And even with my mom. If I am not around, my siblings would try to give her her medications, or whatever, or they want to take her out, she will always tell them, ask Pearl<sup>+</sup>. Ask Pearl first. She knows better. She [her mother] trusts my judgment” [Participant 1, age 51].

Another woman described the overlap between her roles as daughter and nurse, especially near the end of her mother’s life:

I was very stoic near my mother’s end of life, my family would look to me, everyone would accuse the nurses for killing her, [but] they weren’t doing

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<sup>+</sup>Name changed to protect the identity of the participant.

anything differently. I could tell them, do what you need to make her comfortable. You can tell me on the QT. It makes their life easier, my dad's life easier, and my mom's passing easier. I have my nurse's face on a lot when I went into my mom's room. And my daughter said to me 'can you take off your nurse's face, and put on your daughters face.' I was doing this for everyone else. [Participant 8, age 67]

Another woman discusses being a primary caregiver for both her parents, and taking on that role for her in-laws, despite having a partner and sister-in-law in the picture. She explained how she took on the role:

Because I am a nurse, I don't, probably some part of it is being a woman. We tend to be the caregivers and nurturers. With my in-laws, I am fortunate. I like my in-laws. I know there was a history, a complicated relationship with my husband and his father. And I totally understood that. But I really loved my mother-in-law, so because I cared for them, I am lucky they are such good people, for us too. It outweighed the resentment. I think it's a nurse thing.

At the same time, she went on to explain:

Umm, I think for the most part I am just very grateful that I get the opportunity to do so. Um, there's the odd time there is resentment. I think I wouldn't be human if there wasn't resentment. With my in-laws, like my husband's sister is very good. And very supportive of her parents. My husband is in his own way, but I wouldn't say that it's enough. So, there is times I am a little resentful that he seems to think it's okay that I just go over and stay overnight with his mom when she had her knee replacement, or make extra meals. I mean he is grateful, but I am thinking 'why don't you go over and stay overnight with her?' Yeah there is resentment for sure. Sometimes with my parents, my sister lives out of town. And sometimes the day-to-day stuff, I don't know if I am resentful, when she does come down she does a lot in a short period of time. Just sometimes, I get frustrated. [Participant 7, age 56]

While in some cases the participant was the only available caregiver, at other times women discussed the shared caregiving roles between other family members, primarily adult children and siblings. Often geography was the reason participants took on a role as informal caregiver.

We knew at a young age...My mom has always lived south near my sister [name redacted]...and I've always lived north near my dad. When my parents separated when I was young, I went north with my dad. That closeness from that has always been. So my sister and I have always said, I will care for mom, you care for dad. And I always lived near my dad, so I knew that I would, and I am the support for him because both my brother and sister lived near my mother. [Participant 3, age 56]

Other women had siblings or adult children who often visited, and would be on-call in case of emergencies, or would take care of other caregiving duties from afar, such as dealing with financial matters. For the most part, this arrangement worked in favour of the women, and they expressed gratitude for the additional support, despite taking on the bulk of the burden. Three women alluded to disagreements amongst siblings over financial matters, or when family members made an attempt to assist from afar:

Um, no not so much. My brother is in the States seems to have his own opinions about what is going on. But he is not realistic as he is not here to see what's going on. And I tell him that, [Participant 7, age 56].

Some women brought up times of frustration or exhaustion when talking about how they felt in regards to taking on the assumed role of caregiver. However 8 of the 9 expressed feelings of honour and happiness in being able to provide care for their family members. Participants described it as a 'blessing' to be able to spend time with parents, and discussed how grateful their parents are for the care. Two participants who work in palliative care described how lucky they are to be able to spend quality time with their parents, when they saw so much loss in their paid work as a nurse. One nurse described what she enjoys and what she doesn't enjoy about her informal caregiving role as follows:

Um, just that I am able to. That I can, that I can give back to them. They, they've been very good parents. And that I just have the opportunity. I see people all the time in my job losing people way too soon, so they don't necessary get that opportunity. Someone my age is dying and their parents are watching them die. So, I just feel very fortunate that I can do this. And I can. [Participant 6, age 57]

Another participant said,

I get that quality time with them. And I know, especially in my job in palliative care, that they are not going to be around forever. So being able to spend time with them. Even if it's just listening to my mom go on about the health care system and how it's not supporting people, is nice. [Participant 7, age 56]

The one exception to this trend was the one participant who provided care for her husband with a traumatic brain injury. In response to this question, she felt her relationship changed with her husband, and saw herself as his nurse, no longer his wife. She blamed herself for assuming this role; however she felt it was necessary to ensure he received consistent and quality care, something she believed the current health care system neglects to offer. This is a common topic of discussion among many of the

women when asked about the differences between providing care in their paid nursing role versus their unpaid caregiving role. All believe that family members are necessary in order to provide comprehensive care to ailing family members or friends. Only relying on government supports would leave large gaps in care, and by the women providing the care themselves, or supplementing it, they knew the work was being done, and being done right. This lack of support from the health care system is discussed in greater detail later in the analysis.

An interesting concept brought up by several of the women who were informal caregivers for their parents was the role reversal of providing care. Two of the women spoke thoughtfully about the change in their relationships with their parent(s):

My mother's biggest concern was me having to turn her...having to wash her...and I realized then I am doing for her what she used to do for me. The roles changed. We cried over that one. It was emotional [Participant 8, age 67].

While the women seemed fine with this role reversal, another participant admitted it was personally difficult when her mother, who was her primary support system and someone she called when she needed advice or help, could no longer fill that role:

I have found it very interesting to see in the last probably 4 years, how our roles have reversed. Yeah, and my mom has gone through some issues, but my mom was significant, and I find her not childlike, but sometimes very needy and um, when I say roles-reversed it's like, she has always been my nurturer, my caregiver, my support person. And it's kind of reversed. Like she calls me when she needs help, when things aren't going right. That kind of thing. So that's what I mean when things have reversed. [Participant 6, age 57]

Although it seemed more instinctive to provide caregiving to a child, Participant 5, who was a caregiver for her adult daughter, rejects this assumption. Her daughter had experienced a head injury, but described her as once an independent business-woman. Her daughter was supporting herself, had a successful career and was "pretty much done", before she experienced her head injury. The injury put the nurse back in a caregiving situation to provide for her daughter, a role that she thought she was finished with during that phase of her life.

#### **4.5.5. Moderators and mediators of stress: 'I need another set of hands'**

Several nurses offered simple responses such as unwinding with a glass of wine, or taking a bath, when describing how they mediate stress and fatigue as a result of trying to balance work and family roles. It was unclear whether having additional family members in the picture contributed to or mediates caregiver fatigue. One woman attributed familial support as cultural:

Everyone takes, you know, everyone takes responsibility of taking care of her. It's easy to, you know, I get home my nephews and nieces ask if I have to go out for just a couple hours. They can come and stay with grandma....I think it's our culture too. We grew up like that. [Participant 1, age 51]

Another nurse considered herself fortunate to have her adult sons assist with her father's care, "...both my sons are miners and work over the world. When they are home, as long as someone is there, I have a close network that can fill in when I am not there" [Participant 3, age 56]. Another alluded to the stress among siblings when there is more than one informal caregiver in the picture, "...a lot of stuff that went on about that. Particularly amongst siblings, that's right. Money was the big one. And also, certain family members felt my spouse should have been helping more than he was. And I didn't" [Participant 5, age 60]. Two major challenges reported about the lack of resources to alleviate these stressors included not being able to pay for private homecare and concerns about being able to afford retirement.

#### ***Support from the health care system***

When discussing systemic issues that contributed to stress and fatigue, the number one issue raised by the nurses centered on the current inadequacies in the health care system. While two of the women spoke about accessing supports that were useful to them, such as a seniors' centre with a meal program, or local non-profit organizations which their parents were involved with, most expressed frustration with the mediocre care provided by the health authority and barriers to accessing it. The women reported how their parents were frustrated with home support, and the constantly changing care aides who come into their homes. Not having consistent workers made it difficult for the care recipients to build a relationship, and instead the recipients relied on their informal caregivers. Interestingly, these women worked for the same health authority that they and their families had become frustrated with. They expressed

frustration not only with inadequate care provided to their family members, but also with the inadequate support within their jobs. The same woman who was off work due to an injury experienced on the job, without pay, because her manager did not witness her workplace accident said:

This is the thing, there just isn't enough staff on a floor. It's not even that we need more nurses. If I had a care aide with me, I could do everything fine. It's just having that support there. Changing someone? Taking them to the bathroom? I need another set of hands, I need another body. Even just going around making sure people are eating, or someone needs a cup of tea? That takes up time, the smaller things that add up. Safety for us, and our clients and our patients. It's unacceptable how this has been able to get on. It's upsetting, and I can't do it anymore. It affects me; I go home feeling like a bad nurse. Because I can't do my job well. This is the level I want to work at, but I am not reaching it. It's like the system or health authority, is not allowing us to do that. [Participant 9, age 47]

It is surprising that the same individuals who worked in residential care, and were deeply committed to their work, still preferred to care for their parents within their own homes. One participant says, "seeing [my mother in law] being in her own home? I worked in residential care at one time, and seeing residential care change, it was a pleasure to see her in her home" [Participant 5, age 60]. Another participant discussed providing care for her mother and her experiences working in emergency care as follows:

So I think we, the families who take care, who cares, who care for their elderlies should get a lot more support from the government because it costs them so much. And a lot of elderlies are the ones occupying beds in the hospital right now. Yeah, pretty much like, I am not really sure, because I work in the recovery room, but when I used to work in emergency and on the wards, more than half of our patients were elderly, who are waiting for placement. [Participant 1, age 51]

Another nurse expressed surprise by the lack of services available to her father when he needed them the most. When her father received a quadruple bypass, she said she panicked. Despite being familiar with the system, having worked with social workers when she had clients who were discharged, it wasn't until she was put in that same situation that she realized how inadequate the system is. She explained that it is a "catch-22" – that her father was too independent and strong to receive support, but he only seemed that way because she was supporting him in every possible way:

I was inquiring, like to what degree is he, does he qualify to get anything right? And it sounds like he is way too healthy. Because I am doing everything for him, if you look through a window into his place, it looks like everything is running



smoothly. But it's only running smoothly because I am there hours a week like, from doing his shopping, his cleaning, his cooking, I meal prep for him. Making sure his meds, dad will pick up his blister packs, but he still not always taking them, or is he giving himself the right insulin? Because we all see as nurses, it's very unsettling to send people home and they know they don't have those supports. So you know, the geriatric community really suffers. Especially people in the city, up here, in the north in a community of 5000 people there isn't so many so many supports. [Participant 3, age 56]

The women brought up very specific gaps in the services that are available, including operating hours. For example, one nurse describes,

Um, accessibility to community supports would be a big thing. Because, um not always are they operating at times when shift workers, as a nurse, could use those supports. Normally they are 9-4, 9-3:30, 9-5 operations. And they have very fixed schedules, I am talking because I am from small town, British Columbia, so they have schedules 2 weeks in advance. And if there is an emergency situation, there is no way you can get into those community supports. As much as the health care system says "closer to home" those supports that are needed, that would keep people closer to home, to give people a break or much-needed assistance, aren't there. That's what they cut first. [Participant 5, age 60]

Another nurse said,

I am seeing a big need, well there is no home care. It's just a joke. When my mother in law has her knee surgery it was entirely up to the family to come in and care for her. Unless we hired someone to come in and care for her. With my parents, again, when my dad had a surgery, there was a bit of a crisis, to me, I am called. There is nobody there. There is no home care. With my mom, who just had a surgery, same. There is no extra support for these people unless they want to pay for it themselves. There is a lot of talk out there today, maintaining seniors at home, letting them live at home, and at risk. But they aren't really doing anything to put any supports in place. [Participant 6, age 57]

#### **4.6. Discussion of Relevance for Grant Proposal**

The pilot project confirmed what was already known through the literature on double and triple duty caregivers regarding the experiences of stress and fatigue within formal and informal caregiving work. The key finding of this pilot project expanded on how this stress, fatigue and feelings of pain affect the nurses' job performance, work-life balance and family dynamics. When discussing stress and fatigue, sleep is rooted in almost every topic of conversation. While nursing is known to be a physically demanding job, the pilot project found a considerable amount of the women were actively working through the pain of knee replacements, tendonitis and back pain. A larger study may

explore if this is a determinant of age, or if nurses experience pain at higher rates than their peers of the same age, who are not nurses or informal caregivers. It may also bring more attention to the significance of work-place accidents among nurses.

The literature also informs us that informal caregiving affects the ability of workers to arrive to work on time and work a continuous shift without interruption (Minha, 2012). This pilot study provided a glimpse of how some nurses were able to balance their work environments with their informal caregiving duties by banking sick days, switching shifts and utilizing vacation time. The idea of creative scheduling is a unique finding not yet explored in current research on double and triple duty caregivers. The importance of a supportive work environment consisting of women is also discussed, reinforcing the importance of a feminist perspective within this field of research.

Both positive and negative family dynamics as a result of caregiving duties and responsibilities has been explored within the academic literature. This pilot project revealed that all of the nurses assumed their informal caregiver role as a result of being a woman, a nurse and a daughter, wife or mother. Although many relied on siblings or other family members to share the caregiving duties, all women interviewed were the primary caregiver. It is assumed that these patterns occur as a result of socially constructed gender and caregiving roles, but a larger study could further substantiate this conclusion.

This pilot project expanded on the literature regarding mediators and moderators of stress and fatigue, particularly by exposing the lacklustre role the nurses felt that the health care system played in their caregiving dilemmas. It is also interesting to find that nurses who worked in long-term care and believed in their work also rebuffed the option of moving their loved one into a similar facility.

Two particularly noteworthy findings were identified in the pilot study: 1) the differences between nursing qualifications in terms of being a registered nurse or licensed practical nurse; and 2) the different experiences of double duty and triple duty caregiving in a rural versus an urban community. These topics need to be explored further in order to capture how they shape nurses' experiences. Thus, a distinction should be made between Registered Nurses (RN) and Licensed Practical Nurses (LPN) with regards to contextual factors. Registered nurses hold a four-year baccalaureate

degree in nursing, and specialize in a variety of areas, such as surgery, pediatrics, oncology, etc. Licensed Practical Nurses hold a two-year nursing diploma from an accredited college. Both have different scopes of practice, and therefore make different salaries. A comparative study between registered nurses and licensed practical nurses that are double or triple duty caregivers would be a relevant way to learn more about how education, socio-economic status, and job responsibilities differently affect the health and wellbeing of nurses. One nurse sums up this experience when discussing her retirement decisions:

Retirement? You know what, it's not even on my mind. It's on my back of my mind. I have no savings. I am poor, I am quite poor. It's ridiculous. I am not even thinking that right now. My parents are like, why are you going back to school, why don't you work full time and make money. They don't understand. Retirement I haven't even thought of. The only thing I think is when I get older, when I can't physically do the job? Maybe I'll teach. I have thought about my future. I want to do my bachelors, to open doors. LPNs are quite limited in what they can do. Their scope is limited. A RN opens doors. I check the job board at Coastal Health, and there are 180 nursing jobs for RNs and only 4 LPNs. And I think three of them are out of town. And casual....I haven't thought about retirement, I don't want it to fall on my daughter. I can't think of it right now, I don't want to dwell on it. I feel like I'll make myself upset. My mom retired and when I was struggling financially she was like, no I can't help you I need to save for my retirement. And I was like oh, oh well. I was really struggling....so pretty upsetting when you don't have the support anywhere. I constantly get 1-800 numbers, and I can't claim bankruptcy because I need student loans. Not having enough money, I guess I am off the question, but it's a catch-22 in nursing. You want to be a nurse, you want to help people, you go to school, you go into debt to go into school. [Participant 9, age 47].

Moreover, the diverse experience of double and triple duty caregivers who live in rural versus urban areas merits further study. Living in a rural area influences the kinds of supports offered to caregivers and could therefore affect an informal caregiver's level of stress or burden. Small towns that offer few respite options, and are difficult to access, intensify the burden on informal caregivers (Morgan, Semchuck, Stewart & D'Arcy, 2002). Interestingly, nurses in rural areas also discussed their ability to count on neighbours and friends to help fill the gap in services, showing how remote communities work together to care for their vulnerable populations without formalized programs or services.

Only women were interviewed for this pilot project, but a growing number of men are joining the nursing field and will experience similar situations as they become

assumed caregivers for their family members as well. Another large gap in this pilot project is that ethnicity or cultural background is not examined. One woman mentioned that it was her culture, and not her nursing qualifications, which resulted in her taking on an informal caregiver role in her family. Other than the aforementioned, race and ethnicity was not asked about or discussed anywhere else. However it should be mentioned that race and ethnicity is an important demographic characteristic to consider when comparing licensed practical nurses and registered nurses. There are fewer barriers to become certified as a licensed practical nurse; therefore the positions are often predominately populated by individuals with vulnerable backgrounds (eg. single mothers, new immigrants).

The results of this pilot study highlight a number of important additional directions for future research on double and triple duty caregivers. Firstly, a larger study with a greater number of nurses would ensure the reliability and validity of the study findings. A larger sample population of double duty caregivers would provide confirmatory evidence on the findings of the pilot project (Weil, 2017). Secondly, a mixed methods approach to include contextual information such as marital status, education, income, work/family conflict scales, and sleeping patterns, would provide a comprehensive explanation of other moderators of stress. For example, licensed practical nurses and registered nurses who are in different income brackets will experience different types of stress. Nursing qualifications also affect their job responsibilities and duties and also contribute to different experiences of stress. Some nurses who also have a partner/significant other may receive greater support with their caregiving duties than a woman who is single, separated, divorced or a single mother. Starting with a quantitative survey to collect demographic information and caregiving intensity may explain the differences in how stress, fatigue, work performance and work-family conflict is experienced. Following up with an in-depth qualitative interview to concentrate on the emerging themes would provide greater insight into this population of caregivers. A follow up interview may also provide the participant with more comfort in sharing their experiences, without fear of compromising their job. Providing certificates of confidentiality is one way to reassure participants that bringing up incidents that occurred in their work environments, such as workplace accidents will not put their employment in jeopardy.

Finally, inclusion of a comparison group of nurses who are *not* providing any form of informal care to a family member would be an important way to learn more about

issues such as sleeping aids and/or knee replacements, and the impact on care provision. These two topics consistently surfaced within the interviews, and should be further explored. Overall, this area of research would allow us to ascertain if any health-related outcome differences are the immediate result of shift work and physical job demands within the nursing profession, or something experienced by only those nurses who are simultaneously providing informal caregiving.

## **Chapter 5.**

### **CIHR Grant Proposal**

The following section presents a mock grant proposal based on the CIHR Project Scheme: Spring 2018 guidelines, as outlined in Appendix G (pg. 76).

#### **5.1. Proposal Information**

##### **5.1.1. Project Title:**

Double and triple duty caregiving and its effect on personal health and wellbeing

##### **5.1.2. Lay Title:**

The effect of simultaneously performing formal and informal caregiving on nurse health and wellbeing

##### **5.1.3. Lay Abstract:**

The average Canadian caregiver is a woman between the ages of 45 to 54, and is balancing paid employment with unpaid caregiving duties. Statistics Canada (2012) defines a caregiver as someone who is providing care to family members or friends with long-term health conditions, disabilities, or issues associated with the effects of aging. In 2012, 8 million Canadians were in this caregiver role; 30% of Canadian women reported they provide care to a family member, and of the caregiver cohort between 45 to 64 years of age, approximately half are caring for a parent (Minha, 2012). It is estimated that three-quarters of informal caregivers are also balancing employment (Fast et al., 2011). Furthermore, 70-80% of older adults living in the community receive their care from informal caregivers (Canadian Caregiver Coalition, 2014; Fast et al., 2011) Thus, caregiving is primarily undertaken by families, specifically women, and will be experienced by most Canadians at some point in their lives.

Indirectly, the health care system relies on women to informally share the burden and cost associated with caregiving. Caregivers in Canada contribute more than 5 billion in unpaid labour annually (Fast et al., 2011). If these women work in the nursing profession, there is often an expectation by other family members that they should assume the role of primary caregiver for an older adult requiring care (Depasquale et al., 2016b; Ward-Griffin, St Amant & Brown, 2011). However, nurses are also part of an aging work force, many of whom continue to work. In 2010, 64.1% of women ages 55 to 59 were employed, and the employment rate of women 60 to 64 years of age doubled, from 21.5% in 1996 to 41.4% in 2010 (Galarneau & Carrière, 2011). The aging demographic of nurses can result in an increased risk of burnout, and therefore, a decrease in a nurse's physical and emotional health and wellbeing, as well as high job turnover, which can increase health care costs. Current gaps in literature include examining nurses who are double or triple duty caregivers, as well as how different nurses' roles result in more or less stress, which in turn produces precarious job performance and difficult work-family balance. For example, a licensed practical nurse or registered nurse hold unique responsibilities and duties that contributes to different feelings of pain and fatigue.

This study will address the following research questions with a focus on a sample of nurses working in the British Columbia health care system:

**Overarching Primary Research Question:** How does being a double or triple duty caregiver among nurses in BC contribute to a woman's health and wellbeing?

- RQ1: How do the responsibilities of double or triple duty caregiving contribute to experiences of pain and fatigue?
- RQ2: How do the responsibilities involved in double or triple duty caregiving contribute to job performance and work-family balance?
- RQ3: How do the experiences of double and triple duty caregivers differ between registered nurses and licensed practical nurses?

By addressing these research questions, this work examines the effects of double and triple duty caregiving on a woman's health and wellbeing. Question one investigates the impact caregiving can have on health, while question two examines the impact of caregiving on work performance and familial relationships. Finally, question

three explores how nurses experience pain, fatigue, job performance issues, and work-family conflict differently based on their qualifications.

Institution Paid:

Simon Fraser University, Department of Gerontology

Partnered/Integrated Knowledge Translation Project:

No

Is this a clinical trial?

No

Does this application contain a random controlled trial?

No

In order to carry out the proposed research in this application, is an exemption from Health Canada under Section 56 of the Controlled Drugs and Substances Act required?

No

Does this application propose research involving Indigenous People?

No

Does your proposal address TCPS2 – Chapter 9 Research Involving the First Nations, Inuit, and Metis Peoples of Canada?

No

Are sex (biological) considerations taken into account in this study?

No

Are gender (socio-cultural) considerations taken into account in this proposal?

Yes.



Gender is a focus of this study, as the topic examines caregiving roles – which are often socially constructed as a “woman’s role” (Baines, 2004; Hooyman & Gonyea, 1999), and is in fact primarily occupied by women (Minha, 2012). This study also examines the nursing profession, which is comprised of 92% females and only 8% of men in British Columbia (Canadian Nurses Association, 2016).

Containment Level:

N/A

Environmental Impact:

N/A

## 5.2. **Subtask: Descriptors**

Descriptors:

Caregiving, formal and informal caregiving, double duty caregivers, triple duty caregivers, nurses, psychosocial wellbeing, health, work-family balance.

Themes:

1. *Health Services Research* is the primary theme classification for this grant application. This research contributes to the growing literature on double and triple duty caregivers in order to improve the efficiency and effectiveness of health professionals and the health care system. The multi-method research contributes to this emerging field by examining how the caregiving responsibilities in both formal and informal relationships contribute to positive or negative work and familial dynamics. It also elucidates how multiple role demands influence the wellbeing of nurses as caregivers.
2. *Social, Cultural, Environmental and Population Health Research* is a secondary theme with the goal of improving the health of population of Canadian caregivers through a better understanding of how socially constructed gender norms affect their caregiving duties and how this in turn affects personal health and occupational performance.

Suggested Institutes:

Simon Fraser University, Department of Gerontology shares a similar research mandate to the CIHR. The Gerontology Research Centre (GRC) interdisciplinary approach serves as a focal point for research, education and information on individual and population aging, which would align with this research.

Areas of Science:

1. Sex and Gender Health/Sex-and-Gender-Based Analysis – Clinical, Health Systems and Population Health Research
2. Health Services and Systems/ Knowledge Translation Research and Implementation Science

Methods/Approaches:

Qualitative Methods/Interviews

Statistics & Modeling/ Multivariate Analysis

Knowledge Translation/Translation Research

Study Populations/Experimental Systems:

Life Stages/Older adults

Sex and Gender/Female

Patients and Caregivers/Formal Caregivers

Patients and Caregivers/Informal Caregivers

Occupational/Health Care Professionals

## **5.3. Research Proposal**

### **5.3.1. Concept**

#### ***Significance/Impact***

Nurses who are providing formal caregiving and are also caring for a family member or friend are referred to as *double duty caregivers*. These individuals are further

classified as double duty elder caregivers if the individual is providing care for an older adult, or double duty child caregiver; if the nurse is providing care for a child. Finally, the term *triple duty caregiver* is applied to many women who are employed as nurses and are also caring for an older adult such as their parent(s) or parent(s)-in-law as well as children of various ages (DePasquale et al., 2016a). The Canadian population is aging, and it is projected that by 2063, 25% will be over the age of 65 (Statistics Canada, 2014). The aging population, combined with falling birthrates, women's increased participation in the work force, higher divorce rates, and greater geographic mobility (Keefe, Glendinning & Fancey, 2008), will limit the availability of informal caregivers.

In Canada, the population of the work force who are 55 years of age and older continues to grow. The employment rate for men in this age group has increased from 30.5% in 1997 to 39.9% in 2010, and the employment rate for women in this age group has increased from 15.8% in 1997 to 28.6% in 2010 (Carriere & Galaneau, 2011). The average age of health care professionals is changing at a similar rate, with the number of nurses in Canada aged 55 and older increasing from 80,501 in 2007 to 95,633 in 2016. The number of nurses between the ages of 35 to 54 also declined by 8.9% (Canadian Institute for Health Information, 2017). The aging demographic of nurses will increase the likelihood that employed nurses will simultaneously be providing informal care to elderly relatives. These double duty caregivers are frequently women, some of whom may also be caring for children, as a part of the sandwich generation, making them a triple duty caregiver. The "sandwich generation" is a term used to describe the middle-aged generation of women who are caring for their younger children, while balancing this with the demands of caring for aging parents (Mitchell, 2014). The majority (60%) of reported Canadian caregivers are juggling these responsibilities with paid work, and 25% of caregivers consider themselves "sandwiched" between caregiving for an older adult and caregiving for a child (Minha, 2012).

Women who hold the role of double duty or triple duty caregiver are more likely to suffer poor physical and mental health (DePasquale et al., 2016b; Minha, 2012), struggle with their job performance (Scott, et al., 2006; Minha, 2012), and experience work-family conflict (DePasquale et al., 2016b; Grzywacz et al., 2006; Stephens & Druley, 2001). According to Statistics Canada, 30% of individuals caring for an older adult report five of the nine possible signs of psychological distress, and are the largest group of individuals who need to access health services (Minha, 2012). For example, one million Canadian

family caregivers consulted a medical professional as a result of a caregiving responsibility; 402,000 of these were caring for a parent. In comparison, 175,000 report caring for a spouse and 120,000 report caring for a child (Minha, 2012).

Of the caregivers who are employed, 43% indicate that their caregiving roles affect their ability to get to work on time, and have had to either leave work early, or take time off during a shift (Minha, 2012). In 2007, 1.5 million work days per month were missed by 520,000 employed caregivers due to informal caregiving responsibilities, and 313,000 employed caregivers had to reduce their hours of paid work to provide caregiving to family members (Fast et al., 2011). This can result in job loss, reduced income, or being passed up for promotions. Financial burdens and hardships associated with caregiving also played a large role; 10% of family caregivers of an older adult stated that their caregiving duties prevented them from individual employment (Minha, 2012). Finally, balancing paid and unpaid caregiving roles interferes with family dynamics (Grzywacz et al., 2006), and, in fact, women reported that their roles as caregivers for older adults interfered with their other familial roles, such as being a mother (Keefe & Fancey, 2002; Stephens & Druley, 2001).

The health care system relies heavily on family members and friends to help care for the rapidly aging Canadian population in order to share the burden and costs associated with caregiving. If these caregivers are women who work in the nursing profession, there is often an assumption that they should care for older adults (Ward-Griffin, St. Amant & Brown, 2011), resulting in role captivity (Depasquale et al., 2016b), where the women feel trapped by their caregiver roles. Poor physical and emotional health and wellbeing, challenging family dynamics, and high job turnover can have large societal costs, including health system inefficiencies. There is a current gap within the literature examining how the health and wellbeing of nurses is shaped by the imbalances between high job and family demands.

This work will examine the effects of double and triple duty caregiving on the personal health and wellbeing of Canadian nurses in British Columbia, a population of caregivers never studied before. The work will also examine how the pain and fatigue experienced impact job performance and work-family balance. Finally, an examination of the demographic characteristics of nurses will help determine how education and qualifications, income and family status can moderator or mediate pain, fatigue, job

performance, and work-family conflict. This will be done by examining some differences between licensed practical nurses and registered nurses as it can be hypothesized that different nursing roles will experience pain and fatigue differently which in turn will effect job performance and family dynamics. The limited Canadian literature on double and triple duty caregivers have yet to explore a comparison of this unique population of nurses.

### ***Purpose***

The purpose of this study is to collect data and to expand upon the limited literature on double duty and triple duty caregiving. To date, there has been one Canadian study on double and triple duty caregivers and no focus specifically on nurses in British Columbia. There has also been no comparison made in the literature between different nursing roles or job duties. The pilot project guiding this larger study establishes the need for further examination on a number of different issues concerning double and triple duty caregiving. These issues include how sleep plays a key role in the negative experiences of performing caregiving duties, the physical nature of nursing work and experiences of pain, the difficulties balancing shift work with informal caregiving duties, unique family dynamics, access to support based on geographic location and the lack of support from the health care system.

A quantitative online questionnaire, and qualitative follow-up study, completed by double and triple duty caregivers, will contribute to the limited empirical research that exists on this specific group of caregivers. As seen in the research questions below, further empirical data on this topic ensures that individual and institutional resources for this caregiving population exist, to help prevent burnout and work errors within the nursing profession, stop turnover, and increase work satisfaction, ultimately saving money for the health care system.

**Overarching Primary Research Question:** How does being a double or triple duty caregiver among nurses in BC contribute to a woman's health and wellbeing?

- RQ1: How do the responsibilities of double and triple duty caregiving contribute to experiences of pain and fatigue?

- RQ2: How do the responsibilities involved in double or triple duty caregiving contribute to job performance and work-family balance?
- RQ3: How do the experiences of double and triple duty caregivers differ between registered nurses and licensed practical nurses?

### ***Completed pilot study***

In 2017, nine double duty and triple duty caregivers were interviewed over the phone. These women were employed as registered nurses or licensed practical nurses in British Columbia and were providing informal caregiving to a family member. The results of the pilot project established two unique findings: i) the importance in exploring the differences between nursing qualifications, and thus nursing roles and duties and ii) difficulty of accessing respite and community supports in remote communities. Five general themes emerged from the pilot project: feeling of fatigue, experiences of pain, the importance of a team mentality in one's job performance and work-life balance, family dynamics and the lack of support from the health care sector to moderate/mediate stress.

Questions for the pilot project interview guide fell into four categories: 1) stress and fatigue, 2) job performance, 3) personal life, including family relationships and social opportunities, and 4) mediators and moderators of stress. See Appendix D (pg. 70) for the interview guide. The findings of this study assisted in informing the development of the quantitative and qualitative interview guide for this grant. For example, sleep deprivation is referred to in the questions around stress and fatigue. Primarily, this topic centres on how a lack of sleep contributes to exhaustion and experiences of physical pain as a result of nursing work. The nurses interviewed in the pilot study were not forthcoming about how their informal caregiving affected their job performance, yet they referred to switching shifts, the workplace culture, difficulty in booking appointments, and distractions from their informal caregiving duties as interfering with their paid work (e.g. phone calls, text messages). Again, the women were not immediately forthcoming with how their employment influenced their family dynamics, but when further questioned, discussed feeling frustrated or lacking patience towards family members. When answering these questions, most women explained that this is due to a lack of sleep, working night shifts, or feeling exhausted.

Finally, when asked about the mediators or moderators of stress, fatigue, and work-family conflict, many of the women refer to financial constraints, a lack of resources in their rural communities, or being single mothers. These contextual factors are a major theme uncovered in the pilot project, which should be captured in a larger study through a comprehensive set of background questions. Nursing qualifications and educational levels (whether the subject is a registered nurse or a licensed practical nurse), household income, and marital and family status are all referred to as sources of (or contributing to) pain, exhaustion, poor work performance, or work-family conflict. For example, some women with adult children or partners have additional support in providing informal caregiving. An example of how financial constraint influences stress, was licensed practical nurses stating that it was not financially viable for them to retire, despite having concerns about their ability to complete work tasks based on the physical nature of their jobs.

### **5.3.2. Feasibility**

The purpose of this study is to provide evidence-based knowledge and insight into the effects that double and triple duty caregiving have on the well-being of nurses. Specific attention will be paid to how these effects contribute to experiences of pain and fatigue, decreased job performance, and work-family balance. There is also an opportunity to compare the different nursing qualifications of double and triple duty caregivers. This will help us to learn more about how socio-demographic characteristics and contextual factors mediate or moderate fatigue, pain, job performance, and work-family balance.

## ***Methodology***

### **Design**

This grant proposes a multi-method or mixed method study of female nurses providing multiple formal and informal caregiving duties. Johnson, Onquegbuzie and Turner defined mixed methods research as:

...the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection, analysis, inference

techniques) for the broad purposes of breadth and depth of understanding and corroboration. (2007, p. 123)

Using a mixed-methods approach allows for greater exploratory and confirmatory meaning to be developed from the data, as the qualitative survey will hone in on the themes, and augment the outcomes found in the quantitative survey. A mixed methods approach allows the research to expand on these themes, as the topic is a relatively new field, with limited support in the literature (Johnson, Onwuegbuzie & Turner, 2007). Mixed methods research is appropriate to address the research questions in this study; quantitative data will be used to determine how caregiving roles are associated with experiences of pain and fatigue, work-family balance, and job performance; while qualitative data will delve deeper into why these associations exist.

Phase one of data collection will use a quantitative online survey that participants can complete at their discretion on an electronic device of their choosing. The online survey will consist of approximately 50 close-ended questions, and will take approximately one hour to complete. These demographic data will help determine if and how the different educational levels for LPNs and RNs (a 2-year college diploma versus a 4-year bachelor's degree respectively), income levels, urban versus rural dwelling, and having a spouse or other family members who are able and willing to share in the informal caregiving burden, will moderate the experiences of pain, fatigue, work-family conflict, and job performance of double and triple duty caregivers. Independent variables include caregiver duration (e.g. years of caregiving, intensity, frequency and type), financial impact of caregiving, living arrangement of the care recipient and the care recipients cognitive/physical levels. Caregiving status will allow a comparison between double and triple duty caregivers, to learn more about the sandwich generation of nurses in this triple duty role. Caregiving outcomes can differ depending on how many years of caregiving, the intensity of caregiving duties, or the blurring of caregiving boundaries, therefore is it important to capture caregiving frequency. The dependent variables selected to capture the health and wellbeing of double duty and triple duty caregivers include experiences of pain, fatigue, stress, depression, psychological wellbeing, work-family conflict, and job performance.

Phase two will entail a qualitative interview completed in-person. It will consist of approximately 30 open-ended questions, and will take between one to one-and-a-half



hours to complete. Appendix H (pg. 77) expands on the 3-year project timeline for this project. Validity and reliability will be established by questioning the applicability and consistency of the findings at different points during the interview, as well as across participants (Long & Johnson, 2000).

## **Sample**

Phase one will involve a survey of 400 women who work as registered nurses or licensed practical nurses in British Columbia. The 400 selected participants in phase one will be purposefully selected based on: employment status (full-time versus part-time), rural versus urban dwelling and cultural diversity. According to the Canadian Nurses Association there are 37,774 nurses in British Columbia; 56% are employed full-time, 44% are part-time or casual. Thus the participants interviewed will consist of part-time (n=176) or full-time (n=224) employees. Roughly 6.1% of British Columbia nurses work in “rural or remote” jurisdictions and should therefore account for n=24 of the sample population of 400 (Canadian Nurses Association, 2016). These sample numbers will ensure the sample population is representative of the nursing population in British Columbia. There are no provided statistical information regarding cultural diversity or sexual orientation of nursing staff in British Columbia, therefore using the 2011 Canadian Census which estimates 25% of Canadians are a part of a visible minority group (Statistics Canada, 2011), 100 of the participants selected should be a part of what Statistics Canada describes as a visible minority. A sample of 400 will also allow for adequate statistical power to detect small to medium effects in the order of  $\beta \geq .10$ , using OLS regression with 10 independent variables. Sample criteria include women between 45-67 years of age, and reside in either urban or rural settings. This age bracket was chosen as it is important to look at the baby boomer population who are more likely to be double or triple duty caregivers. All participants must work within British Columbia, be fluent in English, and be able to complete the questionnaire independently. As phase one involves an online survey, (see Appendix I, pg. 78), participants must have some level of computer competency. Recruitment will involve a snowball technique using a poster (such as that seen in Appendix E, pg. 73). A site-based recruitment technique will also be used, for example accessing the Vancouver Coastal Health Research Institute, the body that approves research completed through hospitals in this health authority (Vancouver Coastal Health, 2017). Accessing a governing body like the VCH Research Institute will assist in recruitment, as they distribute posters, set up

presentations and assist with screening. However, it is important to note that using a snowballing and site-based recruitment strategy will involve the majority of nurses coming from relatively similar geographic location.

Phase two will entail a purposive sampling method, in which participants will be selected based on the following criteria: i) agreement to be contacted, ii) a significant range of ages, iii) a range of different nursing qualifications. The demographic variation in purposive sampling will ensure representative coverage and inclusion of different groups (Sandelowski, 1995). This phase will facilitate the elaboration of the major themes that were derived from the original online questionnaire. For example, the qualitative data will provide additional detail about the inability to retire due to financial constraints and how other family members may assist the nurses with informal caregiving duties. The 40 selected participants from phase one will vary in age, and will work as either a registered nurse (n=20) or a licensed practical nurse (n=20). This will ensure a comparison can be made between the two groups. Similar to phase one, the 40 selected participants in phase two will be purposefully selected based on: employment status (full-time versus part-time), rural versus urban dwelling and cultural diversity. The goal of this type of participation selection will ensure a heterogeneous sample where further comparisons can be made. This qualitative study will be implemented by student research assistants and will take place in-person. Participants will be asked about 30 open-ended questions, such as those seen in Appendix D (see pg. 70). All participants will need to fill out an informed consent form, like the one shown in Appendix H (pg. 77), for both phases of the study. This will ensure that the participants understand the potential risks and benefits of the study and their right to drop out at any time.

One of the largest challenges identified within both Phase 1 and Phase 2 of this project will be recruitment of a population that is very busy, with little or no free time to participate. Participants will be assured that their invaluable input will contribute to greater work, and hopefully future resources, for this vulnerable group of caregivers. They will also be offered a small honorarium of \$50, and a set of recommendations to address work-family balance and stress based in the findings, to encourage their participation in both phases of the study.

## Questionnaire Development

One of the major findings of the pilot study was how some demographic characteristics (eg. education level, socio-economic status, geographic location) influenced double and triple duty caregivers and their experiences of fatigue, pain, fatigue, job performance, work-life balance and family dynamics. Hypothetically, this finding may be due to the different educational and income levels between registered nurses and licensed practical nurses. Family and marital status, as well as place of residence/dwelling, also influenced the nurses' experiences of pain, fatigue, job performance, and work-life conflict. The interviewees in the pilot study who had spouses or adult children living at home or in the same town, had additional support to assist with caregiving and help provide respite. Therefore, careful consideration will be made when collecting the contextual characteristics of the nurses, and distinguishing between nursing qualifications.

The online questionnaire in Phase 1 will utilize several established measurement instruments including the inter-role conflict scale (Stephens & Druley, 2001), a Likert-type scale that asks yes/no questions such as, "I do not have enough time do everything I want to in a day" and "I do not have enough energy to do everything in a day". The inter-role conflict measure has been found to correlate with marriage satisfaction and age of children ( $r=.62$ ) in previous research (Stephens & Druley, 2001). Positive correlations were also found between inter-role conflict and depressive symptoms ( $r=.22^*$ ), instrumental stress ( $r=.24^{***}$ ), and leisure activities ( $r=.41^{***}$ ) (Stephens & Druley, 2001). A depression scale will be important to capture the typical feelings of depression during formal and informal caregiving duties. The Patient Health Questionnaire (PHQ-9) asks respondents to rate 9-items and how much they have bothered them in the past two weeks. In a current study used on caregivers the Cronbach alpha coefficient was 0.77 (Moreno et al., 2015). The Epworth sleepiness scale (ESS) is a valid and reliable tool for measuring sleep habits during the day. A high correlation coefficient ( $r=.75$ ) was found between ESS scores measured two years apart (Waage et al., 2014). The conditions of the work effectiveness-II (CWEQ-II) (Laschinger, Finegan & Shamian, 2001) scale have been used in previous studies to measure nurses' perceptions of work empowerment such as access to information, support, resources, opportunities, and formal and informal power. The correlation coefficients' ranged between  $r=.74$  and  $r=.82$  for these associations, ensuring reliability and validity (Guo et

al., 2016). The Financial Impact Scale (FIS) assesses the economic cost of informal caregiving and has been used in conjunction with the Zarit Burden Inventory to measure financial wellbeing, yielding a Cronbach's alpha of .93 (Todtman & Gustafson, 1991). The six dimension scale of nursing performance (6-D scale) evaluates nurses' performance in a number of different fields, and has proven weak, but statistically significant, in testing emotional intelligence amongst nurses ( $r=.26^*$ ) (Beauvais, Brady, O'Shea, & Griffin, 2011). The 6-D scale has also shown positive correlations in some aspects of nurses' job satisfaction ( $r=.28^*$ ) (Taskase, Kershaw & Burt, 2001). Finally, the Zarit caregiver burden scale is a caregiver self-report measure with 22 items asking the caregiver to rate their caregiving experience from 0 (Never) to 4 (Always). Hérbert, Bravo, and Prévile (2000), provide the most frequently cited information on reliability and validity for the Zarit Burden Inventory. The researchers show the measure has good internal consistency reliability, with a Cronbach's alpha coefficient of .92.

Phase 2 will consist of many of the qualitative questions used in the pilot project due to their relevance (Appendix D, pg. 70). Women interviewed in the pilot project did hesitate to talk about some aspects of their paid employment. Methods to confirm confidentiality will ensure that the nurses interviewed may be more secure in revealing information about their work performance, specifically calling in sick, work-place errors, or distractions within the work environment. Finally, the pilot project revealed some discrepancies between the experiences of licensed practical nurses and registered nurses. This was primarily in terms of income and retirement decisions, as well as some of the job duties involved in different nursing levels. For example, registered nurses are often in management positions and involve doing less of the physical tasks such as transporting or toileting patients. Ensuring that there is an equal amount of LPNs and RNs interviewed in phase 2 will provide an opportunity to compare the two groups.

### **Data Analysis**

The study will involve two stages of data analysis. Phase 1 consists of 400 online questionnaires that will be analyzed using SPSS 24 software to test for associations using bivariate and multivariate analyses. Independent variables include caregiver duration (which will include years of caregiving, intensity, frequency and type), financial costs associated with caregiving, living arrangement between the caregiver and care recipient and care recipients level of cognitive and/or physical impairment. The

dependent variables selected to capture the health and wellbeing of double duty and triple duty caregivers include experiences of pain, fatigue, stress, depression, psychological wellbeing, work-family conflict, and job performance. To capture the differences between licensed practical nurses and registered nurses, as well as other predictors of work-family balance, several covariates will be examined. These include: age, partner status, education level, income, family status, nursing qualification, work demands, job type (full/part-time, salary/contract), and social support. The association between double or triple duty caregiving is moderated by factors related to the individual (e.g. ethnicity, education). Whereas the mediator variables, which explain how and why the external physical events occur (e.g. stress, social support, coping) may influence the stress or fatigue experienced by double or triple duty caregivers. Thus mediating factors such as available (or unavailable) additional social support will also be captured in the covariates examined.

Phase 2 data from the 40 follow up interviews will be transcribed, imported, and analyzed using NVivo (version 11.4.2) statistical software. Initial coding will be used to discover more about the participants' views and experiences of caregiving, and this data will then be compared across interview participants, and grouped into themes. This qualitative analysis will help elaborate and contextualize the major themes derived from the results of the quantitative survey. Debriefing the results of the interviews within the research team, discussing codes, and examining comparisons between the quantitative results via triangulation, will ensure rigor and thoroughness (Long & Johnson, 2000).

### **Knowledge Translation**

The Canadian Institute of Health Research proposes that knowledge translation should:

Deliver the proposed output(s) and achieve the proposed contribution(s) to advancing health-related knowledge, health care, health systems and/or health outcomes....opportunities to maximize project contributions to advance health-related knowledge, health care, health systems and/or health outcomes should be proactively sought and planned for..." (Appendix G, pg. 76).

This research on double and triple duty caregivers would provide tangible knowledge to be transformed into policy and practice. Presentations to different

workplaces such as Vancouver Coastal Health, the College of Registered Nurses of BC, the College of Licensed Practical Nurses of BC and caregiving groups such as the Family Caregivers of British Columbia, will increase awareness amongst nursing professionals and caregivers to educate about the effects of double and triple duty caregiving on overall well-being. Plain language summary reports will be educational tools for both registered nurses and licensed practical nurses who may fit the demographic characteristics of the caregivers within this study.

Workshops that present the key findings of both phases of the study, and engage the double and triple duty caregivers to reflect on their own experiences of pain, fatigue, and exhaustion, job performance, and work-life balance, can be offered to determine how nurses can be better supported. This will allow researchers to learn how project findings can best be applied within nursing practice. These presentations will also inform those professionals in management and administrative roles about the importance of a healthy and supportive workplace.

Finally, publishing the research findings in reports and journals will ensure knowledge dissemination and mobilization of the topic area among other researchers and academics. Ideally, educators and students who may not fit into the inclusion criteria of this study, but might find themselves in this position one day, can access these journal articles. This may encourage candid conversations with family members about caregiving responsibilities, or possibly encourage pre-retirement planning.

According to Biggs, Lowenstein, and Hendricks (2004), a multi-disciplinary approach to research adds richness and substance, combining unique ideas and perspectives. This research will be relevant to both the nursing profession as well as the gerontology field, emphasizing the importance of transdisciplinary research. Therefore the findings of this study could be shared at both nursing and gerontology conferences such as the Canadian Association of Gerontology Conference, and the Nursing and Healthcare Conference. A project budget, found in Appendix J (see pg. 82), explains the expenses of this research project in further detail, and primarily how the funding will be allocated for knowledge translation.

## **Expertise, Experience, and Resources**

*This section will not be included in the requirements for the Capstone project, but would be completed for in an authentic CIHR grant proposal.*

### **5.4. CIHR Complete Summary**

The purpose of this grant proposal is to fill existing knowledge gaps and to further expand on the results of a small pilot project. There has been no research on nurses in British Columbia who are simultaneously performing informal and formal caregiving roles. Also there is a gap in literature comparing licensed practical nurses and registered nurses, to further explore how the health and wellbeing of nurses may differ depending on different roles. Notably, the pilot study findings indicate the experiences of stress and fatigue are rooted in the poor sleeping patterns of double and triple duty caregivers. Stress, fatigue and experiences of pain in turn affect the nurse's job performance, work-family balance and family-dynamics. This pilot study also finds a difference between double and triple duty caregivers, based on contextual characteristics (e.g. family/martial status, urban versus rural dwelling, education). In short, there appears to be variation in how nursing qualifications affect stress, fatigue, pain, job performance, work-family balance and family dynamics.

It is known that informal and formal caregiving duties lead to experiences of physical and mental exhaustion (DePasquale et al., 2016b; Minha, 2012), poor work performance (Fast et al., 2011), poor job satisfaction (Boumans & Dorant, 2015; DePasquale et al., 2017; Minha, 2012), and precarious family relationships (Grzywacz et al., 2006; Keefe & Fancey, 2002; Stephens & Druley, 2001). Nevertheless, double and triple duty caregivers play an important part in sustaining the health care system, spending an estimated 12.6 million a year in expenses related to their caregiving role (Canadian Caregiver Coalition, 2014). However, as health care workers, they are an aging demographic (CIHI, 2017) who are working in a high-risk, demanding profession (Boumans & Dorant, 2015), and are more likely to enter an informal caregiving arrangement as they age (Minha, 2012). This not only impacts their personal health and well-being, but also has a systemic effect on the larger health care system.

A mixed methods approach will provide a greater understanding of the health and wellbeing of double and triple duty caregivers. Phase one will involve an online questionnaire for 400 women between the ages of 45-67 who are nursing full time or part time and are also providing some sort of informal care to a family member or friend. The first phase will create a profile of a double or triple duty caregiver experiencing pain, fatigue, poor work performance and work-family conflict. Phase two will involve selecting 40 individuals from phase one for an in-person qualitative interview to learn more about their physical and mental health, job performance, work-family conflict and family dynamics. Phase two will provide a comparison between nursing qualifications, and caregiving intensity, which directly lead to, or perpetuate/disseminate the stress involved in these roles.

The limitations of the pilot project were addressed in this CIHR grant proposal in the following ways: i) by providing a deeper understanding of the contextual factors among nurses and ii) providing a comparison between nurses with different qualifications. However it is important to note that despite including a larger sample population, there would likely be a self-selection bias amongst the nurses who participate. The study also neglects to study men, who are a growing demographic of nurses within Canada and are becoming more active in providing informal caregiving. Finally, including a comparison group of non-nursing individuals would explain if the experiences of stress, fatigue, poor job performance and difficult family dynamics were experienced by individuals in other professions beyond nursing, and not a direct result of the blurred boundaries of providing both formal and informal care. Ideally, the results of this CIHR grant will provide future research directions to enhance workplace supports and provide stronger home/community care. Ensuring a skilled and healthy workforce and creating a homecare system with enhanced community supports will support double or triple duty caregivers and alleviate the competing care demands.



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## Appendix A.

### Pearlin's Stress Process Model Applied to Alzheimer's Caregiver Stress

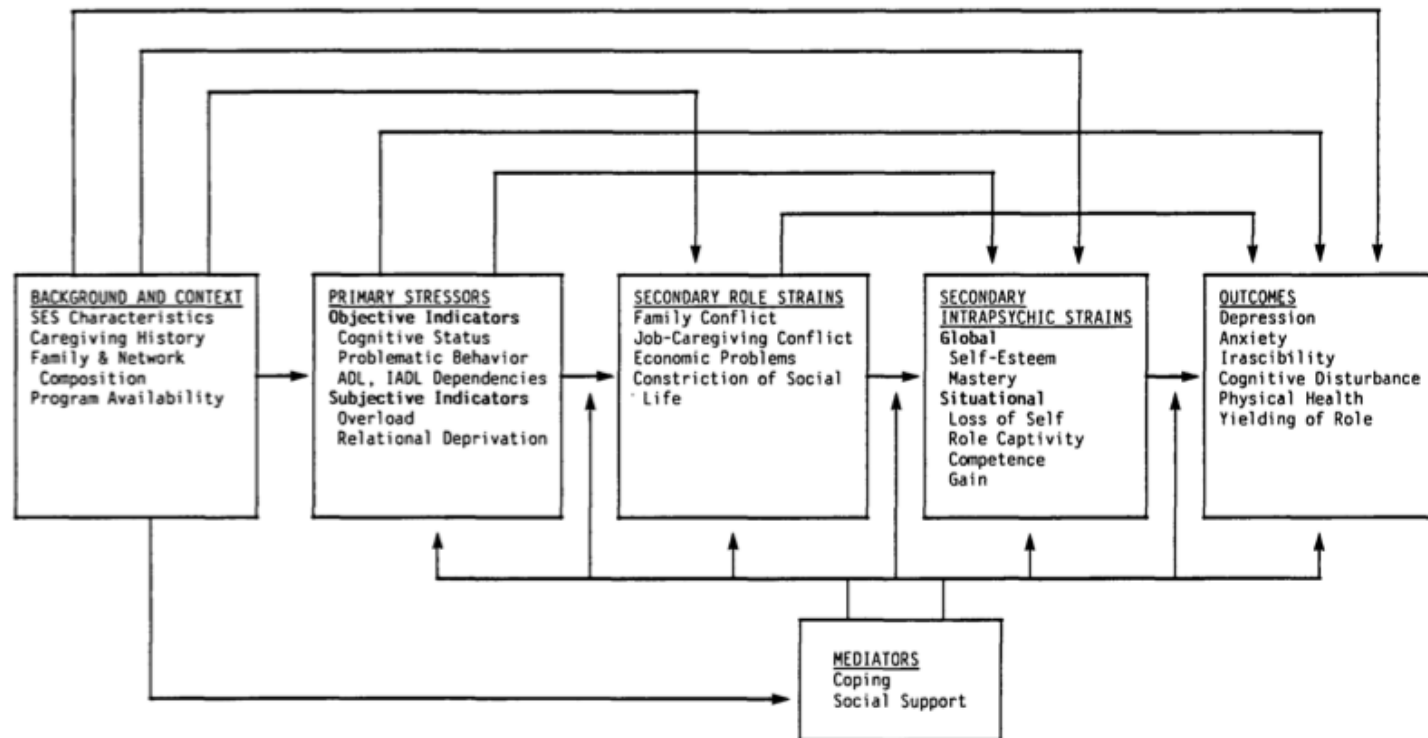
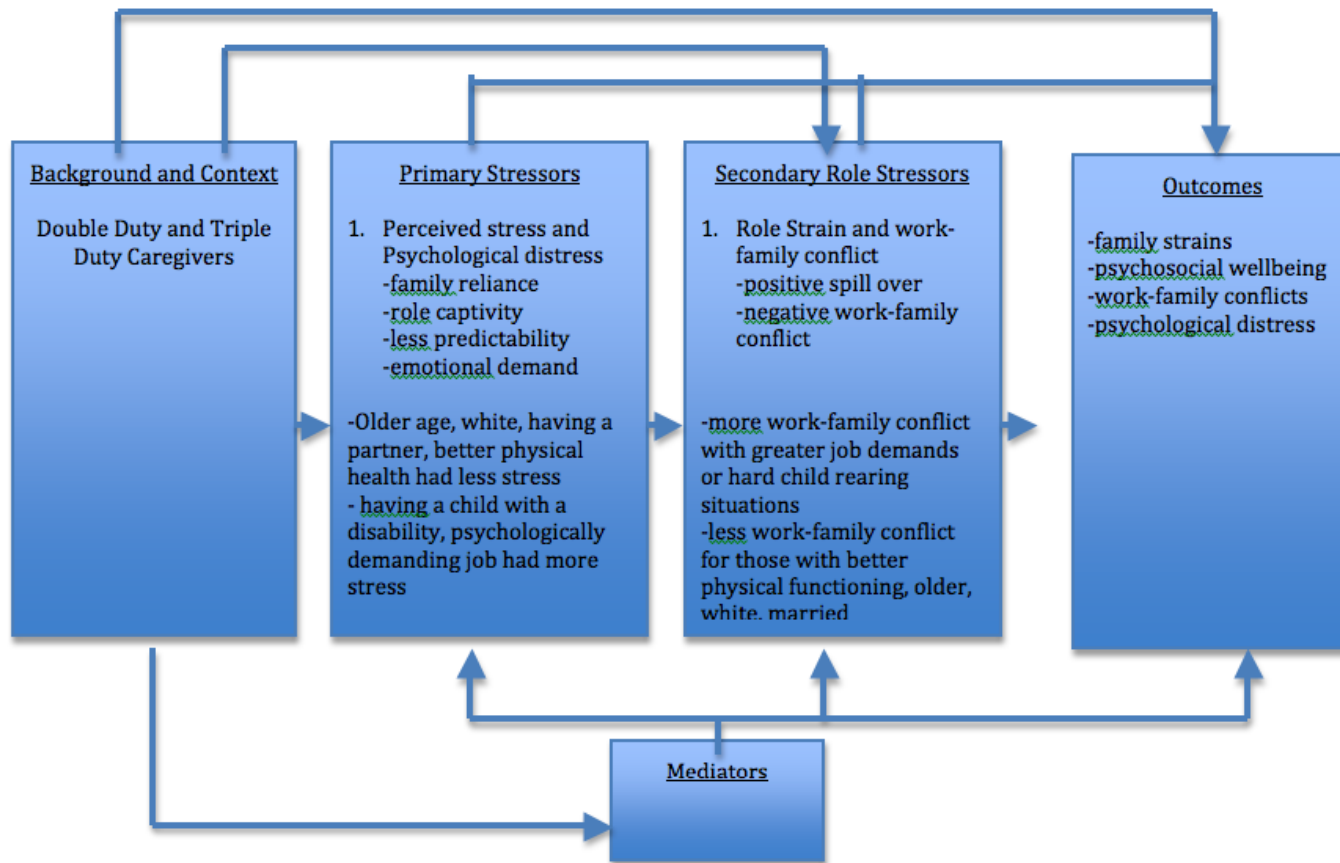


Figure A.1. A conceptual model of Alzheimer's caregivers' stress. The stress process is made up of four domains: the background and context of stress; the stressors; the mediators of stress; and the outcomes or manifestations of stress.

Source: Pearlman, L. I., Millan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist*, 30(5), 583-594. Used with permission.

## Appendix B.

### Adaptation of Pearlin's Stress Process Model Applied to Double Duty and Triple Duty Caregivers



## Appendix C.

### The Double Duty Caregiving Scale

<b>Dimensions of DDC</b>	<b>Initial Item Pool (n = 57)</b>	<b>Items Deleted Based on CVI<sup>a</sup></b>	<b>Provisional DDCS (n = 49)</b>	<b>Items Deleted Based on EFA<sup>b</sup></b>	<b>Revised DDCS Tool (n = 33)</b>	<b>Sample Items</b>
1. Expectations (expectations to care for elderly relatives)	Self (9) Family (4) Professional (3)	-1 -1 0	(8) (3) (3)	-5	Familial (5) Professional (4)	Because of my health care background – I have high expectations of myself to provide care to my relative
2. Supports (supports used to manage caregiving)	Personal (4) Professional (4)	-1 -1	(3) (3)		Personal (3) Professional (3)	As a caregiver for my elderly relative – My workplace supports me to provide care to my relative
3. Negotiating Strategies (strategies used to negotiate personal/professional boundaries)	Setting limits (10) Making connections (13)	0 -3	(10) (10)	-4 -5	Awareness of boundaries (3) Active resistance (3) Making connections (5)	Because I am a health care provider who also provides care to my relative – I set a limit of what type of care I will provide my relative
4. Caregiving Interface (CI) (degree of blurring between professional and personal caregiving)	CI (10)	-1	(9)	-2	Perceptions of CI (4) Consequences of CI (3)	Because I am a health care provider who also provides care to my relative – I feel like I am caught between two worlds (professional and family)

<sup>a</sup> Content validity indices <sup>b</sup> Exploratory factor analyses

Source: Ward-Griffin, C., Keefe, J., Martin-Matthews, A., Kerr, M., Brown, J. B., & Oudshoorn, A. (2009). Development and validation of the double duty caregiving scale. *Canadian Journal of Nursing Research*, 41(3), 108-128. Used with permission, licensed under a CC BY license.



# Appendix D.

## Interview Guide

Application # 2017s0376

### Phone/ In-Person Interview Guide (Qualitative)

Thank you very much for agreeing to participate in this study on nurses who provide caregiving for family members! I will start off asking some background socio-demographic questions.

#### Background

1. What is your gender? 01 Male 02 Female 03 Other (Specify)
2. What is your year of birth?
3. What is your CURRENT living arrangement?
  - 01 Never married
  - 02 Married and living with spouse
  - 03 Living with a partner (2 years or more)
  - 04 Living with a partner (less than 2 years)
  - 05 Married or partnered but living apart/in separate households)
  - 06 Divorced/separated
  - 07 Widowed
4. In total, how many people, including yourself, reside in your household?
5. Who are you providing caregiving for?  
(According to Statscan, Caregivers in Canada are defined as those aged 15 years and older providing help or care within the past 12 months to either: 1) someone with a long-term health condition or a physical or mental disability, or 2) someone with problems related to aging.<sup>2</sup>)
6. What nursing qualifications do you hold? What type of nursing do you practice?  
(Probe: How long have you worked in this practice? How many hours per week do you usually work?)

#### Caregiver (work)

Let's start by discussing some thoughts that you have about your nursing work and if and how your caregiving roles affect your paid job as a nurse.

#### *Fatigue*

7. Do you ever experience any type of physical pains from your paid work as a nurse? Probe: What types of pain i.e. neck, back, feet, legs.
  - a. How does this intensity/duration affect your personal life? How does it further affect your nursing work? How does it affect your unpaid caregiving duties?

#### *Stress and Sleep*

8. How long does it usually take you to fall asleep? [Probe: does this vary based on working a night shift, day shift or when off-schedule]?
9. How many hours do you usually sleep a night? [Probe: does this vary based on working a night shift, day shift or when off-schedule]?
10. Do you find your quality and quantity of sleep affects your day-to-day functioning? (could also probe: could you give me some examples/tell me more about...)
11. Do you find that the quality and quantity of your sleep affects your paid work performance? For example, do you find it hard to focus on multiple tasks? Do you use your breaks to nap?

### *Job Performance*

I would like to explore in more detail how the nursing profession (shift work, poor sleep quality) affects your job performance.

12. Do you ever find it difficult to concentrate/focus on a single task? Is your ability to multi-task in your fast-past environment effected affected at all? (Probe: how often/if this happens frequently, occasionally, sometimes...)
13. Do you ever find it difficult to remember particular aspects of your job? Can you elaborate? [Appointments, patients names or ailments, etc]. (Probe: how often/if this happens frequently, occasionally, sometimes...)
14. Have your caregiving duties ever affected your paid work performance? Can you give me some specific examples?
15. Have you ever had to take time off work because of your caregiving responsibilities? [Probe: absenteeism's, arriving late, leaving early, relying on other staff] also ask how often this has happened?

### Caregiver (family)

Now I would like to explore whether your own family life and relationships are affected by your nursing work.

### *Mood*

16. How would you normally describe your mood while performing caregiving duties?
17. How did you become a caregiver for your parent? Was it an unspoken, expected role? Or was this something that you both discussed and decided upon? How do you feel about this role?
18. What are your favourite parts of providing caregiving for your parents? How do these positive aspects affect your general mood/well-being?

### *Personal Life*

Being a nurse, as well as a caregiver, might affect the time that one has to take care of themselves. I am now going to ask you a couple questions about how your caregiving specifically affects your personal life. After that we'll complete the interview with some questions on supports that you find help or hinder any stress that you might experience in your role as caregiver add or detract stress from your caregiving role.

19. Have your retirement decisions been influenced by your caregiving relationships with your parents? In-laws? What about in the future?
20. Do you ever miss out on social opportunities such as certain events or gatherings (parties, visiting friends, dinners) because of your caregiving duties? (What about leisure pursuits, hobbies, travel?) How does this make you feel?
21. Does your caregiving role affect your relationships with other family members (e.g., children, spouse)? Friends?

*Mediators and Moderators*

Finally, to conclude our discussion, I would love to hear your thoughts on community supports and advice that you might have for other families.

22. Ideally, what kinds of community supports do you think would be the most useful to you and your family so that you can deal with any challenges that you experience? What about other families? How so? Provide examples.
23. What advice would you give to other nurses of a similar life stage?
24. What do you like to do to unwind from a stressful or busy day? Ideally, what would you like to do, if you had more time or resources?
  - a. Do you have any coping strategies (positive or negative) that you would like to share with me that you deem helpful in balancing your work/family?

That completes the interview. Thank you so much for your participation in this study. Do you have any final comments that you would like to add about working as a nurse while providing caregiving to one of your parents?

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# Appendix E.

## Recruitment Poster



Application #2017s0376



### Research Participants Needed

#### ARE YOU:

- ✓ A NURSE?
- ✓ OVER THE AGE OF 45?
- ✓ PROVIDING SOME FORM OF CAREGIVING FOR YOUR PARENT OR OTHER FAMILY MEMBER?



I AM LOOKING FOR PARTICIPANTS TO INCLUDE IN A PROJECT AS A PART OF MY MASTERS RESEARCH "DOUBLE DUTY AND TRIPLE DUTY CAREGIVERS AND THE EFFECT ON 'PERSONAL HEALTH AND WELLBEING'". PARTICIPATION INVOLVES A 30-40 MINUTE PHONE INTERVIEW. I AM INTERESTED IN LEARNING MORE ABOUT NURSES WHO BALANCE THEIR WORK AND FAMILIAL CAREGIVING RESPONSIBILITIES AND HOW THIS AFFECTS THEIR HEALTH AND WELLBEING. RESULTS WILL HELP IDENTIFY POTENTIAL RISK FACTORS AND REINFORCE SUPPORTS NEEDED.

RESEARCH CARRIED OUT IN THE DEPARTMENT OF GERONTOLOGY AT SIMON FRASER UNIVERSITY.

If you are interested or have more questions, please contact:  
Mhairi Campbell



Version #1, 2017/08/16

# Appendix F.

## Informed Consent

Application #2017s0376

**SIMON FRASER UNIVERSITY**

**(VERBAL SCRIPT) INFORMED CONSENT FORM**

**TO PARTICIPATE IN A RESEARCH PROJECT**

“Hello, my name is Mhairi Campbell. As a part of the requirements for my Master of Arts in Gerontology degree at Simon Fraser University I am completing a mock grant proposal and am including a small pilot study where I interview participants. This is under the supervision of my professor, Dr. Barbara Mitchell.

The purpose of this study is to interview nurses to learn the effects, if any, the balancing of caregiving roles has on their health and wellbeing, which in turn effects their work performance and personal relationships. Therefore I want to learn more about women’s roles as nursing staff who provide informal caregiving to their parents and I would like to include your opinions/experiences.

Your participation is voluntary. You have the right to refuse to participate in this study. If you would like to participate, this interview will take approximately 30-40 minutes and can be completed over the phone immediately, at a later date, or in person at a location of your suggestion.

There are no foreseeable risks to you from taking part in this study, and there may or may not be direct benefits to you from participating. If you are uncomfortable (anxious, fearful, embarrassed shameful) at any time answering questions about your employment or family life, and wish to stop the interview, we will end the interview at your discretion.

Information that you give me will be kept strictly confidential and stored in a secure location, however you should be aware the telephone is not considered a confidential means of communication, therefore confidentiality cannot be guaranteed. If you give your consent to participate, you will have your identity disguised in the interview material using an ID number. Your name will not appear on any written reports, and no one will be given access to your name or personal information. Information will be collected using a recording device, which will be erased after it is transcribed. If you do not wish to be recorded, I will take handwritten notes, which will be destroyed after they are transcribed. Only the primary investigator (Mhairi Campbell) and Supervisor (Dr. Barbara Mitchell) will have access to this information, which will be password protected. As per SFU Policy the data transcribed will be kept on a USB in a secure location (under lock and key) for 2 years, then destroyed.

You may also refuse to answer any or all questions that you do not feel comfortable in answering, or, you may withdraw from the study at any time without consequences to you employment, education or services.

The main study findings will be reported in my capstone project for the requirements to complete my Masters of Arts in Gerontology. There are no financial incentives for participation in this study however a copy of the completed project with study findings can be sent to you, if you wish.

Taking part in this study is entirely up to you. Do I have your or verbal consent to participate? (Y/N)\_\_\_\_\_. Another option is to provide you with a copy of the consent form via email. If you wish to do this, could I have your email address? (Y/N). \_\_\_\_\_ . Email address:\_\_\_\_\_.

Do I have permission to record our interviews? (Y/N)\_\_\_\_\_.

Would you like a copy of the completed project at the end of study, which will include the project findings? If so, do I have your permission to store your contact information under lock and key at Simon Fraser University? (Y/N). \_\_\_\_\_

Thank you for your time”

Date\_\_\_\_\_

YYYY/MM/DD

## **Appendix G.**

### **CIHR Project Scheme: Spring 2018 guidelines**

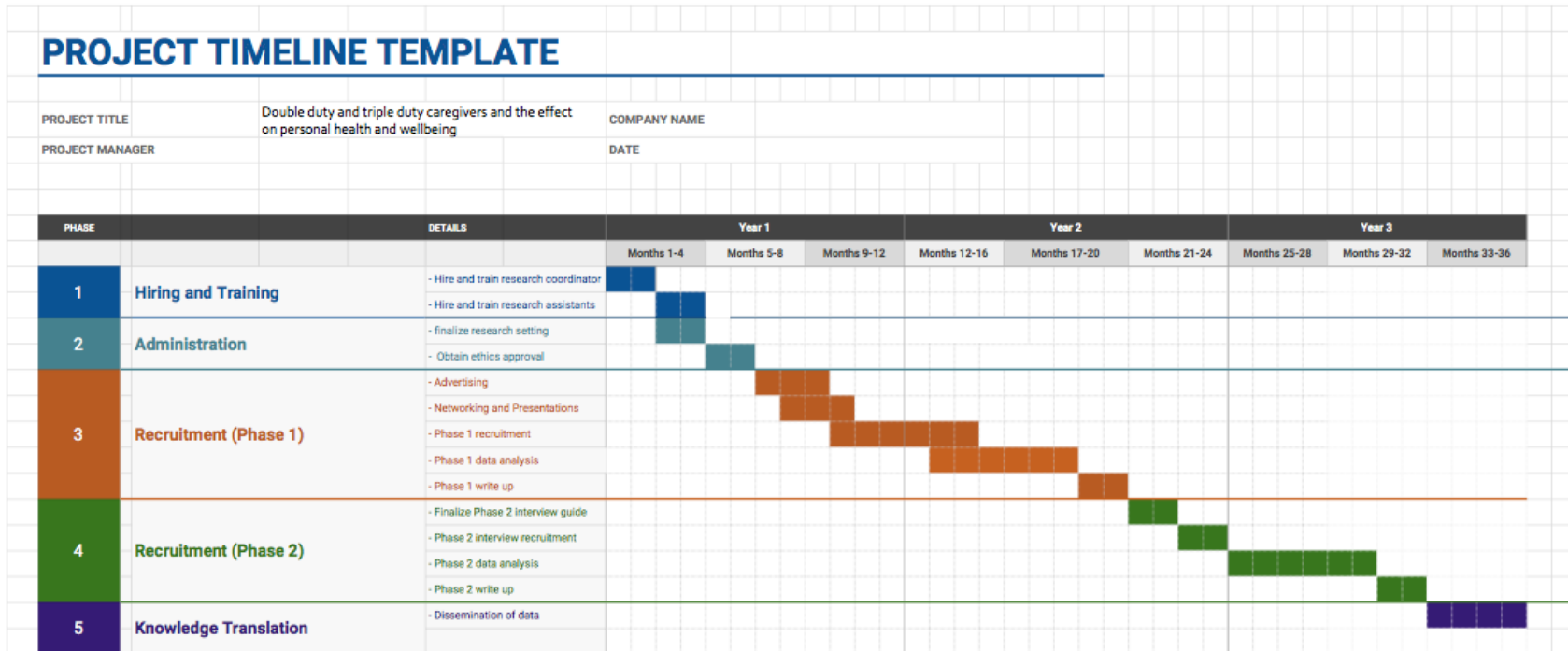
**Description:**

The accompanying PDF document shows the guidelines for the CIHR Project Scheme grant. The document lists all required steps to completing the application, the majority of which was used as a template for completing Chapter 5 of this project.

**Filename:** Project Grant\_Spring 2018 Application Instructions – CIHR.pdf

# Appendix H.

## Timeline





# Appendix I.

## Online Interview Guide (Quantitative)

1. What is your gender?
  - 01 Male
  - 02 Female
  - 03 Other (Specify) \_\_\_\_\_
2. When were you born? (Record the year of birth)
3. What is your CURRENT marital status or living arrangement?
  - 01 Never married
  - 02 Married and living with spouse
  - 03 Living with a partner (2 years or more)
  - 04 Living with a partner (less than 2 years)
  - 05 Married or partnered but living apart/in separate households
  - 06 Divorced/separated
  - 07 Widowed
4. What is the highest level of education that you have attained? Is it:
  - 01 Less than high school
  - 02 High school graduate
  - 03 Some college or university
  - 04 College diploma or equivalent in specialized non-degree training
  - 05 University degree
5. What was your TOTAL HOUSEHOLD INCOME for the last year?
  - 01 under \$20,000
  - 02 20,000 to \$50,000
  - 03 50,001 to \$75,000
  - 04 75,001 to \$100,000
  - 05 \$100,001 to \$125,000
  - 06 \$125,001 to \$150,000
  - 07 over \$150,000
6. Do you live in:
  - 01 A house that you own
  - 02 A house that you rent
  - 03 An apartment or condo that you own
  - 04 An apartment or condo that you rent
  - 05 Adult child's home
  - 06 Other (Specify) \_\_\_\_\_
7. Compared to people your own age, how would you rate your overall physical health at the present time?
  - 01 Poor
  - 02 Fair
  - 03 Good
  - 04 Excellent
8. How many hours a week are you currently nursing:
  - 01 Full-time (30+ hours/week)
  - 02 Part-time (less than 30 hours a week)
9. Why do you usually work less than 30 hours a week?

- 01 Own illness/disability
  - 02 Child care responsibilities
  - 03 Elder care responsibilities
  - 04 Other personal/family responsibilities
  - 05 Going to school
  - 06 Could only find part time work
  - 07 Did not want full-time work
  - 08 Full time work under 30 hours/week
  - 09 Other (Specify)
10. In total, how many people, including yourself, reside in your household?
11. Who lives with you in your household (i.e. at least 6 or more months)?
- 01 Nobody
  - 02 Your spouse (partner)
  - 03 Your children (How many?) \_\_\_\_\_
  - 04 Your mother
  - 05 Your father
  - 06 Your mother in-law
  - 07 Your father in-law
  - 08 Grandchildren (How many?) \_\_\_\_\_
  - 09 Brother or sister (How many?) \_\_\_\_\_ j
  - 10 Other relative (Who?) \_\_\_\_\_ How many? \_\_\_\_\_
12. If you have children living at home, what is the occupation of your child(ren)?
- 01 Full-time student
  - 02 Part-time student
  - 03 Full-time paid work
  - 04 Part-time paid work
  - 05 Unemployed/looking for work
  - 06 Unemployed/not looking for work
  - 07 Homemaker
  - 08 Other (Specify) \_\_\_\_\_
13. What are the purposes that your child continues to live with you?
- 01 Economic reasons (e.g. to save money, expensive housing)
  - 02 School-related reasons
  - 03 Relationship break-up
  - 04 Transitional/temporary (e.g., waiting for housing, job, travel)
  - 05 To receive help with her or his children
  - 06 Health-related reasons of child
  - 07 Health-related reasons of parent (you and/or your spouse)
  - 08 To help you and/or your spouse in other ways (Specify)
  - 09 Other (Specify) \_\_\_\_\_
14. Are you providing any form of caregiving to the older adult who is residing with you?
- 01 Yes
  - 02 No
  - 03 Unsure
15. We're interested in the kind of help and support that you give the older adult who resides with you/ Please indicate how often you provide the following types of help and support:
- (01=always, 02=sometimes, 03= rarely/never)
- a. Household Chores (e.g., doing their laundry)
  - b. Transportation/Shopping

- c. Information and advice
  - d. Financial assistance
  - e. Housing support (e.g. providing free rent and/or board)
  - f. Emotional support, if necessary
  - g. Discussing important life problems and decisions
  - h. Spending time with each other
  - i. Help when sick, if necessary
  - j. Assistance with personal care (e.g., help with bathing, dressing)
16. On a scale of 1 to 5, 1 being “not at all” and 5 being “completely”, how happy are you with your marriage/partnership?
17. On a scale of 1 to 5, with 1 being “Strong disagree” and 5 being “Strongly agree”, to what extent do you disagree or agree with the following statements?
- a. My job reduces the amount of time I can spend with my family.
  - b. Problems at work make me irritable at home.
  - c. My job takes so much energy I don’t feel up to doing things that need attention at home.
  - d. Family matters reduce the time I can devote to my job.
  - e. Family worries or problems distract me from my work.
  - f. Family activities stop me from getting the amount of sleep I need to do my job well.
18. If you had more time for yourself, what type of leisure activity would you ideally like to spend more time doing?
- 01 Social activities (e.g., church attendance, visits to cinema, restaurants, sporting events, day or overnight trips, playing games, participation in social groups)
  - 02 Physical activities (e.g., active sports or swimming, walking, physical exercise)
  - 03 Productive activities (e.g., running errands, gardening, home improvement, preparing meals, unpaid community work, paid community work, other paid employment, lifelong learning)
  - 04 Creative activities (e.g., playing an instrument or singing, creative writing, painting or drawing, sculpture, dramatics, going to concerts and theatre productions)
  - 05 Continuation of current leisure activities
  - 06 Sit and relax/do nothing
  - 07 Travel (i.e., more than a day or overnight trip)
- Answer the following questions on a scale of 1-5, 1 being strongly agree and 5 being strongly disagree:
19. I do not have enough time to everything I want to do in a day
- 01 strongly agree
  - 02 agree
  - 03 neutral
  - 04 disagree
  - 05 strongly disagree
20. I do not have enough energy to do everything I want in a day
- 01 strongly agree
  - 02 agree
  - 03 neutral
  - 04 disagree
  - 05 strongly disagree
21. I have to put off doing things at work because of the demands on my time at home

- 01 strongly agree
  - 02 agree
  - 03 neutral
  - 04 disagree
  - 05 strongly disagree
22. My job produces strain that makes it difficult to fulfill my family duties
- 01 strongly agree
  - 02 agree
  - 03 neutral
  - 04 disagree
  - 05 strongly disagree

## Appendix J.

### Project Budget

Category	Amount (in thousands)
<b>Research Staff</b>	
<b>1 Project Coordinator:</b> Responsible for coordinating the overall research project, performing administrative tasks, hiring and managing research assistants, overseeing participant recruitment, managing online quantitative questionnaires, overseeing qualitative participant interviews as well as performing interviews, reviewing statistical analyses, arranging and preparing scholarly journals and conference presentations. $\$24.00/\text{hour} + 12\% \text{ benefits @ } 20\text{hrs/week} \times 50 \text{ weeks/yr} = \$26,880/\text{yr} \times 3\text{yrs} = \$80,640$	\$80,640
<b>2 Research Assistants:</b> Hired at the beginning of the project, graduate students who, under the supervision of the Project Coordinator will assist in recruiting participants for the online questionnaire as well as conducting the participant interviews and support the Statistical Analyst with transcribing qualitative interviews. They will also assist in the preparation of workshop materials and written reports and knowledge translation piece. $\$20/\text{hr} + 12\% \text{ benefits @ } 20 \text{ hrs/wk} \times 50 \text{ wks/yr} = \$22,400/\text{yr} \times 3\text{yrs} = \$67,200$	\$134,400
<b>2 Undergraduate Interviewers:</b> Hired part-time positions during the second half of the study, these student interviewers will assist in the qualitative in-person interviews. $\$14.50/\text{hr} + 8\% \text{ benefits @ } 10\text{hrs/wk} \times 50 \text{ weeks/year} = \$7,830$	\$15,660
<b>Consumables</b>	
NVivo Training	
SPSS Training	
<b>Transcription</b> $1 \text{ hr interview} \times 5 \text{ hr transcription} \times 40 \text{ interviews} \times \$21/\text{hr} = \$4,200$	4,200
<b>Statistical Analyst</b> Hired at the beginning of Year 1 this graduate student would be in charge of setting up the data files and creation of code books, overseeing and distributing the online questionnaire and be in charge of the SPSS and NVivo management, analysis and interpretation. $\$31.00/\text{hr} + 12\% \text{ benefits @ } 20 \text{ hrs/wk} \times 50 \text{ wks/yr} = \$34,720 \times 2\text{yrs} = \$69,440$	\$69,440
Travel for Data Collection	\$1000
Miscellaneous Costs Office supplies, postage, advertisements, $\$750/\text{yr} \times 3\text{yrs} = \$2,250$	\$2,250

Category	Amount (in thousands)
<b>Non-consumables</b>	
Laptops HP 15.6" Touchscreen Laptop - Silver (Intel Core i5-7200U / 1TB HDD / 8GB RAM / Windows 10): \$799.99 x 12% taxes x 2 =	\$1,791.97
Microsoft Office Microsoft Office Home & Student 2016 (PC) - English \$149.99 x 12% taxes x 2 = \$335.98	\$335.98
Flash Drive Lexar JumpDrive S75 128GB USB 3.0 Flash Drive - Black \$69.99 x 12% taxes x 4 = \$313.56	\$313.56
NVivo Subscription \$350.00	\$350.00
SPSS Subscription \$98	\$98.00
<b>Voice Recorder:</b> <b>Olympus DM-720 Digital Voice Recorder:</b> <b>\$199.99 x 12% taxes x 2 = \$447.98</b>	\$447.98
<b>Knowledge Translation</b>	
<b>Presentations</b> <b>Room Rental:\$100/4 hours = \$100 Project Summaries:\$14 package x 50 packages = \$700</b> <b>Refreshments for 45: \$52.99 fruit platter + \$46.99 hummus and vegetable platter + \$29.99 dessert platter + \$60 coffee = \$189.97</b>	\$989.97
<b>Conference Presentations</b> <b>Travel costs for project coordinator to attend two conferences:</b> <b>Canadian Association of Gerontology and Nursing and Healthcare Conference: Resistration:\$395 + \$799</b> <b>Flights (Canadian destination): \$750 x 2 destinations = \$1,500</b> <b>Hotel:\$200 incl taxes/night x 10 nights (5 nights/conference) = \$2000</b> <b>Per Diem: \$57/day x 10 days (5 days/conference) = \$570</b>	\$5,264
<b>Manuscript/Journal Publication Preparation, publication, fees, etc</b> <b>\$2,000 x 2 journals = \$4,000</b>	\$4,000
<b>Other</b>	
Participant Honoria Phase 1 survey participation: \$10 x 400 participants = \$4,000 Phase 2 interview \$40 x 40 participants = \$1,4000	\$5,400
<b>Entire Amount Requested</b>	<b>\$326,581</b>