# Female care partners' experiences of their relative's transition to nursing home: a critical feminist perspective

By

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## Author's declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

## Acknowledgments

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## 1. Abstract

The decision to transition a relative to a nursing home is usually preceded by many months or years of physical and emotional care. While women continue to do most of the care work throughout their lives due to socially and culturally constructed gender roles, little research has explored female caregivers' experiences in the transition of a relative to a nursing home particularly through a critical feminist lens. The purpose of the study was to explore care partners' perceptions of this transition through a gendered lens, including changes in relationships with relatives and care workers. Semi-structured interviews were conducted with seven female care partners of nursing home residents. Data were analyzed using the voicecentred relational method. Three main themes emerged: 1) Care as women's work; 2) Relational care; and 3) Nursing home care. The study provided insight into the situatedness of women who transitioned a relative to a nursing home. Care was taken on willingly, with emotional commitment and a sense of duty which society constructed for them. Care was always embedded in relationships, before and after the transition, impacting the care partners and relatives' quality of life. The Covid—19 pandemic affected their experiences significantly. Future considerations of nursing home care improvements should include relational aspects of care, an understanding of the situatedness of women as care partners and of women as care workers. Further research is needed exploring the impact on relational care among care partners, residents, and care workers due to the Covid-19 nursing home restrictions.

## 2. Literature Review

## Introduction

Moving into a nursing home is a significant life event for families. The road to nursing home admission often follows months or years of increasing caregiving responsibilities for informal care partners such as relatives. Globally, more women than men enter informal caregiving, with 80 percent being female, highlighting gender inequalities of who carries the weight of care work (Cascella Carbó & García-Orellán, 2020). Family caregiving continues to be viewed as a moral obligation for women; it is expected that the caring role is taken on willingly, and that women possess a nurturing and caring identity which comes with the knowledge and skills to perform care tasks (Eriksson et al., 2013; Levine et al., 2010). Due to these internalized social norms, women tend to take on more and more responsibilities to keep their relatives at home longer and avoid nursing home admission, even when they struggle with exhaustion and their own health problems (Crawford et al., 2015).

Unfortunately, the transition to nursing home care often comes after a traumatic experience or a crisis, such as a significant fall or a sudden decline in physical or cognitive abilities (Crawford et al., 2015). For care partners, especially for spouses, this transition often means separating from a life partner, and may mean experiencing feelings of guilt, sadness, loneliness, anxiety, and resentment, as well as a sense of relief (Crawford et al., 2015; Hennings & Froggatt, 2019; Palacios-Ceña et al., 2019; Reuss et al., 2005). In reality, caregiving does not end after nursing home admission, and relatives continue to provide approximately ten hours per week of informal care in nursing homes (Barken et al., 2016). Female care partners particularly seem to continue caring in ways that are structured by gender roles and expectations in the

nursing home, engaging in physical and emotional care and checking on care staff to ensure their relative receives quality care (Puurveen et al., 2018).

While much of the research around transitioning to a nursing home, and the care involvement there, considers all care partners, minimal research attention has been directed toward the gendered perspective of this experience, and the gendered perception of care partners' roles and relationships during this transition. This investigation is essential to understand the experience of women during this transition, and to explore how inequities in resources and power shape their journeys to deciding to end caregiving at home and to move their relative to a nursing home. Further, it is valuable to examine the relationships between female care partners and care staff after nursing home transition. Therefore, a critical feminist lens should be applied to explore this transition, as women's experiences have largely been ignored in the creation of knowledge while enforced by structures of society (Smith, 2005). Hence, using a feminist approach means applying a critical lens to explore inequities, power and social structures which shape the experiences of care partners before, during and after their relative's nursing home admission.

## What is Gender?

Gender is not created by the biological differences between men and women, and boys and girls; it is related to how one is perceived and expected to think and act as male and female because of the way society is organized (World Health Organization, n.d.). It is a social construct (Connell, 2012; Risman, 2004), and the process in which differences are created (Holmgren et al., 2013), for example, differences in norms, behaviours and roles associated with being male or female which shape the life experiences of women and men. Further, gender inequities intersect with other types of discrimination such as racism and ageism, creating further inequities for women in minority groups (World Health Organization, n.d.).

Gender, then, is embedded in social relationships at the individual, structural and institutional level, hence organizing society in the ways people interact as men and women, how people interact with each other, and how people perceive, organize, and implement institutional, government and public policy (Calasanti & Slevin, 2001a). Gender roles, then, are the result of discourses created by categorical thinking, influencing how we act and express ourselves based on either being male or female (Connell, 2012). For example, gender roles regarding caregiving are the result of different opportunities and constraints created by categorizing people as male or female (Risman, 2004). At the individual level, a woman may feel it is her duty to be the caregiver of the family because socially and culturally, women have been placed in the caregiving position (Risman, 2004). For example, in the workplace women and men may face different expectations even if they occupy the same role, positioning men as superior performers (Risman, 2004). On the structural level, disparities are created by unequal distributions of resources, often embedded in policies (Risman, 2004). For example, when the provision of childcare is not part of the social support system, it becomes very costly for families, hence becoming a privilege rather than a right, and giving women unequal opportunities to participate in work outside the home. Further, workplace culture continues to be rigid by not allowing much flexibility to either men or women when it comes to balancing work, home, and raising a family (Risman, 2004).

As a result, inequities in access to resources are created where women face barriers in all aspects of social life due to societal structures and processes, leading to the lack of decision – making power, including resources and decisions around caregiving throughout their lives

(Armstrong & Armstrong, 2002). Throughout this research, gender will be viewed as relational, operating at individual and structural levels, and associated with power and inequities (Calasanti & Slevin, 2001). Consequently, the following sections explore the inequities of women who are involved in caring for a relative at home and in the nursing home.

## What is care and who delivers it?

In this literature review, the term 'care partners' are considered as spouses or life partners, adult children, other relatives, and friends or neighbours, while 'female care partners' include wives, life partners, sisters, daughters or daughters-in-law, nieces or female friends and neighbours. Globally, 80% of care at home is provided by informal care partners (Cascella Carbó & García-Orellán, 2020). In Canada, the average age of a caregiver is between 49-64 years of age, and almost one quarter of people 65 years and older are caregivers providing care to a spouse or partner; this increases to 50% for the age group 85 and older (Arriagada, 2020). Further, 54% of Canadian caregivers are female; however, this statistic is not limited to personal care, but is based on all care activities including transportation, housework and house maintenance, and financial help (Arriagada, 2020). Therefore, it may underestimate women in caregiving. Almost half of Canadian seniors over the age of 75 care for a spouse, while over half of Canadians between 45-54 years of age care for a parent (Arriagada, 2020). Canadian women spend more time than men providing care to a family member in all age groups, with 35% of senior women spending 30 hours or more per week caring for a spouse (Arriagada, 2020).

Care is not simply a task or job. On the contrary, care encompasses several categories of complex tasks, such as care management, assistance with household chores and everyday living activities, as well as personal, social and emotional care, hence defining care as a relationship rather than just a task (Armstrong & Kits, 2004). When viewing care as a relationship, it must be

viewed as physical labour (caring for) but also as emotional labour (caring about) (Calasanti & Slevin, 2001b); therefore, care work can be both physically and emotionally demanding (Foner, 1994; Kramer, 2005).

Care as physical labour encompasses several categories of tasks including instrumental care, personal care and social-emotional care (Armstrong & Kits, 2004). Instrumental care includes tasks like financial management and helping with cleaning and meal preparation, while personal care includes getting in and out of bed, bathing, dressing, and helping with eating (Armstrong & Kits, 2004). Looking at gender differences, women tend to engage more in personal care and tasks that arise daily, while men engage more in instrumental care and tasks that arise daily, while men engage more in instrumental care and tasks that arise daily, while men engage more in instrumental care and tasks that arise daily.

While the physical labour of care can be exhausting and restricts the autonomy of the care partner as daily schedules are shaped by the person they care for (Glenn, 2012b), it also highlights the emotional labour it takes to commit to care. Since relatives often provide informal care, the 'caring about' aspect of care highlights the emotional labour invested into caring for someone. Care implies a social connectedness and a sense of social attachment, so care partners must manage the emotions of the person they care for in addition to their own emotions that arise with the changes in the relationship while watching a relative decline physically and cognitively (Calasanti & Slevin, 2001b).

Caregiving can be isolating and restricting, and women typically experience worse health outcomes and more physical and emotional distress such as anxiety, depression, and physical decline than men (Calasanti & Slevin, 2001b; Crawford et al., 2015; Uccheddu et al., 2019). This increased stress could be the result of internalized social disapproval that women perceive when they can no longer meet the care needs of their relative (Sutherland et al, 2017).

On the other hand, men's lower incidences of depression and anxiety may be explained by men seeing care as a task they accomplish, withdrawing themselves emotionally, while on the other hand, women may not feel the accomplishment because such care has always been expected of them (Calasanti & Slevin, 2001b).

Evaluating the literature, it is difficult to distinguish between different levels of caregiving of female spouses and female daughters or daughter in laws. Most study participant populations were equally divided between spouses and as care partners. A study by Holmgren et. al (2014) included only adult children as care partners, while Hennings et.al (2013) included only spouses as care partners. Yet most of the themes such as feeling obligated to be involved in care and feeling stress with the responsibility of care were similar. The study by Ott et. al (2007) included spouses as well as children, and while not distinguishing between different levels of care, it found that care partners living with the person they cared for experienced more stress. Bramble et.al (2009) was the only study distinguishing between spouses and children as caregivers, finding that daughters struggled to fill the many roles caring for their aging parents, their own children and attending work outside the home, while spouses were described to have difficulties managing the care at home and experiencing health decline due to stress. However, most of the studies did not describe different care levels or care experiences of spouses compared to children.

There are also gendered differences in how male and female caregivers are viewed in their abilities to provide care at home. For example, research in the home setting reveals that some nurses do not expect male care partners to provide physical care and hence are not subjected to disapproval for not participating, while female care partners are expected to engage in care beyond physical care and are met with disapproval if they decline involvement in more

complex physical care (Sutherland et al., 2017). Further, male and female care partners receive different support from family. Male care partners tend to receive more collaboration and support if they require help (Bramble et al., 2009). On the contrary, female care partners who are seen struggling with caregiving are viewed as not having the capacity to provide care at home (Sutherland et al., 2016). Additionally, female care partners show more resilience and often downplay the need for help, trying to decrease the load on society and avoiding feelings of failure, even when caring for a relative at home has become unbearable (Eriksson et al., 2013). In fact, women are still likely to be the primary care partners for their disabled husbands even when disabled themselves (Calasanti & Slevin, 2001b; Williams et al., 2017).

## Gender and care

Without doubt, care is hard work physically and emotionally; however, care work performed by women is often hidden at home, and therefore undervalued and viewed as unskilled work (Armstrong & Armstrong, 2008). A detailed exploration of gender and care offers an explanation why most care work is provided by women, and why this unpaid labour is not viewed as productive work.

Historically, the division of work and home has its origins in the age of industrialization when men's work was moved into productive industrial jobs with paid wages, leaving women's work inside the home as economically insignificant and invisible (Glenn, 2012a). This left women economically dependent on men and without power (Armstrong & Armstrong, 2008; Laxer, 2013). The social construct of gender significantly enforces gender stereotypes around family care, indicating the responsibility of any care, may it be childcare or elder care, will fall within the women's scope of practice (Cascella Carbó & García-Orellán, 2020). Therefore, ideologically and financially, women are socially coerced into the responsibility of care with

little power deciding how much time and energy they can or want to commit to this unpaid work, because there are often few alternatives and giving up care is viewed as a lack of commitment or failure by society (Glenn, 2012b)

With the rise of capitalism and the free global market economy, the demands for service and retail jobs have increased. These jobs are often part-time, low paid and without benefits, and often occupied by women trying to support their families and make ends meet, hence leaving women struggling between the demands of earning a living and providing care (Glenn, 2012b; Laxer, 2013). As women juggle work and care responsibilities, they tend to reduce employment hours, take pay cuts, or work in less productive jobs, making it clear that structurally there are fewer alternatives for them (Braedley, 2013; Calasanti & Slevin, 2001b). This struggle to combine care and work responsibilities is the result of work structure and culture (i.e., working a full time 40 plus hour week leaves little time to attend to family care and chores at home), hence the workplace as an institution is not designed for neither women nor men to succeed at work and at home at the same time (Risman, 2004). Consequently, women often work part-time and therefore have fewer financial means and earn fewer benefits throughout their lives to pay for formal care, may it be childcare or elder care.

## Transitioning to the nursing home

Transitioning to a nursing home is typically not a choice most people want to make. It comes with losses, and adjustments to roles and relationships (Hennings & Froggatt, 2019). The decision to transition out of full-time care is often the result of a crisis, for example after a significant decline and increased frailty in the relative, and increased stress on the care partner, especially when support is limited (DeSilva & Curzio, 2009). Interestingly, there are often family disagreements, leaving the care partner (the spouse for example), out of the decision-making

process while the adult children take over this responsibility (Palacios-Ceña et al., 2019). For example, some female care partners are often overridden and dismissed by adult children in the decision-making process of care placement, despite being the full-time care partner (Palacios-Ceña et al., 2019). The decision to transition out of full-time caregiving is likely gendered as well. While women may feel obligated to meet gender roles and continue care beyond their abilities, men are in a much more privileged position to ask for help as they often have more financial means to pay for care and may not see care as a commitment they need to fulfill (Calasanti & Slevin, 2001b).

Moving a relative to a nursing home can be traumatizing and is often associated with negative experiences such as disrupting social relationships and leisure life for care partners, impacting physical and mental health (Reuss et al., 2005). Female care partners describe feelings of guilt of having abandoned their relative and continue to feel responsible for their care (Palacios-Ceña et al., 2019). Research by Bramble et al (2009), Carlson and Lundberg (2018), Hennings et al (2013) and Ott et al (2007) highlights that a loss of meaning in life after nursing home admission is common, and that the sense of responsibility to care continues along with feelings of grief, worry and depression. While none of these studies specifically examined gender in the experience of this nursing home transition, it became clear that these are likely experiences of female care partners, as their study populations were between seventy and eighty percent female.

Assumptively, the transition out of full-time caregiving due to institutionalization should result in more time for oneself, more socialization and better health outcomes. However, female care partners tend to have worse health outcomes than male care partners after stopping full-time caregiving (Uccheddu et al., 2019). The differences in health outcomes may be explained by the

gendered roles in care. There is some evidence that some men can emotionally withdraw from the care role and focus on the task, while women appear to grieve the loss of the relationship in the caring role, hence feeling emotionally distressed after the nursing home transition of a relative (Calasanti & Slevin, 2001b). Bramble et al (2009) specifically found that female care partners sleep fewer hours, exercise less and enjoy less leisure time than male care partners of nursing home residents, perhaps suggesting that men can disconnect from the care responsibility more easily.

Regardless, the transition to move a relative to a nursing home is overwhelming, stressful, and often involves a lengthy wait either in hospital or at home (Reuss et al., 2005). The autonomy in this transition is often limited due to the typically urgent nature of the process because of trauma or crisis, and care partners often feel unsupported before, during and after the nursing home admission (De Silva & Curzio, 2009). While the literature suggests some gender differences in the experience of this transition, especially based on power such as income and social pressure, further research is needed in exploring this experience through a gendered lens, specifically focusing on women's situatedness to understand what influences their decisionmaking power.

#### **Care in nursing homes**

There is little consistency across Canadian provinces in terms of what facilities are called that house older adults who cannot be cared for at home. In the context of this study, the term nursing home is used. This term suggests a comfortable place of care and relationships; however, it also implies that the skills required to provide care work are simple and unskilled, and encompass those anyone performs at home (Armstrong, 2013). Hence, it provokes the notion that care work provided there is easy and similar to skills needed to perform activities of daily living

at home. This further supports the assumption that care work in a nursing home is not skilled labour, thus undervaluing care work.

In Canada, a nursing home falls under the Long-Term Care Facilities umbrella and is defined as a living accommodation for people who require on-site delivery of 24-hour, 7 days-a-week supervised care, including professional health services, personal care and services such as meal, laundry and housekeeping (Government of Canada, 2004). This definition describes an institution, and in fact the history of the long-term care system is rooted in poorhouses, institutions that used to house people who could not care for themselves including older people, people with mental illnesses and disabilities and people living in poverty (Estabrooks et al., 2020). The Canada Health Act, established in 1984 created 'free' medical care for all Canadians; however long-term care including nursing homes were excluded from the Canada Health Act because those services were deemed not medical, and therefore could fall under services provided in the community (Picard, 2021b). Nowadays, nursing homes in Canada are operated and regulated under provincial governments. Of the 2076 nursing homes, 54% are privately owned (29% for-profit and 23% not-for-profit) and 46% are publicly owned (Canadian Institute for Health Information, 2021).

Nursing homes are medicalized operations for people who are considered medically stable, yet not cured or healthy enough to return home and care for themselves (Diamond, 1992). In fact, the complexity of care delivery has increased over the past decades, as most nursing home residents have many comorbidities and are in advanced stages of dementia, leaving care staff with limited time and resources to focus on the quality of life of residents and to form relationships (Knopp-Sihota et al, 2015). Undoubtedly, many nursing homes try to focus much effort on creating home-like environments for residents, increasing quality of life, creating

private spaces and focusing on resident-centered care; however, it is challenging due to complex care needs, leaving little time beyond completing and documenting basic care and medical tasks (Knopp-Sihote et al, 2015; Rijnaard et al., 2016). Diamond (1992) describes a nursing home as an institution of checked boxes and administrative language: "These boxes did not merely reflect needs; they defined certain needs as well and they erased others. Most basically, they erased identities of people whom they described as social actors. The women and men living here did not write in these documents nor did they read them. They did not speak in the charts. They were spoken about" (p.127). This describes institutionalized bodies wherein daily care tasks revolve around how to define, nourish and maintain the body, often without context or identification of the actual person as an individual (Wiersma & Dupuis, 2010). Nursing home care workers often find the time-consuming documentation associated with care work challenging, as it takes time away from caring for the residents; however, time spent together performing intimate care tasks can build emotional attachments between residents and care workers (Rodriguez, 2011). These emotional attachments are formed over being from a similar social situation, for example care workers and residents and mostly female, and from shared life experiences (Rodriguez, 2011).

Nevertheless, data on quality of life in nursing homes involving people who live, work and volunteer there is not routinely collected, highlighting the invisibility of care work in nursing homes (Estabrooks et al., 2020; Laxer, 2013) Without data, the effort to address the quality of care and the quality of life of nursing home residents has been limited, so nursing homes in Canada continue to be negatively viewed, with people frightened to move into one, especially with the crisis that unfolded in nursing homes during the first year of the COVID-19 pandemic (Picard, 2021a).

The Covid-19 pandemic has impacted caregiving significantly. Covid-19 outbreaks in nursing homes have and continue to impose visitor restrictions, hence limiting how often and how long care partners can visit, and which care activities they are allowed to take part in. Emerging research on the impacts of visitor restrictions is highlighting that emotional distress, and social isolation has resulted in mistrust of the care provided by care workers, hence has strained relationships between care partners and nursing home care workers (Avidor and Ayalon, 2021). The impact of Covid-19 on nursing homes, the residents and care partners took on a significant role in the conversations between the researcher and the participants during the interviews.

## Gender in nursing homes

Exploring the role of gender within nursing homes is important in aiming to understand relationships and inequities within this setting. In Canadian nursing homes, 65-70 % of residents are women and between 80-90 % of care workers are also women (Armstrong, 2013; Estabrooks et al., 2020). Therefore, it can be assumed that most relatives visiting and volunteering informal care in the nursing home are also women (Estabrooks et al., 2020).

Additional inequities related to ageism and racism in Canadian nursing homes are created, with 70% of female care workers being over 40 years of age, and 60% of female care workers speaking English as a second language (Armstrong, 2013; Estabrooks et al., 2020). Thirty percent of nursing home care workers work part-time, receiving fewer benefits, less union coverage, and less job stability than full time workers (Laxer, 2013). Further, 90% of care workers are unregulated health care professionals; neither their education nor the care they provide are standardized, leaving them without a voice or power over their jobs (Estabrooks et al., 2020). This puts many women in precarious situations. Some work several jobs in addition

to fulfilling caring roles at home, leaving them with fewer resources in terms of time, power, social relationships, and income, creating inequities in their work and home lives (Armstrong & Armstrong, 2002). Overall, care work in the nursing home is situated within the social gender construct, as care work in the nursing home, and care work performed by women outside the professional environment involve similar skills, time, and energy (Baines & Armstrong, 2019).

Nursing homes are hierarchical in nature, creating conflicted relationships between the workers based on a fight for power and autonomy, highlighting gender as an issue in this environment (Jervis, 2002). Further, nursing homes are gendered through the different roles women occupy within the institution (Diamond, 1992), creating differences in power through formal versus informal care; worker versus visitor, disabled versus able-bodied, and therefore shaping the different relationships within the setting (Holmgren et al., 2013). Additionally, conflict is created between care partners and care workers in nursing homes and usually revolves around unmet physical care needs of the residents (Palacios-Ceña et al., 2019). The difference in power created by gender roles produces tension, especially between female care partners and the mostly female care workforce, as the boundaries between informal care by relatives and formal care by workers are almost indistinguishable (Armstrong & Armstrong, 2002; Puurveen et al., 2018). Meanwhile a care partner, as the person who knows their relative best, may feel disrespected, ignored, and powerless (Holmgren et al., 2014), while the care workers as the paid professionals continue to feel judged in their work by relatives of residents (Reuss et al., 2005). These conflicts highlight gender in terms of the value of paid versus unpaid care work, giving paid care workers more power and authority over the unpaid informal care partner, establishing rules and restrictions over what care partners can and cannot do in the nursing home (Holmgren et al., 2013). These roles and relationships are constantly evaluated; managers demand efficient,

task-oriented care workers while care partners value resident-centered care around physical and emotional well-being, hence resulting in care staff feeling undervalued and powerless (Abrahamson et al., 2009). It seems that power relations are at the root of the gender issues in the nursing home, which are created not only by the hierarchical nature of the nursing home, but also between residents and care workers, residents and care partner, as well as between care workers and care partners.

## Care partner involvement in the nursing home

After the nursing home admission, the responsibility as care partner continues, and for female care partners especially, the involvement in care is a necessity rather than a voluntary commitment (Bramble et al, 2009; Holmgren et al, 2014). Not only are they involved in care for their relatives, but they often take on roles as volunteers, engaging with and helping other residents with activities of daily living (Barken et al., 2016). Female care partners continue to feel responsible to be present in the nursing home, while some male care partners feel less guilty about not being involved, and justify their absence with work and important social commitments (Holmgren et al., 2014).

The care partner role as advocate is important to speak for those who cannot communicate needs, and to monitor the work by professional care workers in the nursing home (Carlsen & Lundberg, 2018; Ekström et al., 2019). This includes surveillance of medical care, and many care partners mistrust nurses and their ability to make good medical decisions (Baumbusch & Phinney, 2014). Since nursing homes are institutions, and the jobs there are based on tasks, it can be assumed that it is the lack of 'care' as in emotional labour that is often under criticism by care partners, or when tasks are not completed as care partners might expect. It is important for most care partners to maintain emotional, meaningful relationships with their

relatives, and they realize that care staff cannot replace their love (Barken et al., 2016). This highlights that while care involves emotional labour, it is assumed that care staff perform care without emotional commitment and affection (Calasanti, T., & Slevin, K., 2001b). This assumption is grounded in the nursing home being an institutionalized, task oriented and biomedical environment whose structure hinders emotional attachments (Diamond, 1992). In reality, care workers indeed form emotional attachments to create dignity in their workplace, and to create a sense of purpose in making the residents' last moments of their lives happier and meaningful (Rodriguez, 2011). However, emotional attachments are viewed by managers to interfere with the professional care environment and are often discouraged (Rodriguez, 2011). Further, this assumption is supported by the biomedical model of care, which as a framework to care focussing solely on managing medical issues of the body, without considering psychosocial factors affecting health and well-being (Ostaszkiewicz et al., 2018). Care work in nursing homes is structured by hierarchy and task based schedules requiring much documentation, but the emotional work done by staff is not acknowledged (Diamond, 1992).

In summary, it can be assumed that nursing homes are gendered and feminized as seen in the structure of nursing homes and the relationships within, despite efforts to impose rational structures such as assessments, check boxes and funding based on care objectives. The emotional labour is erased, as are the identities of those living and working there (Diamond, 1992).

### Summary

The transition to a nursing home is a significant and often traumatizing event for families. The road to deciding to give up caregiving at home follows months or years of heavy care responsibility for especially female care partners. Women continue to provide care beyond their abilities to fulfil the socially constructed role as caregiver, partly as an internalized gender role

but also influenced by relatives and healthcare providers, who have their own gendered notions of who should provide care.

While the move of a relative to the nursing home means giving up most of the physical care work, informal caregiving continues after the nursing home admission. In fact, it is mostly women who continue to feel responsible to ensure adequate physical and emotional labour is performed by nursing home care workers, and they spend a significant amount of time offering emotional and functional support to their relatives.

Care partners, especially women, not only fulfill a care role in the nursing home, but they are also trying to establish relationships with the professional care workers to ensure their relatives' care needs are met. Consequently, conflicts and power struggles often arise over the expectations of care versus the reality of the task-based nursing home environment. Both the female care partners and female care workers fulfill similar gender roles as caregivers at work and at home. Within the institution of the nursing home, they are struggling for power and autonomy over their jobs and roles, and over the well-being of the relatives and residents they care for. It is obvious that care work at home and care work in the nursing home are both shaped by relational and structural gender, creating differences in expectations, power, and resources.

There is a lack of research examining the transition of female care partners from caring at home to becoming care partners within the nursing home, especially through a gendered lens. It is important to engage a feminist perspective to explore what structural and relational gender forces influence this experience, and how they create inequities in resources and power for female care partners before, during and after the nursing home transition.

## 3. Research Purpose and Research Questions

## **Research Purpose**

The research purpose of this study was to explore care partners' experiences and perceptions of the changes in their roles and relationships during their relatives' transitions to a nursing home, with a specific focus on gender. It was important to examine these transitions through a critical feminist lens to better understand the standpoint of female care partners, and to explore inequities in decision making power and resources during the nursing home transition. Examining these transitions through a gendered lens helped create more knowledge about the situatedness of women in the nursing home transition of their relatives, including their perceived changes in relationships and their role in the care environment of a nursing home.

## **Research Questions**

1. What are female care partners' journeys and experiences of the transition to moving their relatives into a nursing home?

2. How do female care partners perceive their role when their relative is living in a nursing home? How has this role evolved from caring at home to caring in the nursing home?

3. How do care partners describe the changes in relationships including the relationships with care workers in the nursing home?

4. How are care partners' experiences of transitions shaped by and impacted by gender?

## 4. Methodology and Theoretical Framework

A critical feminist perspective was applied to form the theoretical framework of the study. Feminist theory starts with the understanding that the world we live in was created by men, and that women have not been given the voice to take part in shaping culture and society (Smith, 1987). Smith (2005) argues that knowledge of society must always be from a situated position in it, and that women, as the oppressed group in society, have not been the subject of all knowledge created. Rather, the ways people think, and act are shaped by society, written in rules by men and for men, which shape institutions such as work, home, and school (Smith, 1987). Hence, this mode of organization of society refers to the rules of relations where people and their experiences are objectified based on the administrative processes that define and manage the different institutions, such as home or work (Smith, 2005). Because these institutions have been created without women's knowledge or experiences, the rules of relations prevent the traditional basis of knowledge of women's individual perceptions, but instead place it externally; hence, the knowledge is biased and enforced by the order of society (Smith, 2005). This creates a disembodiment, where the person's mind and body are shaped by the external ruling relations. The feminist approach, on the other hand, starts by exploring how individual attitudes, behaviours and experiences are shaped by social situatedness and the power relations created by social structures (Smith, 2005). In essence, this feminist approach is a situated approach, recognizing that the basis of knowledge should be from the situated experiences of person. This approach also recognizes that knowledge is created by individuals in social situations and that it is always partial and incomplete (Harding, 2016).

Care work traditionally has been shaped as a women's domain in the institution of home, and this study aimed to explore the experiences of women as care partners in the home and how

they transition to being a care partner when their relative moves into a nursing home. The research intended to explore the care partners' perspectives and experiences from a feminist perspective; this included viewing these experiences through an equity lens that is shaped by the care partners' social positions as women within a patriarchal society. The literature review, on the other hand, highlighted that the research around caregiving and the transition to the nursing home was not viewed as gendered, despite most participants being women in most of the studies. Hence, the literature shared narratives of women, without recognizing them as socially situated experiences and without analyzing the structural factors that influenced gendered experiences.

In addition to researching female care partners' care experiences within the sphere of home, this study also aimed to explore their experiences as care partners within the institution of the nursing home, which is also gendered. Including a theoretical framework around an ethic of care was helpful in informing the experiences of care partners in relation to the care work performed by care workers in the nursing home. Tronto (1998) provided an ethic of care as a moral and political perspective which can orientate or guide care objectives. She views care as a moral obligation that is within us, and a practice that aims to maintain and repair our bodies, ourselves, and the world we live in (Tronto, 1998). The actions of care are described as caring about or paying attention to the need of caring, caring for or assuming the responsibility to meet a need that has been identified, caregiving or responding to a particular need, and care receiving or recognizing the effect the care has on the person who is cared for (Tronto, 1998). Therefore, an ethic of care provides guidance on attentiveness, responsibility, competence, and responsiveness to offer a broader understanding of care as productive work. It also highlights that care is a fundamental human need; however, as women's work in the home and as work in the nursing home, it is private and hidden away from the broader social sphere (Tronto, 1998).

Tronto's ethic of care cannot be understood outside of the social and political context in which care is embedded. This is an important political aspect to the critical feminist approach as it aims to discover the injustices of who provides care, and who is able receive care.

#### 5. Methods

## 5.1 Research Design

To explore the experiences of care partners in the transition of their relatives to a nursing home, a qualitative research design was applied. Qualitative methods can help provide a rich and detailed description of a life experience and can give voices to those who have not been heard (Sofaer, 1999). In terms of this study, a qualitative design supported the exploration of unique experiences of female care partners in the process of their relatives' transition to a nursing home, examined if this transition was gendered and contributed to creating new knowledge about how these experiences were shaped by social structures.

Secondly, the voice-centred relational method informed the narratives of female caregivers, because this method focuses on the different voices and perspectives of the research participants which are often filtered in patriarchal society (Brown & Gilligan, 1991). This method supported the critical feminist approach of the study, as it aimed to explore the body, relationships, and conflicts within a societal and cultural context of participants (Brown & Gilligan 1991). Hence, this method gave a voice to female care partners, their experience of their relative's transition to a nursing home, the context of relationships, conflict, and choice, and their situatedness within social structures that have created disparities in caregiving.

## **5.2 Recruitment**

Recruitment took place between January and April 2022. Participants were recruited through nursing homes in New Brunswick, with the goal of recruiting participants from urban and rural areas. Nursing homes in anglophone regions of the province were identified through the Department of Social Development website, which listed the nursing homes (Government of New Brunswick, n.d.). The homes were contacted via email. Twenty-seven nursing home administrators were contacted with the research information and were asked if they were able to identify female care partners of nursing home residents, who had moved to the nursing home within the last 6 to18 months. The researcher asked the nursing home administrators to get care partners' consent to be contacted by the researcher to provide them with greater detail about the study, hence offering a more active recruitment method. Several nursing homes were unable to engage in the active recruitment process due to time constraints and ongoing Covid-19 outbreaks at the time of recruitment, however they agreed to share the research recruitment poster and information with residents' family members via their email list. Due to the difficulties related to the ongoing Covid-19 outbreaks in nursing homes, recruitment was expanded to social media. In addition, community organizations related to senior care and nursing home care were contacted and asked to share the research recruitment poster on their social media or with their email lists. Overall, recruitment proved to be difficult, as it took place during a time of heightened Covid-19 outbreaks in nursing homes.

## **5.3 Participants**

Participant inclusion criteria were being female, having a relative who had moved to a nursing home within the last 6-18 months and having been the primary care provider before and

after nursing home admission. Female care partners were considered wives or life partners, sisters, daughters, daughters-in-law, nieces, friends, and neighbours. Primary care providers in the context of this study were referred to as the person or persons who were most involved in caring for the relative. While primary care providers are also often the legal substitute decision maker, they did not need to have this legal obligation to be significantly involved in providing care. A time frame of 6 to18 months was chosen to ensure that female care partners had an adequate amount of time to situate themselves and adapt to the nursing home structures and routines. Meanwhile, it also provided enough time for reflection on the care experiences prior to the nursing home transition, including the changes in the care role and changes in relationships. However, due to slow recruitment, participants who had been care partners at a nursing home for longer than 18 months were accepted into the study.

Overall, seven female care partners were recruited to participate in the study. Six lived in New Brunswick, and one in Saskatchewan. Their ages ranged from 52 to 79 years. The number of years of care ranged from two to ten years, while they had been care partners in the nursing home between seven months and four years. Five women were care partners in urban nursing homes, while two cared for a relative in a rural nursing home. Four care partners were married, one was widowed, one lived in a common-law relationship, and one was single. Two participants cared for their husbands, four cared for their mothers and one cared for her mother-in-law. All the women had been employed during their lives; six were retired at the time of the interviews while one continued to work full-time.

Participants were invited by email to a focus group after analysing the findings, to explore their thoughts, questions, and discrepancies. While two participants responded to the focus group request, only one participant agreed to a virtual meeting. The second participant provided feedback by email.

## 5.4 Data Collection

Data were collected by conducting one-on-one interviews with female care partners of nursing home residents between January and April 2022. Interviews were held either by phone or via Zoom. They were semi-structured, using guiding questions while allowing flexibility to encourage participants to share their stories and experiences freely. Interviews ranged from 40 to 90 minutes.

Written or verbal consent was required by all participants prior to participation in the interviews. Participants who were comfortable with printing, signing and scanning consent forms provided written consent. All other participants gave verbal consent at the beginning of their interview. Consent forms were reviewed prior to the interview with all participants. Lastly, all verbal consents and interviews were voice recorded and transcribed verbatim before analysis.

As part of data validation, participants were invited to a focus group to discuss the findings of the study. Only one participant agreed to an additional virtual meeting, which was not recorded or transcribed. Comments were noted in writing by the researcher, and no discrepancies were found from the feedback of one participant.

#### 5.5 Data Analysis

The data analysis was guided by the voice-centred relational analysis (Brown & Gilligan, 1991). This approach focuses on four distinct ways to explore experiences of self, the particulars of relationships and the situatedness of the experience and relationships in societal and cultural

frameworks (Brown & Gilligan, 1991). The decision to use voice-centred relational analysis was guided by the research purpose of this study, as it explored the narratives of the female care partner's role within the transition of their relative to a nursing home. Specifically, it concentrated on their perception of the care partner's role before and after nursing home admission, and their evolving relationships, including those with care workers at the nursing home.

The analysis encompassed four different readings of the transcripts, with each reading focused on a different narrative (Brown & Gilligan, 1991). The first reading involved paying attention to the story that is being told by the participant, while the researcher reflected on self, related to the position in the story and society (Brown & Gilligan, 1991). For this study, the first reading paid attention to the story of the participant as they described their journey of being a care partner and how the transition of their relative to the nursing home evolved. In addition, I reflected on what is being said and how this was situated within my own experiences of caring responsibilities and working in a nursing home.

The second reading focused on the 'I', while the researcher listened for how the participant spoke about herself in the narrative (Brown & Gilligan, 1991). Therefore, I could pay attention to how the care partner spoke about herself, her experiences, feelings, and opinions linked to being a care partner, how the changes affected her and how she felt about her relative's move to the nursing home. In addition, paying attention to how the participant spoke about herself enabled me to better understand how the participant situated herself within her social world, thus being able to explore additional identities that may be important to her. The use of voice-centred relational method provided an important structure for addressing intersectionality.

The third reading listened for relationships with others (Brown & Gilligan, 1991). This analysis focussed on exploring the relationships of the care partner with the relative she cared for, other relatives involved or not involved in care and the care workers at the nursing home. Specific attention was given to interpersonal conflicts between the care partners and nursing home care workers.

The fourth reading emphasized listening for the situatedness in the social and cultural context of the participant (Brown & Gilligan, 1991). Here, I focussed on analysing how gender impacts the experience of being a care partner and the decision on a nursing home admission. In addition, the analysis concentrated on how gender shaped the transition to the nursing home and the adjustment to a different care role in the nursing home. Further, this included exploring how gender created conflicts between care partners and nursing home care workers.

This relational method of analysis offered a guide to explore specifically for conflict and injustice (Brown et al., 1991), hence further supporting the feminist approach of this study. Therefore, it was possible to listen for a care voice which is concerned with attachment (or detachment), being loved (or not being loved) and being listened to (or not listened to); while also listening for a justice voice that is concerned with unequal power relations, oppression, and unfairness between people (Brown et al., 1991). Specifically, in the third reading, attention was paid to the voice that expressed concerns about care and how the care partner related it to attachment, attention, and responsiveness, while the fourth reading explored the voice of equality and fairness (Brown et al., 1991). This part of the analysis offered a deeper investigation into female care partner's perception of conflict and choice of their responsibility or commitment to care within the institution of home and the nursing home, hence paying attention to social obligations and positions of power within society.

Besides using voice centred relational method, data were organized by further themes to answer the research questions. Depicting relationships between themes, as well as similarities between participants' experiences was achieved by using visuals such as hand-drawn diagrams. These were helpful in organizing the initial themes, which were later refined and described by the overarching main themes, as shown in Figure 1.

## 5.6 Reliability and validity

Ensuring credibility of the study was important to show that the methods and resulting data and findings accurately reflect the realities experienced by female care partners. Creswell & Miller's (2000) framework to select validation procedures was utilized to select validation procedures relevant to the critical feminist research paradigm. They suggested that qualitative researchers apply a lens using the view of people who conduct, participate in, or read and review the research, and assuming that each lens represents a socially constructed reality that participants perceive to be true (Creswell & Miller, 2000). Therefore, validation ensures these realities were accurately represented, and were assessed by the following strategies: Reflexivity, collaboration, peer debriefing and member checking (Creswell & Miller, 2000).

Disclosing assumptions, beliefs, values, and biases is important within reflexivity to understand where the researcher is positioned within the realities of the participants' narratives and the social and cultural forces that shape their experiences (Creswell & Miller, 2000). My own situatedness within the paradigm of caregiving and gender was described in detail below and represents the lens of the researcher.

The second strategy applied was collaboration, which ensured respect and support for participants (Creswell & Miller, 2000), and to create an environment where participants felt as

active and equal contributors (Sword, 1999). This was achieved by being mindful of the difference (or connection) through social position and power (Sword, 1999). Collaboration was related to the participants' lens to the paradigm of caregiving and gender, hence increasing the validity of the research. The interviews were conducted in a dialogic and relational manner to ensure the participants were given a voice, without imposing or interpreting their experiences unjust through the inequity lens. Lather (1986) argues, that in critical feminist research it is important to accept participants' contradictory experiences. This means, recognizing and respecting the participants' ambivalence about being care partners.

Other collaboration strategies included memoing and employing thick, rich description in the analysis (Creswell & Miller, 2000). Memoing was used as a validation tool to record the perspectives and reflections of the researcher along the way (Birks et al., 2008). This in-depth engagement was achieved by journaling throughout the interview and data analysis process to record reflections, interpretations, or questions (Birks et al., 2008). Thick descriptions allowed the researcher to describe vivid details or experiences, interactions and relationships in the data analysis (Creswell & Miller, 2000). This method contributed validity by engaging the lens of the reader, who by engaging with the thick, rich descriptions could relate in their experience and situatedness within the paradigm of caregiving and gender. By ensuring that individuals' stories were told within context, and that quotes are used for supporting findings, readers might be able to think about the transferability of these findings to their own context.

Member checking was an additional validation tool which shifted the validation process to the participants' lens, wherein they reviewed the findings of the research to confirm or disapprove the narratives, and whether the narratives make sense and reflect their realities (Creswell & Miller, 2000). A summary of the findings was shared with all participants, and they

were invited to a focus group to discuss the findings. Only one participant agreed to participate in a focus group, so I held a virtual meeting, where we discussed her perception and feedback, which were incorporated into the final version of the findings.

This validation tool was important to address false consciousness, in which the researcher might assume wrongly that the experiences of women are the result of the patriarchal society, when instead women mindfully chose to spend their time caring for family members (Caven, 2006). In other words, Lather (1986) argues that false consciousness implies imposing inequities on the participants and dismissing their perceptions and experiences. Member checking was used throughout the research process. The interview process included opportunities to reflect on gender roles and care, and to explore the ambivalences of the participants' experiences as female care partners.

Lastly, peer-reviewing and debriefing is a validation method that can help the researcher by challenging assumptions, asking hard questions and providing support during the research and writing activities (Creswell & Miller, 2000). The peer reviewer provided another lens to ensure credibility, and I utilized my thesis supervisor and thesis committee for support throughout the research and writing process.

## **5.7 Ethical Considerations**

Ethics approval for this study was received through the Lakehead University Ethics Review Board. Participation in the study was voluntary, and participants were informed about the risks and benefits of the study in writing and verbally prior to the interviews, and before consenting to participate. There was minimal risk in participating, due to the qualitative nature of the study design using semi-structured interviews; hence, participants were able to share as little or as much as they personally deemed comfortable.

For ethical consideration, one-on-one interviews were conducted to give participants the opportunity to talk freely, and for the researcher to be able to apply the voice-centred relational research method and analysis. Anonymity of participants was preserved by masking their names and those of their relatives, and by assigning them pseudonym names on the transcripts and in the data analysis. Due to only one participant agreeing to a virtual meeting to discuss the findings, maintaining anonymity was not an ethical concern at that stage.

Data storage, such as the audio files of the interviews and the transcripts, as well as consent forms were saved on an external hard drive accessible only to the primary researcher.

## 5.8 Situating myself within the research

The interest in this research and my position related to the subject was greatly driven by my career as a healthcare provider in the nursing home setting, but also by my lived experience as a woman, a mother, an immigrant and by my upbringing in a society driven by strong family politics that tried to establish gender equality.

I was born and raised in East Germany; a communist country established in the German sector occupied by the Soviet Union after the Second World War. Due to the loss of many men in the war, women were crucial in rebuilding the country, the economy, and the population (von Ankum, 1994). It was expected that women fulfilled the dual role of productive worker and child bearer, and East Germany invested greatly into training girls and women in industrial jobs through the education system and establishing publicly funded childcare, to ensure women could fulfill the dual role of productive worker and child bearer (Rosenfeld et al., 2004). Growing up, it

was my experience that both parents were in the workforce; both of my grandmothers, my mother and my friends' mothers worked full-time. In addition, it was my experience that housework was shared equally between my parents, and later between all members of the household. Hence, I grew up in a privileged position oblivious to gender inequities. Today, I realize that my mother and grandmothers faced enormous pressure to balance work and family life despite government policies that supported gender equality.

My ideal of the woman as an equal member of society was starting to be challenged as I started a new life and career as a healthcare provider in long-term care in Canada. My observation was that most care partners were indeed female; most were spouses, daughters or daughter in laws. Many were caring for more than one relative, i.e., many had another parent or parent-in-law, either at home or in another nursing home, creating stressful situations of trying to meet many different care needs. However, it was my observation that many female care partners struggled with giving up control and letting the nursing home take over the care of their relatives. Therefore, conflict between care staff and care partners were daily occurrences, creating stressful situations for residents, their relatives and care workers.

Further, I met many female residents and spouses who had spent either their whole lives working in the home and raising children or had stopped working once their children were born. Their experiences were different to my experience of having had a working mother and grandmothers. In the narratives of the people I met in nursing homes, I often heard statements such as: "It was the right thing to do" or "But I had no choice". Due to my privileged position, I was unable to make sense of what it meant.

Having children of my own provided a glimpse of what it meant to have fewer choices. With limited childcare options leading to part time work (often on contract and without any

benefits), I started to understand that choices are limited when constantly juggling work and home life without structural support. I was not alone, because in the nursing home setting, I shared this struggle with many other women, who juggled motherhood and work, constantly trying to switch shifts to accommodate childcare availability, all the while fighting for recognition for the hard work they were doing and for being seen as professionals.

In starting this research and entering a wealth of literature on gender and caregiving, I could see how my experiences are the product of social structure and forces that have created this gendered society where women as carers face so many inequities.

Therefore, as a researcher I wanted to hear female care partners' experiences of their caregiving transitions, in particular their narrative of having or not having had a choice, and why? Additionally, the relationships and conflicts of female care partners with care workers was worth exploring to understand gender in nursing homes and to eventually find solutions for better care partner - care worker relationships.

My position was that of an ally and someone in a similar social location as the female care partners, as I am a caregiver but also a care worker. Hence, my research position was located within the structures of society that define gender roles at home and in the nursing home.

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# 6. Findings

### 6.1 Participants' Stories

The following section introduces the women and the relatives they cared for, including each woman's life setting, circumstance of their care role, and the relationships to the relatives they cared for. Table 1 summarizes all participants' demographic information.

Participant name	Age	Marital status	Relative	Relative name	Time of relative in nursing home	Total time caring for relative
Donna	67	married	Mother-in-law	Agnes	1 year	5 years
Brenda	68	married	Husband	Barry	3 years	8 years
Amy	52	single	Mother	Dorothy	10 months	2 years
Sandra	63	common-law	Mother	Irene	1 year	2 years
Mary	74	married	Husband	Robert	7 months	10 years
Carol	69	widowed	Mother	Margaret	4 years	9 years
Charlotte	79	married	Mother	Glenda	2.5 years	8 years

**Table 1.** Participants' demographic information

### Donna

Donna was a 67-year-old retired nurse who cared for several relatives. Besides her mother-in-law, Agnes, who lived in a nursing home, she also cared for her father who lived in a special care home. She described Agnes as a second mother. Donna defined that caring was one of her traits as a healthcare professional, but also that her family expected her to take the lead in her mother-in-law's care. Donna visited Agnes at home daily to provide physical and emotional care, while her husband took over his mother's financial responsibilities. After a broken hip, Donna's mother-in-law needed nursing home care, and it fell on Donna to communicate this to

her husband's siblings and their families. She struggled with this role and the stress of moving Agnes to a nursing home. While she considered caring for her mother-in-law full time at home, she eventually decided against it realizing this would have been be too hard on her body. This led to feelings of guilt, especially as Donna stated that women have a duty to care, and that elder care was a continuation of her mother role.

After the nursing home admission, Donna was not able to visit Agnes for many months due to COVID-19 restrictions. When visiting later, they spent their time chatting and enjoying being together. Donna described feeling fulfilled by the emotional care she provided to Agnes. She felt that the care workers took good care of Agnes, and she felt respected when addressing care concerns.

In my interview with Donna, she expressed that women often did not have a choice in taking on a care role, but that they were considered better carers than men, who she pointed out often detached their emotions from the care task. To Donna, the emotional and relational aspect of caring for Agnes fulfilled her.

#### Sandra

Sandra was a 63-year-old retiree, who cared for her mother Irene who has was living with dementia. Sandra lived away from her mother for many years, but they always maintained a close relationship. She was pushed into a care role at a young age as the oldest female sibling, caring for other children and adults. Her partner helped her care for her mother; she was also supported by several siblings. Most of her siblings lived far away from her mother, but one lived locally.

Initially, Sandra's mother moved into her house where she tried to provide 24-hour care while continuing to work full-time. Sandra experienced this as a very stressful time, which was physically and mentally demanding resulting in her own health problems. Although she was able to get approved for daily homecare support, Sandra struggled to fulfill the role of carer and full-time employee outside the home. Without proper support from her employer, Sandra saw no other way but to quit her job to assume 24-hour care of Irene. Sandra felt that providing care was a very hard job without any recognition. For her, it brought on feelings of hopelessness. However, she described that as a woman, it was her duty to care and that she didn't have a choice, especially when it came to deciding to give up her job. While sensing that this was not fair, she described that society was structured in that way, and was the result of raising boys and girls differently.

After a hospital admission and an assessment, Sandra's mom required nursing home care. She described feeling guilty since she had promised Irene to care for her until the end. Her sibling (local) did not support Sandra's decision to move Irene to a nursing home, which caused conflict not only for Sandra, but also for her mother and the care workers at the nursing home.

After the nursing home admission, Sandra's focus in life was caring for herself and her own health, so she could be there for her mother. She was generally satisfied with the nursing home care, however, continued to provide physical care when the need arose to protect her mother's dignity. Having a close relationship with Irene brough her fulfillment, and Sandra enjoyed their time together during their visits.

#### Mary

Mary was a 74-year-old retiree who cared for her husband Robert who had dementia. They lived in a rural area. Mary described a strong bond to Robert whom she shared a life and

business with. She described being dismissed by health and social care providers throughout her journey of caring for Robert at home and then at the nursing home. Additional difficulties in finding a day program, respite care, and consistent home care left Mary very stressed and frustrated. With support from her daughter, Mary was able to arrange respite, and later permanent admission for Robert at a local nursing home. While she experienced relief, she also grieved their separation especially during periods of Covid-19 lockdowns. She also felt guilty for not being able to care for Robert until the end. At the nursing home, Mary continued to provide some physical care, but tried to focus on companionship. Her relationship to the care workers was complicated, as she felt they did not engage in the emotional aspects of care for Robert and did not take the time to get to know the needs of the residents.

Despite feeling guilty for her inability to care for Robert at home, Mary did not think that care is women's work, but rather described that people do have a duty to care for relatives. She described herself as privileged having been able to work outside the home for much of her life. Although she realized that some aspects of gender in care have changed, she felt society continued to push the 'care is women's work' agenda. Mary continued to strive for balance between caring for Robert, caring for herself, and adjusting to life alone in a society which she described as couples oriented.

#### Brenda

Brenda was a 68-year-old retiree who cared for her husband Barry at home. Barry's declining health and hesitation to seek help put a strain on their marriage before he needed full-time care. Caring and working full-time affected Brenda. She experienced physical and mental health decline before deciding to retire early to care for Barry. This was very conflicting for Brenda, and she described feeling hopeless as she perceived her freedom to have been taken

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away. On one hand, she wanted independence, but on the other hand, her duty to care for Barry as his wife was very strong. She believed that care was her duty as part of the marriage and as a woman, but she also felt that in a marriage, partners have a duty to care for each other. Brenda expressed internal conflict and guilt in all the decisions she had to make for Barry and herself. When the option of a nursing home admission arose, Brenda sensed relief and advocated for herself when Barry refused to go. In the end, Brenda took charge and told Barry she could not care for him at home and would separate from him if he did not agree to move.

After the nursing home admission, Brenda continued to feel conflicted between her sense of duty to care for Barry, her worry about him, and her wish to move on with life. Barry was well cared for at the nursing home and loved by the care workers, which offered relief for Brenda as she struggled with guilt about visiting or how to continue their relationship. She expressed the desire to move on and seek a new relationship while continuing to care for Barry. Brenda felt that care was a very hard job, especially when it was seen as duty. She sensed that women needed to continue to fight for their freedom and independence, both of which Brenda has been learning to embrace.

#### Carol

Carol was a 69-year-old retiree, and widow who cared for her mother, Margaret. Carol and Margaret had a close relationship their entire lives, lived in neighbouring houses, and worked as a team when Margaret's husband passed away at a young age. Carol helped care for the family her siblings. She did not describe being a care partner as a job, but rather, she saw care as a relationship, and a role she took on willingly to help 'parent' her mother to the end of her life. However, she felt a strong sense of duty to care as the oldest female sibling. While caring for Margaret at her home, Carol had help from other family members, but she took on all the physical care and the care management.

After a fall and a hospital admission, Margaret needed nursing home care which devastated them both, as Carol described having had many happy years enjoying retirement with her mother. Carol had many concerns about care in the nursing home and felt very guilty at times to have agreed to move Margaret into an institution. She argued that care at home would have been better, but that it would have been socially isolating for Margaret. Carol did not feel respected as an equal partner in care in the nursing home, and it was her experience that care workers could not bring the emotional aspect into their jobs. She had been a strong advocate for her mother and other residents, and felt this strained the relationships with care workers, as they saw her as a complainer.

The Covid-19 pandemic and subsequent nursing home lockdowns separated Margaret and Carol, resulting in Margaret declining, while Carol described suffering terribly with her inability to care for her mother. She felt she had lost two years of their lives – time they would never get back.

Carol described having committed her whole life to Margaret, by spending her days volunteering at the nursing home and socializing with her mother and other residents. Carol stated that despite her care concerns, she could let go of some of the care tasks, as they got in the way of enjoying her relationship with Margaret.

#### Amy

Amy was a 52-year-old single, working professional who cared for her mother Dorothy. Having had no children of her own, this was her first experience caring for a close relative. Amy shared the caring responsibilities with her brother who lived locally while Amy travelled one and

a half hours each way to visit her mother whenever she could. Amy held a powerful role in her family as the first female to finish university. As a healthcare provider, Amy described wanting to help people, so when her mother became ill, she took on the duty to care for her in the hospital and later in the nursing home. She also felt that as a woman and oldest sibling, the responsibility to care was expected from her.

With Amy's demanding work schedule, she struggled mentally to combine her work with caring for her mother, and experienced guilt over the demands of caring for Dorothy and the need to care for herself. After Dorothy moved to a nursing home, Amy became Power of Attorney and continued to provide care, but also found her voice to communicate that she needed help from her brother. Amy has been able to prioritize caring for herself first, so she could better care for Dorothy.

While Amy felt that Dorothy had been receiving dignified care at the nursing home, she often had the impression that she was not respected as a care partner by care workers, especially when her tasks overlapped with those of a paid care worker. Amy mentioned that she was the mom in her relationship to Dorothy. However, it was important to her to maintain a meaningful relationship with Dorothy that was mutual and did not revolve around care tasks. She accomplished that, she said, by keeping her emotions out of care tasks and care decisions.

#### Charlotte

Charlotte was 79-year-old married retiree who cared for her mother Glenda. Charlotte and Glenda have shared a close relationship and have supported each other as working professionals their entire lives. Before Glenda's move to a nursing home, they lived in neighbouring houses. Glenda lived at home with Charlotte's help until her health declined. She was diagnosed with dementia resulting in a move to a nursing home. While caring at home,

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Charlotte managed all the care with the help of her husband and her daughter. She felt that care was not a job but that it was physically and mentally very draining, inducing feelings of guilt and conflict. She wanted to care for her mom and enjoyed the relationship aspect, but she realized that her and her husband also deserved a relationship and a life.

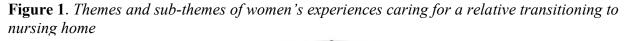
Charlotte described the care Glenda received at the nursing home as inadequate. She stated that the care workers appeared to have limited time and little compassion. Further, she did not feel welcome, or that her voice was heard. Charlotte described experiencing a lot of guilt, as she realized she could have provided better care at home. With limited support in rural areas, she recognized caring at her home was not possible. The nursing home where Glenda has been residing continued to lock down periodically with Covid-19 outbreaks, and Charlotte described feeling devastated that she was separated from Glenda.

Charlotte did not think that care was women's work, and that care, including the emotional work involved, was a learned skill. However, she understood how women continued to be pushed into this role by society and found it discriminating.

Glenda has been focussing her time on advocating for Glenda and for nursing home residents in general. She felt that nursing home care was inadequate and that the continued lockdowns due to Covid-19 were harmful and unjust to residents and their family members.

# 6.2 Introduction to the findings

The analysis of the interview transcripts resulted in three main themes and nine subthemes (see Figure 1). Section One explores care as women's work (theme 1): 'care is hard work', 'care is emotional', and feeling 'guilt over self-care'. Section Two is concerned with the relational aspect of care (theme 2) and offers detailed descriptions of 'changing relationships', 'meaningful relationships' and 'disconnected relationships'. Section Three provides detailed narratives of nursing home care (theme 3), including 'lack of emotional care', 'who owns the care?' and 'Us and them'.





## 6.3 Section 1 - Care as Women's Work

Figure 2. Care as women's work themes



#### 'I don't see it as a job, but it has become the job of the women.'

Most participants described that care was not work, and should not be women's work; however, some participants concluded that caring is a hard job, and most agreed it to be a woman's responsibility. While they realized that it seemed discriminatory to assume that care was women's work, they were all cognisant that there appears to be duty to care for a relative.

*Carol*: But no. I don't see it as a job, but it has become the job of the women in the family to care for those in nursing homes.

*Charlotte:* I don't think women – I think that's discrimination in a way. I mean women are probably – we probably made our own bed or we probably are different. We're just different so we care – we care in different ways maybe. But I don't think totally, wholly, it should be the women's responsibility to be that caregiver.

Interviewer: But where does that – where do you think that assumption comes from, that women often – because fact is women often are the caregivers especially in elder care. It is often the women that are the advocates, that do the care. Where do you think that comes from? Charlotte: I just think that's something that is dated. I think it just came forward, forward, forward and I see some male nurses at the care facility, and I think, good on you, and they're all very – they seem kind in their demeanor. They just seem this is who they're meant to be, a nurse. And like I don't have a, I guess an answer like you might be expecting. But I think it just came from previous generations and it was inbred into us that we should care and be kind and give to others. Whereas I must say since I married my husband, he's come a long way. He's more caring than he once was. (laughs).

Despite their statements that care should not be women's work, they all admitted that it

felt like their duty to care for relatives. However, they all discussed how their sense of that duty

was impacted by societal influences. Most of the married women identified the institution of

marriage as the pivotal reason for taking on the care responsibility. Additionally, Brenda

identified the institution of religion as a significant reason for her sense of duty to care.

Brenda: Well, I guess they have a choice, but I think most women that would be their choice, to take care of them.
Interviewer: Their willing choice or their sort of sense of duty?
Brenda: Well, sense of duty.
Interviewer: You think that sense of duty is pretty strong?
Brenda: Oh, I think so.
Interviewer: Yeah.
Brenda: Well, it's the old values, hey? You get married for life and good or bad, death do us part. If you are, you know, if you have a -- I was born and brought up Catholic and that was part of my vows and ---.

Further, Carol described how the institution of marriage created traditional gender roles,

that put women in charge of caring for the home and the children.

*Carol:* We're just going back to, you know, the very start of time. The men went to work, they bought -- they made the money. The women, we kept the home. We did the groceries; we reared

the children. Interviewer: Yeah. Carol: But nobody thought about at some point us women are all going to get tired (laughs).

Sandra elaborated on the assumption that care is women's work based on one's

upbringing. She identified that since she was the oldest female siblings in the family, the duty of

care fell on her.

*Sandra*: I mean I was taking care of siblings that were even older than me that I was, for whatever reason, I was the one who took over that role. I don't know why. *Interviewer*: You don't know why.

*Sandra*: Well, because the older sibling was, they were male, so the other siblings were younger and the, they were females so.

*Interviewer: Right. So, you're saying that, that women generally get pushed into that caregiving role and men are not due to their upbringing.* 

**Sandra**: True. Yeah. I do believe they just get, yeah, that's the first thing they look for and I think it's all because of, you know, the mother figure. The mom takes care of everything. Like daddy goes out and goes to work. You know, like so they put you in that category. Daddy goes out and does all the work and brings home the bacon and mom cooks it up. You know, and takes care of the children and makes sure everything's running, yeah.

## Care is emotional

#### 'I'm saying, that the females become more emotionally involved.'

Based on the assumptions about gender roles and the division of labour, some

participants concluded that women are better at care than men. In their experiences, men in

Canadian society are neither expected to care, nor do they often bring the emotional aspect into

the caring responsibility. Donna specifically described that women bring more emotions and

intuition into care, and stating that women make better carers than men.

**Donna:** I think being a woman, you're more in tune to the emotional part of it. And it makes you think you're looking at your parent more than a man might. I don't know how I can explain it. I just think that as a woman you might see something that a man might not pick up. I'm saying, that the females become more emotionally involved and they feel like they're looking out for them more.

Carol shared her observations from being a care partner in the nursing home, and

described that men visit, and women do the care work.

Carol: But no. I don't see it as a job, but it has become the job of the women in the family to care for those in nursing homes.
Interviewer: Absolutely.
Carol: Because look at it. It's the daughters-in-law and the daughters that visit the male component.
Interviewer: Yeah.
Carol: I see them come in to visit their fathers. The ball game goes on or the golf game was talked about, and they have their coffee and then they've got to go, you know. It's a visit.

## Care is hard work

'So yeah, stressful, yes, very, very, very, stressful.'

All participants described how stressful caring for a relative was. Sandra, Mary and

Brenda who lived with their relatives and provided 24- hour care at home, described situations of

constant mental and emotional strain.

Sandra tried to continue working outside the home, while her mother, who lived with her,

required 24-hour supervision, demanding diligent planning of her day as well as planning of her

mother's needs, including constant worry about her safety.

Sandra: It was horrible because I was trying to do my job and I was trying to... I'd call home. You know what you are doing, mom? You know, are you watching TV? You know, how's it going? And, you know. And then I'd come home and have supper or I'd, you know, get my uncle, her brother, to come down and check on her and sit with her, especially if I had to work until 9:00 o'clock at night. Because I couldn't get home until, you know, 9:30, quarter to 10:00. So, you know, I had supper ready. I would always have the breakfast ready. You know, have her lunch set up. You know, stuff like that so that I could... I knew she was eating. It's like here's your, you know, and that she had her pills on time. So yeah, stressful, yes, very, very, very, stressful.

Mary also described a similar situation when caring for her husband at home, as he

required constant need for movement and supervision, leaving Mary with few breaks and

constant physical and mental stress. She realized she could not do it by herself and was able to

ask for help.

*Mary*: So, I guess it would've been about three years ago, he just had so many obsessions, you know. Like he would spend all day outside if you'd let him picking up pine cones or weeds or obsessed with going for a walk. We'd go for a walk, we'd be out for an hour and we'd come back and ten minutes later, well let's go for a walk and we had been for a walk. So, that's when I called home care because I thought, you know, I needed some supports. Somebody to spend time with him doing some of those things, you know, to give me a break. (Pause). There were times that were really tough. I really leaned a lot on my daughter. (emotional/crying).

Meanwhile, Brenda described worrying about Barry's declining health and fear of him

dying as the biggest stressors.

**Brenda**: And it's a huge relief. And it wasn't like I -- like, I didn't have a lot to do with him. Like, I, you know, made meals and stuff like that. He was a pretty good patient. Like, he would -- it's the mental strain. **Interviewer**: So, what -- so what makes it mentally so hard for you? **Brenda**: Okay. So, he's -- he -- every morning when I get up, I come downstairs, and I look in the living room to see if he's still alive. And -- so, every day that goes through your head, 'Is he gonna be alive?'

Even though Amy did not provide physical care for her mother at home before the nursing home admission, she described how physically and mentally draining it was caring for her in the hospital. She experienced guilt for feeling physically exhausted when using her days off from her job to drive to the hospital. Her stress was caused by worrying about her mother's health and well-being, and Amy tried to manage by spending all her free time visiting her. She eventually found her voice to communicate her needs, consequently finding balance between working and caring for her mother.

**Amy:** I just try to take it day by day. I wasn't coping very well. I think at first, I was exhausting myself to drive back and forth because on my days off, I would drive down to see mom. So, you know, our family was really great because they could go in at first and visit and they did, but

now, you know, they can't visit so it's up to my brother and I. So, you know, like there are a couple of things I had to say to him was, you know, you know, when I have a day off, it's not really a day off. Like I'm sorry to tell you that, but you know, not trying to put the burden on you, but sometimes I just need a day off to not just have a day off. You know, not travel or like today is my day off so and I'm feeling a lot more guilty free.

### Guilt

# 'I felt guilty and that I was letting her down.'

The participants' narratives also highlighted their struggle between feeling relieved and

attending to their own needs versus their continuing sense of duty to care. After the nursing

home transition, Sandra recognized the need to focus on her physical and mental recovery and on

self-care.

**Sandra:** My health is great. I actually go to bed and sleep. It's nice. And I get a sound sleep. It's like it's nice.

Interviewer: That's good.

*Sandra*: Yeah. So yeah, I've, yeah, getting back on track. It took me about six months before I could get a good night's sleep. So, it's, it took me, you know, my body trying to get back on track of a normal. So now it's normal.

On the other hand, she also described feelings of guilt after the nursing home admission

of her mother, as she felt responsible to care for her until the end. Her siblings supported her

decision about the nursing home move and affirmed to Sandra that she deserved to care for

herself and live her life.

**Sandra**: I felt like I was letting her down because in the beginning no matter when, like years and years and years ago, I said mom, I'll take care of you. It's okay. You know. And I felt guilty and that I was letting her down.

Interviewer: You felt responsible for her.

Sandra: Yeah. Yeah. So.

Interviewer: That sounds tough.

**Sandra:** I just felt, you know, I was going through all of that, and I mean even talking to the siblings that came home now, I said, you know, I should probably, you know, take her out and bring her back and they're going, no, you can't. Like don't do this to yourself. You have a right to live too, and you can't be doing this.

Charlotte also described feeling guilt about not having done enough to keep her mother at home, while also realizing that she has a duty to her relationship with her husband. She deeply cared for her mother and her husband but felt torn about how she could meet both of their needs, and her own.

Charlotte: Well, I guess my daughter tells me I think too much, but I'm wondering, I'm thinking, well, what would have happened if I'd brought her home. Where would we be today? Where would my mom be today? And people I speak with who I consider – I appreciate their words of wisdom, I would say. They tell me, well, you know, you would become to hate the situation. You would – if you knew that you had to be in your home 24/7 as a caregiver, you wouldn't enjoy it. And I would not want to be hateful toward my mother. Interviewer: So, you would think you would feel resentful if... Charlotte: I might and I might not. But then I would also feel I'll lose my husband. I'm in - I must be with my mom, but he deserves – he doesn't always have to be there and I know that he would want to be with me doing things. Interviewer: Right. Charlotte: It's just I feel torn in that respect, I guess. Interviewer: Yeah.

Charlotte: And I could maybe have done more for my mom...

Mary explained similar feelings of guilt after her husband's admission to nursing home.

While she described feeling like she should have been able to care for Robert at home longer, she

also realized that this is part of the grieving process and the adjustment to a life on her own.

*Mary:* Well, you know, at first, I really had a lot of guilt feelings (emotional/crying), but it's getting better. I know that that's the place he needs to be. I'm not as frustrated as I was. *Interviewer:* Do you – where are these coming from, these feelings of guilt? Why is there guilt? *Mary:* Well, I feel that I should have been able to manage him with, you know, some supports at home. So, I know – I mean I'm smart. I know that it's just part of the grieving, I think, that you go through. (emotional/crying). Yeah, I know I need to practice self-care and my daughter says, you know, you've been up there twice this week, why don't you do something for you. You know, so I will.

Carol mentioned having regrets about moving her mother to a nursing home, which were

exasperated by her dissatisfaction with the care there. She felt frustrated while continuing to take

care of most of her mother's physical needs. She felt torn about wanting to care for her mother at home, but not having the resources to do so, and realizing that the nursing home provided a place of social engagement for Margaret.

**Carol:** I've had to work that out with the Nursing home because somebody whose moms in their care are getting six hours a day. That Carol's the personal service worker. And it took them a long time to realize that. Right now, even still, I do everything for her other than she's now full-time in the wheelchair. And I, with my health and especially now since the loss of my husband, I mentally don't trust myself to hold onto her so then she has to be... and that's my biggest regret. I said I just feel like I should be taking one-third of what it's costing me to have mom here for the housekeeping, for the organization. I did all her clothes. All of her clothes. I provide everything she needs. Mom has sensitive skin from her cake of soap to her box of Kleenex. You are not providing, other than her meals, on a daily basis. I just didn't see the care and I thought this would be easier to have her home. But would it be easier for me, yes. Would it be good for mom? No. Then she would become more isolated.

# 6.4 Section 2—Relational Care

In section 1, the emotional aspect of care was described, that women felt was essential to provide good care; something they felt women were better at than men. In this section, care is examined as a relationship, involving interpersonal interactions, and including emotional responses by the care receiver and the care provider. For all the participants, care involved 'caring about' the relative. In essence, care was embedded in close relationships for all participants. Taking on caring responsibilities was already part of close relationships of those who lived together. Mary and Brenda, who cared for their spouses, described how care was rooted in their love and closeness with their husbands.

*Mary:* So, we'll sit and, you know, we'll share the apple and he'll hold my hand and he knows I'm his wife. We've always been close. But I've learned that I need to make decisions for what I think are best for me because it's me now.

**Brenda**: Yeah. I mean, it's -- you want to do it because, you know, you love these people. *Interviewer:* Right.

**Brenda:** I loved him. I expected -- that's what you do. Like, if -- and I know, as sure as I'm sitting here, if it had been reversed, he would have done it for me. I know that.

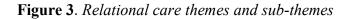
For Charlotte and Sandra who cared for their mothers, and Donna who cared for her mother-in- law, care emerged from within their existing relationships. Closeness and love were also the basis of their relationship and the reasons they took on care for their relative.

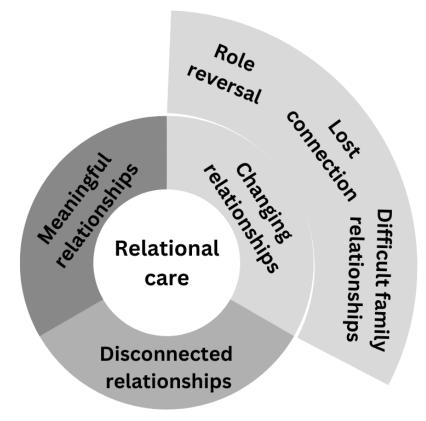
*Charlotte: Well, my mom and I, seeing that we're only daughter - mother/daughter, we were always very close.* 

**Sandra:** Now, I would call mom. Every Sunday, we'd set it up. I would talk to her. We would, you know, I would chat with her and stuff, but it was a long-distance relationship. And but when I was here, because we moved with the children, you know, I was always seeing mom all the time. I was always seeing, we were, you know, we had a great social... we were always together so to speak.

*Donna:* It's sad because I saw her every day. *Interviewer:* Yeah. *Donna:* So, since she broke her hip, I have only seen her spontaneously. Her and I were very close. She's like a second mother.

In this section, the following sub-themes related to care as relational are described: 1) Changing relationships; 2) Meaningful relationships and 3) Disconnected relationships. Note that additional themes emerged related to the sub-theme of 'changing relationships', including 'role reversal', 'lost connections' and 'difficult family relationships' which highlight the differences in experiences based on the type of relationship, i.e., they were differences for women who cared for spouses and women who cared for mothers. Figure 3 provides a visual overview of the themes and sub-themes of relational care.





## **Changing relationships**

## Role reversal: 'I am parenting my mother on her way out.'

When care dynamics changed, relationships changed as well. Several participants who cared for their mothers described a role reversal in their relationships. Both, Carol, and Amy felt they assumed the mother role.

*Carol*: I look at it now that Mom's the child and I'm the parent. *Interviewer:* Okay. *Carol:* I am parenting my mother on her way out.

*Interviewer:* How do you find your relationship has changed to your mom because of all of this? *Amy:* I feel that I'm the mom. You know what I mean?

## Lost connection: 'He kind of checked out.'

For those who cared for their spouses, like Brenda and Mary, assuming a care role also

affected the relationships to their partners. Brenda described how Barry's health problems and

inability to care for himself strained their marriage, leaving Brenda feeling frustrated and

disconnected from her husband.

**Brenda**: And I think it was the – so I guess, his health affected our marriage. Interviewer: Right.

**Brenda**: Because he stopped, you know, wanting or able to do things. He had no energy. He was always, you know, laying down. But the thing is, we couldn't talk about it because he wouldn't talk. And, there was nothing you could say to him that would, you know, convince him to go. So, I just kind of let him – I thought, well, I can't fight with you about this. If you want to live like this, I guess you're going to have to. So, anyway, but we all knew. I mean everybody knew that he wasn't feeling good. So, and he – the thing about Barry is that he thinks he's hiding this stuff and he – you know, so we won't worry and all this thing, but it's so evident that we all – the kids know what it was like. He just, you know.

Anyway, so that affected in our marriage in the fact that he just wasn't – I mean he did things. He got groceries. He did laundry and stuff like that, but there was no fun. Interviewer: Right, he wasn't really engaged. Brenda: No, he wasn't. He kind of checked out.

When Brenda discussed the prospect of moving Barry to a nursing home, he refused to go

as he was unable to see how much the caring responsibility wore on her. Her statement described

a sense of hopelessness, and that continuing to care for Barry was not an option. In return, she

asserted her power to free herself from the caring responsibility.

**Brenda:** So, I told Barry I got mad at him and I said, Barry, I'm not asking you to go. I'm telling you, you gotta go. And I said, I'm going to move out. That's where I'm at. I said, I can't do this anymore.

Mary spent many years caring for her husband at home and taking on a decision maker and advocacy role in their relationship. She described always having been very close with him, and that the nursing home admission separated them physically and emotionally. She shared that she wanted to continue to feel connected to Robert as his wife, and described how they engage with each at the nursing home.

*Mary*: No, we visit and if a care part comes up, then yeah, I care for her, but mostly it's we visit and it's good. We'd chitchat. We'd laugh. We play games. He likes to play crokinole. He likes to play shuffleboard. He loves football, the Ryders, we were season ticket holders for many, many years. So, my son in law taped some games and he likes to watch those over and over and over. Last night, we watched world ladies curling because we used to curl together. We look at picture books. He has – he's not able to read the newspaper anymore so about three weeks ago, I discontinued that. So, we talk. He's lost a lot of his vocabulary. So, you know, we facetime with the kids. Last fall, I used to take him out for walks or drives and we'd have a little picnic.

Meanwhile Brenda shared that she considered seeking connection to others outside her

marriage after Barry moved to the nursing home, suggesting that their connection had continued

to sever further after the nursing home admission.

**Brenda**: Now -- and I've talked to friends about having another relationship some day. I don't really -- I don't really think -- sometimes, you know, you think about it, and you think -- I do miss male companionship.

## Difficult family relationships: 'I'm happy that I have Power of Attorney.'

Care is relational, and in many care relationships, there are other family members who

are also involved in the care of the relative. Some participants spoke of conflict between family

members over care decisions. At first, Amy described being a 50/50 care partner relationship

with her brother, but then further on admitted that it was not.

*Amy*: And we try to split the time 50/50 so no, he is -- like, I call him like the book-smart kind of the deal, and then I try to physically be there. Because he's only like five, 10-minute drive away, right, and I'm an hour and a half away.

**Amy**: So, just having the different views of money, like -- so financially my brother will -- we both have access to her bank account and her passwords and stuff like that. But every move that he makes, like, he'll leave me an email or, you know, something like that. But it's -- I'm happy that I have Power of Attorney.

Amy continues to describe her brother's dependence on her for every decision, that needs

to be made for their mother, and that even in an emergency, she has the responsibility to advise

her brother on actions to take.

*Interviewer:* And it sounds like -- you mentioned earlier before too that you brother, like, when your mom fell in the house; that instead of calling 911, he called you first, instead of calling 911. *Amy:* Yeah, he did, yeah. And he was scared. Like, he was like -- *Interviewer*: Yeah.

**Amy**: -- she's going to kill me, and whatever. And I said, look you just put your big girl's panties on, and you run upstairs, and you hand the phone to Mom, and I got it. And I just said, Mom the ambulance is coming, I don't really care if you talk to me again, I don't live in your house.

Sandra, who had Power of Attorney for her mother, discussed her conflict with a sibling

who did not agree with the Irene's nursing home admission. This created stress, as she is tried to

manage the relationship with her sibling, with the care workers, and with her mother.

Sandra: Oh, they're [the nurses] sweethearts. They call me and they tell me anything that's going on. I chat with them. I always make sure I have a little chats with them about anything, you know. And again, too, it's, as I was trying to say, it's so difficult with having a sibling who is fighting me all the way all the time. I get horrible texts and stuff like that of, you know, moms in an institution and you put her there and it's just mind-boggling of all the stuff I....
Interviewer: Oh, okay. So, she, she does not agree that your mom should be in the nursing home.
Sandra: No. She wanted her to move in with her.
Interviewer: Okay.
Sandra: And it's like you can't take care of yourself and you want to take care of mom.
Interviewer: Now is she allowed to visit your mom there?
Sandra: She is now, yes.
Interviewer: Okay.
Sandra: And it's, and again, I get a text every time she visits. Yeah, mom wet herself and no one was around the TV's off and she's, you know, it's just endless garbage.

# **Meaningful relationships**

# 'I want to be with them.'

Participants all described how physically, mentally, and emotionally straining caring for a relative at home was. However, after the nursing home admission, their involvement in physical care decreased significantly. In fact, most women shared only limited details about care tasks, while providing rich descriptions about how care in the nursing home revolved around engaging in meaningful relationships and focused on spending time together.

**Amy**: The less care for me, right, and then I do self-care, and then I can, in turn, be a better participant in not worrying about my mom as much. My care right now involves not worrying about her as much and just kind of trying to get back to a sense of normalcy, like calling her up and like, you know, she'll call and I'll go, hello, what's going on, how is your day? You know? Like things that are normal.

**Donna**: Actually, I don't do any physical care with either one of them anymore. So, that's nice. Now, I feel when I go, I'm more what I want to be with them. I'm visiting. I'm sitting with them. We usually bring in a treat, a tea or a coffee. We can no longer – that hasn't eased up yet, we used to be able to use one of their little family rooms or dining rooms, but we can't do that yet. But we go right to their room and can close the door and you can spend time there. So, that's nice.

**Sandra**: No, we visit and if a care part comes up, then yeah, I care for her, but mostly it's we visit and it's good. And when we were visiting way before this, before they put so many restrictions on, we'd go out on the patio. We'd chitchat. We'd laugh. You know, we had, it was good visits.

# **Disconnected relationships**

# 'So why don't you ever call me?'

The Covid-19 pandemic and the subsequent visitation restrictions in the nursing home greatly impacted the participants, as they became physically separated from their relatives for long periods of time, restricting opportunities to provide care, and connect and engage in their relationships. In general, participants' narratives were significantly guided by the ongoing pandemic and nursing home visitation restrictions at the time of the interviews.

Carol's mother was already living in the nursing home when it closed to all visitors in March 2020 for an undetermined amount of time. Her description of the nursing home locking down highlighted imminent panic, as she realized the potential consequences of being separated from her mother and leaving her unable to care for her.

**Carol:** It was, what was it. A Friday that, March the 13th. I always stayed on Friday to have supper with mom. We were late. It was probably 6:30 or so. I come out. I'm down the hallway and the receptionist is still there, and they're putting up posters. And COVID-19 and then I see screening and I approach the desk and I said to the receptionist, she said, oh Carol. She said I

have to tell you that we've shut down. I said who's shut down? She said the building will be shut down because of COVID and there'll be no visitation. If you, you could imagine her dismay. I turned around so quickly and started back towards the unit that she came and took me by the wrist, and she said you can't go back in. I knew you were still here. I didn't want to go out and bring you out and I'm crying at this point. And have this scene inside. So, I said to myself I will stay. There was myself and four other people still there with loved ones that the receptionist knew from our sign-in sheet. So, she waited us out. So, she said you can't, Carol. You just can't. And I said, well what, what am I going to do? What am I going to be able to do? And I just, I can't leave her here. And there's no one picking up the six, five, six hours a day that I do. And that's exactly how I put it to her. And she said, well you have to speak to someone else about that. But you'll be well informed. You'll know about it. I said will there be visiting.

Two years later, Carol reflected on the impact of the lockdowns and visitor restrictions.

She grieved the time she lost with her mother, as well as the cognitive decline her mother

experienced without adequate socialization.

*Carol*: But today, I look at Covid. It took her ability to be social. It took her ability to verbalize. It took away her dignity. It took away all, if not all, her social skills. She had --- (very emotional). *Interviewer*: And you couldn't be there for her. *Carol*: Yeah.

Charlotte, whose mother moved to nursing home just before the pandemic started,

described that the care at the nursing home had become worse during the Covid-19 pandemic,

triggering feelings of guilt of moving her mother to a nursing home. Her narrative framed the

emotional struggle of feeling helpless over the nursing home Covid-19 rules and regulations.

Charlotte: It's – it's terrible. (crying). Interviewer: It does sound like it really upsets you. Charlotte: Yeah. I guess I'm torn. Sorry. Interviewer: No, don't be sorry. That's okay. These are very hard things to talk about. I realize that. It's okay to be emotional. Charlotte: I didn't plan for this, I guess. When I see things the way they are now, I wonder if I should've kept her home rather than put her in a place like that. (Very upset and crying).

Despite the visitor restrictions, Charlotte committed to continue to care for her mother to

the best of her abilities. She described the emotional and physical strain of continuing care at the

nursing home, while also highlighting the fulfillment this commitment brought, because she

deeply cared about Glenda.

Interviewer: So, do you visit her every day even if it's a window visit? Charlotte: I do. Interviewer: Yeah. And does that impact your social life at all? Like having, you know, knowing that you're going to be visiting her every day? Charlotte: Yes, it does. It does, but if I don't, then I - I feel more fulfilled if I do. Visiting every day is tiring plus we talk each night for an hour so I'm pretty much drained at the end of the day.

Communication and staying connected during periods of visitor restrictions were

described to be challenging by many participants. Brenda explained difficulties keeping in touch

with Barry at the nursing home, who had access to his own phone and laptop. However, as they

kept missing each other's calls, both grew frustrated with their inability to connect.

## *Interviewer*: So, you were able to talk to each other?

**Brenda:** But -- so, anyways, he says, 'So why don't you ever call me?' I said, Barry I do call but you never answer.' Because -- I don't know what he's doing. And even now, like -- so, he'd bring that up, you know. I say, Barry, call whenever you want, call me.' Because, I said, 'I'll call you and you don't answer.' And I don't know if he's not hanging it up right, because it always goes to voicemail.

Communication and the ability to maintain connected when physically apart also strained

Mary's relationship to her husband whose advancing dementia limited connection via phone or

video call, hence reducing their ability to connect as a couple. Consequently, Robert declined

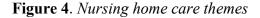
physically and cognitively which further restricted his ability to spend time and engage in the

activities, he used to enjoy with Mary.

*Mary*: So, we talk. He's lost a lot of his vocabulary. So, you know, we facetime with the kids. Last fall, I used to take him out for walks or drives and we'd have a little picnic. But with Covid, I wasn't able to do that. So, last week, I was able to take him out for a walk after about 4 or 5 - Iguess it was about the beginning of November was our last walk and I really noticed that he didn't use the muscles the same, you know. He – so, that, as the weather continues to stay nice, we'll try to do that at least once a week.

# 6.5 Section 3—Nursing home care

This section is concerned with the care partners' perceptions of their role in the nursing home. While relationships were discussed in section 2, it is important to highlight relationships to care workers in these sections, to show the situatedness of the care partners within the nursing home environment. The following sub-themes emerged from examining how care partners perceived their role in the nursing home: 1) Lack of emotional care; 2) Who 'owns' the care? and 3) Us and them. Figure 4 offers a visual summary of the themes of nursing home care.





#### Lack of emotional care

'I think those caregivers should still have time to be compassionate.'

Although, Charlotte realized that the focus in the nursing home was on completing care tasks leaving little room for emotional aspects of care, she felt that care workers should still be compassionate towards residents and their families.

**Charlotte**: For the most, it's like the ratio in there was supposed to be eight per one and that equated to, I think, if you get only two hours, point something per resident. So, I don't – I think – I think those caregivers should still have or take the time to be compassionate toward the family, at least take a few moments to have a word with the families. Same with the management. Take time to stop in the hall and say, hey, I heard your mom was not doing well last night.

Sandra felt that the care workers did not fully engage their emotions when caring for the residents. She perceived that care workers performed a job, as 'nurses'; and that they tried to 'care for' the residents. Although, she perceived the care work to be missing the emotional aspect of care, Sandra stated that the family members filled the 'caring about' gap in nursing home care.

Sandra: I think it's how close you are to this person. Like I know the nurses and that, they get to know them but they're not right in them. Interviewer: They're not family, yeah. Sandra: Yeah

## Who 'owns' the care?

#### *Whenever I attempt to have a voice, it's – it's not with an open mind'*

Many participants described conflicting relationships to the care workers in the nursing home, especially when it came to physical care tasks, and overlapping responsibilities between the paid care work that care workers performed versus informal care work performed by care partners. Who 'owns' the care described the struggle of care partners being seen as valuable members of the care team, as the person knowing they their relative's needs, and as the person who wants to make decisions about their relative's care. Amy described how she helped her mother become more mobile with her wheelchair, and in return received unsolicited comments from the care workers, indicating that the care workers did not respect her input in care. She highlighted that she knows best what her mother needs, that she 'owns' the care, and wants input in her mother's care decisions, despite care workers being responsible for her mother's day-today care.

*Amy:* So, that's where I come in and I'm the daughter and, you know, I get the negative feedback, you know. I'll take her feet things off her wheelchair and, you know, make her move her feet around and, you know, and her arms a little bit. And she was like, you know -- I get comments like, you know, who died and made you a physiotherapist, you know? I'm like, I'm the best thing you got, Mom. You know what I mean? Like we're doing it, you know what I mean?

During the interviews, many examples were shared of care partners feeling dismissed and

not heard by nursing home care workers and management. These stories highlighted the

disconnect between the women and the care workers, hence the separation of the work done by

care workers and by care partners. Both Carol and Charlotte felt they had no voice, felt

disrespected and not in charge of 'owning the care' or have a say in decisions making about their

relative's care.

Interviewer: Do you feel that you're respected by the staff when you have concerns? Carol: There's times I feel I haven't been heard and my new word, I think maybe within the last year is if this were your mother, would this be acceptable? And I hate to say it but, and my biggest problem is I have yet, and I shouldn't be using names, I have yet to have been there with all the changes of the care coordinators, to find one that has satisfactorily sat down, listened to my concerns, told me how they were going to be addressed and see them addressed. If I really want something done, it's not right that I have to rely on going to a nurse that I know very well who knows mom and say to her I'm not getting anywhere. Could you, you advise me what to say next. You know. And I hate to do that but on maybe two or three occasions I've had to.

**Charlotte**: Well, you see, if she were home, if I were able to have assistance at home or have gotten in care so that my husband and I have to have a life too - so do other families. So, if I were able to have gotten care at home, she would've been home. She might have been cared for better. I would like to hope this. At least I would've been able – I would've been the employer. I would have been able to look in and see how things are going. This way, my hands are tied and I cannot – I have no say. Whenever I attempt to have a voice, it's – it's not with an open mind, it's always, we're right, you're wrong.

#### Us and Them

#### 'There's other women caring for my mom.'

In section 1, it was highlighted that participants felt, women are better carers than men. Given that most care workers in nursing homes are also women, it was worth exploring whether care partners felt connected to care workers, because they were also women caring for their relatives. Although, some participants felt disrespected by care workers, others observed satisfactory care, because they perceived the 'other women' 'caring about' their relative.

Amy stated that she was satisfied with the care her mom received in nursing home, because there were other women who provided care. She felt a sense of belonging among other women, who cared for her mother, women she assumed 'care about' her mother with emotional commitment, re-enforcing gender roles and that women are better at care giving.

**Amy**: I don't always have to be there. You know what I mean? Like I don't have to be at the hospital. If we didn't visit, you know, she missed people. But there're -- women now, there's other women caring for my mom. And that's okay. You know what I mean? That I'm not there to care for her, because I know she's getting the best care in her own setting, right? Like she picked the place, and they were very warm and receptive. And the main goal that I like about is that they're there for my mom.

Brenda's narrative also suggested that she was satisfied with the nursing home care. She kept referring to the care workers as 'the girls', reinforcing the gender roles of care, but also highlighting the connection to other women who cared for Barry. 'They' cared about Barry, 'they just love him', confirming to Brenda that Barry was well 'cared for' and 'cared about'.

**Brenda:** You know, for a long time he kept saying, 'You don't have to come up here, you know. You don't have to come up here.' And I said, 'Well, no, I, you know, want to come visit you.' You know, every once in a while. If it's been two days, I think, I wonder how he is, I better go see. That kind of thing. And -- but he -- and he's still got his mind. So -- and he's a real joker and all that. Well, they just love him. The girls just love him. They go in there and carry on with him. On the contrary, Carol shared a negative experience. Her narrative clearly separated herself from the women who cared for her mother. Her description of 'Betty', 'somebody' or 'no one' caring for Margaret signified a disconnect, and the missing 'caring about' aspect of care. As Carol described doing care tasks using strong 'I' statements, her frustrations of having to do it alone became obvious. She could not relate to 'them' as other women who also 'cared for' and 'cared about' her mother.

**Carol**: What bothers me is that person -- let's just say it's Betty. I don't think there's any Betty out there. Betty has nine clients. Mom is one of them. So, Betty gets Mom up, washed, dressed, and makes sure her breakfast is either brought in or taken to the dining room. Betty or somebody else moves Mom into the lounge. Somebody moves Mom back to the table. Okay. Nothing, but then -- yet I, the daughter, when I go in and see she doesn't have her dentures in, she doesn't have her glasses on, she doesn't have her watch on, she still has her slippers on, and she's sitting in shit, or she's cold. From the time I take -- usually most times when I get there, I'm the one taking her from the dining room table -- to the time I leave, I've not seen Betty. The list that's over the bed on Mom's room --she's supposed to be on a two-hour pinpoint check. Interviewer: Right

**Carol:** No one's ever approached Mom at any hour to check to see that the pinpoint. No one approaches her -- and they know now that she's a two-man lift, and I mean this has been, what, maybe nine months. No one ever approaches us when we're sitting or comes into the room and says, 'Oh, excuse me, Carol, I just wanted to check your mother, see if she needed to be changed.'

#### 7. Discussion

The aim of this study was to explore female care partners' experiences and perceptions of the changes in their roles and relationships during their relatives' transitions to a nursing home. It was important to examine these transitions through a critical feminist lens to explore the standpoint of female care partners, and to understand their situatedness within the spheres of home, the nursing home and within the relationships to their relatives and to the nursing home care workers.

The findings highlighted three main themes. First, they rationalised care as women's work; that work is hard and emotional, and that giving up this work induced guilt. Section one of the discussion will situate the findings within the existing literature, and within the feminist lens.

The second section details relational care, and how care was embedded in relationships. The experiences of women highlighted that while their life circumstances changed including their care role, their desire to maintain meaningful relationships with their relatives remained. Further, the findings highlighted that the Covid-19 visitor restrictions in nursing homes significantly impacted the relational aspect of care due to physical separation of residents and their care partners.

Lastly, the third section discusses the main findings of how care partners perceived themselves within the institution of the nursing home. The importance of relational care in nursing homes continued in section three of the findings, highlighting that care partners viewed emotional care as an important indicator of care satisfaction. Further, aspects of emotional care connected care partners and care workers, creating a feeling of belonging for the care partners, as they felt 'other women' 'cared for 'and 'cared about' their relatives.

#### 7.1 Section 1 - Care as women's work

The main theme of care as women's work offered some insight into the women's perceptions of care and their situatedness in society. While participants felt society had created this role for them due to gender constructs, they all felt a sense of duty to take on care for two reasons: 1) As a wife or as a female sibling, they felt that they had the responsibility to care; 2) Because of their love and care for their family member, they felt morally obligated to care. In the literature, the sense of duty and obligation as a reason for women to take on the care role is commonly supported (Eriksson et al., 2013; Hennings et al., 2013; Levine et al., 2010; Puurveen et al., 2018; Williams et al., 2017). However, participants in my study shared that they took on the care role willingly because they loved and cared about their relative. They balanced this with also understanding that their journey into caring was shaped by societal expectations. In essence, this created two realities in which the women existed as care partners. Smith's (2005) rules of relation organize society and distinctively separates different societal institutions. For example, home and work are differently organized, and while women operate in both of those realities, they are not blended, and women operate differently in both domains (Smith, 2005). Further, Smith (2005) argues that the experiences of women in both domains of home and work are shaped by the social structures created by patriarchy. Their understanding of 'care as women's work' was historically created by the order of society (Smith, 2005). In my study, it became apparent that the women's perceptions of their place in society as care partners was indeed enforced by societal expectations--they felt a sense of duty to care as women, as wives and as female siblings. Hence, the assumption that taking on care was their duty as women represented the situated reality, while their expression of love and care for their relative perhaps represented their own reality.

The study reinforced the existing knowledge of care being hard work, often a 24-hour job, and participants felt they received little recognition for this. The literature highlights that it is often women who have to fill several different roles and obligations including that of a family carer and worker outside the home (Bramble et al., 2009; Holmgren et al., 2014). In my study, several women described juggling caring for a relative at home while also holding a paid job outside the home. They described that despite enjoying their work, they did not receive enough support from their employers for their dual roles. In the end, they saw no other way but to leave their paid jobs and assume 24-hour care of their relative. Examining this through a feminist lens, it became clear that the decision to choose care over work was influenced by their situatedness in society as women who felt it was their duty to care. Participants perceiving to have a duty to care re-enforced the ruling relations described by Smith (2005). In this case, the ruling relation described the discourse that care is women's work. As it was apparent in my findings, some women were unable to keep their paid jobs as they did not have enough care support and resources at home, and not enough support in their workplaces for their care situation. This supports the notion that care work is often undervalued and invisible, and that care and work are clearly divided entities (Armstrong & Armstrong, 2008). Hence, the participants were not able to exist in both the care and the work environment due to limited support from employers and from health and social care. This highlights the unequal distribution of resources and the rigidity of workplace culture which are both shaped by the gender (Risman, 2004). Therefore, the experiences of the women in my study were very much situated within the social structures where care and work continued to be divided, and some of the women saw themselves responsible and without choice to leave their jobs and take on 24-hour care of their relatives.

While the women in my study identified themselves as feeling responsible to care for their relative based on gender roles, they also identified that care included an emotional component. They described a 'caring about' skill they possessed as women that made them 'better' at caring for their relative. Some women also distinguished that men seemed to solely visit their relative at the nursing home while women provided both physical and emotional care. In the literature, women are often described as having a greater emotional commitment to care (Bramble et al., 2009; Williams et al., 2017), and that men are perceived to be the visitors and not involved in care in the nursing home (Holmgren et al., 2014). While this division in roles in nursing homes could easily be justified with the explanation of gender roles, it is important to recognize that despite their perceived duty to care, the women clearly identified themselves as having better emotional skills than men, making them better at caring. On one hand, Tronto's (1998) ethic of care describes the actions of care as caring about or paying attention to someone else's needs, caring for or assuming the responsibility to meet a need that has been identified, responding to that particular need, and recognizing the effect the care has on the person who is cared for. Therefore, care could be viewed as a complex skill set, and as valuable and productive work that the women in my study perceived to own, hence clearly giving them an advantage, even power over men. On the other hand, the perception that women offer better emotional care than men, does indeed reinforce the gender roles of care within the discourse of 'care as women's work'. Men as human beings have emotions. When they are care partners to relatives, they experience anger, grief, devotion, and love, and these are embedded in the relationships to the people they care for (Giesbrecht et al., 2019).

The perception of the women owning complex care skills including emotional commitment can be used to examine their feelings of guilt after their relative's move to a nursing

home. The study highlighted that while women recognized the need to care for themselves after their relatives' transition to nursing home, they also experienced significant guilt over not having done enough and over enjoying time to care for themselves. These findings align with the literature. Several other studies have identified that despite feeling relieved, women experience guilt after a relative's nursing home admission (Hennings et al., 2013; Hennings & Froggatt, 2019; Reuss et al., 2005). Situated within gender roles, the guilt of giving up care at home is positioned within the discourse of 'care as women's work', a duty the women felt they could no longer perform after the nursing home transition. Additionally, care often becomes part of a woman's identity, no doubt because of the ruling relations that Smith (2005) describes, however, it is important to not dismiss the power and purpose of caring for a relative the participants described.

In summary, the experiences, and perceptions of care as women's work in the study is situated in the gendered discourse of social structures. The findings and discussion confirmed that women perceived a duty to care for their relative as wives or as female siblings, but that the duty also came from a place of love for their relatives. Most importantly, my study pointed out an important viewpoint-- that of the women perceiving care as women's work because they felt that they were better emotionally equipped to care than men. While the participants re-enforced the societal gender roles, it is of utmost importance to not dismiss the perception of power they perceived in their care role.

## 7.2 Section 2 – Relational care

Section two discusses the findings that care is embedded in relationships, and that the nursing home transition was accompanied with changes in relationships for the women in my study.

One of the main findings of relational care was that every participant's care journey evolved through existing relationships. Whether they were wives, daughters, or daughter-onlaws, they described a loving and close connection to their relative, which were important components of their care roles, even as care impacted and changed their relationships.

When care roles changed, so did relationships. For examples, spouses experienced lost connections as the care for their husbands became increasingly demanding. Due to taking on a decision-making role or an advocacy role, spouses felt frustrated with the disconnect their evolving care role brought. The literature that focusses on evolving relationships of people with dementia and their spouses describes how the desire to continue caring are based in strong existing connections between the spouses (Merrick et al., 2016). For sund et al. (2015) further described that despite diminishing connections due to cognitive and physical decline, the sense and need for love and emotional attachment remained.

Daughters who cared for their mothers described a reversal in care roles, where the daughters took on the role of the mother, with one woman stating that caring for her mother-inlaw was a continuation of the mother role. Hammar et al. (2021) described a similar role reversal. While Hammar's study included both male and female care partners, it was noted that a female care partner made the statement of feeling like she was caring for a child (Hammar et al., 2021). Applying a feminist lens noticed that the sense of taking on the 'mother role' in caring for a relative may be embedded in the women's described sense of duty to care, which is rooted in the societal expectation of women being caregivers.

Relationships continued to evolve after the nursing home admission. However, what stood out in the findings was the desire to continue to engage in meaningful relationships more so than taking part in functional and physical care in the nursing home. The literature generally supports the premise that care partners longed to feel connected to their relatives after a nursing home admission (Barken et al., 2016; Førsund et al., 2015; Hennings & Froggatt, 2019; Pritty et al., 2020). Though it was highlighted that care partners wanted to maintain the care role, they visited more often in order to manage their guilt after the nursing home admission (Pritty et al., 2020). On the contrary, the findings of this study suggest that care partners found physical care tasks to interfere with maintaining meaningful relationships, whereas all the care partners described that engaging in shared activities with their relative when visiting gave them a sense of connection.

The assumption that 'visiting' a relative in nursing home to provide care stems from the view of the division of care in this institutional setting, which separates paid care and informal care, therefore essential care and non-essential care (Kemp, 2021; Kemp et al., 2013). The consequences of viewing care partners as informal carers and non-essential were described in the findings of my study. When the Covid-19 pandemic locked down nursing homes, care partners became physically and emotionally disconnected from their relatives. During these times of lockdown, the participants found it difficult maintaining connection through technology such as phones, video calls or window visits, due to the cognitive decline of their relative or missing each other's phone calls. They expressed frustration and a sense of injustice, along with grief about the time they lost with their relative--time they would never get back.

We are only starting to understand the consequences of the Covid-19 nursing home lockdowns on relationships. Some of the emerging literature highlights the frustrations, and feelings of grief and loss of family members who were no longer involved in caring for their relatives (Kusmaul et al., 2022; McAiney et al., 2021). The resulting decrease in communication between care workers and care partners resulted in less transparency and more distrust in the nursing homes (Kusmaul et al., 2022). While the findings of my study only gave a glimpse of the impact on relationships between care partners and their relatives as well as between care partners and care workers, more research is needed to examine the consequences of the Covid-19 visitor restrictions on relational care in nursing homes. A look through the feminist lens gives an indication of the injustice of the lockdown protocols in nursing homes. They highlight the division of paid and essential care versus informal and non-essential care, and the assumption that informal care partners were mere visitors and not valuable members of the care team (Kemp, 2021; Kusmaul et al., 2022). By locking out essential care partners, the assumption was created that care partner's work is unnecessary. This further underlines the invisibility of care as women's work (Armstrong & Armstrong, 2008).

In summary, this section highlighted the relational aspect of care. Care was always embedded in relationships, and relationships evolved as the relative's care role changed. Throughout their care journey, participants always longed to maintained meaningful relationships, and it is important to highlight that providing physical care interfered with maintaining meaningful connections with their relatives. It is crucial to highlight that the covid-19 visitor restrictions disconnected the relationships between care partners and their relatives, and that urgent research is needed explore the consequences of the prolonged disruption of the care partner – relative relationship.

#### 7.3 Section 3 – Nursing home care

Section three discusses how the care partners perceived their roles and relationships in the nursing home. Continuing from discussing relational care in section 2, the findings suggested that relationships were deeply embedded within the care environment of the nursing home as well. Most women in my study viewed the inclusion of emotional care as a significant indicator of care satisfaction in the nursing home. While some participants identified the lack of emotional care as a lack of the overall quality of care, others felt a sense of belonging to the care workers as 'other women' when they sensed care workers were able to offer emotional care.

Situated in the structure of nursing homes, emotional care can often not be provided due to the disembodiment of the work there, which is expected to be efficient, uniform and documentable (Abrahamson et al., 2009; Diamond, 1992). Their experiences were guided by the medicalized environment of nursing homes that focusses on maintaining bodies and their functions, disembodying care work (Diamond, 1992; Gubrium & Holstein, 1999). Regimented tasks identify residents as bodies that are to be cared for, hence eliminating identity and emotional labour (Diamond, 1992; Paterniti, 2000). Therefore, individualized care including emotional care is often not possible, and relatives such as the care partners in this study felt dismissed by and disconnected from the care workers (Holmgren et al., 2013; Palacios-Ceña et al., 2019). Additionally, the literature confirms that the perceptions of relationships between care workers and family members is satisfactory when care expectations by the family are similar to those of the care workers (Abrahamson et al., 2009). Most women in my study felt satisfied with the care their relative received when they felt the 'caring about' aspect of care was satisfactory, and when care workers were perceived to engage in emotional and relational care with their relative.

On the other hand, most conflicts between the care partners and care workers were described as revolving around physical care tasks. The women in my study highlighted how they knew best what their relatives needed. Often, they felt disrespected and received unsolicited comments when helping with care tasks. The literature confirms that these conflicts are common between care partners and care workers. In a study by Crawford et al. (2015) care partners experienced a lack of decision making power over the care of their family member. Further, care partners often did not trust care workers to know what their family member needs, and they felt as if they constantly needed to manage and monitor the care (Ekström et al., 2019).

Examining these conflicts through the feminist lens, it becomes obvious that these conflicts were about power over who owns the care in the nursing home. Within Smith's (2005) ruling relations, society created the discourse of 'care as women's work', so when talking about 'owning the care', it creates questions about who is responsible for what aspect of care in the nursing home, where mostly women are cared for by other women? Care is a set of tasks, however as shown above, it is also deeply rooted in relationships. This creates different expectations of who is responsible for what tasks in the nursing home, when they likely overlap, when care partners and care workers are mostly women.

During the interviews, it became clear that women who took on the care willingly out of love and care for their relative, struggled with giving up this care role in the nursing home. While structurally the care role was imposed on them by the discourse of care as women' work (Smith, 2005), the women likely cared for their relative with great purpose. So, with the nursing home admission, a great sense of purpose may be lost. With the constant need to monitor or manage care, women likely continued to hold to this purpose.

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These blurred boundaries of paid care and informal care in nursing homes makes supporting relationships between care partners and care workers difficult (Puurveen et al., 2018). Care partners continue to be seen as visitors as opposed to essential members of the care team, further devaluing the contributions of care partners in nursing homes (Kemp, 2021). Utley-Smith et al. (2009) and Ryan et al.(2000) showed that care workers in nursing homes view relationships with family members as difficult and time consuming, and that they prefer to be viewed as the professional care worker, while the family's job is it to visit and spend time. While care workers' perceptions were not examined in this study, the findings revealed that care partners perceived a separation between themselves and the care workers.

Nursing homes are highly gendered environments with the majority of care workers also being women (Armstrong, 2013). Their role in a gendered environment and society is highly undervalued and stigmatized as well (Armstrong, 2013; Booi et al., 2021).

Therefore, the findings of my study highlighted that care partners often spoke of 'us' vs 'them', perhaps by holding on to their purpose of feeling responsible for the care of their loved one. They realized that 'other women' could have the ability to offer care, both physical and emotional, to their relatives. When care satisfaction was high, care partners praised care workers for the ability to 'care about' their relatives, even using phrases like 'they just love him'. The belonging to 'us' emphasised that women, whether paid worker or informal care partner can engage in emotional care and therefore in relational care. In situations that showed care dissatisfaction, 'they' was often used to point out the care workers as 'the others'; those who 'did not care', and those who 'dismissed me', clearly highlighting a separation between care partners and care workers. In the literature, the importance of good relationships and rapport between care partners and care workers is at the basis of what is perceived as 'good care' (Barken & Lowndes, 2018; Bramble et al., 2009). However, the findings of my study can add another layer of the care partner and care worker relationship by highlighting the situatedness of the women in the nursing home structure.

In summary, relational care in the nursing home was perceived to be an important aspect of care satisfaction for the participants. Recognizing a lack of emotional care created a separation between care partners and care workers, and a perceived dismissal and disrespect. However, when participants felt that care workers 'cared about' their relative, they felt they belonged among other women caring for their relative. The experiences of the women are situated in the highly gendered environment of the nursing home, where professional care work is also undervalued, and care workers and care partners fight for recognition of their contribution to the care of residents.

## 8. Reflection on the Methodology

Using voice-centred relational method as a framework for this study created an opportunity to highlight the participants' individual stories and their perception of being a care partner, while also highlighting some of the inequities created by social structures that shaped their experiences as women and care partners. Without this method, the social structure of gender, and how it intertwines with the domains of care and the nursing home, could not have been highlighted. Further, using voice-centred relational method made it possible to emphasize that all care is embedded in relationships. This theme underlined that at the root of care is a

human interaction, that impacts both, the care receiver, and the care giver within the structure of home and the nursing home.

Using a critical feminist lens opened the opportunity to highlight the participants' experiences as female care partners within the structures of society. Using this lens underlined existing gender roles, and how the women identified with these gender roles. However, by employing voice-centred relational method in the analysis, it was possible to continue to emphasize the women's own voices without imposing gender roles or inequities on them.

## 9. Strengths and Limitations of the Research

Qualitative research surrounding nursing homes continues to be rare, and this study gives a voice to the experiences of relatives caring for nursing home residents. Family members, often labelled as 'informal caregivers' are usually not included in quality assessments of nursing home care, but this study highlights that their part in care is significant, and that their valuable work adds to the quality of life, to not only residents, but also to care partners themselves.

Further, this study was conducted during the Covid-19 pandemic that impacted nursing homes, their residents and families, and care staff significantly. This research adds important findings of this time period, that created enormous inequities for women in general, for nursing home residents, who were isolated from co-residents, family members and any other socioemotional support for many months at a time.

Lastly, using voice centred relational method as an analysis tool and a critical feminist lens provided avenues for an in-depth exploration, through several lenses. This in-depth analysis was supported by the small sample size, that allowed to employ voice centred relational method as a time intensive analysis tool.

A limitation of the study was that recruitment took place at a time when Covid-19 continued to impact nursing homes, and many nursing homes were locked down to visitors. Nursing home administrators were unable to help with recruitment as their focus continued to pertain to Covid-19 outbreak management. This led the expansion of recruitment beyond the province. Hence, not all participants were from New Brunswick. This is a limitation, as differences between experiences of participants from New Brunswick, and one participant from Saskatchewan were not explored, but could have been present.

Further, it was also noted that discussions about relationships between care partners and care workers were given limited attention during the interviews, as only one participant had experience being an active participant in care in the nursing home before the Covid-19 pandemic policies limited visitations. The rest of the participants moved their relatives to nursing homes directly before or during the Covid-19 pandemic. Therefore, interactions between care partners and care workers had been very limited and reduced to communication via phone. As a result, care partners were unable to participate in care and were likely unable to build rapport with care workers.

Lastly, the study explored experiences of women as care partners without specifically considering differences between spouses and daughters. While some differences in findings were highlighted between the two groups, it was not the intent of the study to explore differences in their experiences in detail.

## **10. Impact on practice**

The study highlighted several points that can be taken into consideration for practice. First, care is a gender issue and women continue to expect to be the caregiver of relatives. This

study highlighted that women typically do not receive enough structural support when caring for a relative, being unable to work in a job and care for someone at the same time. The stress of being a caregiver and not having sufficient support can affect women's physical and mental health. Addressing gender as a determinant of health in caregiving could pave a path for better structural supports for care partners such as home care or financial support, to ensure they can work and provide care at the same time. Further support could greatly extend the time care partners can care for a relative at home, possible delaying or avoiding nursing home admission altogether.

Second, the study strongly emphasized that care, especially emotional aspects of care, do not end with a nursing home admission, and that many nursing home residents continue to be part of family dyads. They are emotionally linked to their relatives through caring relationships, and the study showed that care partners continue to seek meaningful relationships with their relatives who live in nursing homes. However, nursing homes traditionally do not consider the resident as part of an already existing dyad, neither do they traditionally consider the impact of the nursing home transition on the relative. Hence, the findings of the study have emphasized that relatives of nursing home residents are not just visitors. They are an important part of the care team; they are in meaningful relationship with the residents, and physically separating them by means of visitor restrictions has significant impacts on the physical and emotional well-being of both the residents and their relative. It is imperative for nursing homes to consider these impacts and re-visit policies and procedures to ensure relatives and residents can engage in meaningful relationships and connect in person, even as Covid-19 continues to impact nursing homes.

Further, the study emphasized that care is emotional, and usually embedded in relationships, although most participants found that care workers did not emotionally care for their relatives. This was their perception, but this may not have been the reality for care workers. They are human beings, who care for the residents. They often form relationships with residents, which aids to the meaning and purpose of their work (Booi et al., 2021). With care in nursing homes being disembodied, i.e., care workers are merely performing tasks, this has negative impacts on how care is perceived by the residents and their relatives, and how satisfied care workers are in their jobs. Care is relational, and this aspect cannot be erased. The current structure of nursing home does not allow for care to be relational. Hence, reconsidering nursing home care and recognizing relational care as part of this care system could enhance care quality, relationships between care partners and care workers, and job satisfaction for care workers.

In summary, the following recommendations should be considered: 1) Develop policies that consider the resident-relative dyads as existing and continuing relationships, that should be considered in the nursing home transition, in care planning, every-day care, quality of life and evaluations of nursing home care; 2) Develop policies that avoid the separation of residents and their relatives, and ensure the continuation of informal care and meaningful relationship while dealing with managing contagious diseases; 3) Recognize that care is relational, and an important an aspect of care provision in nursing homes. Relational care should be considered in care planning, care evaluation, care worker job development and satisfaction. Further, relational care should be a measure of quality of care when evaluating programs and services in the nursing home. 4) Recognize that care continues to be viewed as women's work, and that most women willingly take on this socially constructed role, while also seeing the injustice in it. To elicit

change, care needs to be viewed as valuable work in order promote social change that supports care as work.

## **11.** Conclusion

This thesis aimed to explore care partners perception of their relatives' move to a nursing home, while exploring within a feminist lens. The findings of the study revealed three themes. First care was perceived as women's work. Situated within societal norms, women felt it was their duty to care and giving up care induced guilt, while they also highlighted that care came from a place of love and 'caring about'. Despite care being hard work, that impacted women physical and emotionally, they perceived to be good at caring. Bringing the emotional aspect into the caring role, they perceived to be better at caring than men. While this re-enforces gender roles, it was important to recognize their perceived power and purpose in the care role.

Second, the findings revealed that care is relational, and embedded in existing and evolving relationships. All participants wanted to maintain meaningful relationships after the nursing home admission. Further, given the situatedness of the study within the Covid-19 pandemic, the findings revealed that relationships between care partners and relatives became disconnected due to the nursing home visitor restrictions.

Third, participants perceived themselves as dismissed and undervalued in the nursing home setting. The aspect of relational care appeared to be an important contributor to care satisfaction. When the women felt that care workers committed emotional care to their work, care satisfaction was high, while low satisfaction was seen with participants who felt care workers did not 'care about' their relative.

The thesis added an important feminist lens to the experiences of the participants. The findings revealed that their sense of duty to care came from their situatedness in society that views care as women's work. In addition, their experiences surrounding being a caregiver and a worker outside the home, revealed the view of care as undervalued work, as they were unable to find enough support in their workplace, from health and social care to keep their jobs while also caring for their relative. Lastly, it was possible to examine the participants' experiences within the nursing home environment, that is highly structured and gendered, and where relatives and care workers compete for recognition of their contributions to care. The findings discovered that care is relational, and that care partners expected good care to include a 'caring about' aspect. However, given the medicalized and disembodied structure of nursing home care, emotional care was perceived by the care partners to be often missing, impacting care satisfaction.

The study offered important insight into qualitative research of nursing homes, which continues to be rare. Further, it gave care partners an important voice, as their position or perspective usually are not included in the evaluation of quality of services in nursing homes. This thesis was conducted during a significant time. The Covid-19 pandemic impacted nursing homes considerably, so including the care partners' voices provided important findings that documented the Covid-19 pandemic and its impact on nursing homes. The finding of the importance of relational care in nursing homes adds to the need to further research the impact of the Covid-19 pandemic on the relationships between care partners, residents, and care workers. Besides informing future research, the study could help inform practice guidelines for supporting caregiving for female care partners. More advocacy for women who care for relatives is needed, to ensure their work is valued, and to ensure they receive adequate supports to sustain this role while supporting their own physical and mental health. For nursing home care planning and

evaluation, it needs to be considered that care is relational and an important aspect of the quality of life of residents and their relatives, as well as the job satisfaction of care workers. Therefore, maintaining meaningful connections between residents and care partners in infection control situation, such as Covid-19, is of utmost importance.

## 12. Reflection on the Research

As my thesis journey comes to an end, it is important to reflect on the work, and the impact it had on me. From the beginning, my position as researcher in this study was very much that of an ally. The interest in studying care partner's experiences of their relative's journey to nursing home was inspired by my own connections to care partners. As a healthcare provider, I always drew on connections with residents and their families to add meaning and purpose to my work in a stressful, task-oriented environment. It was within these connections that I built trust. This wasn't always easy, but I always reminded myself, that I 'cared about' them, and that this was the basis of providing good care, and of doing no harm.

When the Covid-19 pandemic started, maintaining these connections to residents and families became more difficult. Relatives were not allowed to visit for many months before outside socially distanced visits were permitted. I struggled morally with these restrictions. It felt wrong and unfair that residents were separated from their families. I constantly experienced guilt. I had to work against my own values of doing no harm and respecting residents' wishes, creating a moral struggle, as my instincts kept telling me that the visitor restrictions would lead to harmful consequences.

When I began working on this thesis, the nursing home I worked at was in full-blown covid-19 outbreak lasting many months. During that time connections to care partners were

limited to phone calls, listening to their frustrations, concerns, and grief, providing reassurance, and sometimes sharing heartbreaking news. I was limited to seeing residents only when necessary. I utilized those necessary visits to offer much needed social interaction. Residents were yearning for human connection, so sometimes we shared conversations, sometimes I just listened, and other times, we sat in silence while choking back tears.

The prolonged social isolation led to significant physical and cognitive decline in residents. This didn't become obvious until movement within the nursing home was no longer restricted, and I could see all the residents again. My initial reaction was: "What have we done? How could we have done this to human beings?" I was hit with intense guilt. I felt we didn't do enough, and that we had neglected residents. The moral injury was and continues to be significant.

I utilized my research to process my experiences, and to give care partners a voice, as they desperately needed to be heard. Further, I wanted to find answers. What went wrong? How could we have let this happen? How can we do better in the future?

As a novice researcher, I was guided by my sense of justice. Specifically, the anger and grief about the Covid-19 situations in nursing home, fueled my curiosity, and my drive to find answers and elicit change. Additionally, I felt that my emotional connection and experiences about the research led me to have meaningful, in-depth interviews with the participants. I felt connected to them through shared experiences, shared anger and grief and a shared drive to do justice. Without, the emotional connection, I might not have been able probe conversations and hence find some of the important themes of my research.

Further, implying a feminist lens as a methodological framework to my inquiry opened a new horizon for myself as a woman and caregiver to my children. I could not help diving into

my own emotional world to explore what it means to be a woman, a mother, a healthcare worker, and a student researcher, and how my experiences have been shaped by societal structures, especially expectations around care and gender roles. I found myself feeling a lot of conflict between my various identities, i.e., mother, women, researcher, healthcare worker, and wondering which of those are my own versus those who were imposed on me socially. Like the participants in my research, I feel a lot of power in raisin children and fulfilling a care role, while also feeling undervalued and unsupported to be fully engaged in that care role and the role of healthcare worker, student, and other various identities, that contribute to the purpose of my life. Overall, the journey of writing this thesis has come with a great sense of humility. There has been tremendous growth, intellectually and emotionally, that contributed to my work, my research, and my experience as a human being.

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# 14. Appendices

# Appendix 1 – Demographic Questionnaire and Interview Guide

## **Demographic Questionnaire for Care Partners**

Participant Code\_\_\_\_\_ Fill in the blanks or circle answer as indicated. You may choose to not answer any of these questions.

- 1. What is your age? \_\_\_\_\_
- 2. How many years have you been caring for your relative? \_\_\_\_\_

3. Have you previously cared for another relative?

If yes, for how many years? \_\_\_\_\_

- 4. What is your marital status?
  - a. married
  - b. common-law
  - c. single
  - d. divorced
  - e. widowed
- 5. What is your employment status?
  - a. Full-time
  - b. Part-time
  - c. Self-employed
  - d. Unemployed
  - e. Retired
- 6. Are there other family members, relatives, friends, or other community members who support caring for your relative? Please list their relation to you, i.e., sister, brother, friend, neighbour etc.

## **Interview Guide**

## 1. Tell me about yourself

2. Tell me a little bit about your relationship with your relative.

## Prompts:

- a. How long have you known each other?
- b. How would you describe your relationship with your relative?

## 3. Tell me about caring for your relative.

#### Prompts:

- a. How long have you been caring?
- b. How did you come to be a caregiver?
- c. What was life like for you and your relative before the nursing home admission?
- d. How much time did you spend caring for your relative?
- e. What was your experience dealing with increasing care needs?
- f. Were you able to ask for help? Who did you ask for help?
- g. How has covid-19 impacted your experience as care partner?

## 4. Tell me about the nursing home admission

## Prompts:

- a. When did you make the decision about moving your relative to a nursing home?
- b. Who made the decision? Did anyone help you make the decision?
- c. How did the decision affect you?
- d. Tell me about how you experienced the move of your relative to the nursing home?

e. How has covid-19 impacted your experience of transitioning your relative to nursing home?

5. Tell me about your involvement in the care of your relative at the nursing home?

#### Prompts:

- a. How often do you visit? What brings you to visit?
- b. What care tasks do you help with on a regular basis?
- c. How has the separation from your relative affected you?
- d. Describe your relationship with the care staff?
- e. Has your relationship with your relative changed?
- f. How has your social life been affected before and after the move to nursing home?
- g. How has Covid-19 impacted your involvement in care in the nursing home?

#### 6. How does being a woman affect being a care partner? How does it affect decision-making around

#### caregiving?

#### Prompts:

- a. How do you think being a woman affect your role in caregiving? How did your upbringing shape your role as carer? Who did the care in your family?
- b. Is care a job? What is care?
- c. Do you think care is women's work? And why or why not?
- b. How does being a woman affect your role in decision making around caregiving?

c. How does being a woman affect your involvement in caregiving? Do you think it would be different if you were a man and if so, how?

d. What do you think are the expectations as a woman in terms of caregiving? Do you think that women have a choice in caring for relatives? Do you think expectations for men in terms of caregiving are different? Why can men not care?

e. How does age impact your role as care partner? Do you think that age impacts how others view your ability to provide care?

# **Appendix 2 – Consent Form**

#### **Consent Form for Participants**

I, \_\_\_\_\_\_, agree to participate in the project "Care partner's experiences of their relative's transition to nursing home: a critical feminist perspective" as described in the letter of information. I agree to the following:

- $\checkmark$  I have read and understand the information contained in the Information Letter.
- ✓ I will be asked questions and my answers will be audio recorded.
- ✓ I agree to participate.
- $\checkmark$  I understand the potential risks and benefits to the study.
- ✓ My participation is voluntary, and I can refuse to participate in any aspect. I may choose not to answer any question I am uncomfortable with.
- ✓ I can withdraw from the study without penalty. Within three months of the interview, I can withdraw my consent by contacting Julia Besner via email <u>jbesner@lakeheadu.ca</u> or phone at (506) 343-6170. All my information will be removed from the project.
- ✓ That the data will be securely stored on an external hard drive, for a minimum of 5 years following completion of the research project, then it will be deleted.
- ✓ I will remain confidential. My name will not be used, nor will any identifying information, including in any publications and public presentations of the study results.
- ✓ I understand that the research findings will be made available to me upon request.
- $\checkmark$  All of my questions have been answered.

If you would like to request a copy of the results upon completion of this study, please complete your desired method of contact:

Email: \_\_\_\_\_\_
Mailing Address: \_\_\_\_\_

Mailing Address: \_\_\_\_\_\_ Postal Code: \_\_\_\_\_\_

By consenting to participate, I have not waived any rights to legal recourse in the event of research-related harm.

Participant Name (please print)

Participant Signature

Date

or

If you have any questions about this study, please feel free to contact Julia Besner at <u>jbesner@lakeheadu.ca</u> or (506) 343-6170. This study has received ethics approval from the Research Ethics Board at Lakehead University. If you have any questions related to the ethics of the research and would like to speak with someone outside of the research

team, please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca

#### **Appendix 3 – Research Ethics Board Approval Letter**



Research Ethics Board t: (807) 343-8283 research@lakeheadu.ca

January 06, 2022

Principal Investigator: Dr. Elaine Wiersma Student: Mrs. Julia Besner Health and Behavioural Sciences Lakehead University 955 Oliver Road Thunder Bay, ON P7B 5E1

Dear Dr. Elaine Wiersma and Mrs. Julia Besner:

Re: Romeo File No: 1469030

On behalf of the Research Ethics Board, I am pleased to grant ethical approval to your research project titled, "Female care partners' experiences of their relative's transition to nursing home: a critical feminist perspective".

Ethics approval is valid until January 6, 2023. Please submit a Request for Renewal to the Office of Research Services via the Romeo Research Portal by December 6, 2022, if your research involving human participants will continue for longer than one year. A Final Report must be submitted promptly upon completion of the project. Access the Romeo Research Portal by logging into myInfo at:

#### https://erpwp.lakeheadu.ca/

During the course of the study, any modifications to the protocol or forms must not be initiated without prior written approval from the REB. You must promptly notify the REB of any adverse events that may occur.

Best wishes for a successful research project.

Sincerely,

Youra

Dr. Claudio Pousa A/Chair, Research Ethics Board

/sa

955 Oliver Road, Thunder Bay, ON, Canada, P7B 5E1 | lakeheadu.ca

## Appendix 4 – Recruitment Letter to Nursing Home Administrators

Dear Administrator,

My name is Julia Besner, and I am a graduate student at Lakehead University completing a master's in public health. I am completing a thesis research project titled: "Female care partners' experiences of their relative's transition to nursing home: a critical feminist perspective" You are receiving this letter because I am recruiting **female care partners of residents who have moved into the nursing home in the last 6-18 months** to participate in the research study. Female care partners are spouses or partners, daughters, nieces, sisters, close neighbours, or family friends.

The purpose of this study is to explore the experiences of women as care partners before, during and after the transition of their relative to a nursing home. It specifically wants to explore the experiences of women in their involvement in care and in the decision to move forward with a nursing home admission. Further, the study hopes to explore how women adjust to the care role in the nursing home, and to the relationships with care workers. It also examines whether women feel, they experience disadvantages or face obstacles when caring for a relative at a nursing home. Information from this study will add important knowledge to the study of women's experiences as primary care partners and will help in promoting changes at the policy level in nursing homes.

This study would involve interviewing the participants via online web conferencing such as Zoom. The interview lasting approximately 45 to 60 minutes. As nursing home administrator, you would be helpful in identifying potential participants, and asking their permission to be contacted by me to be informed about the study. You or another designated nursing home employee such as the Director of Nursing, or the Director of Recreation **may use the attached email script titled: "Letter/email to Nursing Home Care Partners from Nursing Home Administrator" to contact care partners about the study.** 

This not a facility study, and participation or not being involved in the study will not affect the care the residents and their care partners receive, and neither care staff nor management will know who did and did not participate. If you have any questions or would like to discuss this research further, please contact me via email jbesner@lakeheadu.ca or phone (506)343-6170

This study has received ethics approval from the Research Ethics Board at Lakehead University. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team please contact **Sue Wright at the Research Ethics Board at 807-343-8283 or** <u>research@lakeheadu.ca</u>.

Thank you for your time and consideration. Sincerely yours,

Julia Besner Graduate Student

# **Appendix 5 - Letter/email to Nursing Home Care Partners from Nursing Home Administrator**

Dear Care Partner,

You are receiving this letter because you are a care partner of a relative living in a nursing home. You are being invited to participate in a study titled "Female care partners' experiences of their relative's transition to nursing home: a critical feminist perspective". The study is conducted by Julia Besner, a graduate student at Lakehead University.

The purpose of this study is to explore the experiences of women as care partners before, during and after the transition of their relative to a nursing home. It specifically wants to explore the experiences of women in their involvement in care and in the decision to move forward with a nursing home admission, as well as their relationships with care staff at the nursing home.

This study would involve interviewing you via online web conferencing such as Zoom. In this interview lasting approximately 45 to 60 minutes.

Participation or not being involved in the study will not affect the care your relative receives in the nursing home, and nursing home management or care staff will not know which care partners participated.

If you would like to learn more about the study from the researcher, you can contact Julia directly at <u>jbesner@lakeheadu.ca</u> or phone (506)343-6170, or you may give us (the Nursing Home Administration) your permission to share your phone number and email with the researcher, so she can contact your directly to inform you in more detail about this study. Thank you for your time and consideration.

Sincerely yours, Nursing home administration

# Appendix 6 – Phone Script for Potential Participants

Hello \_\_\_\_\_\_. My name is [Julia Besner], and I am graduate student working on a research project about female care partners. I received your contact information from [NAME OF NURSING HOME ADMINSTRATOR] because you gave him/her permission to be contacted about the study.

The purpose of my study is to explore the experiences of women as care partners before, during and after the transition of their relative to a nursing home. I specifically want to explore the experiences of women in their involvement in care and in the decision to move forward with a nursing home admission. I also hope to explore how women adjust to the care role in the nursing home, and to the relationships with care workers.

This is completely voluntary, and your participation would not affect the care you or your relative receive at the nursing home. All the data that will be collected, will be anonymous, so people will not be able to attach your name to your information. I will never use your name when I present and write about this study. I do ask if we can audiotape our conversation so that I can have an accurate record of what we discussed. I then look for common themes among what all participants have said. We will use some quotes from the written transcripts in publications and presentations.

If you are interested, please let me know. I'll be in contact with you to explain a little bit more about the project and set up a time for the interview that will be convenient for everyone.

Do you have any questions for me?

If yes:

What would be a good time for the interview?

If no:

Thank you so much for allowing me to contact you. I hope you have a good day.

# Appendix 7 – Letter of Information for Participants

Dear Care Partner:

As a care partner of a person living in a nursing home, I would like to invite you to participate in a research study. The study is titled "Female care partners' experiences of their relative's transition to nursing home: a critical feminist perspective".

Taking part in this study is completely voluntary. Please read this information letter carefully to understand what is involved, before deciding whether you would like to take part. After you have read the letter, please ask any questions that you may have.

## PURPOSE

The purpose of this study is to explore the experiences of women as care partners before, during and after the transition of their relative to a nursing home. It specifically wants to explore the experiences of women in their involvement in care and in the decision to move forward with a nursing home admission. Further, the study hopes to explore how women adjust to the care role in the nursing home, and to the relationships with care workers. It also examines whether women feel, they experience disadvantages or face obstacles when caring for a relative at a nursing home. Information from this study will add important knowledge to the study of women's experiences as primary care partners and will help in promoting changes at the policy level in nursing homes.

The Principal Investigator of the study is Julia Besner, a graduate student in the department of Health Sciences at Lakehead University and can be contacted at <u>besnerj@lakeheadu.ca</u> or (506) 343-6170. Julia is working under the supervision of Dr. Elaine Wiersma, who can be contacted at <u>ewiersma@lakeheadu.ca</u> or (807) 343-8010 Ext. 7250.

# WHAT IS REQUESTED OF ME AS A PARTICIPANT?

You will be asked to participate in a one-on-one interview via a web video conference such as Zoom, which may last 45 - 60 minutes. The interview will be audio recorded. You would be asked questions about your experiences of transitioning your relative to a nursing home, your involvement in the decision of the transition to the nursing home, your involvement in care before and after this transition, and your relationships with the care workers at the nursing home. You will also have the opportunity for a second interview if you wish to provide additional information. Further, you will be invited to participate in a focus group via Zoom to discuss and comment on the findings of the research.

# WHAT ARE MY RIGHTS AS A PARTICIPANT?

This study is completely voluntary. You are under no obligation to participate. You are free to withdraw at any time, up to three months after your interview. If the interview causes you emotional distress or discomfort, and you wish to end the interview, you may choose to reschedule or chose to withdraw from the study. If you change your mind, you can contact the principal investigator, Julia Besner at <u>besnerj@lakeheadu.ca</u> or (506) 343-6170.

# WHAT ARE THE RISKS AND BENEFITS?

There are no known risks involved in participating in individual interviews, however, people may feel emotional upset at discussing some views. Some of the questions asked during the interview might make you feel uncomfortable or upset. If you express anxiety, distress, or discomfort we can end the interview and reschedule for another time. You may also choose to withdraw from the interview and the study altogether. The researcher will protect participant identity and confidentiality. Participating in the research will not impact the care of your relative in the nursing home, and nursing home management or care staff will not know which care partners participated in the study. While there are no immediate benefits to participation in the study, however, findings from this study may help people in the future in similar situations.

# HOW WILL MY CONFIDENTIALITY BE MAINTAINED?

All information that is provided will be kept confidential. Your name and any other identifying information will be removed and replaced with a pseudonym. Every attempt will be made to ensure that your name or identity will not be identified in study findings. The information collected can only be accessed by the principal researcher and her supervisor.

# WHAT WILL MY DATA BE USED FOR?

The study results will be published in a written thesis and orally presented in a thesis defense. Study findings may also be published in open access journals, or at research conferences. Participants will not be identified on any publications or presentations. All identifying information will be removed. Only the researcher and her supervisor will have access to the data.

# WHERE WILL MY DATA BE STORED?

The de-identified data, key to the codes (linking real names and pseudonyms), and the consent forms will each scanned and stored on an external hard drive which is passcode protected. All personal information will be stored seperately from the anonymized data. The original paper copies will be destroyed after scanning. Data must be stored for a minimum of 5 years following completion of the project, then it will be destroyed.

# HOW CAN I RECEIVE A COPY OF THE RESEARCH RESULTS?

A summary of the research findings will be provided to you if you wish. If you would like to receive a copy, please complete your contact information on the Letter of Consent.

# WHAT IF I WANT TO WITHDRAW FROM THE STUDY?

If you wish to withdraw from the study, please contact Julia Besner at <u>besnerj@lakeheadu.ca</u> or (506) 343-6170. All your information can be removed from the project up to three months after the interview.

# **RESEARCHER CONTACT INFORMATION**

If you have any questions about this study, please feel free to contact Julia Besner at <u>besnerj@lakeheadu.ca</u> or (506) 343-6170, or her supervisor Elaine Wiersma at <u>ewiersma@lakeheadu.ca</u> or (807) 343-8010 Ext. 7250.

# **RESEARCH ETHICS BOARD REVIEW AND APPROVAL**

This research study has been reviewed and approved by the Lakehead University Research Ethics Board. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team, please contact Sue Wright at the Research Ethics Board at <u>807-343-8283</u> or <u>research@lakeheadu.ca</u>.

Appendix 8 – Recruitment Poster

Are you a female care partner of a relative living in a nursing home?

This study will explore the experiences of women as care partners before, during and after their relative's transition to a nursing home. Your perspective will help shape the understanding of women as care partners, and will help promote the quality of life of persons living, working and volunteering in nursing homes.

Participation would involve a 45-60 min virtual interview (online or by phone).



Interested or have questions? Please contact: Julia Besner Email: besnerj@lakeheadu.ca Phone: 506-343-6170

This research study has received ethics approval through the Lakehead University Research Ethics Board (#1469030)

