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Jodi Swan

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APPROVED/APPROUVÉ

Thesis Examiners/Examineurs de thèse:
N/A

(First Reader/Supervisor/Directeur(trice) de thèse)
Diana Coholic, Ph.D.

(Second Reader/Co-supervisor/Co-directeur(trice) de these)
Leigh MacEwan, Ph.D.

(Committee member/Membre du comité)

Approved for the School of Graduate Studies
Approuvé pour l'École des études supérieures
Dr. David Lesbarrères
M. David Lesbarrères
Director, School of Graduate Studies

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Abstract

This research examined the experiences of older Prince Edward Island women in providing care to an aging parent, partner, family member, or friend. I investigated these experiences using a feminist lens to recognize the valuable experience of women and use their voice in bringing attention to the issues related to caregiving. This study was designed to answer three research questions:

- 1) What is the experience of older female caregivers living on Prince Edward Island?
- 2) What does it mean to be caregiver?
- 3) How do Prince Edward Island women describe caregiving?

These questions were designed to determine what experiences, meaning, and description caregivers assign to their work and what can be learned from these experiences.

Previous research in the field of caregiving has largely focused on quantitative measures of caregiver burden, activities of daily living, or access rates for caregiver support. I conducted one-to-one, in-depth interviews based on open-ended questions designed to encourage participants to share their experience. This qualitative study has advanced understanding of the caregiver experience on Prince Edward Island by highlighting the challenges faced in providing care, as well as the positive growth associated with the role.

The findings offer insights in engaging family caregivers in policy and strategy development and implementation. It also offers a vision for the continued integration of social work services for aging Islanders and their families. The need for specific skills and training in gerontological social work, including a focus in end-of-life care, advocacy, and counseling support has been demonstrated.

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Chapter 1 – Introduction

The voices of female, family caregivers are important and need to be recognized. Their experiences can help shape and inform strategy creation, policy and procedure development, and recognition of their significant impact in society. The informal care contributions to Canadian society are staggering and, with little recognition, family caregivers continue to fulfill their roles, often at a significant personal cost. As our population ages, we are witnessing significant shifts in the delivery of health care. On Prince Edward Island, these demographic changes, combined with a high incidence of chronic disease, are placing an increased demand on family caregivers to provide care and support, often with limited assistance from formal care systems. This demand along with challenges in accessing services is straining the acute care system, with older Islanders occupying acute care beds awaiting long-term care placement or the systems to support care at home. My qualitative study examined the experiences of older female caregivers to determine what knowledge can be gleaned to effect strategy development, changes in policy and practice, and the evolution of the role of social work in delivery of gerontological services.

The literature review section of this thesis focused on two distinct areas of caregiving research: policy, strategy and planning, and gender, socialization and the caregiving experience. Demographic trends indicated that Atlantic Canada has the highest number of older citizens, and the area is aging faster than the rest of Canada (Keefe, 2012). This demographic tsunami is contributing to increased health care costs, ability to generate tax revenue, and a limited workforce to support those who require care. The issue of informal care gained status with the 1996 General Social Survey collection of data and, since that time, caregiving has received attention as an important research area. Turner and Findlay (2012) indicated the majority of caregivers are women. Hollander, Liu and Chappell (2009) calculated the economic contribution of family

caregivers at \$25 billion – a staggering figure, which could not be absorbed by the formal care system. Canada has been undergoing a period of health care reform. This reform has contributed to a de-institutionalization of care for older adults, with a significant burden of care falling to family caregivers (Sinha, Anderson, Griffin & Wong, 2015; Giesbrecht, Crooks, Williams & Hankivsky, 2012; Corpus Sanchez International Consultancy, 2008). As Romanow (2002) indicated 80-90% of homecare is delivered by family or friends. The federal government, in the midst of discussions around a new multi-year health accord, suggested that those provinces with a higher number of older adults receive proportional funding for services, as well as accountability measures for the delivery of provincial health care services.

The Institute for Research on Public Policy (2015) released a publication outlining the design for a national seniors' strategy. This strategy would be comprehensive and integrated and treat aging as a lens through which all discussions and policy development would occur. It would also ensure that family and friends who provide unpaid care are acknowledged and supported. There have been repeated calls for the development of this strategy due in large part to the advocacy efforts of the Canadian Medical Association, Canadian Nurses Association, Canadian Association of Social Workers, and the Canadian Association of Retired Persons. It is hoped that the strategy would result in significant policy changes in the area of caregiver support and recognition, including changes to the existing tax credits and programs. Martin-Matthews, Tamblyn, Keefe, and Gillis (2009) identified key areas for policy development related to caregiving, including: a national homecare program and the role of family caregivers as well as economic security for caregivers and work and caregiving. The existing Compassionate Care Benefit (CCB) has been recognized as a significant step forward in supporting working caregivers, but it is only available to those who are providing care at the end-of-life and does not address those

common situations whereby caregivers are providing years of care to those with a chronic illness. Dykeman and Williams (2013) also indicated that social workers have challenges in supporting clients trying to access the CCB.

The impact of informal caregiving on the economy and labour market has not been ignored. It is widely understood that the majority of the workforce is needed to support Canadians living with chronic disease, either through the provision of hands-on care or employment-based tax contributions. Torjman (2015) indicated that there are six million Canadians in the workforce providing care. These individuals will face economic risk to provide care (Torjman and Makhoul, 2010). As Lily, Laporte, and Coyte (2007) suggested, caregivers will also face challenges related to their health and productivity, and may be forced to retire to provide care. As Neumann and Amaratunga (2006) found, women are twice as likely to retire to provide care.

Bozalek and Hooyman (2012) indicated that women are exploited in their caregiving role, both at home and in the labour market. It is widely assumed that women are available to care (Jaffe and Blakely, 2000). Pope, Kolomer, and Glass (2012) found that there are two ways in which one becomes a caregiver – either as the result of an immediate issue or gradually assuming responsibilities over time. The majority of caregivers do not recognize the role as they are simply completing tasks they have performed throughout their lives (Brewer, 2001). It is important for caregivers to identify themselves as such, as there are benefits associated with doing so (O'Connor, 2007). Caregivers face numerous transitions, which often include the development of relationships with health care professionals. Chen, Sabir, Zimmerman, Suitor, and Pillemer (2007) found that even with transitions to long-term care, family caregivers still retained an attachment to their role as caregiver and were indeed offering care within a variety of health care settings.

One of the most widely researched areas in family caregiving is that of caregiver burden. Adelman, Tmanova, Delgado, Dion, and Lachs (2014) indicated that there are a number of risk factors for caregiver burden including being female, residing with the care recipient, social isolation, and financial stress. The majority of studies in this area are often based on a quantitative design, therefore not offering the rich, powerful voices of caregivers in explaining the demands of the caregiving experience. Keating, Swindle, and Fletcher (2011) found that rural caregivers were more apt to experience challenges such as isolation and loneliness. Turner and Findlay (2012) noted that there are a number of positives associated with caregiving, including personal satisfaction and a closer relationship with the care recipient. Caregivers often require education and support in their role. Moreover, Armstrong and Kits (2001) indicated that there are significant provincial variations in support to family caregivers. Lazar (2011) found that caregivers cited a lack of support as a source of stress and fatigue. Sheehan's (2012) work with caregivers in Newfoundland and Labrador also noted that caregivers were viewed as empowered and self-directed learners, but also affirmed the findings of Keating et al. (2011) that caregivers faced loneliness and isolation.

The final section of the literature review examined the influence of ageism and advocacy in caregivers' experiences. It was noted that ageism is the most tolerated form of social prejudice (Revera, 2012). This ageism also carried over into interactions with health care providers, with medical student Nathan Stall (2012) calling for a zero-tolerance policy and the need for mandatory curriculum in gerontology. Black and Dobbs (2014) reviewed the concept of dignity and cited autonomy as a significant component to dignity. Jaceleon and Henneman (2014) also noted the importance of recognizing and supporting a patient's dignity as an essential component of nursing education. Caregivers are often called upon to advocate not only for themselves but for their care

recipients in terms of quality and access to services and benefits, changes to policy, and the development of strategies and plans. The province of British Columbia appointed Canada's first Seniors' advocate in 2014, offering a beacon of support and service to older British Columbians and their family caregivers.

On Prince Edward Island, the recommendation for the development of a caregiver support strategy has also not been recognized, nor has the voice of family caregivers been given due recognition. This stands as a significant gap in understanding, and formed the basis for this thesis research. The purpose of my study was to explore the experiences of older, female caregivers who are often marginalized and give voice to their reality. I identified a need for the rich, descriptive findings that accompany qualitative research and the recognition of the voice of women when a feminist lens is used. As aforementioned, there are significant economic issues associated with family caregivers, combined with the existing and future demographic changes that need to be addressed. More importantly, the care and support of these family caregivers is essential to the quality of life for all Islanders. As the province continues to allocate funding for homecare services, it has been noted that a number of caregivers are still in need of timely access to quality services including primary care, education, and support. This led to the development of three research questions:

1. What is the experience of older female caregivers living on Prince Edward Island?
2. What does it mean to be caregiver?
3. How do Prince Edward Island women describe caregiving?

My qualitative study recruited a purposive, criterion sample of 15 female participants, aged 60 years and older, who were providing, or had provided care, within the past year to a partner, parent, older family member, or older friend. The data was gathered from semi-structured

interviews with the participants and analyzed using thematic analysis. The limitations identified included that there were no males included in the study, and that care provision focused solely on that provided to older adults. The sample was relatively homogeneous with no ethnic minorities or Indigenous participants, as well as no individuals within a same-sex intimate dyad.

This chapter provided an overview of the thesis material and how it will be presented. It identified the significant milestones in the development of caregiving research, as well as key findings in the area. This chapter also outlined the design taken with this research, as well as the limitations associated with this approach. The following two chapters will examine the important findings in caregiving research as it pertains to my research questions.

Chapter 2 – Policy, Strategy, and Planning

Canada is home to leading researchers in the field of caregiving and the works of Keefe (2012, 2011, 2010, 2009), Chappell (2011, 2009), Neysmith (2006), Torjman (2015, 2010), Keating (2001, 2000), and Fast (2011, 2001, 2000) will form the framework of this literature review. Each of these female scholars have greatly contributed to the knowledge base and championed the role of research in the field of caregiving. They have contributed to the creation of policy and advocacy efforts in support of caregivers. The various publications and studies reviewed link social work to the fields of gerontology, nursing and healthcare, psychology, women's studies, and economics. The general findings of the caregiving literature examined focuses on (a) caregiver burden including emotional, physical and financial effects, (b) the gaps in strategy to support older Canadians and caregivers, and (c) the impact of an aging population and the resulting caregiving requirements as they pertain to the economy and state of healthcare in Canada. Each of the aforementioned findings will be considered at a macro and mezzo level, i.e., the federal and provincial response to the issue of caregiving.

The literature review is comprised of two chapters, based on distinct areas within caregiving research. The first chapter is focused on exploring key themes related to caregiving research including the role of policy, strategy and planning. The second chapter is focused on socialization, women's roles, life transitions and the caregiving experience. Each of these themes will be explored in the context of current research, as well as highlighting seminal works in the field of caregiving research. Each of these themes are related to the general caregiving literature through a number of connections. In developing and shaping policy, strategies and plans, stakeholders can address some of the significant over-arching issues such as health care reform, tax credit changes and program development that will help to alleviate issues around caregiver

burden, as well as addressing the impact of an aging population. The gaps in strategy and support will serve to address societal expectations around family caregivers and provide them with the services they need to fulfill this integral role. These socially constructed images of family caregivers define, to some extent, our life transitions, and how women experience them in relation to caregiving. The impact of an aging population has also created an entrenchment of ageist attitudes and behaviours (Revera, 2012; Stall, 2012). These limiting and destructive attitudes are contributing to how policy is shaped, how services are delivered, and how family caregivers are being viewed. These ageist attitudes are for the most part, quite negative and need to be addressed by policy makers, health professionals and members of society. The chapter will focus on material as it pertains to caregivers of older adults, analyzed with a feminist lens. It does not include male-focused studies or caregiving for other populations such as children, or those with disabilities or mental health issues. The material includes a review of existing macro and mezzo policy documents, reports, and strategies aimed at addressing issues of caregiving for older adults.

Caregiving research has become increasingly prevalent over the past decade. This interest can be attributed to a number of factors including significant demographic trends. Canadians are aging, and the population of Atlantic Canada, which is home to the country's oldest citizens, is aging faster than the rest of Canada (Keefe, 2012). Mass media has been drawing attention to the "demographic tsunami" and the effects it will have on Atlantic Canada, including increased healthcare costs, the ability to generate tax revenue, and a limited workforce. The opening statement of the Victorian Order of Nurses (VON) Caregiving Manual (2005), reminds us that caregiving is not a new phenomenon. In 2005, an estimated 3.8 million Canadians who were age 45 years or older (35%) were providing informal care to a senior with a short or long-term health condition. The majority of these caregivers were women (Turner & Findlay, 2012). These

demographic changes coupled with national and provincial health care restructuring are downloading the responsibility of care onto unpaid caregivers. “Informal caregivers are individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental conditions” (Canadian Caregiver Coalition, 2003, p. 1). It was in 1996 that Statistics Canada’s General Social Survey first included data measuring the care provided to Canadians and, since that time, caregiving has become a mainstream issue. The fact that Statistics Canada has been gathering information on caregiving is, in itself, indicative of the value of caregiving and the need for ongoing timely research. Caregiving has garnered research attention in the areas of caregiver burden, care associated with particular populations, economic impact, work-life balance, the need for caregiver support, and education and policy development (Hollander, Liu & Chappell, 2009; Chappell, 2011; Cranswick & Dosman, 2008).

Caregiving has become a “hot topic” due to a number of factors, including primary health care reform. The current state of health care reform in Canada sees a de-institutionalization of care, particularly associated with the older population (Sinha, Anderson, Griffin, & Wong, 2015; Giesbrecht, Crooks, Williams, & Hankivsky, 2012; Corpus Sanchez International Consultancy, 2008). This shift from long-term care/acute care usage to homecare has contributed to the demand for informal care in our communities. According to Romanow’s Report (2002) on the future of healthcare, it was believed that homecare could be delivered in a more cost-effective manner. Thankfully, the report recognized that homecare could not exist in Canada without informal caregivers. I think this is one of the main reasons why homecare is viewed as being so cost-effective. The report provided an estimate that anywhere from 80-90% of homecare is provided by family and friends. During the Romanow Commission’s public consultations, commission

members heard from various interest groups that there were “concerns about the particular burden homecare places on women” (p.184). This seminal report focused on needed health care reform and the issues associated with providing care to an aging population. The report highlighted the need to recognize, value, and support family caregivers. Dr. Cindy Forbes, President of the Canadian Medical Association (CMA), has called for the provision of better home care through the CMA’s “Demand a Plan” advocacy appeal focused on securing a seniors’ plan (Forbes, 2016). The importance of home care for older adults has also been widely touted by the Canadian Home Care Association (CHCA) in their publication on advancing quality improvement and integrated care (2015). The CHCA has also recognized the value of home care in their report “Home care in Canada: From the margins to the mainstream” (2009). The focus on homecare will be more widely discussed later in this literature review.

There are other reasons why caregiving is an important research topic, including the effects on the economy and labour markets. The current demographic predictions indicated that there is going to be significant economic issues related to our aging population. We are not going to have the workforce to support those who require financial assistance through existing public programs nor are we going to have the workforce to provide hands-on care for those aged individuals who require support (Department of Finance Canada, 2012). This all points to an ever-increasing burden on families to either pay for care or provide it themselves.

There is also the economic fallout related to employee absence when informal care is required. The Maytree Policy Focus (March, 2010) indicated that those who provide informal care do so at the risk of their own economic security. The majority of those providing care have little or no taxable income making current benefits and credits all but useless. Torjman and Makhoul (2010), authors of the Policy Focus, included suggestions for policy reform to benefit caregivers.

These proposals included an expansion to the Employment Insurance (EI) Compassionate Care Leave to include care for those with chronic conditions. At present, only those who are providing care to someone at end-of-life are eligible. Given that there is an increased prevalence of chronic health conditions for Prince Edward Islanders as compared to the national average, it would be necessary for this policy to expand its scope to have any major benefit on Prince Edward Island (PEI's Healthy Aging Strategy, 2009). The changes to Employment Insurance on Prince Edward Island, announced in 2014, will increase the difficulty of qualifying for benefits for the Island's seasonal workforce, particularly those who reside in the capital region. The second recommendation suggested an extension of the Canada Pension Plan (CPP) provision to protect the retirement earnings of caregivers who must temporarily leave the workforce to provide care. The third recommendation was to make current tax credits for caregivers refundable to ensure that households unable to pay income tax received some money from the government to help offset their caregiving costs.

The Maytree Policy in Focus (2010) also highlighted the fact that the economic value of informal care is estimated at more than five billion dollars, although the majority of research pegs this contribution at 25 billion (Hollander, Liu and Chappell, 2009). This boon, i.e., the care provided by unpaid caregivers to the health and economic sectors, will continue to be highlighted as the country and its provinces move toward the provision of homecare as part of its current reform mission. On Prince Edward Island, these issues have been given little attention and usually as part of a subset of broader research. The provincial government has been working to restructure the delivery of healthcare. The finger has been repeatedly pointed at our seniors for their use of healthcare services. This perceived higher usage rate, combined with a population high in chronic diseases, is putting Islanders' access to appropriate and timely healthcare in jeopardy.

The Prince Edward Island government, in its 2008 system review conducted by Corpus Sanchez International Consultancy (CSI Consultancy), indicated that “caregivers will be treated as partners in care” (p. 18). The Island’s Healthy Aging Strategy (2009) identified caregiver support as part of its expanded services. It is hoped that my graduate research, that is the focus of this report, will help the Prince Edward Island government in achieving its aim “to work collaboratively with key stakeholders in strategy development”. It is essential that governments listen to the experiences of caregivers, especially with the ever-increasing move to community-based care. As of 2009, Prince Edward Island’s homecare budget was less than half of the national average and was the lowest in the country per capita for persons over 75 years of age (Government of PEI, 2009).

The Prince Edward Island Department of Health and Wellness has made significant investments in homecare in an attempt to “stem the tide” and cut healthcare costs, while allowing Islanders to age in place. The previous Health and Wellness Minister Doug Currie, in an address to Rotary in November, 2012, indicated that the investments in homecare are supported by a strong network of family and community caregivers. When questioned about the support for these caregivers, the minister was unable to point to any firm, specific measures of support other than respite and the proposed development of an Island-wide wellness strategy. The Prince Edward Island Wellness Strategy was launched in January, 2015, and spoke to the issues Islanders face in achieving health and wellness. This included the need to address the prevalence of chronic disease rates through personal habits related to activity, diet, smoking, and alcohol consumption, as well as support for mental health and addictions. The strategy and its goals for older adults and caregivers will be more closely examined further in the literature review.

Policy, Strategy and Planning

In examining the literature on caregiving, the pivotal role of social policy, strategy and planning came to the forefront. As Westhues (2006) stated, “social policy is a course of action or inaction chosen by public authorities to address an issue that deals with human health, safety or well-being” (p.8). To date, the course of policy action at a federal level has done little to address the needs of older, female caregivers. It has been widely recognized that family caregiving associated with our aging population is a policy priority, not just in Canada but throughout the world (Canadian Caregiver Coalition, 2014; Greenberg, 2013; Neysmith, 2006). Fast and Keating (2000) stated “the collective effect of demographic, social, economic and policy trends has made caregiving a policy issue of utmost importance in Canada” (p.1). The 2011 federal election was touted as the first in which caregiving and the needs of Canada’s aging population were on the agenda of every major political party and platform (Makhoul, 2011). In spite of the fact that the 2007 Throne Speech committed government to support people caring for older adults, very little has been done nationally to assist caregivers. Lazar’s (2011) work also indicated that each province is responsible for deciding what kind of care system it will develop, how it will be regulated, and how it will be funded, further increasing the disparity of services across the country.

The federal government provides little direction to the provinces in terms of meeting the needs of caregivers or their recipients. With the expiration of the Canada Health Accord in 2014, there is no formalized agreement around funding and health care service delivery amongst the federal/provincial and territorial governments. The previous Conservative government allowed the Accord to expire, therefore limiting the amount of federal/provincial/territorial discussion on caregiving issues and the need for policy to address significant issues for older Canadians. The philosophical approach of the previous government was to divest itself of responsibility for health

care, other than what is required by the Canada Health Act. It has been noted that since the federal Liberals have come to power, they intend to deliver on the development of a new health accord that will include an additional 3 billion dollars over the next four years, for additional and improved home care services, including palliative care as well as mental health. This commitment was also outlined in Prime Minister Trudeau's mandate letter to federal health minister Dr. Jane Philpott, with a key priority being a new multi-year health accord.

The Canada Health Transfer - the federal government's transfer payment program, transfers funds to the provinces and territories for the purpose of meeting national criteria for publicly provided health care. This federal transfer imposes few restrictions on how the provincial governments allocate funds amongst competing healthcare priorities (Neysmith, 2006). It is interesting to note that homecare is not part of Canada's public funded health care program. Homecare is viewed as a cost-effective measure in caring for older adults, with the bulk of the care being provided by unpaid family caregivers. As Neysmith (2006) stated, "we know that this (caregiving) proves costly to many women as they age; yet our social policies and health care services seem unable to ameliorate, let alone eliminate, these costs" (p. 398.) These costs include financial costs, as well as the costs to caregivers' physical and emotional health and well-being, and the burden of social expectation to care. This only serves to further marginalize female caregivers. There have been repeated calls for homecare to be included as part of the services provided under the Canada Health Act, thereby ensuring some level of consistency and quality in services across the country. The Romanow Commission (2002), Canadian Home Care Association, Canadian Nurses Association and a host of others have repeatedly advocated in favour of a national homecare program.

The federal government also has responsibilities for health and health care delivery, including services for First Nations and the Inuit, active and veteran members of the military, and prisoners in federal penitentiaries. The veterans' component of health care delivery has been integral in recognizing the role of family caregivers and provides a number of lessons for the provinces, as they face an increased aging population. Veterans Affairs Canada (VAC) has three pillars for health and medical support programs, which are: (1) the Long-Term Care Program; (2) the Health Benefits Program (Programs of Choice), and (3) the Veterans Independence Program (VIP). The VIP is the home and residential care program, "designed to complement existing federal, provincial and municipal health care programs in the provision of services and benefits that are not otherwise accessible to Veterans as residents of their home province" (Government of Canada, 2013, p. 3). The guiding principles of the VIP included respecting the individual's right and personal independence to receive care at home, "as well as personal and familial responsibility in planning and providing care appropriate to the Veteran's health needs" (Government of Canada, 2013, p. 4).

Veterans Affairs Canada has led the way with homecare and support programs, recognizing the vital contributions of family caregivers in providing care to an aging family member or friend. VAC also recognizes the cost savings associated with home care, directly attributed to family caregivers. The most inspiring document on family caregivers in relation to the VIP is James Struthers' (2007) "They suffered with us and should be compensated: Entitling caregivers of Canada's Veterans". Struthers (2007) highlighted the plight of Veteran widow caregivers and their advocacy journey in achieving recognition and services for their role in supporting Veterans. Throughout the document, Struthers (2007) referenced the contributions of these family caregivers and strongly stresses the fact that VAC officials recognized that the health of the caregiver was

paramount in ensuring the success of the VIP. Veterans Affairs Canada also led the way in the development of their homecare program by ensuring that counselors be trained in social work and gerontological skills, in partnership with the renowned Family Studies and Gerontology program at Mount Saint Vincent University. This training shaped the counselors awareness around delivery of service and ensured that a transition from a sole client-centered approach would be expanded to include a family-centered focus. The front-line staff of VAC quickly recognized that the contributions of caregivers needed to be captured, and therefore changed their processes to include a caregiver assessment. This would be a fundamental component for provincial homecare programs to enact.

A Gerontological Advisory Council (GAC) was established in 1997. It included leading Canadian advocates for informal caregivers: Neena Chappell, Evelyn Shapiro, and Norah Keating. These women, and others on the council, quickly recognized the need to enhance the rights of caregivers to VIP benefits. In achieving access to continued VIP services, veterans' widows were not the first to embark on advocating for continued services; in fact, the initial voices were those of field counselors and some bureaucrats with VAC. It was in the 1990's that other groups started advocating for an extension of services for veteran spousal caregivers, including the Royal Canadian Legion and the War Amps of Canada. Initially, "the policy change was revenue-neutral, given the rapid attrition of Canada's Second World War veteran population" and, of course, political timing was right with the approaching sixtieth anniversary of V-E Day (Struthers, 2013, p. 126). The Chretien government did not initially extend these services in making veterans' widows' eligibility for the VIP retroactive. Eventually, the government extended services to veterans' widows' who had been providing care since the inception of the VIP in 1981. The Veterans Affairs VIP model of homecare and their lessons learned from research and practice

would be of benefit to the provinces and territories who have responsibility for the delivery of public homecare services. At present, veterans issues are receiving renewed attention with the current federal government re-opening district offices to better provide front-line services to Canada's service personnel ("Charlottetown Regional Veterans Affairs Office to Reopen in 2017", 2016).

Our federal and provincial governments need to develop policy to ensure that timely and appropriate resources, services, and benefits are provided to Canadian caregivers across geographically diverse provinces and territories. Prince Edward Island, although the smallest of Canadian provinces, faces some issue with delivery of services. Our rural communities are struggling to stay vital and vibrant, with the younger generations seeking employment in the West where there are more plentiful opportunities for gainful employment. Our seniors are battling isolation and the need to travel to access services that are more readily available in the urban centres. At present, a piecemeal approach is occurring with neighbours and not-for-profit organizations providing coverage for such things as meals, transportation, social engagement, and support. The development of policy and standards would provide a framework for collaborative services, recognizing the roles and contributions of all stakeholders; i.e., a provincial caregiver support strategy would address both informal and formal networks. It is widely accepted that there is a need for suitable policy development to address the issues of caregivers and, in particular, gender-sensitive policy that addresses the need of female caregivers (Gahagan, Loppie, Rehman, MacLellan & Side, 2007; Sims-Gould & Martin-Matthews, 2008). Gender, and the role of females, in providing care informs a significant component of the caregiving literature. One of the primary reasons for this is the ongoing social expectation that women will provide care and the fact that the majority of women do so, whether as a mother, partner, or daughter.

Chappell and Hollander (2011) stated the need for policy options to support caregivers. Chappell and Hollander (2011) cited the fact that the formal care system could never replace or compensate for the support provided by informal caregivers. Caregivers make great sacrifices to provide care; those who wish to continue in their role should be supported in doing so. At present, there are five credits/deductions at the federal level to support caregivers, although only one can be claimed per year. Canada lags behind other countries in its support of informal caregivers. In 2009, the Nova Scotia government was the first to create what was reported as the only existing direct allowance for family caregivers in Canada. There are a number of stipulations that need to be satisfied before the \$400 per month allowance will be distributed but this acknowledgement of informal caregivers is significant.

There are numerous suggestions as to what can be done to improve policy including Stadnyk's (2006) recommendation that caregivers be consulted in policy and program development. In Martin-Matthews, Tamblyn, Keefe, and Gillis (2009) it was identified that Canadian researchers in the field of caregiving are noted for their rigour and relevance in research. They identified six key areas for policy development:

- a national homecare program and the role of caregivers;
- the role of men in caregiving;
- economic security for caregivers;
- respite care;
- financial support for caregivers; and
- work and caregiving.

They also acknowledged that limited progress has been made on extending the research/policy partnership into improved circumstances for frontline caregivers. We are still facing the social

belief that families are available to provide care to their older members and are obligated to do so. The call for a caregiver framework that acknowledges the value of family caregivers in legislation, policy and practice is past due.

Benefits and Tax Credits

At present, the federal government offers five credits and deductions that caregivers can access. Each of these are non-refundable and provide minimal amounts of money. Family caregivers incur significant out-of-pocket expenses for supplies and other services associated with their role. There have been repeated calls for the federal government to create a refundable tax credit that would provide much needed cash to family caregivers. It is assumed that such a refundable credit would, by no means, meet the expenses incurred.

The federal Liberal government, at the turn of this century, recognized caregivers in its most distinguishable move to date – the creation of the Compassionate Care Benefit (CCB) available under the Employment Insurance Act. This benefit championed by the work of Senator Sharon Carstairs, was an important first step in recognizing the role of end-of-life caregivers, who were facing time away from the labour force to provide care to a family member who was at significant risk of death within the near future. “The CCB allows eligible employees to take up to eight weeks leave, including an unpaid two week waiting period, to care for a dying family member” (Keefe, 2011, p. 20). The federal government announced in May, 2015, that there would be enhancements to the CCB allowing claimants to receive up to 26 weeks of benefits during end-of-life caregiving and an expanded period of 52 weeks, which would be made effective January 3, 2016. The federal Liberals promised a \$190 million commitment to expand the CCB and as of January 3, 2016, honoured the previous Conservative government pledge of 26 weeks for family caregivers. The benefit is also affiliated with the federal and provincial labour codes and offers job

protection for those taking time off to provide care. Provincially, compassionate care leave provides job protection for the employee, regardless of whether or not they qualify for the CCB (Baranek, 2004). The limited uptake of this benefit resulted in the expansion of who qualified as a care recipient in need of support to include not only immediate family members, but family members of a spouse or common-law partner and those individuals to whom the caregiver is close, e.g., a friend or neighbour.

At present, there is still limited uptake with the CCB which has been attributed to a number of issues, including: a general lack of awareness about the benefit, how to access it, the bureaucracy associated with submitting an application, the two week waiting period before benefits will be given, the limited amount of financial support (55% of average insurable earnings), an approximate 28 day period without pay, and the cessation of the benefit upon the death of the care recipient, thereby not acknowledging the bereavement time required for family caregivers (Keefe, 2011; Geisbrecht, Crooks & Williams, 2010). The most significant drawback associated with the CCB for older female caregivers is the fact that many have already retired and are, therefore, not eligible to receive benefits under the programs of Employment Insurance.

The work of Dykeman and Williams (2013) highlighted the challenges faced by social workers, who are recognized as vital components in communicating the existence and support offered by the CCB. Social workers, who are serving end-of-life clients and their caregivers, often have a number of challenges in discussing the CCB, including the acceptance of the life-limiting diagnosis by the caregiver. Social workers who participated in the study indicated that they had limited knowledge of the benefit and, often times, recognized that the limited amount of financial support provided, simply would not support the caregiver in taking leave. The most significant challenge related to the timing of the CCB application, is that caregivers would often apply for

benefits based on the prognostication of death and would usually miss the window to receive full benefits as the care recipient often died prior to the receipt of the full course of the benefit. This creates a significant challenge for Prince Edward Island as the majority of individuals would not have ready access to a trained social worker unless they were part of the provincial palliative care program or were receiving social work support through an acute care admission. This combined with the fact that a number of Island families do not access hospice palliative care services early in the diagnosis also contributes to a gap in information between professional and family caregivers.

Planning for an Aging Population

In light of the recent federal election, there have been repeated calls for the development of a national seniors' strategy, led by the Canadian Medical Association (CMA), who have mounted a very broad and vocal advocacy campaign to raise awareness about the state of health care in Canada and the impact of our aging population. The CMA has been supported in their efforts by numerous national groups including the Canadian Nurses Association (CNA), Canadian Association of Social Workers (CASW) and the Canadian Association of Retired Persons (CARP) to name but a few. The Institute for Research on Public Policy published "Designing a National Seniors Strategy for Canada" in October, 2015, which outlined four basic principles:

- 1) the strategy must be national in scope;
- 2) the individual must be at the centre of the strategy;
- 3) the strategy must be comprehensive and integrated, thereby incorporating a variety of elements including health care, the built environment (manmade surroundings and infrastructure), social and economic policy, and the social determinants of health; and

4) the strategy must ensure policy-makers treat aging as a lens through which all policy discussions are assessed, and not as an isolated policy issue.

These four guiding principles in conjunction with the priority areas of focus that older Canadians:

- 1) remain independent and engaged members for as long as possible;
- 2) lead healthy and active lives for as long as possible;
- 3) have access to person-centred, high-quality, integrated care as close to home as possible, provided by those who have the knowledge and the skills to care for them; and
- 4) ensure that family members and friends who provide unpaid care are acknowledged and supported.

These four actions would provide a strong foundation on which to go forward and serve Canadian seniors and stakeholders with dignity and respect.

The recognition of unpaid caregivers has not received the attention it should, despite the fact that the Parliament of Canada unanimously adopted a motion declaring the first Tuesday in April as “The Invisible Work Day.” This day was designated to recognize the importance of the “invisible” unpaid work carried out by parents and caregivers on behalf of their children and aging family members, as well as the volunteer work done in the community. Canada is the first country in the world to create this day. The province of Manitoba has led the way within the provinces/territories with Bill 42 – The Caregiver Recognition Act which was proclaimed in June, 2011. This act serves to recognize the valuable contribution of family caregivers as well as the need to work collaboratively in developing and accessing the necessary supports. The key provisions of the act included an advisory committee that provides advice and recommendations to the minister; consultations with the minister, caregivers and other key stakeholders; principles

related to how caregivers should be treated in dealing with the health system and in their workplace, as well as the establishment of an annual Caregiver Recognition Day.

The other key literature reviewed as part of a national approach to strategy/plan is the Government of Canada's Action for Seniors (2014) which demonstrates the Conservative government's thinking around family caregivers, with a focus on the labour and economic impact. To that end, the government introduced the Canadian Employers for Caregiver Plan (CECP), which is a plan, focused on maximizing caregivers' labour market participation. To appear more sympathetic to family caregivers, the plan touts other supports including an investment in project funding directed at helping those who care for a loved one with dementia as a means to stay connected to the workforce and the implementation of the non-refundable Family Caregivers Tax Credit. It also highlights the Compassionate Care Benefit (CCB) that has great merit, but limited uptake. As discussed earlier, it does not address the situation of those who are providing long-term care or those who do not qualify for Employment Insurance (EI) benefits.

Employment, Labour and Caregiving

The labour sector is one in which caregivers are gaining visibility, due in large part to the impact family caregiving is having on the employment sector. There are more than 6 million people, (35%) of the workforce, in Canada providing unpaid, informal care (Torjman, 2015). The Government of Canada's report "When work and caregiving collide: How employers can support their employees who are caregivers" (2015) recognized that employed family caregivers are attempting to balance the demands of their paid employment and their caregiving responsibilities, with their caregiving role, resulting in increased costs for employers in the areas of absenteeism, productivity, and performance. Caregivers are also feeling the pinch in that the care they are providing also impacts their health, financial situation, productivity, and, ultimately, the decision

to either stay in the labour market or retire (Lilly, Laporte, & Coyte, 2007). These employed caregivers are less able to work over-time, travel for work, and take advantage of professional development opportunities, which further marginalizes caregiving women, who are already paid less than their male counterparts. This affirms the belief that women with a male employed partner, should sacrifice their paid employment to provide care (Armstrong and Armstrong, 2001). The report also cited that 1.6 million caregivers take a leave of absence from employment; 600,000 reduce their working hours and 390,000 quit their jobs to provide unpaid care. The number of women entering the workforce continues to rise and it is widely accepted that their role in caregiving affects their participation in the labour market. According to Day and Brodsky (2007), women are more apt to take leave from work to provide care and support and are also more likely to work part-time jobs in order to have some flexibility in their schedule. This in turn affects their ability to access employment-based benefits.

Neumann and Amaratunga (2006) stated that “women are twice as likely to retire into caregiving therefore it is essential that caregiving is recognized and integrated into retirement income systems” (p. 22). This would provide some measure of support for those who participated in the labour force, but what about the women who have provided unpaid care all their lives? In Torjman’s (2009) commentary “The Three Ghosts of Poverty” we are reminded again about the impact of caregiving on labour force participation and income, as well as the fact that many seniors live on limited, low incomes and are also responsible for the costs not covered by insurance or medicare, putting further strain on an already precarious financial situation.

The initial lack of awareness about the effects of family caregiving on employment served as a barrier to providing support due, in part, to the fact that employees were not self-identifying as caregivers. They most likely viewed their caregiving responsibilities as part of the general social

contract around care for older adults. This speaks to a need for broader public discussion and awareness around what constitutes caregiving and the impact it has on the caregiver's overall well-being. The Employer Panel on Caregiving that resulted in the publication "When work and caregiving collide: How employers can support their employees who are caregivers" (2015), identified benefits to creating workplace policies that support caregivers including, the recognition and respect for the roles employed caregivers are filling; providing workplace supports such as information and access to employee assistance programs (EAP); implementing paid/unpaid leave; and a willingness to embrace flexible working hours.

Employers are starting to see the magnitude of the demands of informal care and how broad an affect it can have in the workplace. A study by Ceridian (2015) estimates that \$5.5 billion in productivity is lost due to caregiving. This loss is detrimental to the economy and the workplace. Employers are faced with having to replace skilled workers, which is often a difficult task in Atlantic Canada given a significant portion of the population seek employment opportunities in the West. This makes succession planning a significant challenge, not only for big business, but also for smaller, private business. Those older caregivers who return to the workforce after an absence, face ageist attitudes. Employers believe that older workers require a greater investment in retraining than upgrading the skills of younger workers (van Snellenberg, 1995).

Palliative Care, Advance Care Planning, and Physician Assisted Death

The one policy area where caregiving issues receive attention is in relation to employment and labour. This is due to the impact that family caregivers are having on the economy and production within the Canadian workforce. In order to address both caregiver and employer needs, the Compassionate Care Benefit (CCB) was created in 2004. The federal funds identified during the budgeting process were targeted to an employment insurance benefit for family caregivers

providing care to a loved one at end-of-life. The creation of this benefit speaks to many areas of importance both federally and provincially around caregiving: family caregivers and the burdens they face providing care; the desire of dying individuals to be supported at home, and the need for acknowledgement of the role of hospice palliative care. In 2014, Member of Parliament, Charlie Angus, moved a motion (M-456) to establish a pan-Canadian strategy for palliative and end-of-life care. The basis of the motion was to provide consistent, quality end-of-life care across the country, as opposed to the existing patchwork of services. Mr. Angus stated in his op-ed piece “what is needed is coordinated discussion especially as our population ages and health costs rise” (Huffington Post, 2014). He urged federal/provincial/territorial (F/P/T) dialogue on the delivery of services, recognizing that such services are a provincial responsibility; but there is a role for the federal government to identify best practices and delivery models.

There are various groups and organizations across Canada advocating for such services, including the Quality End-of-Life Care Coalition of Canada (QELCCC), the Canadian Hospice Palliative Care Association (CHPCA), and the Canadian Medical Association (CMA) to name a few. The CHPCA has been a strong advocate for the delivery of quality hospice palliative care from coast to coast to coast and together with the QELCCC, has championed an integrated approach to care that focuses on the person and family, through “The Way Forward” initiative. The Way Forward is a collaborative initiative that was supported with funding from the Government of Canada and the various stakeholders of the QELCCC. As the document stated: “As our population ages, we must ensure that all Canadians have access to palliative care services integrated with their other care to help them manage symptoms, enhance their lives, give them a greater sense of control, and enable them to make informed choices about the care they want” (CHPCA, 2015, p. 4). The number of deaths in Canada is expected to increase 33% by 2020 and

the current number of Canadians having access to hospice palliative care is estimated at 15%. (QELCCC, 2005). The 2005 framework that led to the development of The Way Forward also referenced the need for disseminating information about hospice palliative care to the vast numbers of family caregivers “who are increasingly being asked to provide medical care that was traditionally performed by medical staff (QELCCC, 2005, p. 3). The Way Forward also served to address the need for Advance Care Planning (ACP) and necessary discussions with family, caregivers, and health practitioners. It is every much based on the social work principles of respect for the client and their autonomy, as well as the financial benefits to the health system, highlighted by less dependence on acute care hospitalization and emergency room visits. The integrated approach allowed for open communication, psychosocial and spiritual support, pain or symptom management, identification of goals of care, and referrals to expert palliative care services if required. This care is provided across the continuum of health services – from home, primary care provider offices, hospitals and long-term care; equally as important this care will be provided by an inter-disciplinary team. The Way Forward promoted a culture shift, away from a death-denying society to one that openly discusses and examines how loss, dying, and death are a part of life. The document also provides guidelines for F/P/T governments in developing policies that include:

- 1) adopt the framework’s vision, goals and principles;
- 2) establish policy expectations for all care settings and providers;
- 3) develop tools to assess current capacity to provide an integrated approach and to identify gaps and build capacity;
- 4) create legislation/regulations to ensure all settings are accountable for implementing the policy;

- 5) establish guidelines and standards of care consistent with national norms of practice; 6) develop remuneration systems and incentives to support the delivery of an integrated palliative approach;
- 7) support communications across settings and seamless care transitions;
- 8) support education of health care providers in all settings;
- 9) develop a communications strategy; and
- 10) establish the indicators and monitoring system to assess program and evaluate impact.

These recommendations, when considered within the area of delivery – home care, long-term care, primary care and acute care, can lead to increased quality of life not only for recipients but for their family caregivers as well.

As part of the development of The Way Forward, a number of polls were commissioned, including an Ipsos Reid (2012) poll that surveyed Canadian general practitioners (GP's), family physicians (FP's) and nurses. The poll revealed that most were not comfortable with discussions around advance care planning but indicated that tools and resources would be welcomed. The National Advance Care Planning task group has since developed tools to engage professionals and individuals in discussing and documenting their advance care plans. Health PEI has taken the lead in promoting advance care planning in the province and have implemented some protocols, particularly in acute care around determining if the patient has a documented plan, although the consistency around this practice is not known. The poll also revealed the need to have advance care planning discussions with healthy patients, not just those with chronic, life-limiting diagnoses. The poll results cited the need for continuing education opportunities in palliative care. This is a recurring theme in that it also appears in the Canadian Cancer Society's (2016) report, "Right to care: Palliative care for all Canadians," as well as the 2013 study, "What do Canadians think of

advance care planning? Findings from an online opinion poll,” and the 2001 project report, “A rural palliative home care model: The development and evaluation of an integrated palliative care program in Nova Scotia and PEI.” The Canadian Cancer Society’s report “Right to care: Palliative Care for all Canadians” (2016) indicated that course curricula has been developed by organizations such as Pallium and the Canadian Society for Palliative Care Physicians (CSPCP), but leadership is required from universities and governments to ensure it is delivered and “inter-professional due to the team-based nature of effective quality palliative care delivery” (Canadian Cancer Society, 2016, p. 21).

CHPCA has developed social work curricula but, to date, there has been little to no uptake by the schools of social work across the country. In a recent roundtable discussion at the CHPCA biannual conference in 2015, it was suggested that parts of the curricula be included to provide social work students with an opportunity to explore hospice palliative care issues in social work. At present, students would only be involved in reviewing literature and/or research based on their personal interest and the opportunity to choose a topic for exploration within a prescribed social work class. The 2013 report “A model to guide hospice palliative care: Based on national principals and norms of practice” also stressed the need to educate health care professionals on strategies to communicate with individuals on the topics of advance care planning, dying and death. These strategies and resources serve culturally and demographically diverse populations. These are not new recommendations as the 2001 report “A rural palliative home care model: The development and evaluation of an integrated palliative care program in Nova Scotia and Prince Edward Island” pointed to the need for a comprehensive education strategy for health professionals, volunteers and the public. The reports also highlighted a systems gap in public

education in the area of palliative care philosophy, availability of services and client and caregiver rights.

The Harris Decima poll (2014) aimed to “engage Canadians and understand attitudes toward hospice palliative and end-of-life care when faced with a life-limiting illness or aging with chronic diseases”. The responses for Prince Edward Island yielded a number of interesting findings:

- more Islanders have had a family member hospitalized within the last year compared to the national average
- more Islanders have experienced the death of an immediate family member in the past 10 years compared to the national average
- the majority of these deaths occurred in a hospital compared to the national average
- the majority of Islanders (75%) prefer to die at home compared to just 14% in hospital and 10% in other health care facilities
- 47% of Islanders had no awareness about hospice palliative care services
- only 20% of Islanders (the individual or their family) had used hospice palliative care services
- 45% of Islanders have talked with a family member, doctor, lawyer, friend or financial advisor about end-of-life preferences
- the majority of Islanders (74%) don't feel they would have the time to devote to caring for a dying loved one given their current schedule
- a combined 73% of Islanders feel that far too little/a bit too little priority is placed on hospice palliative care by the provincial government.

These responses are quite telling about Islanders perceptions and experiences with hospice palliative care and pointed to the advocacy work that has come about a result of these polls. CHPCA, in response to these findings and the debate around physician assisted death and the Carter decision, undertook a broad campaign as part of their national hospice palliative care week activities, entitled, “Let’s talk about hospice palliative care first,” to help ensure that all Canadians have access to high quality end-of-life care. CHPCA feels it would be a disservice to the principles of hospice palliative care if an individual chose physician assisted death because there were limited and/or inadequate services in their area. This philosophy does not intend to be disrespectful of individual choice, but wants Canadians to make well-informed choices based on the provision of, and access to, quality hospice palliative care services. The Canadian Cancer Society’s 2016 report, “Right to care: Palliative care for all Canadians,” drew attention to the gaps in care across the country citing that, in some regions in Atlantic Canada, less than half of the people who died in hospital received palliative care. The report also noted that a significant financial burden is placed on family caregivers who “carry a substantial cost of the total costs of providing end-of-life care” (Canadian Cancer Society, 2016, p. 11)

The Canadian Cancer Society does an admirable job in highlighting the plight of family caregivers and their need for funding, access, and support for respite and educational services as well as recognition of the unpaid family caregiver’s time in providing end-of-life care. In Ontario, 77% of total palliative care expenses are unpaid caregiving costs, which is in addition to other costs incurred by the caregiver such as supplies. It does not include any estimate for the toll on their physical and emotional health (Chai, Guerriere, Zagorski & Coyte, 2014). The “Right to care: Palliative Care for all Canadians” report is also a strong proponent for information and tools to support ACP and the improved patient and caregiver satisfaction that comes with accessing

hospice palliative care. The nationwide inequities also are apparent in regard to provincially documented frameworks for palliative care practice. Health PEI has conducted preliminary discussions and a draft framework has been developed, but, as of this date, nothing has been released to the stakeholders who participated in the initial consultations nor the broader Island community.

The Carter decision of February, 2015, has brought end-of-life issues to the forefront. With two-thirds of Canadians stating that they would like to have the option of physician-assisted dying (PAD), the level of public dialogue has increased (Environics, 2013). The Supreme Court stated that a prohibition against PAD violates the right to life, liberty, and security of the person under the Canadian Charter of Rights and Freedoms. Canadian parliamentarians were tasked with having legislation in place by June, 2016 that reflected the values of a diverse population of Canadians. The deadline was not met, with Members of Parliament and Senators debating changes to the bill that included access for mature minors. Senator Serge Joyal also argued for broadened eligibility. He felt that a number of Canadians experience “grievous and irremediable medical condition(s)” but for whom death was not “reasonably foreseeable” should have access to medical aid in dying. The bill received royal ascent on June 17, 2016 without amendments around access by material minors or those with grievous and irremediable medical conditions. The nationwide discussion has focused on issues of client self-determination, health care professional conscientious objection, and the need for a pan-Canadian palliative care strategy. There are a number of ethical and moral decisions at the heart of this issue, including protection of the vulnerable. There is a concern of “subtle or overt pressure on older adults and persons with disabilities to accept or pursue physician-assisted dying” as well as those with mental health issues and neurological conditions such as Alzheimer’s disease (Webb, 2015, p. 18).

The final report of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (2015) listed a number of recommendations including the need for provincial and territorial governments to act in collaboration with the federal government in developing and implementing a pan-Canadian strategy for palliative and end-of-life care, including PAD. The report also called for curricula and continuing education programs for health professionals related to the provision of PAD as well as provincial/territorial public education on end-of-life care. The CMA submission to the Federal External Panel on Options for a Legislative Response to *Carter vs. Canada* (2015) highlighted the findings of their cross-Canada town halls that indicated that although PAD is a divisive issue, there was common ground on the importance of ACP and the need for a comprehensive palliative care strategy. The CMA also indicated the need for federal action to ensure national guidelines based on consistency between the provincial/territorial government approaches or Canadians would be left with a patchwork of conflicting programs. The April 25, 2016, town hall hosted by Prince Edward Island MP, Sean Casey, heard the same concern – the need for consistency in legislation across provinces.

In February, 2015, the College of Physicians and Surgeons of Prince Edward Island adopted guidelines for PAD in the event that an individual be granted access to the service by applying to the courts. This move, provides Island physicians with guidance on how to proceed, based on similar ones already developed in Alberta, Saskatchewan, and Manitoba. These guidelines included the caveat that physicians must inform their patient about alternatives, “including comfort care, palliative and hospice care, pain and symptom control, and other available resources to avoid the loss of personal dignity” (CBC, 2016). The Canadian Association of Social Workers have also issued a discussion paper in response to the decision and the first reading of Bill C-14 (An Act to amend the Criminal Code) and to make related amendments to other Acts

(medical assistance in dying), which also encouraged the federal government to develop pan-Canadian standards for palliative care, as well as PAD. The unique perspective and expertise of social workers is also recognized in calls for the integration of teams caring for Canadians considering PAD. These social workers should also receive specific training and education in the area. The CASW also called for exemptions for social workers who provide services relating to medical assistance in dying. The exemptions were put in place to protect social workers who do not wish to partake in medical aid in dying based on personal moral or ethical objections. The exemptions also served to protect social workers who participated in medical aid in dying during the window prior to the bill receiving royal ascent.

The timelines required in which to pass Bill C-14 brought an immediacy to these issues, yet there was no dedicated timeline provided for a pan-Canadian palliative care strategy or a financial commitment from the federal government to continue to fund the implementation and capacity building associated with The Way Forward. The federal Liberal government has committed \$3 billion to home and palliative care, prescription drug support, and improved mental health care. How the provinces and territories will choose to spend these funds remains to be seen. What is evident is that Canadians will need to continue to advocate for access to quality hospice palliative care services and be cognizant of the supports required by vulnerable populations who may be coerced into choosing PAD by a poorly funded health system overwhelmed by the current demographics of chronic care patients and older adults.

Provincial Strategies and Caregiving

The Prince Edward Island government has undertaken a significant review of health care delivery in the past decade that examined the role of primary, acute, homecare, and long-term care. A number of reports have been issued, highlighting the need for integrated services (CSI

Consultancy, 2008; Government of Prince Edward Island, 2009). Along with a review of the health system, various sector reviews were also conducted, including the Ascent Strategy Group's 2008 report, "Trends, projections and recommended approaches to delivery of long-term care in the province of Prince Edward Island 2007-2017". This report highlighted a number of recommendations including the development of an "aging at home" strategy which would include the need for expanded home care services as well as other program developments to reduce the need for institutionalization. The report indicated that facility replacement is necessary to provide modern accommodations for those requiring long-term care. This recommendation was highlighted as a goal in the province's subsequent 2009 aging strategy. The number of long-term care beds required in the province is also questioned. The Ascent Group's 2008 report suggested maintaining the number of provincial beds. One has to wonder if this is a logical conclusion, given the demographic trends, incidence of caregiver burden, and the issue of distance caregiving. It is indicated that the province should look to the private sector for the development of additional long-term care beds, with the government subsidizing these spaces. The report suggested that the philosophy of care be based on the premise that the majority of residents in long-term care are those with some level of cognitive impairment, yet there is no mention of the need for a provincial dementia strategy, increased staff education, and recognition of the care and burden assumed by family caregivers for those with care recipients in long-term care. The "Trends, projections and recommended approaches to delivery of long-term care in the province of Prince Edward Island 2007-2017" (2008) report estimated that 80 percent of residents of long-term care have a form of dementia, contributing to the increased complexity of care required within long-term care. The report also stated that there are concerns in identifying an appropriate assessment tool that examines psycho-geriatric needs, dementia, and screening for those who are under 60 years old

and experiencing mental health or special needs, and require long-term care. It also pointed to difficulties in accessing professional support staff for long-term care residents including physiotherapy, occupational therapy, audiology, and dental care. The Prince Edward Island Dental Association has been advocating for changes in delivery of services for long-term care residents for over a decade. It is interesting to note, that until 2015, social work services were not part of the day-to-day interdisciplinary team in long-term care. The report failed to mention the contribution or recognition of the value of social work in long-term care.

The Ascent Group (2008) also pointed to a significant policy change, as of 2007, the Department of Health and Wellness has incurred increased costs for the delivery of long-term care based on the subsidization formula which looks solely at income versus the previous income and assets measure. This policy change brought Prince Edward Island in line with other jurisdictions such as New Brunswick and Nova Scotia. The Prince Edward Island Department of Health and Wellness is responsible for health care costs, including nursing and personal care, incontinence and infection control measures, along with basic personal supplies for hygiene and grooming. One of the most significant issues related to long-term care is the wait time for placement. The report pointed to an average wait time of 41 days, but steady increases in 2006 and 2007 point to wait times in excess of 8 weeks. In the majority of cases, these individuals are waiting for placement in acute care beds thereby creating a bottleneck that causes delays in other services provided in the acute care setting. The province has attempted to ameliorate this challenge by creating a “home first” program. In this program, individuals are returned home to their family caregiver, with some care and support, until such time as a long-term care bed becomes available. It is also possible that an individual may be transferred to another provincial health care setting, such as a rural hospital, to await placement. Each of these approaches comes with specific benefits and challenges. In

returning an individual to their home to await placement, it is felt that the individual is in a more suitable environment and can make life-changing decisions surrounded by family and in the comfort of their own home. The challenges of this approach are multifaceted with the primary burden of care being placed on the family caregiver, along with the tremendous emotional pain and relationship strain caused when the individual is moved to long-term care placement. Unless there are plans implemented to support the care recipient and caregiver, one can anticipate that this transition to long-term care creates additional stress on both parties, beyond what normally occurs when the transition is made from acute care.

The report also featured the role of the provincial homecare program and its connection to the long-term care program. The Prince Edward Island homecare program is viewed as a preventative approach “for unnecessary, premature or prolonged institutionalization and intended to supplement the care and support from family and friends” (Ascent Strategy Group, 2008, p. 14). The program has seen, and is expected to see, an increased demand for service based on a number of factors including the aging population, chronic disease rates of Islanders, shorter hospital stays, increased life expectancy, increased desire to receive end-of-life care at home, and the expectation to receive faster access to more services. The Health PEI annual reports indicated an overall decrease of one percent from 2010-2011 to 2014-2015, for all populations, and a slightly higher decrease for those 75 years and older. The Ascent Group (2008) indicated that provincial home care spending to date (2008) is less than half the national average per capita for the population over the age of 75.

The CSI Consultancy report “An integrated health system review in PEI: A call to action; a plan for change” (2008) focused on the need for change in health care delivery and suggested that care is best provided locally in family health centres, i.e. the primary health care sector. The

idea is that Islanders should have access to the same type and quality of services as other Canadians. The human resource implications for delivery via these centres encouraged Health PEI leadership to consider new roles and expanded scope of practice for the interdisciplinary team. The report also pointed to an aging workforce and health human resource shortages that will only increase with time. The gaps in human resources, combined with employment that does not reflect scopes of practice for some positions, also created a significant issue. Although social work is not mentioned, I believe this to be an issue in the lack of awareness of what the profession can contribute, as well as the lack of access to social work services experienced by Islanders. CSI Consultancy (2008) highlighted the unique challenges that Prince Edward Island faces in delivering health care, including the largely rural population, a reference to “traditional values,” and the strength of community. There is a smaller tax base to help fund the increasing costs of health delivery.

CSI Consultancy (2008) suggested the need for provincial frameworks and standards for seniors’ health. It has only been in recent weeks that focus groups have been convened to gather information around a seniors’ health strategy. The process began with engaging key stakeholder groups, yet the Department of Health and Wellness did not advise the consultants to engage the PEI Seniors’ Secretariat, who fall under the Department of Family and Human Services. The mandate of the secretariat is to provide policy and program advice to government and other organizations to improve the quality of life for seniors. It was not until a press release was issued, that secretariat members were made aware of the strategy development. Health PEI had also engaged support to draft a palliative care framework for the province, but that has yet to move beyond the internal system.

The 2015 report “The way forward: a roadmap for the further development of the integrated palliative approach to care for Prince Edward Island” highlighted the call for a provincial strategy that promotes “flexible, seamless, patient-centred, high quality evidence based palliative care for Islanders in the setting of their choice” (Health PEI, 2015, p. 9) The CSI Consultancy (2008) report also gives some voice to family caregivers, encouraging health officials to view them as partners in care, although there is no formal recognition. There is no mandated assessment of family caregivers who have a recipient receiving home care, no provincial tax incentives aimed at supporting family caregivers, and no caregiver support strategy as recommended by CSI Consultancy (2008). The report encouraged the use of community and voluntary resources in health care delivery, and specifically in supporting family caregivers. To date, non-government organizations help to fund equipment for seniors on a case by case basis, offer support group meetings, volunteers for in-home respite, and day programming services. The Health PEI 2012-2013 annual report indicated the release of a caregiver support strategy, although the only government document uncovered was a caregiver handbook focused on a stroke care model. Health PEI recently announced a provincial stroke navigator position to assist stroke patients and their family caregivers; and subsequently announced a patient navigator position. It is hoped that a similar position will be created to support all family caregivers or that the patient navigator has skills specific to supporting family caregivers and their issues.

CSI Consultancy (2008) also reviewed the long-term care program indicating that there are significant variations in the quality of services being delivered to seniors and the fact that there is no single legislative framework under which all (public and private) facilities operate. Island families noted the discrepancies in training requirements for public and private facilities. The report recommended annual audits that are publicly available and shared with residents and their

families. This recommendation has been debated in the Prince Edward Island legislature, as recently as 2014, some five and a half years after the report was released. The health minister of the day indicated that his government would look at ways of being more transparent with the information gathered during private nursing home inspections. At present, the provincial website has a section for inspection reports but no data is listed.

In 2009, the province released a healthy aging strategy aimed at building a single, integrated system of care, grounded in evidence based decision making. This approach to integrated health services is cited as a source to maintaining health, well-being and independence for individuals and caregivers by the provincial government. According to the Department of Health and Wellness, this integration is to be based on clients, caregivers, community, physicians, hospitals and primary care networks. Although strides have been made to integrate the system, users are claiming there are difficulties in navigating services. The Department of Health and Wellness indicated that government is well aware that homecare has been historically underfunded and has experienced significant shortfalls in programming relative to the rest of the country. It also pointed to homecare as more cost-effective than long-term care but, in doing so, no recognition is given to the voice of caregivers, the services they provide at no cost to the system and no recognition of the costs they incur while providing care. This “strategy” falls short in that it is not inclusive of the issues Island seniors face and appears to be more of an internal action work plan. The document does not reflect the voices of Island seniors or their caregivers.

In keeping with a continued focus toward health care integration, the province re-engaged CSI Consultancy in 2010 to create a provincial design of transition management. The CSI Consultancy report “Transforming how we provide care to Islanders by connecting the continuum” (2010) identified gaps in services whereby individuals were not able to access services such as

adult day programs; the ineffective use of acute care emergency departments, and the recognition that departmental silos created challenges to integrated delivery (CSI Consultancy, 2010, p. 7). The crux of these gaps came back to the need for timely and concise communication between Islanders, health professionals, and leadership within the healthcare system.

The gaps in day program access exist despite the fact that there are reported challenges in maintaining numbers. There is a “need to ensure services are more widely understood and that providers are equipped with the information needed to support conversations with families regarding options to support improved access” (CSI Consultancy, 2010, p. 7). The ineffective use of acute care emergency departments is attributed to the absence of strong community and primary health care access, with Islanders left to seek services at inappropriate locations resulting in extended wait times for service. CSI Consultancy very candidly stated that Islanders’ perception of healthcare is tied to acute care. They also acknowledge the need to deconstruct departmental silos in an effort to create a continuum of care, to be led by primary healthcare and home care renewal. Interestingly enough, the table outlining types of services and care by health sector only acknowledged the role of social workers within home care. The roles of social workers in acute hospital-based care, mental health and addictions, primary and community based care were not listed or recognized (CSI Consultancy, 2010, p. 12).

CSI Consultancy went on to list a number of recommendations including:

- build a culture that supports services close to home;
- involve patients and families in care planning earlier in process;
- reduce barriers to accessing financial supports;
- enable in-home assessment for additional supports;
- establish strategies to avoid premature admission to long-term care;

- set and manage expectations of individuals and families;
- ensure effective transportation services;
- conduct pre-admission screening to help ready patients to return home as soon as possible;
- establish a “home first” approach;
- leverage multi-disciplinary, collaborative teams to plan care;
- a refocused emphasis on an enhanced model of primary care;
- define core primary health care teams;
- ensure individual access to a family practice/primary care setting;
- enhance access to professional support services at home and in the community;
- ensure access to community supports;
- initiate a home care project for program planning and case management;
- establish geriatric assessment teams;
- create an education strategy for transition management and
- enhance patient/family education.

These recommendations would serve as a tremendous foundation for recognizing the role of family caregivers, and their need for communication, education, and support, all while building primary and home care networks designed to save the system money.

The Department of Health and Wellness released a wellness strategy in 2015, which the previous health minister cited as supporting family caregivers. The document recognized the burden on caregivers but went on to state “more support will be required from families, friends and the community at large” to support those dealing with chronic disease or illness (Government of Prince Edward Island, 2015, p.4). The strategy also highlighted the strong sense of community

that is felt on Prince Edward Island. It also highlighted the demographic shift that is occurring within small rural towns and communities experiencing out-migration in favour of more urban settings for the purpose of being closer to service hubs.

The federal, provincial, and territorial ministers responsible for seniors also released their “Thinking about your future: plan now to age in place” publication in 2015, encouraging Canadians that aging in place means “having access to services and the health and social supports you need to live safely and independently in your home or your community for as long as you wish or are able to” (Federal Provincial Territorial Ministers Responsible for Seniors, 2015 p. 1). The report also encouraged individuals to think about their role as a caregiver, what resources and respite services they would use to help them, and the creation of a self-care plan for those who may find themselves in a caregiving role. The shortcomings of this document was that, without a definition of what constitutes a caregiver, many may not self-identify. In not providing what services may be available within a jurisdiction, the onus is left to the individual to navigate a convoluted system.

The most comprehensive document regarding caregivers and their issues on Prince Edward Island was released in 2011 by Centre Canadien de Leadership en Evaluation – a feasibility study on implementing a provincial support network for Acadian and Francophone caregivers on Prince Edward Island. The Centre Canadien de Leadership en Evaluation noted that there is no caregiver group with a mandate for advocacy and support in Prince Edward Island, similar to those found in Nova Scotia (Caregivers Nova Scotia) or Alberta (Alberta Caregivers Association), or nationally with the Canadian Caregivers Coalition. It was also indicated that support networks such as VON, Alzheimer Society of PEI, Hospice PEI and Canadian Association of Mental Health, operate mainly in English, which is a challenge for minority populations in the province. This issue is even

more relevant in light of the recent immigration surge in the province. Centre Canadien de Leadership en Evaluation suggested that caregivers need to be encouraged to ask for support and that the creation of a bilingual 1-800 telephone information line may help to alleviate some of the stress experienced by caregivers.

The federal and provincial governments have numerous opportunities to support family caregivers through effective policy development and change, strategic planning and action, and recognition of the valued contributions, not only to their care recipients but to Canadian society. It is hoped that these opportunities will be embraced.

Chapter 3 - Socialization, Women's Roles, Life Transitions, and the Caregiver Experience

In this chapter I discuss socialization, women's roles and feminism, life transitions and the caregiver experience. It is widely acknowledged that each experience is unique to the individual, but similarities in caregiver burden and positive experience have been acknowledged. Caregivers seek to find a balance between caring, other social and physical pursuits, and in some cases employment. This section also examines how one becomes a caregiver and how the role is recognized. The literature reviewed also includes material on filial responsibility, the importance of relationships in the caregiving experience, caregiver support and education, transitions and ageism and advocacy.

Gender, Socialization, and Caregiving

The inter-weaving of care and gender has had a profound effect on the female life course. In the 1980's, feminists began exploring the phenomenon of care in earnest (Rummery & Fine, 2012). According to MacKinnon (2009), the act of investigating women's issues without employing feminist theory may result in making women the focus of the problem, instead of the social structures that continue to devalue them and their work. In examining the concept of socialization in relation to caregiving roles, it is important to provide a definition of the term. Walker (1992) defined socialization as a complex interactive process that involves at least three elements: observation, initiation, and internalization. This socialization process also serves to oppress women through their interaction with men. By virtue of gender, there is an unequal balance of power and privilege.

Renowned social work researcher, Nancy Hooyman, and her colleague, Vivienne Bozalek (2012), highlighted a number of facts and issues pertinent to feminist caregiving research. Bozalek and Hooyman (2012) noted that women have been historically exploited in their role as caregivers,

both within the home and labour market. They believed this is a result of societal assumptions about women's role in care work. The role of socialization as a process is significant in that women are taught to be caregivers, whether by modeling behavior or responding to positive social reinforcement. There is an implicit expectation that women will care and are available to care. Jaffe and Blakley (2000) reinforced the belief that women, regardless of their age, health, or existing commitments will be available to provide care. The 2001 paper by Eales, Keating and Fast illustrated that there is no longer a large group of full-time homemakers who are available to provide informal care, as the majority have joined the labour market. Unfortunately, this labour force participation has not negated the social expectation of care provision, but has only added an additional role to try and balance. A role strain perspective postulates that individuals may experience negative mental and physical health due to the multitude of various roles which they are socialized to portray (Reid and Hardy, 1999). The role of caregiver is thought to be that of an innate, biological calling as well as one in which people, namely women, are socialized to fulfill (Brewer, 2001). Brewer (2001) also highlighted that the socialization of females to provide care is also a cross-cultural phenomenon. Some cultures may turn to their sons when in need of care, but the actual physical care is usually provided by women. This pattern of socialization holds true in Canada: "when a family member needs care, a spouse will be the number one choice to fill that role, followed by a daughter or daughter-in-law" (Poirier, 1998, p.1).

Life Transitions

Caregivers go through several transitions during their time as a caregiver – journeying with the care recipient between home and acute care, acute care and homecare services, community care, long-term care, and the individual's transition out of the caregiver role. Giosa, Stolee, Dupuis, Mock and Santi (2015) conducted research examining caregivers' experiences during care

transitions of older adults. This qualitative study revealed that transitions often involve shifting responsibilities from formal providers to family caregivers, who often feel ill-prepared to manage care. The findings indicated that both case managers and caregivers agreed that caregiver assessment was a critical component to easing the transition. The assessment would reveal family dynamics and the caregiver's knowledge base, whether they understood medical terminology, had medical skills such as bathing, and wound care, and if they had an understanding of the health care system and how to navigate. Giosa et al. (2015) found that the acute care phase, while often short, provided a tremendous opportunity for assessment and knowledge building, leading to better support for the caregiver. Caregivers also felt that health care providers could do a better job of facilitating conversations around care and what to expect. They also indicated that the most significant challenges they faced when returning home was social isolation and insecurity about their abilities to provide care.

Prince Edward Island based research on supporting older adults and caregivers in transitions between health services found some similarities. This mixed-method research by Weeks (2014) determined that Island caregivers face a number of challenges, including:

- finances,
- caregiver support and respite;
- lack of knowledge and information about health services;
- attitudes towards older adults and their value in society;
- need to have an advocate/health navigator;
- choosing not to use services that are available;
- lack of personal planning for the future;
- quality of services available and issues with specific services.

The caregivers who participated in the focus groups indicated that they preferred to receive information in-person or in print. They thought there was a shortage of long-term care space, and there was inadequate care in some long-term care facilities. They also thought there were high resident to staff ratios, a lack of stimulation for residents, and staff qualifications and levels of training were not consistent between government and private facilities. Caregivers also noted challenges in continuity between services, as well as accessing referrals from family physicians that makes transitioning between services frustrating. On a positive note, caregivers cited the support of Island not-for-profits in providing services and information. Weeks (2014) indicated the need for future research and evaluation in determining the effectiveness of respite programs, as well as how to utilize homecare services.

The caregiving experience is shaped by the daily situations that arise in providing care. These situations can cause various stresses, including a toll on the caregiver's physical and emotional state, as well as financial challenges and the social isolation that often results from caring for an individual with progressive illness. The caregiver experience is shaped not only by their relationship with the care recipient, but relationships with their partner, siblings, children, and the extended community. Caregivers often benefit from educational support in their role, such as material on various health conditions, how best to support the care recipient in activities of daily living and self-care. Caregiver support can take various forms, such as respite care, community-based support groups, and web-based resources (Sheehan, 2012). Where caregivers reside can also have a profound effect on their experience and ability to access services.

The Caregiving Experience

In this section, I will discuss specific issues pertinent to caregiving: a general overview, relationships, burden, positives, loss, education and support, geography, ageism, dignity, and advocacy.

An overview of caregiving. The work of Pope, Kolomer and Glass (2012) indicated that people become caregivers one of two ways. The first is an event or events that trigger the individual's awareness (or that of the old person) that support may be required. These events can be instantaneous, due to events like a stroke or car accident, or may evolve with time due to deteriorating health, financial problems or the loss of social ties. The second is due to a specific conversation initiated by either the older adult or individual. It is interesting to note that the role of caregiver is usually not easily acknowledged by women, in that they are performing tasks for which they have been socialized. Research shows that caregivers are providing care that is more complex as a result of chronic health conditions and, in some cases, specialized care required at the end-of-life. This level of care has also been noted as a defining factor in identifying oneself as a caregiver. In Barber's (n.d.) work, "The Career of Caregiving", spouses do not define themselves as a caregiver until the care recipient has reached a level of impairment at which most children would have withdrawn from the caregiving role. As indicated by Brewer (2001), women fail to acknowledge tasks such as meal preparation, laundry and housework as caregiving because these involve tasks that women have performed throughout their lives. This lack of acknowledgement on the part of women in claiming their caregiving role, may also serve to keep them oppressed. In not recognizing the contributions they make in providing care, women are de-valuing their own contributions, which, in turn, have not been valued highly enough throughout society. It also creates a situation whereby these caregiving women are not likely to voice concern in requesting support and services.

O'Connor (2007) also pointed out that caregivers are often overwhelmed and have little time to reflect on their role within the situation. O'Connor (2007) also pointed out that assuming this role means recognizing that much of the mutuality of the relationship has been lost. The research findings published in "Self-identifying as a caregiver: Exploring the positioning process" also stated that often times it took the suggestion from a health professional or physician waiting room reading material for people to acknowledge that they were indeed in a caregiver role. O'Connor's (2007) work also recognized that there were benefits associated with identifying as a caregiver, including:

- a fostered sense of connection with others;
- an increased ease with which services could be accessed and utilized; and
- the extrinsic self-reward manifested in personal growth and the knowledge that the work they were doing mattered.

Caregiving is provided with the context of our social networks and relationships, but is there an inherent responsibility to care? Stuifbergen and Van Delden (2011) identified that there is some expectation across the majority of cultures for individuals to provide care to older adults. Their work cited various theories of filial obligation including reciprocity, the idea that the older adult is owed care; a friendship model which is based on the present relationship between the caregiver and older adult; and obligation, that individuals, namely adult children, are obligated to provide care because they can. The reciprocity and obligation theories are documented in the Ontario Family Law Act that states: "Every child who is not a minor, has an obligation to provide support, in accordance with need, for his or her parent who has cared for or provided support for the child, to the extent that the child is capable of doing so" (Lakra, 2002, p. 21). The same obligation applies to spouses and same-sex partners. Ting and Woo (2009) pointed out that all

provinces in Canada have enacted filial responsibility laws, although actions around care for older adults are rare. A recent incident in Nova Scotia highlighted the pressure family caregivers are experiencing. A grandmother with mild dementia, who was being cared for by her grandchildren, was left at a Halifax, Nova Scotia, emergency room as her family could no longer cope with her care. The woman was not ill but spent more than a week in the emergency department because family refused to take her home. The article in *The Chronicle Herald* (2016) indicated that “nurses are crying and social workers are desperate” according to Dr. Samuel Campbell, Chief of Nova Scotia’s largest emergency department. He went on to say that some families are not planning for the long-term care required by their loved ones. The response from the provincial health minister, Leo Glavine was “part of that ... is educating our senior population so that they know that there could be another avenue for them to get the care they need” (“Nova Scotia family leaves grandmother in ER for a week during Florida trip”, 2016). He did not acknowledge the role of the caregiver or the tremendous burden under which they provide care.

In reviewing the concept of responsibility for care of older adults, Theixos (2013) stated that there is “a social phenomenon that filial obligation has a moral component that aligns with our collective morality narrative: the ‘good’ child takes care of his/her parent, the ‘bad’ child does not” (Theixos, 2013, p. 67). This narrative is particularly strong for women who have been socialized to be “good girls”. Ting and Woo (2009) suggested that the majority of people are morally and culturally responsible and would provide care to aging adults, without documented law. Policy makers and governments would be better served at examining and trying to understand the obstacles to providing care.

Caregiving and relationships. At the heart of caregiving are the relationships that form our social networks – the caregiver and care recipient, caregiver and partner, caregiver and formal

service providers and caregiver and system relationships. Often times, older women are providing care for their aging partner. This can impact all facets of the relationship – emotional, sexual, financial, social etc. (Small, n.d.) Spouses are the last ones to identify as being a caregiver due to the relationship and established care patterns. The spousal relationship is also important for older female caregivers when the spouse is not the recipient of care. Caregivers have mentioned both positive and negative feelings when trying to balance caregiving demands and intimate relationships. Respondents to Caring.com’s marriage survey noted that the pressures of caregiving contributed to alienation from their partner and was cited as a contributing factor in separation and divorce. The majority of survey participants were grateful for the support and understanding of their partners (Matthiessen, C., n.d.). Other family relationships, namely sibling relationships can often face discord when facing a caregiving situation for older parents. This discord usually arises from a disagreement regarding whether or not care is required and in the majority of cases, when there is an unequal division of caregiver duties (Family Caregiver Alliance, n.d.).

The relationships with formal care professionals are often both rewarding and challenging. Chen, Sabir, Zimmerman, Sutor and Pillemer (2007) indicated that the family caregiver maintains their role as caregiver even after formal care begins. The relationships between facility staff and family caregivers are significantly associated with family caregiver depression. Chen et al. stated that “the quality of staff and family interactions can serve to reassure family caregivers that their family members are being cared for in a compassionate way, or it can exacerbate anxiety about the quality of care (Chen et al., 2007, p. 257).

Sawatzky and Fowler-Kerry’s (2003) research examining the impact of caregiving, provides rich qualitative data about the experience of family caregivers and their relationships. Sawatzky and Fowler-Kerry indicated that participants describe their experience as “life changing

and consuming” (p. 279), with significant changes in lifestyle, including forced choices such as retirement. The participants indicated that they drew on family, community and homecare supports, as well as formalized services which addressed equipment and supply needs. Advocacy was also highlighted as caregivers felt they needed to have a presence in the care institutions. They were often discouraged and disappointed by the lack of responsiveness to their advocacy efforts. The one common thread that ran through caregiver negative experiences hinged on poor communication between health professionals and caregivers. The caregivers felt the need for continuity in care providers to build and maintain trust.

Caregiver burden. Caregiver burden has received a great deal of research attention. Adelman, Tmanova, Delgado, Dion and Lachs (2014) indicated that there are a number of risk factors for caregiver burden including the following: female, lower educational attainment, residing with the care recipient, depression, social isolation, financial stress, higher number of hours spent caregiving, and a lack of choice in being a caregiver. There were also substantial risk factors that included the provision of round-the-clock care, providing care to a high or increasing care needs recipient (e.g. dementia, end-of-life), and care transitions from such relocations as home to acute care or long-term care or significant changes in the care recipient’s health. Beach et al. (2005) indicated that these risk factors should trigger referrals for a caregiver assessment and that physicians should play a great role in assessing family caregivers; in collaboration with social work colleagues.

Gahagan, Loppie, Rehman, MacLellan and Side (2007) demonstrated that these beliefs, i.e. the lack of acknowledgement of the caregiver role coupled with socially constructed gender roles, has created greater vulnerabilities for female caregivers, including the impact on their health, leisure time, finances, work-life balance, and the lack of effective public policy to support them in

their caregiving role. The benefit of this study is that it examined the perceptions and experiences of caregivers using a qualitative approach. The research resulted in a call to action, to ensure the health of unpaid caregivers, and to recognize their care as an essential social service.

Giesbrecht, Williams and Hankivsky (2012) examined the diversity of end-of-life family caregiving and reminded researchers to be cognizant of gender-based analyses and, in particular, how this analysis intersects with culture, socio-economic status and geography, all of which contribute to very diverse caregiving experiences. Fletcher, Fast and Eales (2011) indicated the health and social consequences of care may lead to increased costs to the public system if the health and welfare of informal caregivers is not recognized. Fletcher et al. (2011) thought that additional strain would be placed on the system if both care receiver and caregiver required support from health care services. This would negate the cost-saving measures associated with informal care. Although this quantitative study of Fletcher et al. provided information about the effects of caregiving, one can only surmise what the day-to-day experience of caregiving is like such as the need to change social plans, the physical and mental challenges, and the out-of-pocket expenses incurred by the caregiver. Fletcher et al. also noted that these effects, particularly the health-related and stress concerns, are more prevalent in the women providing care. This is due in part to the type of care they provide; the more physically demanding and time-consuming activities of daily living. These research findings would benefit from the rich, descriptive story of the experience and the ability to hear the voice of the female caregiver.

Allen and Walker's (1992) study drew attention to the aspects of women's experiences including caregiver perception and the experiences associated with caregiving work. Allen and Walker (1992) employed a feminist theoretical approach using a qualitative methodology to explore the experience of daughters caring for their mothers. Allen and Walker (1992) thought that,

as a result of their study and the use of this perspective, the quantitative approach to caregiving tasks was deemphasized. The experience of the caregivers was highlighted and, in doing so, valued the women's own analysis of their experience. This work highlighted the need for qualitative, feminist research on the issue of caregiving.

Positives of caregiving. Turner and Findlay (2012) stated that 95% of informal caregivers reported positive aspects including personal satisfaction, enjoyment associated with providing assistance, and the fact that the care they provided made them feel closer to the care recipient. As Chappell (2011) pointed out, caregivers experienced self-affirmation, enjoyment and a sense of satisfaction. The same findings were illustrated in Fast, Niehaus et al (2002) profile of Canadian chronic care providers.

Another effect highlighted by McIntosh et al. (2012) was that caregivers assumed new roles, specifically ones that their husbands had fulfilled prior to requiring care. Although the research findings indicated that the participants found the roles stressful, one would think that after mastering the task or developing a level of familiarity that a sense of empowerment and self-satisfaction would follow.

Caregiver loss. One negative effect associated with caregiving includes the concept of loss. As the demand for end-of-life care increases and the desire of many to die at home, so too will the number of informal caregivers increase. Each of these caregivers will experience the loss of their care recipient. In the work of McIntosh, Williams, Eby, Duggleby and Leipert (2012), it was noted how deeply caregivers were impacted by the loss. This finding was also supported by research conducted by The Change Foundation (2011) as the longer hours of care for a palliative patient combined with their evolving health status added to the caregiver's distress. The issue of loss is something that social workers need to be aware of particularly when providing counseling

and bereavement support to caregivers. PEI is a model of care for palliative services and supported by the not-for-profit group of Hospice PEI and other hospice groups. They provide bereavement support to all Islanders regardless of their location, through one-on-one informal bereavement support or community-based support groups.

The concept of loss does not only refer to the physical loss of the care recipient but the other accumulating losses experienced by the caregiver. These losses would include the loss of the initial relationship dynamic between caregiver and care recipient, loss of independence, loss of control and as mentioned by some caregivers, the loss of their sense of self. As noted by McIntosh, Williams, Eby, Duggleby and Leipert (2012) this loss was more evident in spousal caregivers who regarded themselves as part of an intimate partner dyad.

Caregiver education and support. Support and education for caregivers was another dominant theme that emerged from the literature review. In Keefe's (2011) report it was noted that the current system is limited and inconsistent creating discrepancies for caregivers. The same was noted by Armstrong and Kits (2001) that there is significant provincial variation in support available to informal caregivers. The Senate's report (2009), "Canada's Aging Population: Seizing the Opportunity," also indicated that availability and accessibility to services varies widely across the country. These disparities were also noted between rural and urban areas. I wonder if these discrepancies would be any more pronounced on PEI, given that the majority of support, including day respite programs are only available in urban centres. In Lazar's (2011) report it was indicated that feedback from informal caregivers pointed to a lack of support as an important source of stress and fatigue. Keefe (2011) stated "more public support for caregivers would not only demonstrate greater recognition of caregiving, it would also reduce the need for formal care, delay

institutionalization and relieve the cost pressure on home care and health care systems” (Keefe, 2011, p. 1).

Education plays an important role in how caregivers approach their work and what knowledge they are armed with as they endeavour to provide care. A number of online resources have emerged including Saint Elizabeth’s “Caring for Family” information and support site, as well as the Canadian Virtual Hospice’s series of how-to videos to support family and professional caregivers. This begs the question, how well known are these resources? Do caregivers have the time and knowledge to access them? Are they meeting their needs? In Sheehan’s (2012) study of the learning and educational activities of unpaid caregivers in Newfoundland and Labrador, caregivers are viewed as empowered, self-directed learners who faced the challenges of providing care with resilience and commitment. The educational needs of caregivers were explored in relation to their ability to access services and supports. What was noteworthy was the discussion around what they were being educated about and how they were learning to play their role as a caregiver. The study also highlighted the gaps that existed between professional and unpaid caregivers despite the notion of working for a common purpose. The study participants also revealed that there was an expectation that they should provide care equipped with the same knowledge and health-based literacy as their professional counterparts, despite the fact that they had little or no training in their role. Another significant outcome of Sheehan’s (2012) study was the recognition of the value of a network or group. The participants valued and saw power in their numbers, particularly when facing challenges within the system or social structure.

Warrick, Peckham, Watkins, Padjen and Williams (2014) evaluation of the Caregiver Framework for Seniors Project (CFSP) demonstrated the benefit of matching well trained care coordinators who provide intensive case management and ongoing counseling with family

caregivers. The CFSP program provided family caregivers with the support and guidance, along with a small \$1500 discretionary budget to manage services and care needs. The CFSP met the goals of Ontario's vision for client and caregiver support in that it recognized the critical role of family caregivers, called attention to high risk caregivers and high need care recipients; and strengthened linkages between homecare and community supports providing greater system integration. Additional benefits included engagement of family caregivers as active decision makers in formal care, encouraged caregivers to guide the conversation, sustained informal caregiving for a longer period and utilized client-centred principles. Caregivers also cited increased capacity to cope due to the enhanced counseling services and better knowledge of where to access help.

Other supports for caregivers include adult day programs, respite long-term care beds, and in-home respite made available through homecare or private services. These formal services provide a much needed break for family caregivers. Caregivers also make use of support groups offered by non-profit organizations such as their local Alzheimer Society, Heart & Stroke Foundation, Cancer Society or faith-based institution. Online resources also provide a wealth of information and support for family caregivers including specific health issue information (e.g. dementia), online support groups and video resources, and webinars and health system navigation tips. The benefit of online resources and support is ease of access and timeliness of the information for caregivers.

Caregiver living locale. Research also revealed that where caregivers live affects their experience. Jaffe and Blakley (2000) found that caregivers face additional pressure as they are providing care at a time when resources have been cut or eliminated. The PEI Department of Health and Wellness has introduced the Collaborative Emergency Centre (CEC) model to address

the provision of care in rural Prince Edward Island. This collaborative model of care is touted as an innovative way to improve access to both primary healthcare and emergency care. It is hoped that this would provide a level of support not only to the care recipient but their informal caregiver who is often called upon to assess the health of their care recipient and transport them to the nearest healthcare professional.

Keating, Swindle, and Fletcher (2011) noted that rural caregivers face challenges with isolation and loneliness, the same feelings expressed in Sheehan's (2012) study from Newfoundland and Labrador. The community consultations conducted by the PEI Seniors' Secretariat noted that supportive neighbours, faith communities, and seniors clubs and groups are working to address this concern.

Ageism, dignity and advocacy. This section of the literature review focuses on the impact of ageism, the need for dignity and respect for older adults and their caregivers, and the role of strategic advocacy in policy and program development, changes in service procedures and empowerment of family caregivers. The term ageism was first coined by Robert Butler in 1969 and is defined as “a process of systematic stereotyping or discrimination against people because they are old” (Butler, 1975 p. 35). Ageism can also apply to other age groups but it most commonly exhibited toward older adults. It includes a range of attitudes and stereotypes that view older people as weak, frail, disabled, and a drain on employers, families, services providers and governments, as well as behaviours that include infantile and patronizing language – language that reflects unflattering stereotypes such as “grumpy old man” and/or the tone and speed in which it is communicated. It is harmful in that it can prevent appropriate assessment and response to social problems and conditions of older adults (Canadian Network for the Prevention of Elder Abuse,

n.d.; Health Canada, 1999). There are also positive stereotypes affiliated with aging such as wisdom and compassion.

The Revera Report on Ageism (2012) indicated that this oppression is widespread and viewed as the most tolerated form of social prejudice in Canada. The Revera Report on Ageism stated that one in five Canadians say older adults are a burden on society; more than one-quarter have experienced discrimination from government, attributed to programs and policies that do not take into account the needs of older people; more than one-third have experienced discrimination from health care professionals and the health care system, with their health complaints dismissed as an inevitable sign of aging; and that eighty-nine percent associate aging with something negative like not being able to get around easily, a loss of independence, and being alone.

Those who participated in the research that informed the Revera Report on Ageism suggested three main changes to combat ageism, including:

- the development of technologies to help older people live independently for longer;
- awareness raising campaigns, with individuals and society as a whole challenging false assumptions;
- organizations to give voice to the issues around ageism and
- to provide more government funding for healthcare solutions that address the specific needs of an aging population (Revera Report on Ageism, 2012, p. 15).

Perhaps one of the most damaging beliefs tied ageism as it pertains to caregivers is the reflection in social policy that “assumes all families are willing, able and capable of providing care to aging parents” (Law Commission of Ontario, n.d.).

The research of Bodner, Bergman, and Cohen-Fridel (2012) found that ageist attitudes are more prevalent in males, which supports similar findings from other researchers (Bodner and

Cohen-Fridel, 2010; Fraboni, Saltstone and Hughes, 1990). Bodner et al. (2012) believe that these gender differences may be attributed to women's social caregiving role and the associated feelings of warmth toward women who provide care. Ageism is the most tolerated form of prejudice and does not appear to have the same significance as racism or sexism. According to the Ontario Human Rights Commission, "it can have the same economic, social and psychological impact as any other form of discrimination". In fact, Wallace (2012) suggested that ageism could be viewed as a social determinant of health.

Health care providers have also been known to use ageist beliefs and practices when caring for older clients. A number of authors have attributed this practice to a lack or limited amount of professional training in gerontology (Rosowsky, 2005; Stall, 2012; Azulai, 2014). This limited amount of training, coupled with students own un-interest in gerontological specializations, could lead to a scarcity of professionals to provide competent, quality services for older adults. Ageism has been shown to have an effect on seniors' health care, including their interactions with professionals, procedures, and treatment decisions (Battams, 2014). Health Quality Ontario (2015) acknowledged that older patients "fall through the cracks" during transitions between physicians, health care locations, and other segments of the health care system. This is another reason to push for continued integration of health care services. Reporter Allan Lynch of the Chronicle Herald (2012) newspaper in Nova Scotia referenced numerous examples of ageist behaviours in health care and quoted one source as saying the "prevalent attitude is that they are dying, so what's to be done?" Lynch (2012) also indicated that health care professionals employ systemic ageism in how personal care directives are interpreted. This leads to the need for greater public discussion and dialogue now that medical aid in dying is accessible to Canadians. Providers should have to

demonstrate that older adults wanting medical aid in dying are not opting for this option in light of family and societal attitudes about burden, costs, and possible need for care provision.

Lagace, Tanguay, Lavallee, Laplante and Robichaud (2012) found that older adults identified ageist language and attitudes in their daily interaction with long-term care staff. This included being patronized, not listened to, and spoken to in infantile language. Research participants also referenced the rigid and constraining routine of long-term care facilities. No doubt these ageist stereotypes permeate each facet of long-term care living including assistance with activities of daily living, social programming, and little to no acknowledgement of self-determination. Lagace et al. (2012) also found that older adults accommodated ageist behaviour so as to “not threaten a critical social tie in the life of the resident” (p. 341). Nathan Stall (2012), while still a medical student, penned a piece for the Canadian Medical Association Journal, entitled “Time to end ageism in medical education”. He suggested a zero-tolerance policy for professionals with reprimand, similar to what would occur in the case of prejudice based on gender, race, religion or sexuality. He also called for mandatory curriculum in gerontology for medical students, including both academic course work and rotational practice.

Ageism, like other prejudices can be compounded by the number of ways in which an individual is oppressed: race, gender, sexual orientation, and poverty (Palmore, 2005; Wallace, 2012). British Columbia’s QMUNITY Aging Out Project (2014) highlights the concerns of the Lesbian, Gay, Bi-sexual, Trans, Queer (LGBTQ) community in being able to receive competent care as they age. The Project calls for changes to intake and assessment for those accessing residential care or assisted living facilities. The current intake form does not include questions on sexual orientation or gender identity, nor do the policies and practices specifically identify LGBTQ concerns around inclusivity and non-discrimination, i.e. protection from harassment and abuse

(QMUNITY, 2015, p. 8). No individual should feel fear about residing in a community due to the fact that they identify as part of the LGBTQ community.

At the heart of quality of life, is respect and dignity for each individual. Black and Dobbs (2014) said that participants defined dignity as autonomy and cited self-reliance and self-sufficiency as aspects of dignity. Other factors that influenced a sense of dignity were interactions and relationships with others, e.g. tone and content of conversation including respect for oneself and others and self-acceptance. Participants noted that the challenges most prevalent to one's dignity were health problems and their consequences, decreased social connections, and dependence on others. These issues coupled with ageist beliefs can be detrimental to the health and well-being of older adults. Black and Dobbs also indicated that adverse life events such as widowhood affected the participants' concept of dignity. Supports to dignity included:

- networks “who help maintain one's sense of dignity during difficult life course events” (p. 1305),
- positive attitudes and beliefs about aging,
- action-oriented behaviours both physical and social, and
- successful resolution of past life course experiences such as caregiving and the death of a spouse.

Jaceleon & Henneman (2014) also noted the importance of recognizing and supporting a patient's dignity as an essential component of nursing education. Jaceleon and Henneman referenced an increase in the number of studies that examined patient dignity but little attention has been paid to family members perspectives around dignity for the older adult in health care. They mentioned that “staff attitude is a key factor in maintaining patient dignity” (p. 435) and that family dignity can be maintained “by keeping family members informed, involved and comfortable ...” (p. 434).

Advocacy. The final piece of this section of the literature review focuses on the importance of advocacy. Advocacy is defined as the act or process of supporting a cause or proposal (Merriam Webster, 2016). Advocacy can take numerous forms such as self-advocacy, peer/support advocacy or political advocacy like that demonstrated by groups who lobby for change. The Canadian Associated of Retired Persons (CARP) has a number of priority advocacy issues, including support for caregivers. The recognition of end-of-life caregivers can be attributed to the work of the Canadian Hospice Palliative Care Association and others who advocated for the Compassionate Care Benefit. In 2014, British Columbia appointed Canada's first Seniors' Advocate, Isobel Mackenzie. She has issued a number of releases and publications highlighting the burden experienced by family caregivers. Alberta also has advocates in place for health, mental health patients, and seniors. A Prince Edward Island listing included advocacy services for individuals dealing with legal issues, disabilities, labour, and women's issues. The most successful provincial advocates in recent memory are those who lobbied for the changes to abortion services. Caregivers are often called upon to advocate not only for themselves but for their care recipients in terms of quality and access to services and benefits, changes to policy, and the development of strategies and plans.

It has only been in recent years that caregivers are starting to give voice to their concerns through participation in various research projects, and in response to a need for services and support. The position statement on caregiver language is one example of this change. The position statement issued by Caregivers Nova Scotia (formally known as Family Caregivers' Association of Nova Scotia) (2002) indicated that the term "informal caregiver" is in itself oppressive. The position paper indicates that the term "informal" diminishes the importance of the role of

caregivers in society and that their response to care giving demands and challenges is anything but informal.

Conclusion

In conclusion, this literature review encompassed broad topics related to family caregivers including the effects of policy, programs and planning, life transitions and the various roles women assume along with providing care, the detrimental impacts of ageism, and the need for advocacy not only for care recipients but for their family caregivers as well.

Chapter 4 - Research Design and Procedures

This chapter on research design and procedures will outline the rationale for a qualitative approach to inquiry through a feminist lens. The study used a purposive sample examining the experiences of 15 older, female caregivers living on Prince Edward Island sharing their personal experiences through a semi-structured interview. The interviews were analyzed using thematic analysis.

The purpose of this qualitative study was to understand the experiences of older female caregivers (those 60 years and older) on Prince Edward Island (PEI) who were providing or had provided care for an older adult within the past year. The rationale in selecting this particular demographic for research is that the majority of caregiving research focuses on the sandwich generation i.e., those caregivers age 45-60 years old. It is my belief that older caregivers face similar demands in providing care but are also faced with other challenges unique to their own demographics. For instance, it is entirely plausible that a 60 year old woman could be caring for a parent, partner, sibling and/or friend as well as providing support to adult children and grandchildren. The experiences of this cohort are, and continue to be, not widely examined particularly in rural locations such as PEI.

Through the analysis of data gathered from in-depth interviews with the participants, I was able to learn about their experiences as an older female caregiver on Prince Edward Island and identified a number of key themes and supporting sub-themes that shaped and identified meanings around participant's experiences as caregivers.

The research was designed to address three key questions:

1. What is the experience of older female caregivers living on Prince Edward Island?
2. What does it mean to be caregiver?

3. How do Prince Edward Island women describe caregiving?

The Role of the Researcher

As a social worker, I strive to be constantly aware of the issues around power in practice and in research. In choosing the design for this study, I recognized that my own limits in knowledge and experience around this issue, my desire to learn about the participants' experiences, and my efforts to keep an open mind in trying to understand the participants' experiences helped to empower their voices and expertise on this topic, and to bring out the richness of their experiences in providing care. I also recognized that I come from a position of privilege, having been born during the second wave of feminism. I grew up in an era where women worked outside the home, attempted to balance work and caregiving for family and friends, and where the glass ceiling and equal pay were part of the social dialogue.

Feminist research emphasizes the need for reflexivity. Bolton (2014) defined reflexivity as: "finding strategies to question our own attitudes, thought processes, values, assumptions, prejudices and habitual actions, to strive to understand our complex roles in relation to others" (p.13) . In conducting this research, I practiced reflexivity by keeping a journal of my own thoughts, feelings and reactions to the interviews and subsequent analysis. I reflected on those notes by questioning my own stance on the issues that were discussed, as well as how my own caregiving experiences were influencing what I was observing. Anderson-Nathe, Gringeri, and Wahab (2013) reminded researchers that we only know the world through our own experiences; that all that we observe, collect and interpret is filtered through our socially and historically constructed selves.

I found myself both emic and etic to the research, that is, at times I was an insider and active participant in gathering and sharing knowledge and understanding of caregiving issues. I

was more of an objective outsider when hearing the emotional stories of participants: their challenges, resilience and overall recognition of their role as a caregiver. The candor of participants and the deeply personal nature of the stories they shared, imparted so much wisdom and a sharing between generations.

My interest in caregiving stems from a life of observing various female role models. I have strong recollections of visiting the inter-generational household in which my father grew up and witnessed my grandmother providing care for her mother-in-law, mother, and older widowed aunts. She was also the primary caregiver to my grandfather during his end-of-life transition.

My own mother was the epitome of the sandwich generation, providing care to two young children, balancing the demands of her profession, and caring for a terminally ill mother, who faced years of living with a life-limiting illness. At present, I am observing my paternal aunts and father who support my 95 year old grandmother who resides in community care. It is interesting to note the level of involvement and the unique differences assumed by my aunts and my father. For instance, one of my aunts, one of whom has assumed primary responsibility, tends to transportation and attendance at medical appointments, as well as errands for special care items and luxuries. My father shares responsibility in assisting with her financial matters and provides transportation when asked. I fully anticipate that as the oldest child, only daughter, and an Island resident that it will be my responsibility to care for my aging parents when the need arises. In preparing for this role, I have instigated discussions around end-of-life planning, which has resulted in the development of an advance care directive and a power of attorney should the situation warrant such intervention. I have also indicated my willingness to be the primary caregiver, if and when such a need arises.

My interest is also based on previous academic studies in the fields of psychology, social work, and gerontology. I continue to be amazed at the mass of information based on previous

warning calls about our aging demographic and the fact that the Maritime provinces would be faced with the challenges of this boom. I am disappointed that very little attention is given to the wealth of experience, knowledge and understanding of this demographic and the lessons they have taught and will continue to teach society. My professional life as a social worker includes care for families within a funeral home setting. I am blessed to witness the peace that comes from a positive caregiving experience and, conversely, the regret that accompanies those who were unable to be involved in a meaningful way. As a young student, I also provided front-line care work in a long-term care setting, which opened my eyes to the important role informal caregivers have within these facilities.

I also think that my volunteer roles have greatly contributed to my knowledge and have shaped my experiences with older adults, their families, and the issues we face as a society. My experiences around end-of-life, particularly those related to my maternal grandmother and paternal grandfather, greatly influenced my participation in the provincial hospice palliative care society. As the Prince Edward Island representative to the Canadian Hospice Palliative Care Association, I am buoyed by their commitment, research, and focus around caregiver issues. Earlier in life, I volunteered and performed paid work in long-term care and those experiences have affirmed my belief in honouring older adults and demonstrating respect, showing dignity and supporting them in informed decision making. My life has been greatly enriched by my interactions with clients and residents, who give voice to the need for recognition of older adults and their abilities and wisdom.

Qualitative design

I chose to use a qualitative design with the primary focus on the depth provided with this methodology to understand another's experiences. As Denzin and Lincoln (2008) stated:

“Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible. These practices transform the world. They turn the world into a series of representations, including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them.” (p.4)

Qualitative research offers an opportunity to explore the participant’s perspective in a manner that gives voice to the phenomena being studied. It exerts the primacy of the data, therefore highlighting and valuing the meaning and experiences of caregivers. It goes beyond surface meaning and quantifiable data, to capturing the essence of human experience (Mason, 1997; Holloway & Wheeler, 2002; Brun, 2015). As outlined by Carey (2012), there are a number of reasons to conduct qualitative research in the field of social work. It offers a more detailed understanding of the issue being studied. Qualitative social work research also helps us understand our practice environment and broadens our understanding of the complexity of the needs of our clients, their relationships, and the vast social context in which their experiences and our practice is based.

My research questions arose out of my own personal experiences and interest in caregiving. If we do not know the experiences of caregivers and the meanings to which they assign their caregiving role, how can we assume that we are best meeting their needs? Qualitative data can reveal the emotion, the intricate nature of relationships, the challenges associated with being marginalized, the lack of recognition of informal care work, and what that means to those who are committed to caring (Carey, 2012; Gray, Agllias, Boddy & Schubert, 2014; Brun, 2015). As Brun

(2015) stated, qualitative research “offers a better understanding of participants’ lived experiences related to the studied question(s) and because the current state of knowledge does not explain the studied phenomena” (p.101). This is particularly true when examining the experiences of older female caregivers on PEI as the last time this demographic was engaged in a significant discussion about their experiences was in 2006. The objectives of the consultation workshop held at that time were to engage stakeholders in a discussion on caregiving issues, identify current resources and services to support caregivers, and identify gaps in supports provided to caregivers. The proceedings report prepared by Weeks and Beattie-Huggan (2006) indicated that a series of next steps were formulated. Some of these have been addressed and others have yet to be achieved. It has been nearly a decade since caregivers were engaged in a process that actively listened to their voices and acknowledged the role they are playing, not only for their care recipients but for our broader society.

As a social worker, it is imperative that I honour the intrinsic value of the person. For me that was best accomplished by using a qualitative research design. It permitted me to engage in dialogue with the participants, to honour their experiences and strengths, and to hear those voices that have been marginalized. The research experience was also aided by social work skills developed during practice, particularly the establishment of rapport with participants, the interviewing skills used in the collection of data, and the reflective nature of the process.

The Canadian Association of Social Workers (CASW) Code of Ethics (2005) highlights the values of the profession to guide practice and research. Social workers are committed to honouring the dignity and worth of all persons and to respect the diversity within society. Inherent in this value is the understanding that each individual has the right to self-determination and choices based on informed consent. Informed consent is the cornerstone of transparent research

participation and to that end, each participant was informed of the study and provided written consent. The CASW Code of Ethics also addresses the need for social workers to act with integrity. This speaks to the need for honesty, diligence, openness and transparency, with a call to promote these values and qualities within the profession and broader social context.

Confidentiality is highlighted as the foundation upon which the participants shared their experiences. As the researcher I am bound to keep confidential any details that would reveal my participants' identities and would only disclose information with their informed consent, which was obtained during the initial meeting. It is also important to note that there are times when social workers need to break confidentiality based on legislation or other situations highlighted within the Code. During the process of this research study, no such situation arose. Finally, the CASW Code of Ethics is based on competency and highlights the need for knowledgeable social workers who engage in reflective practice, seeking out support and consultation when needed. This value speaks to the need for ongoing education and skill development, as well as the promotion of the profession. Also highlighted is the development of the profession and the duty of social workers to contribute to new professional knowledge that best serves our clients. One of the principles of this value speaks directly to research and states, "social workers who engage in research minimize risks to participants, ensure informed consent, maintain confidentiality and accurately report the results of their studies" (CASW, 2005, p. 8).

The establishment of appropriate relationships, and the openness and transparency in practice and research, is foundational to this study. As the researcher, I have always acted in the best interests of the participants and have been open and honest in our dialogue. It is my hope that this thesis will serve their interests in bringing recognition to their experiences and possibly facilitating change to better support caregivers.

Feminist Lens

Qualitative methodology lends itself to a feminist examination of the phenomenon at hand. This perspective acknowledges the gendered/socialized nature of caregiving as primarily “women’s work” and also acknowledges the strengths of the participants (Mason, 1997). As Hesse-Biber, Leavy and Yaiser (2004) stated, “feminists made experience (or experiential knowledge) an important category of research” (p.3).

In incorporating a feminist perspective, we also seek to address the inherent power imbalances between the researcher and participants by acknowledging the participant as the source of expert knowledge (Brayton, Olliver & Robbins, n.d.). As the researcher, I need to be cognizant of the power I possess over how the research is conducted and how the findings are disseminated. During the course of this research, I have been actively engaged in a reflective practice, questioning my power and position of privilege. I approached the interview phase with curiosity and respect for the participants and their experiences, while reflecting on my own experiences and how my way of knowing has been shaped by how I was raised and educated. I have never experienced oppression based on my race, beliefs, or orientation, but have been marginalized due to my gender. This level of awareness has guided my interactions with the participants and, hopefully, demonstrated my respect and appreciation for their experiences.

As a female researcher, I think it is important to acknowledge the feminist lens through which I have approached my research. In the 1980’s, feminists began exploring the phenomenon of care in earnest (Rummery & Fine, 2012). According to MacKinnon (2009), the act of investigating women’s issues without employing feminist theory may result in making women the focus of the problem, instead of the social structures that continue to devalue them and their work. Oftentimes, women’s issues are not given due attention, leading to further marginalization. The

issues of women guide, shape, and inform society. In employing a feminist approach, I have had my own consciousness raised in relation to the experiences of older female caregivers. The participants' experiences have furthered my knowledge and understanding, as well as highlighted the need for a strong and collaborative approach to advocate with, and for, caregivers.

Feminist research is not simply about research of women's issues. It is research that is conducted by and for women. In this particular research study, it is about the exploration of the caregiving experiences of women, informed by the voices of women who are or have been caregivers, with potential to shift the perceptions and future realities for other female caregivers and caregivers as a whole. The research process has resulted in a number of participants wanting to mentor and support current and future caregivers, as well as continue their advocacy work related to caregiving issues, and I will discuss this further in the conclusion. It is essential to not only examine the marginalization of participants based on gender, but to also take a broader view of how age, race, class and sexuality can serve to oppress participants. Indeed, feminist social work is concerned with all oppressions, not just those focused on gender (Brayton et al., n.d.). It is evident that age serves to oppress and marginalize, and that the intersection of gender and age creates a multiple jeopardy for participants. Ageism is rampant in our society and if permitted to continue will demoralize a significant demographic of our population. As our population ages, we need to address the marginalization of older adults and recognize their skills, values and experiences for the wealth and richness they offer our communities.

We must also take into account the geographic context in which the research takes place and its role in shaping the experiences of the participants. Prince Edward Island continues to be a very traditional society that still clings deeply to its patriarchal roots. We need only look at the issue of abortion access on PEI to formulate an understanding of the degree to which women's

voices are heard, acknowledged and responded to with positive policy and timely action. For example, it was not until March 31, 2016 that the government announced that by year end, Island women would have access to local abortion services (The Guardian, 2016).

My interest in caregiving as a research topic, stems from an interest in women's issues. The research questions that were developed came from a desire to understand older women's experiences as caregivers; what meanings they give this work and role; and how a small Atlantic province shapes that experience. My aim was to hear the voices of these women and honour their experiences by shedding light on the challenges they face, as well as the opportunities and richness that the role of caregiver offers.

Procedures

Recruitment

A purposive, criterion sample of 15 females age 60+ years who were providing, or had provided, care within the past year to a partner, parent, older family member or older friend were recruited via a call for participants in the provincial newspaper, *The Guardian*; its seniors' publication, *The Voice for Island Seniors*; and *The Buzz*, a provincial arts publication (see Appendix D). The call for participants in *The Guardian* yielded five participants as well as one who did not meet the criteria. *The Voice for Islander Seniors* resulted in two participants coming forward. One participant was as the result of the call in *The Buzz*. The remaining participants were the result of snowball sampling.

The participants ranged in age from 60-88 years, with the average age being 68.5 years. Eight of the caregivers were providing care to a partner. Seven were providing care to a parent or parents. One of these caregivers was also providing care to a friend. The participants had all completed high school. Ten had completed post-secondary education; three had completed

graduate work; and one had completed post-graduate work. Two of the 15 participants rented their homes, with the remaining 13 owning their homes. The majority of participants had a household income of less than \$75,000 but greater than \$50,000 with three participants earning above \$75,000. Two participants indicated that their household income was less than \$50,000 but more than \$30,000 and two others noted that their household income was below \$30,000. The sample was fairly homogenous with no ethnic minorities or same-sex couples being represented. The participants lived in the three counties of Prince Edward Island, with both urban and rural populations being represented.

Data Collection

In order to conduct research with participants, I first had to receive Laurentian University Research Ethics Board approval. This was granted in May, 2014 (see Appendix A).

A semi-structured, one-to-one interview was conducted with each participant and digitally recorded for analysis. The semi-structured interviews took place in either the participant's home, the participant's office or a private, rented office space neutral to both the participant and the researcher. An interview guide (see Appendix C) was prepared to help direct the flow of the interview. The use of in-depth interviews allowed participants to give depth and richness to their answers (Mason, 1997; Hesse-Biber, 2006). The participants signed an informed consent form (see Appendix B) indicating their willingness to participate in the research and their ability to withdraw from the study at any time. A semi-structured approach to interviewing "allows the feminist researcher to access the voices of those who are marginalized in society ..." (Hesse-Biber & Leavy, 2006, p. 118)

I transcribed each of the interviews, which provided an opportunity for me to reacquaint myself with the data and provided a transcript from which to conduct my review and coding. Each

participant then received a transcript of the interview for their review and were asked to participate in a second interview to verify the transcript and identify any gaps or additional information they wished to share.

One participant died during the course of the research, prior to participating in the second interview. Another participant thought that the transcript accurately captured her experiences and therefore did not participate in an additional interview. I was able to conduct six in-person follow-up interviews which were recorded and transcribed, as well as seven telephone conversations in which notes were taken. This data was included in the analysis, although no new themes emerged.

Data Analysis

The semi-structured interviews were digitally recorded and transcribed verbatim for analysis purposes. The analysis of the data followed the six steps outlined by Braun and Clarke (2006) for analyzing qualitative data using interpretive thematic analysis. The first step was to familiarize myself with the data, which was accomplished by conducting the interviews and transcribing the digital recordings. The audio recordings were then reviewed against the printed transcripts and notes were made to capture tone and emotional responses; primarily crying and laughing. The transcripts were then read and re-read numerous times. The second step was the generation of initial codes or ideas about what was contained in each individual data set (interview transcript) and how these initial codes revealed something of interest in relation to the participant's experiences. The transcripts were manually coded and for the most part driven by the data. In some instances, the initial codes were generated based on elements of caregiver experiences identified in the literature review process. For example, caregiver burden, recognition, and relationships.

The search for themes was the basis of the third step of analysis, and was conducted by reviewing the lengthy list of initial codes that were developed. I conducted this part of the analysis

by designing a visual map that grouped codes into potential themes, e.g. costs of caregiving, and physical and emotional responses to caregiving. The fourth stage of analysis was reviewing themes. This was a process that was conducted at two levels. The first level of analysis involved a review all of the coded extracts contained within a theme to ensure that it made sense. I determined, upon closer examination, that some coded extracts did not fit the theme for which it was originally allocated. This segment of coded extract was then put aside to be reviewed later to determine if there was another theme under which it should be captured or if it constituted yet another category. The second level was to review the themes as a whole to determine if they were representative of the data corpus, i.e., did they form a relationship that connected all of the data gathered to best reflect the experiences that had been articulated. A thematic map was drafted which helped me visualize the relationships between the themes. The fifth step as outlined by Braun and Clarke (2006) is to define and name the themes. This naming process is at the heart of capturing the essence of the theme and how it will shape the narrative of the data to be revealed within the findings. The final stage is the preparation of this thesis. This process will assist me in telling the story of the data which has been gathered. It will also serve to share the voice of the women who participated in this research.

Verification of Findings

As suggested in Cresswell (2007) I employed at least two methods to ensure validity in my research. The first strategy was the use of rich, thick description to convey the findings. As Cresswell (2003) indicated, the use of rich, thick description “may transport the readers to the setting and give the discussion an element of shared experiences” (p. 196). The use of rich, thick description gives prominence to the voice of participants. These descriptions are presented in the following chapter. The second strategy used to ensure validity was clarifying researcher bias

which was achieved through reflexivity, i.e., journaling throughout the data collection and providing an analysis. I was supported in this analysis through on-going discussion with my thesis advisors as well as the support of my social work mentor: a former professor of social work, researcher, life-long learner and caregiver. I was also able to discuss my experiences with other researchers in the field of gerontology. Reflexivity not only included an element of reflective practice but one that also encouraged self-questioning and identification of my own experiences, thoughts and beliefs related to caregiving, and the issues affiliated with this phenomenon.

Conclusion

This chapter illustrated the steps taken to design this research study, the methods used, and how they were positioned related to feminist thought, sample size and setting, as well as the approach to analysis and verification. A qualitative approach to the research, situated within a feminist lens, was highly suitable because it gave voice to the depth of the experiences of female caregivers. It went beyond the surface of quantitative numbers to the meaning and understanding of this critical feminist issue. The next chapter will explore the results of this research process, what the findings revealed in relation to the experiences of older female caregivers on Prince Edward Island, and how these experiences can shape recommendations for policy and program development going forward.

The older female caregivers interviewed for this research have created a series of observations, reflections and recommendations which will be shared, in an effort to not only bring focus and awareness to the issues surrounding caregiving, but also to give voice to a marginalized segment of society. It is hoped that through the research process and the awareness raising that accompanies the dissemination of this research that advocacy efforts will increase, and hopefully result in the adaptation and creation of new policies and strategies to best serve Island caregivers.

Chapter 5 - Research Findings

This chapter will present the results of my research. The data was gathered from semi-structured interviews with 15 female participants age 60 years and older who were providing, or had provided care, within the past year to a partner, parent, older family member or older friend. The first interviews were conducted between June, 2014, and February, 2015. Participants were then provided with a transcript of the interview for their review and asked to participate in a second interview to verify the transcript and identify gaps or any additional information they wished to share. These second interviews took place between March, 2015 and August, 2015. All interviews were recorded and transcribed verbatim. The research questions that this study was designed to address were:

1. What is the experience of older female caregivers living on Prince Edward Island?
2. What does it mean to be caregiver?
3. How do Prince Edward Island women describe caregiving?

The data gathered from these interviews was analyzed and four key themes emerged. The chapter will explore each of these themes. They are issues related to gender; stressors and growth in the caregiving experience; social policy and Prince Edward Island context.

Issues Related to Gender

Social and Cultural Influences

In interviewing female participants and employing a feminist lens through which analysis would be conducted, I was interested in their perspective on socialization and filial responsibility to see if the participants felt women were raised to assume responsibility for the caregiving role. As one participant noted: “It is, it is - to be social and to care for people (how we are socialized). Well, I think women are nurturing – nurturing, compassionate, organized” (Participant 10). One participant referred to the powerful pull of messages and behaviours passed down through the

generations.

“I think maybe that’s part of the reason why as a female caregiver of my generation that even though it might not be conscious, its subconscious that I am responsible for my parents and so I might not say that in one way, cognitively it’s not true, there’s an underlying message there from other generations. I think in other generations for our culture, it was an expectation that you looked after your aging parents or the aging family members” (Participant 14).

Another participant noted the societal expectation that women provide care.

“I think society has that expectation of us as well. You know, this self-sacrificing person, you know, isn’t that women do? They throw themselves on the altar of the family. I don’t think that one has to be selfish about it, but everybody’s got to chip in and particularly when you’re in a situation like me, where you really are the sandwich – a club sandwich. It adds... our daughter has been with us since last fall, so it just adds another dimension to it. As I say, she’s my daughter so she’s my priority and I think that helps me to keep myself in a balance, so I’m not over-reaching and you know, trying to do too much” (Participant 8).

The majority of participants very clearly noted differences in expectations around who would provide care, especially to aging parents.

“I think all my life I’ve been in a caregiving role. I have two younger sisters that are... one is almost 8 years, the other is almost 12 years younger than me and my mother always involved me in their care. I have an older brother who is just two years older than me but when it came to babysitting, I was the one who was babysitting even if he was in the house. It was just the expectation was that I would do that” (Participant 8).

Another participant shared how her parents relied on her and her sister, as compared to her brothers.

“... but some of the responsibilities fall to one of my sister’s and I more, because I think females – you end up with a different role and we run things by our brothers and they offer a different perspective and often a better perspective and so, we’ll take that into consideration, hopefully we come out with the best decisions but it’s interesting, interesting to watch that different role and the way mom and dad have certainly relied on their daughters more than on their sons” (Participant 14)

The participants stated that they felt there were obligations around providing care, not only from the broader society but from themselves. “It’s not what you’d like to be doing but it’s what you have to do” (Participant 4). A number of participants mentioned that it was a personal responsibility to assume the role. “I don’t think I had any options other than to buck up and do it and that was a personal responsibility” (Participant 2). “It’s just something that I feel I have to do. I’m never going to desert my husband and I just do it and don’t question too much about it. That’s all there is to it” (Participant 1). One participant noted the need to care, and it provided an assurance of dignity and compassion for the care recipient. “You just do it because you want to do it and you want ... you care about the other person and you know nobody else does, so if they’re going to get treated with any kind of integrity and compassion, you have to do it. You have to!” (Participant 3). Another participant indicated that often times women assume guilt around the caregiving role.

“I refuse to take on a guilt role. I mean I think that’s where a lot of women fit in, they have this guilt role. I’m not going to go there and neither am I going to see myself as some kind of an angel because I’m doing this. You just do it because you have to. It’s part of what you do as a family. You look after each other” (Participant 8).

Roles and Relationships

Participants also shared a great deal about their relationships with their care recipients, their partners, other family members, and their interactions with the larger system. A number of the women, who were providing care for their partners, noted that they felt it was imperative that they be the front-line caregiver.

“Marriage is not easy –it’s a struggle. It’s a struggle all the time and there’s never a time when ... you thought sometimes you might want to get out this, but you know, it comes out alright and my goodness, we had wonderful times together, really and truly, we thought almost alike after all that time, you really do” (Participant 15).

Another participant spoke about the obligations associated with having a partner. “He’s my husband, so you know I want to take care of him” (Participant 1). Participants mentioned that caring for parents provides its own unique challenges and rewards, such as the participant who felt torn between caring for her father and having time to spend with her husband. Her father was expecting that she would assume the caregiving role similar to that of his late wife. “That it wasn’t his wife anymore, it was his daughter and his daughter had other things going on in her life. I felt like I had a husband and boyfriend living with me in the same house” (Participant 5). One participant noted that the quality of the relationship between parent and the adult child providing care. “I think when I was younger I sort of didn’t get the quality of the relationship and the depth of the feeling and the joy of that very unique relationship and now I do and it’s at a time where I won’t have her for much longer” (Participant 14).

Our relationships and the roles we have greatly influence our experiences. The participants noted that the various roles and relationships they have shaped their caregiver experience – their interaction with their care recipient, their partner, other family members and the system including

physicians and other allied health and public professionals. A number of participants indicated that their gender influenced their caregiving role and that, often times, this was due in part to the expectations of the care recipient or other family members. As Participant 2 explained,

“There are several (women) my age who are doing the same thing, it’s the daughters who are there to help them if they need in the bath, or wash and curl their hair, or the personal things that I think the male gender – brothers, husbands – even when my father was alive, I did things for my mother that he probably could have done but I did, I think because I’m her daughter” (Participant 2).

Participants also noted that while men are involved in caregiving, they usually take on different roles. “I know families that have lots of sons who participate in caregiving particularly for elderly parents but they participate in different ways” (Participant 2). Others referred to the unspoken understanding of who tends to the necessities:

“She’d (mother) never would have said anything but that’s just the way it is. I have two brothers here and they both were very attentive to Mom but they wouldn’t be buying her face cream or making sure she has her Pear’s soap or you know, noticing that maybe I think I should take that sweater to the drycleaner’s or ‘Guess what? Mom needs some new underwear’” (Participant 6).

One participant noted that she was cautious of what behaviour she was modelling for her daughter.

“I talked to my husband a lot about, ‘you know, you’re watching what’s happening to me’ if you’re in this position, don’t do this to our daughter. I don’t want our daughter to be overburdened with ...I don’t want my daughter - I want my daughter to continue to be able to come into my place or into where (her father) is with a feeling of joy and not be coming in and thinking ‘Oh my gosh, I can’t do this today’ so that won’t always be the

case but for the most part, I don't want us to become one more thing on her plate and so I'm cautious of what she watches me do and how she will feel like that's what you do as a daughter" (Participant 14).

The participants also indicated that siblings were either involved and supportive in providing care, or stayed on the periphery of caregiving.

"I've got brothers, a couple of brothers that live there, that as soon as I even whisper something I need or want, they're there to do it or they fix things. That's when families are really supportive. Without supports I'd really have been lost; I'd still be lost" (Participant 12).

Participants also mentioned that often times, those on the periphery really do not understand the care recipient's needs. "She drops in occasionally and she really wouldn't have a clue what Mom's needs are" (Participant 2).

Participants also described their relationships with their partners and felt that programming for them would be helpful, so they could understand the demands these women are/were facing.

"Maybe if there was something for the partners of women caregivers, to help them understand that they can have an active role and how important that is and may not be involved in the care of the person who is being cared for, but just that they need to be aware of what this means for their partner, because some people are sometimes a little clued out or they're just shell-shocked by the whole thing" (Participant 8).

Participants also shared how their caregiving role may be perceived by their partner.

"You know I can pick up some times some resentment from him 'well, how would you have time to do that because you spend all your time with your parents', right? So I guess as a woman, I find myself being caught between the rigour of what I see – I see that mom

and dad needed me, you don't need me and the kids at this point, sometimes really need me but more we're at an easier stage I believe than what we were when they were younger, so as a woman I feel torn by the rigour and the demands" (Participant 14).

On the other hand, other caregivers noted the support they received from their partners. "Honest to God, if he wasn't there for me and if he didn't – like he has no expectations that I'm going to get other things done. He's just the most wonderful person" (Participant 7). One participant indicated that her own health is compromised and having a supportive partner has made a significant difference in her ability to provide care.

"You're really lucky if you get a good husband and a good caregiver and I live with a significant illness and I have a husband who is an excellent caregiver. He nursed his first wife when she died of a brain...so therefore I got that quality in this person who I know I can count on. He would be over there helping my mother in and out of the bathtub if it was necessary, but not everybody has that. Some men do not have that nurturing chromosome even for their wife, let alone an elderly parent and marriages can fail because of those things, ...this life for me now, is like my load has been lightened, because I did all those things by myself for 20 years and now I have help to do it" (Participant 2).

The participants were cognizant of how they may be perceived should they advocate for services. "I got scared that the doctors might all panic and Health PEI might panic and think, 'Oh what's she doing'" (Participant 1). One participant also expressed the notion of what "good little girls" are socialized to do.

"When it came to working around the health care system it was almost like that fear, if I speak up they're not going to give my mother the treatment she needs so I'll be a good little girl ... I even spoke to the head of the hospital about those signs, I said, 'Do you know how

that makes people feel when they walk in and the first thing to hit them in the face is that, you do not tolerate abuse”? I said ‘We, the people who do not abuse this system, feel like this little when that’s constantly in our face because we are scared then to ask the questions, we need to ask because of retaliation’” (Participant 5).

One participant also shared her thoughts on how the tide would turn with more men assumed primary responsibility for family caregiving. “I think that men wouldn’t put up with it and I think that I would, I could probably organize around this issue but I’m too tired to do that right now” (Participant 7).

Intergenerational Importance

Participants also noted the importance of intergenerational interactions:

“They’re putting a kindergarten back to the Beach Grove area. I am all over it! I feel really good about that. I’m encouraged by that little movement, because I think it’s again, part of going back and re-establishing that community in a different way” (Participant 9). Another participant referred to the value in having children bear witness to visiting their grandfather living in long-term care with progressive dementia.

“I think it’s good that they see their grandfather like that. They realize that he’s not like he used to be. No, you can’t shelter the children – they know. They know he’s not well and they know that he’s not coming out. He’s not going to get home.” Participant 11

Women’s Knowing

Participants described something as “women’s way of knowing”, an inherent value within women that allows them to know or understand something differently.

“I don’t think there’s any greater gift than service above self. I think you get it back in spades and sometimes when those opportunities arise and you’ve been involved in

something, whether it's an intimate decision like that, or something that's just very peripheral on the surface, I think you walk away and sometimes there's words to describe it, sometimes there feelings within you that you can articulate but sometimes there are no words. You just know and just knowing is enough" (Participant 9).

They also described a woman's inherent ability to protect and advocate.

"I haven't met a lot of men who are very good at that (advocacy). I haven't met a lot of women who are good at it either but I think we tend to, particularly women who've had children, you're used to advocating on someone's behalf, whether it's with teachers or whoever, you know, to get the results that you need and I think that perhaps maybe we have more life experience with doing that. I tease my sisters that these situations bring out the mother bear" (Participant 8).

Stressors and Growth in the Caregiving Experience

Transitions in the Caregiving Experience

Participants noted that their caregiving experience was defined by a number of transitions – becoming a caregiver, changes in the health status of the care recipient, transition between health care settings, death of the care recipient, and life after caregiving. These transitions were viewed as significant milestones in their experience. Participants indicated that their transition to the role was either immediate, due to a care recipient health crisis, or a more gradual process. "You fall into this caregiver role, we don't wake up and say "Oh I think I'm going to go be a caregiver to an elderly parent" – something happens and you end up in that role" (Participant 2). Other recognized the transition as something gradual:

"I guess you start to identify with that role and then it's very gradual what happened with mom and dad; so it's a much more gradual role and one that I took on, the nurturing piece

and the decision making piece I certainly was really – I felt really privileged to be in that role” (Participant 14).

The transitions were significant in shaping the caregiving experience. Participants shared a great deal of emotion around the transition to long-term care and how they require support.

“I will say to you and I think it’s important to be stated here that leaving my mother at the Beach Grove, was the hardest day of my life. It was. Yeah, I knew that she didn’t want to go but it was the best thing for her because then I knew that I had to keep her safe and I couldn’t provide that safety 24/7, especially when working full-time and even if I took a leave from work, I didn’t know how long it was going to be and I knew there was no turning back with her fragility, yeah, so I knew that this was just not a temporary thing. That it was permanent and it was only going to continue to perpetuate, but it was the hardest day of my life, when I took her there. Yeah, the ambulance went and I came right behind her and it was okay entering the building when she was entering in, but when it came time for me to leave that first evening, I couldn’t even breathe going home” (Participant 9).

Participants also shared the need for support for family caregivers during the transition to long-term care.

“That transition piece is really poorly handled and I think just somebody saying... and the staff would all say ... they’re used to it, because every day they got new residents, people dying. The staff would say, they’d see you going down the hall in a mess and they’d say, ‘Oh he’ll be fine, he’ll be fine’ - no big deal. ‘He’ll be fine, what’s your problem?’” (Participant 14).

Caregivers require support in their role. The participants spoke very candidly about what sources of support they have, would like to have, and what meaning it gives their caregiving.

Caregivers indicated that they made use of formal services from employee-assistance program (EAP) counseling to social work support, as well as the need for formalized, well-developed navigation support and communication around resource access and training. “I think what was the most help to me was when I sought out on my own, EAP ... she was really good and she really stressed to me the importance of me doing for me and getting out doing what I need to do. I found her very, very helpful” (Participant 12). Participants also expressed the need for continued support in their role. “I know there’s a social worker at the QEH, but there’s no sign of any follow-up at all. It was like when I was there, what did she help with? I forget now but I know when I went home from the hospital with him (care recipient), it was like, you’re gone and that’s it and it was like, maybe five years there was no follow-up” (Participant 12).

Another participant noted that the social worker was viewed as the care recipient’s and not there to provide family-centred care. “There was (a social worker) but for my husband. I had a social worker while they thought he was going to a nursing home but once he was coming home, that was it. It was over. I was working with a social worker and nobody ever mentioned anything like that, or ‘(Participant), you have to take care of yourself’.” (Participant 4). Participants referred to the support that came from accessing respite services via day programs.

“They did arrange – at the beginning he had a day in at Brecken House – he hated it. I thought to myself, well I’m kind of enjoying this day, so I said, “Well, let me put it to you this way (care recipient), this is a day when I get a lot of things done or it give me a day off. Maybe I could go to a movie in the afternoon or something or maybe... so you know what, I would really like it if you would keep going because it kind of gives me a day off, you know” (Participant 3).

Caregivers also described their need for timely resources, information, and how these supports are communicated to the general public. As one caregiver noted, the government is known to focus on revenue generation and promotion of the province, but very rarely if ever, do you see the same commitment to communicating resource availability. “You know they can bombard about tourism all the time, but yet to you don’t see anything about health care out there and where are the resources and how do you find these resources to help you through this” (Participant 5). One participant shared a wonderful idea about how to access the necessary information for family caregivers.

“We need information. We need lots of information and it would be nice if you could call 1-800-Caregiver, you know, for my province, for my community. Who do I go to, where do I get a walker or where do I get, you know ... well, we had the money to buy Mom’s hearing aids, what if I need a hearing aid? It’s all those things – what if I don’t have a family doctor?” (Participant 6).

Participants were also quick to share that front-line staff need to be informed about the programs and services offered, not only in their own department but across the health care continuum.

“They need some training for people to help them understand what resources are actually there and what they can access because even though the palliative care nurse that comes to see my him (care recipient) is so fabulous, I found out on my own about the other components of the palliative care that she never mentioned that he could have actually accessed earlier, if I had known about them and she’s fantastic! So imagine the people that don’t have access to any of that stuff” (Participant 7).

Participants noted that physician support was important, but more importantly the right kind of support and dialogue. “The doctor gave us a pad of papers and information kind of stuff, which really wasn’t a lot of help” (Participant 3).

Non-government organizations also offer support groups for family caregivers. Some participants found great comfort in the support they received and how it helped to normalize the process of caregiving.

“With the Alzheimer’s support group, it was interesting because hearing other people’s experiences let me believe that I’m doing okay, because some of them were doing too much. I wish I had made use of the Alzheimer’s support group earlier, but it really didn’t occur to me. I thought of all the time involved but it was an hour, once a month well spent.

No, I find I don’t ... you don’t know, what you don’t know” (Participant 8).

While others found the support group didn’t meet their needs. “I knew I needed support and I tried working with a self-help group but I didn’t find that very helpful” (Participant 12). A number of caregivers mentioned the creation of an organic support group, i.e., friends with shared experiences such as other families with a care recipient in long-term care. “I meet some people now that walk the same road as I’m walking and they give me a hug and they say ‘I know exactly what you’re going through’” (Participant 10).

One participant explained, it provides necessary social interaction for both the caregiver and care recipient. “You can go in and meet this one in the hallway and chit-chat and now, we can put him (care recipient) in the wheelchair and take him up to the foyer and there’s people up around there to talk to...” (Participant 11). As one participant stated, caregiving was an all-consuming topic when meeting with friends who were sharing similar experiences.

“It’s a nightmare right now. For probably the last ten years when I’d get together with my friends, if it was women, it would just be a ... we’d leave there and we’d say, ‘Look, next time we get together we’re going to say we can’t talk about our parents’ because it was just like we were all just totally overwhelmed by the burden and the complexity of the challenges that we are facing, that we didn’t see them coming” (Participant 14).

Non-government organizations have also provided financial support to family caregivers with one participant noting that a specific charity aided in the one-time purchase of specialized medical equipment. A number of caregivers also noted that in accessing programs and services of certain non-government organizations, that they were approached to volunteer with the organization to either participate in advocacy functions, and in particular to help fundraise to meet the organization’s program goals. “The organization was more about fundraising than it was about support” (Participant 3).

Challenges

Participants encountered many demands as a family caregiver, including how to find balance, a lack of time, housing issues related to care provision, care recipient issues related to a specific diagnosis or disease process, and the physical, emotional, social and financial demands of caregiving. Participants described wanting to achieve some level of balance in their lives between the demands of caregiving, personal interests, and managing other relationships.

“It’s a complex situation to be in. There’s so many different facets to it that it’s quite difficult to kind of explain it to somebody, because well, you do this but you also do this, this and this and then there’s the psycho-emotional support but then there’s all the other members of the family and it’s your job and how do you manage that. It’s quite difficult. You’re so occupied with the reality of the day, that you’re not really aware of what you’re

going through because your objectivity is all gone, is all gone and you're just trying to get through your day – wade through the day” (Participant 9).

One participant described the uncertainty associated with family caregiving.

“The challenges of caregiving is to make sure you carve out some time for yourself, otherwise you just get lost in it. It's just continuous and it never stops and you don't know how long it's going to go on. I mean Mom could be with us for another ten years and how do you, particularly if you are in a relationship with a significant other, how do you make time for that?” (Participant 8).

Physical, Emotional, Financial and Social Burdens

Caregivers often experienced physical demands related to care provision. “I'm tired out and I don't know whether I'm ever going to recover” (Participant 3). One participant indicated the stress of caregiving affected her quality of sleep. “So I slept with one eye open because that's one thing you do when you're the prime caregiver, you never really sleep soundly because you have to be aware of what they're doing all the time” (Participant 10). The physical stressors were also accompanied by emotional stressors.

“I was an emotional caregiver, let me tell you. Her physical condition was a little better than it is now. She was still using the walker to go out but emotionally – the emotional caregiver is probably more difficult than the physical caregiver, because the emotional aspect of caregiving can be what really kills you” (Participant 2).

A participant explained how emotional the first few years of her caregiving experience have been.

“Anyhow, you delve right into it – the first couple of years were terrible, I have to say, they were just awful. I think I cried every day probably and more than once a day and it's just gotten better over the years, you know, on certain days, things still aren't good and he's

not the person I married. He's not the same person at all" (Participant 12).

The caregivers also noted that caregiving strongly affected their personal/family finances – a demand that can lead to significant stress. "Our medical expenses were \$10,600 in that vicinity. Now that included trips to Halifax, trips to Moncton, the gauzes - those are not cheap, they add up a lot; the bandages, special bandages" (Participant 1). One participant explained the challenges of living on a limited pension income. "We just have our pensions so there wasn't an abundance of money, for sure and it did run into a lot of money because I had to buy pad protections for him and those cost money" (Participant 11). Participants faced financial stress in funding long-term care placement:

"He's subsidized right, so every year I meet with these people to renegotiate his fees and they tear your money, limb from limb. A new program that went into effect in 2007 because they used to take half of everything you owned and you could live in the house for as long and whatever was left at the end you might get some. Well now they take half of your income, which actually is better for them. When you first hear it, it seems like a good thing because oh well, they can't take your house and they can't take your RRSP's or your money in the bank or anything like that, so that's good. You know, you initially think well that's good but if you're someone who's going to be in there for eight-ten years more, it adds up. They get way more; they get way more than what half of your assets would ever have been worth, ever! So every year it's the same thing; every year it goes up and up and up, and they don't actually know for sure either ..., because they're a bit new at it right. I mean the first two years he was in there, they over charged me by \$10,000" (Participant 3).

The costs of long-term care can also leave family caregivers with very little to come and go on.

“When they (care recipients) go to a nursing home they (provincial government) calculate your income and stuff, now I’m finding it hard there. I know if we had the money I’d pay all my own way, there’s no doubt about it, but we don’t have it but it’s leaving me with very little money and this month now, when everything is paid, I only had \$20 left” (Participant 11).

Participants mentioned they were also asked to cover the cost of care despite the fact that no long-term care bed was available. “She had been medically released by her doctor and so they (government) wanted to start charging us so much and I said, ‘No, you’re not doing that because, guess what? You don’t have a bed for my mother to go to, so until you get that bed’...” (Participant 5). They were also asked to cover the costs of respite care in an emergency situation. “He was out there for 23 days because I had to go in for emergency surgery. When he was out there for 23 days it cost \$1200. Our daughter paid for that because I couldn’t” (Participant 13).

The caregivers also explained that they were also experiencing social losses due to care provision and how it has affected their ability to be socially engaged and active members of their community. “It’s certainly cut into our activities, very much so, in many ways” (Participant 1). Another participant explained how isolated and abandoned she felt in her caregiver role. “Once you get in that situation (caregiving) you very rapidly discover who your real friends are and people kind of disappeared” (Participant 3). Participants stated that time was an issue – there was never enough time to do all the things one would like, either in relation to providing care or finding time for oneself. “Juggling time, sometimes feeling guilt and shame because their request and needs don’t fit your schedule, especially if you are working full time and then you tend to them” (Participant 9). Some participants revealed that non-government organizations such as the Heart and Stroke Foundation or Alzheimer’s Society offer caregiver education sessions. The

aforementioned organizations target family caregivers based on specific disease/incident issues.

As one caregiver noted,

“They had some workshops there a while ago but they were always during the day and could I have asked for it, to be off and be given it? Yeah, I’m sure I could have. The thing is you never know when you’re going to need, like I always feel like ... there’s something else that I might need time for” (Participant 4).

Participants also faced similar challenges with homecare services.

“I did get help from the home care – they came in and they bathed him. At first when it started, they started every day; then they cut the weekends out; then they cut some days out here and there, coming on the last of it, I think they were coming three days a week. There was a lady coming one afternoon a week from 1 to 3:30 – two and a half hours, I really appreciated that time; I don’t think it’s long enough. For me to leave here, if I had business in Charlottetown and drive to Charlottetown and do my business and come back home, it didn’t give me near enough time” (Participant 11).

Participants also noted how their relationships with others affected their caregiving role. The women shared their experiences with their adult children and their involvement (or lack thereof) in helping to provide care and support for the care recipient and caregiver. They also shared that they continue to provide support to their adult children. “You guys don’t understand. You don’t. I mean you come into see him once every two or three weeks and that’s it and you’re there for like twenty minutes and you’re gone. You don’t understand” (Participant 3). Adult children who are experiencing their own life transitions, place demands on the participants. “I help my youngest daughter with her five-week old baby. She is a single mom, who has a relationship with her ex that is tumultuous, so I have to be there for her and she’s my child. She’s my priority”

(Participant 8). One participant shared the phone call she received to let her know that her son was moving to the Island and needed to “re-nest” in order to manage the demands of his own life. “Our son is 27, and he called this morning; ‘Mom, I need to come home. I need to leave here. I need to come home. I need to live with you guys and save some money. I need the support you can give me for a year to get my debt under control’” (Participant 7). They also indicated that other family members were often times not helpful either. “Unfortunately the rest of the family wasn’t stepping in and I was allowing them to do it” (Participant 5). Participants also mentioned that they were involved in grand parenting as time permitted, and noted that the stress of caregiving also impacts their ability to fulfill other roles, such as grandmother:

“Look, I’d be quite willing to take that job on at his (my grandchild’s) house, because I think it’s important for little people to learn what home means. This is my home. This is my territory and do his exploring in his own place and also the other grandmother agreed to help. So we were sharing it, which was nice and also gave us a chance to get to know him” (Participant 1).

One participant shared her frustration in not being able to fulfill the role of grandmother as she had hoped. “I’m not the grandmother that I hoped I’d be. I don’t feel like I’m able to visit them or see them as much as I’d like to” (Participant 4).

Participants also faced issues in relation to housing, either having to find new housing during the course of their caregiving or having to make home modifications to accommodate a care recipient who experienced a stroke or other mobility issues. “‘You better find a place or he will be going to a home and you’ll be living by yourself somewhere.’ Not nice at all. We weren’t nicely treated” (Participant 13). Participants also explained the need to change physical structures to accommodate mobility and to make the surroundings more user-friendly. “My husband gutted

the bathroom on the main floor and made a user-friendly bathroom for seniors. We did a lot of research about that” (Participant 8). Participants indicated that there was something related to the care recipient’s health diagnosis that placed certain demands on them as well, whether it was the aforementioned home renovations to accommodate an older adult or stroke survivor, or a disease-based diagnosis such as dementia. “There’s been a lot to learn about the disease itself, about what to expect about the differences. I’ve done quite a lot of research” (Participant 1).

System-Related Stressors

Participants also mentioned the stress of having to navigate the health care system:

“I went and spoke to some different agencies within government about how I might proceed through that whole cobblestone network of ... it’s like a minefield almost, you know, it’s like a matrix and you’re not sure who to speak to. Within the government, everything is so convoluted and so complex and so many layers, that really no one’s got a handle on it, but what’s more alarming to me, is the shortening of responsibility and accountability within that role, that should be embedded in that role, that lack of – just in the appearance of a good moral compass” (Participant 9).

One participant noted that even information designed to assist you, is almost overwhelming to navigate in the midst of caregiving - “even to find your way through a (helping) tree when you’re trying to cope with significant, serious issues – it’s pretty hard to even do that. You just need somebody to say, “Go do this. Today, you go do this” (Participant 4).

Participants described the homecare experience for them, as well as their care recipients. “It’s not quite what it’s cracked up to be” (Participant 4). Participants also employed private home care services. One participant also referred to the challenges with staff turn-over, which was also discussed as part of the staffing challenges in long-term care.

“I’m stuck with having to re-orient a new person, so I figure, that it takes about half an hour to show them where everything is, what to do, what Mom ... I have a list of things for Mom that need to be done and you know, by the time you finish that, half an hour’s gone by and I figure, I have given them three hours at \$25 dollars, no, actually six hours at \$25 an hour over the last year, of me training their staff” (Participant 8).

The challenges experienced by private homecare services in retaining staff may also be attributed to the fact that the majority of homecare providers are women; i.e. the jobs are care-based, usually low paying and offer little if any opportunity for advancement. Participants also hired homecare support for their recipient in long-term care to ensure that the recipient was not alone at end-of-life. “‘We have to get somebody to sit with Mom.’ So we hired We Care” (Participant 6).

It is widely understood that there are significant wait times at the emergency department in our acute care centres. Every participant touched on the length of these wait times and what they mean for care recipients and the system as a whole. “I thought I would drive myself crazy because you have to go to the emergency department every time and you’re sitting there, oh Lord... It always happens on a Friday night or a weekend or something like that” (Participant 8). Participants also mentioned the wait times associated with long-term care placement. The provincial government list for long-term care is something that has been discussed for years and despite efforts to alleviate the backlog of medically discharged patients in acute care, the list is still noted as being one of the major stressors for care recipients and caregivers alike. “She waited almost a year to get into the nursing because they didn’t have anybody that could do her dialysis” (Participant 5). Participants also indicated that there was limited time to process their losses, when individuals were waiting for the bed for the next individual on the list:

“We came out of that home, all of us, at midnight that night dad died and the next morning

before 8 o'clock they had told us, and actually I was pretty sensitive because I remember what it was like waiting for a bed, so I thought, you know, dad's bed is empty but my brother and I were back in there at 7:45 the next morning, cleaning out dad's room. It was like, 'did that really happen?' It's terrible, but the point really is what you said, that it's all these transitions when you are in those homes; everybody has to get in and clean out that flipping room within hours of the death" (Participant 14).

Participants offered suggestions on how the process may be changed, particularly for those caring for an individual with various forms of dementia or other rapidly shifting decline. "It would make far more sense (to have a rolling long-term care list) and Dr. X has advocated for this for years and he's very frustrated by it, because he sees families struggling" (Participant 8).

Participants cited challenges with the physical and social environments that provide care to older adults. The physical environment of long-term care facilities configuration and need for privacy was indicated. "You couldn't swing a cat in that room. It was scary. Two wheelchairs could not pass in the hall" (Participant 6). One participant noted the need for space and an easier introduction to long-term care for the recipient and family.

"We're in a really difficult situation, it's dad's first day here and he's in a room there with someone who is hallucinating and really bellowing some pretty awful things and he's dying and we're trying to stay really quiet in the room but it's really not a good entry and they said, 'Oh well, we usually take them out into another room', which we came to know of course, 'but those rooms are full right now because he's the third one that's dying in this building right now' and I said, 'Okay, we're going to have to make an alternate arrangement here because we're not leaving dad here like that, so either we're taking dad home again and we'll figure that out, but he's not staying here'" (Participant 14).

Participants also mentioned the need for physical renovations and timely maintenance:

“(He went to) the manor in Montague and that weekend didn’t go so well. So, they didn’t seem to want to take him back after that weekend. The security on the door for one thing wasn’t working, even if it had have been shut ... so apparently they were supposed to have gotten that fixed. That kind of upsets you a bit because they phoned right away and let you know and then all weekend you’re worrying if you should go and get him and the girls said, “No, leave him, there’s not going to be anything happen to him.” Well I hope not!” (Participant 11).

Participants indicated that the social environment and programming didn’t really meet the needs or wishes of the care recipient:

“At the beginning he had a day in at Brecken House – he hated it. He hated it in there because it’s a lot of the activities they do, they are the same as what they do here (long-term care). I mean he’s not interested in painting pictures, like a ten-year old would; that wasn’t his thing or crafts ...” (Participant 3).

Participants explained that the staff was wonderful but the programming piece needed some work. “It was a good program, the girls were excellent and everything but the program itself; like he was colouring, He was doing – he couldn’t do puzzles, what else did he do? I think they played cards – to me it was a babysitting thing, that’s the way I thought about it” (Participant 11). As one participant noted, programming should be based on people’s skills and abilities:

“Respecting their talents and their skills. I mean, everybody has skills and I mean you don’t have to be a university prof or anything like that. There are things – everybody has things that they can do that are important and you can do them right up to the very end, if you can

move, even if you can't move you, there's still something there that you can do. I think that's important" (Participant 6).

Participants stated the need for honesty in communication. A participant mentioned how frustrating it was for the physician to not adequately communicate that the services required were beyond their scope. "It just annoys me that he wouldn't say, 'I can't do it, but somebody else can. I'll refer you.' We've been to Halifax, I think it was 11 times in 2012 and 11 times in 2013 (for specialist care)" (Participant 1). Participants indicated that some of their most significant challenges were with staff. "That's the biggest barrier – it's the staff. I have no credibility for them anymore. Absolutely none" (Participant 3). Participants also noted that staff seem ambivalent to their role in communication and providing a needed sensitivity toward recipients and family caregivers. "They are desensitized. The nurse goes, 'Hey, where's Muriel, did she die or did she move somewhere else?' Yells it! Nice ... real nice" (Participant 14). As one participant mentioned, the approach to providing long-term care seemed to be – "I think a lot of their philosophy is like, 'Well you came in here because you're on your way out, right?'" (Participant 3). Participants also indicated the need to implement a best practices approach in long-term care. "I was really horrified by some of the practices but there really needs to be a look into what's happening with elder care inside the homes" (Participant 14). As one participant mentioned during a discussion around palliative care in long-term care, staff need to be able to communicate differences in care provision and to understand what true care looks like within the long-term care setting.

"We started talking about palliative care and so they arranged a meeting and I wasn't planning on asking the kids because, basically they wanted to know, to change his directive and I thought, that's my decision, not theirs and then I thought, they also wanted to talk too about care and how things might proceed and stuff like that and they talked about ...

actually after the incident they were actually calling his care, palliative care : “So you know we’re going to have the staff – every time the staff goes by they’re going to check and make sure he’s not coughing or choking, just kind of a walk-by, just to make sure everything’s okay and we’re going to make sure that this happens and that happens and he’s going to get good care” and X (our son), when they were done, X (our son) says, “So how is that any different than the care he should have been getting all along?” (Participant 3).

Participants spoke of the need for staff to understanding:

“Can you tell me when I could expect that someone would be seeing my mother, because she has to have dialysis later on today” and she looked at me and she pointed, you know those horrible signs they have on the wall, that say ‘We do not tolerate abuse’ she says and ‘We get to the most urgent patients’ and that was her tone to me” (Participant 5).

Participants also noted the need for ongoing staff education. “There needs to be training and oversight”. (Participant 1).

Participants spoke about the importance of having a presence, despite the location of care.

“Having a presence there (long-term care), knowing the staff and making sure dad knew the staff and finding ways to help him to make connections to other residents and to the staff to ensure that there was a personal connection” (Participant 14). Another participant indicated that her caregiving role did not end when her care recipient entered long-term care. “I’m still looking after him four and a half years later at the nursing home. I actually think they should be paying me to be there” (Participant 3). One participant noted that she relocated to be closer to her care recipient who spent a great deal of time at the Island’s primary referral hospital:

“I was there 12 hours a day from 8 to 8. I moved down to Charlottetown with my daughters and yeah, because I really felt he needed extra care. I think a lot of the time people don’t get the care in hospital they really need and family members do it. I knew enough to know that, having been working in health care all the years that I did” (Participant 12).

In light of the stressors discussed above, the participants employed a variety of self-care strategies. For example, caregivers referred to the importance of self-care and how their faith and sense of humour supported them in their caregiving role. “If I don’t care for myself, I can’t care for anybody else” (Participant 8). Others discussed how their religious and spiritual beliefs helped them to cope; “I praise God every day. I’m a tremendously lucky woman to have a family like this and to be able to stay here in this house” (Participant 15). Humour was also mentioned as being important; “There’s always something that makes me laugh anyway” (Participant 13), as was physical activity; “I joined the gym and I go to the gym a lot and I do yoga, so five days a week I do the gym and yoga so I really and like I say, I do it for mostly my head and you know, the people I meet there and it’s in Rustico – Rustico has a gym and it’s just been a really life-saving thing for me” (Participant 12).

Positives of Caregiving

While there were many stresses inherent in caregiving, participants also expressed positives about their role in providing care. For instance, some of the participants noted that they experienced a sense of fulfillment and privilege in their role:

“Well I guess it fulfills something that I can do. I think if I was able to give care to him and denied him of it, I don’t think that I would feel fulfilled at all. You know, life throws people all kinds of bad things and you deal with what you are given and I never back down from anything and I mean I couldn’t back down from this, this is what it is – everybody’s got

something to bear and this is mine and some days it's rough and some days it's not rough"
(Participant 12).

One participant referred to the value of having time with her parents, which was particularly meaningful after their deaths. "The biggest positive for me was that I spent more time with my parents. You get to ensure that they are getting the right care whether it be their doctor's care or their care at home, that's the positive of it. That's my bonus" (Participant 5). As a result of their caregiving role, a number of participants noted that they developed skills to support the care recipient. "I got so that I could dress it as well as, or better than some of the nurses" (Participant 1).

Caregivers also mentioned that having a grateful recipient and/or family also created positive feelings about their work as a caregiver. "Now I know he's grateful, most the time ... of what I do, but I don't hear it enough, I do hear it some" (Participant 4). "My one sister would always say, 'Thank God you're there because you make it easier' and I think I took some of her guilt away" (Participant 2). Participants indicated that there were a number of positive emotions, namely not having any regrets about their caregiving and feeling good about the care they've provided. "I would do it again, definitely. I had no regrets about doing it and I wish I could have done it longer but I didn't mind what I was doing" (Participant 11). "You can't be looking for external kudos for this. I do it because I will have no regrets. I will have none. The no regret thing is huge for me" (Participant 7). Participants also noted that adding a quality of life for the care recipient was also fulfilling. "Well I guess it's sort of a ... helping the world, the community, the family be a better place and the fulfillment that I would get from being with someone or leaving someone and knowing that because of your role there, their lives are a little bit more enriched, so that's the positive side of it" (Participant 14). Participants also gained valuable skills that were

indicated as having a positive effect. Participants also mentioned that they became a student, not only from a skills perspective, but from a research standpoint. Participants gained skills in providing hands-on care to their recipient, as well as learning to research new treatments for specific issues. As Participant 1 noted, she engaged in her own research to help advocate for a change in treatment for her care recipient. “I started to do a lot of my own research and that’s when things started to kind of go a little bit right” (Participant 1).

System-Related Positives

Participants also mentioned positives in their dealings with health care professionals:

“She, (the acute care social worker), was worth her weight in gold and she would meet me in the hallways some days and sometimes she’d say something verbally and other times she’d say something non-verbally but I always knew that I had her. I had her on my side and she’d give me little cues some time, limited but adhering to her professional ethics and her good code, but she would give me little clips every now and then that I could kind of put together and I’d kind of piece it together and say, “I’m thinking that such and such ...” “I think that’s a darn good idea.” I’d say, “Perfect!” So, I did, that was, that kept me afloat – that professional support, yeah, the social worker. I can’t say enough the need for the good social worker. We don’t have enough, we don’t have the numbers of social workers and we don’t have necessarily the calibre or qualifications within the social work department” (Participant 9).

Participants also noted other positives in their relationships with staff. “You know when my mom passed away, they (the staff) were standing there crying with us, but it was like night and day between the two places (long-term care & hospital)” (Participant 5).

Professionals can also help to alleviate issues faced by caregivers and care recipients. “Her (care recipient) prescriptions were each due at a different time and they can only, under the senior’s drug plan, they can only issue certain ones at certain times. So I talked to the pharmacist and said, you know, ‘Is there any way we can do this because it really is just one of those things that I have to count the pills out into the little thing and then I, oh this one’s out and then two weeks later, this one’s out’. So I talked to the pharmacist and ‘Oh no’, she said, ‘We can sort that out.’ She said ‘She’s eligible because she has dementia and she’s a senior’ so what they do, is they, the first couple of months they kind of give you partial prescriptions, just until they get everything lined up on the right date and so now, for the past month we’ve had this pill pack every week. I can’t even begin to tell you what a relief that is. You don’t even have to call to get them renewed. They automatically have them ready for you” (Participant 8).

All health care providers have the opportunity to support family caregivers and it was mentioned that positive reinforcement was offered by emergency medical services. The new palliative care home care program that sees emergency medical personnel providing home-based palliative care is receiving positive acclaim. “So I called the ambulance at 4 o’clock in the morning and they said, ‘no, you did the right thing’” (Participant 13). Participants also felt positive when front-line staff recognized their advocacy efforts. “People were coming up saying, ‘God, we really appreciate it’, even the nurses were saying, ‘You know, this is so overdue. This should have been done a long time ago’” (Participant 5).

As one participant indicated, honesty in communication is extremely valued. Participants also greatly appreciated physician honesty in diagnosis and process.

“Do you know what your mother’s diagnosis is when she came to you?’ I said, ‘Yeah, they said it was early stage Alzheimer’s.’ He said, ‘That’s correct. She now is moderate. This disease is progressive, it is incurable and it will get worse.’ Just like that, and I thought, you know, thank you for just ... And for telling me exactly how it is, because I don’t know. I don’t know what’s going to happen. Until he actually had that conversation with me, I wasn’t able to have that conversation with her like that. I wasn’t sure how’d you talk about it with people” (Participant 8).

Approach to Caregiving and Meaning-Making

The participants noted their approach to caregiving as well as the meaning it holds for them. The participants assigned meaning to their caregiving; whether it was a reciprocal care agreement between parent and child, or something more philosophical. “It’s a pay-back thing, from being looked after when you were a kid. She braided my hair and looked after me and told me all about the facts of life and it’s payback time now, yeah it is – it’s a gift; it’s a privilege to be able to do it” (Participant 2). “There’s the sort of humanity of working and caring for someone who you’ve loved so much all your life but also seeing other sides that you probably, particularly as a father-daughter would probably prefer not to know or not to see” (Participant 7) One participant communicated that it completed the circle of life – our own personal evolution and understanding of the complexity of life:

“I think no matter who you are it completes the circle of life. It completes your understanding about the coming and the going and then all of the life that happens in between and just as I felt so strongly with my mother, I feel the same thing now, that it’s a privilege to go through this process with someone. It’s not for the faint of heart and it can’t

be a half-commitment. You may not know exactly what you're getting yourself in for, but once you decided to do it, there you are" (Participant 9).

Future of Caregiving

Participants philosophized on what the future of family caregiving is going to look like and possible solutions to support family caregivers. Participants discussed the idea of a coalition or group to support family caregivers and advocate for services, programs and timely communication. They also felt that serving as a mentor to people who are new to the caregiving experience would be of benefit. "I think the best idea that we've talked about today was the idea of a group and, mind you, there are all kinds of people with all kinds of medical experiences, all kinds and we're going to need this more and more as the population ages" (Participant 1).

The participants also reflected on their experience, post-caregiving, as some had transitioned out of the role. "I want to get involved in some of the seniors' stuff because I know I'm heading towards that, not too far distance, and I don't want to be in a boat that I don't have somebody to look after me or have my rights taken away from me" (Participant 5). The participants felt strongly that they would have a role mentoring others or providing helpful assistance and advice. "I've always tried to make sure I share all the information that I know about what people can apply for or what services are out there ,and, you know, it just kind of raised the marker for me that, you know, even when you're in the system, you don't necessarily know everything that's there" (Participant 4). Another participant offered how she intends to support family caregivers after her own personal journey has ended. "You know, if I'm blessed with health sufficient after he (care recipient) is taken, I'd like to be able to find people who are going on the same journey as I am and offer to go in and stay with their partner and let them go" (Participant 10).

As one participant described, the caregiving experience had changed her.

“It’s a new self. I know if you and I had had this interview three years ago when I was coming into retirement, adjusting to retirement when I wasn’t ready to leave the workforce, I was ready to leave the job and take on mom and dad, which in some ways, were easy then compared to what it was going to roll out, I didn’t know. I would have been in a puddle talking about it” (Participant 14).

Participants noted their concerns about who will provide care for them as they age and face uncertain health. “I live in fear of that happening to me (of having adult children not interested in a caregiver role). I’ll be one of those ladies that lays in bed there and doesn’t see anybody for weeks on end; doesn’t know where she is and what she’s doing” (Participant 3) The fear of who will provide care was a real concern for participants. “What I’m terrified about, is I don’t have any daughters. I have two sons so I’m really sucking up to my son’s new bride. He’s getting

Social Policy

The theme of social policy includes findings related to benefits, strategies and plans, that shapes policy and caregiver issues for an aging population. Policy influences most, if not all facets of the caregiving experience at both the macro (federal) and mezzo (provincial) level. At the federal level there are tax credits and benefits to support caregivers, as well as programs and services for a segment of the population. At the provincial level, there are no benefits aimed solely at family caregivers and no legislated, formal recognition of family caregivers.

Tax Credits and Benefits

A number of caregivers identified tax credits and benefits as an issue. Participants indicated that the tax credits were not well explained, nor do they truly provide the support needed by caregivers:

“I didn’t even know that they existed and also I think part of that goes hand-in-hand with, I don’t know what the rules are on it but usually there’s a cap, if you make so much money, you’re not entitled to it. I find that all of those packages for caregivers for any kind of a benefit are all based on low income, so I as tax-payer I get to pay that, but I don’t get to take the benefit of it” (Participant 5).

Some participants expressed challenges in accessing the Compassionate Care Benefit (CCB). As one participant indicated, she had quit her job to provide care to an aging parent and was not entitled to EI benefits. “The only thing I know about is the six weeks you can get with EI. No, I can’t access it. I think it’s dumb because my brother could access it now, because he’s working ...” (Participant 7).

Support for Veterans

The federal government’s Veterans Independence Program (VIP) through Veterans Affairs Canada provides much needed support for the care recipient and alleviates some of the burden from family caregivers. “She’s a veteran of World War II so DVA looks after her very well...she has no financial restrictions to getting good care which I believe can be a very big contributing factor to good care” (Participant 2). Others recognized that without the support, the care recipient would not have the same quality of life. “Part of the reason why dad is so comfortable is because we also have funding through DVA ...this would be a much, much different situation if he didn’t have access to those resources” (Participant 7).

Strategies and Plans

There have been repeated calls for federal strategies to support Canada’s aging population as well as provincial strategies around seniors, caregiving, and palliative care. The participants expressed similar views on the development of a provincial caregiver strategy:

“There’s nothing more fruitless than developing a strategy and not talking to the stakeholders – the people that need to know what they’re doing. I think that they should talk to lots of caregivers – there’s different kinds of care and they should all, whoever is going to develop this kind of strategy better be damn sure that they know what kind of care we’re talking about and it’s not just about wiping their butt and putting them in a chair and putting them in a clean gown; that without all of the other mental and physical and structural supports, I mean you can scrub somebody clean and prop them up but you’re not giving good care unless you’re also making sure their mind is as well as it can be; that they’re stimulated and it’s not just in front of a TV. That they’re with their peers and that they have the whole, I guess it is that holistic – the mind, body- everything together and not just ... we get so focused on the bars in the bathroom and the walker and all those things we think we’re giving good care, but that maybe the best care is 40 minutes twice a week just to talk to somebody and that, they better be looking at all that” (Participant 2).

This sentiment was re-iterated along with the need for action when developing policy. “No, it’s just a strategy. It’s just words. There’s no action associated with it” (Participant 8).

Employment

A number of participants were still employed or had retired to provide care to their care recipient. As aforementioned, access to benefits for family caregivers has been primarily tied to the federal employment insurance program, so women who were no longer working could not access the financial support of the CCB. As one participant stated: “I’ve worked longer because of him (care recipient) being home” (Participant 4). Caregivers who had to retire to provide care also revealed their experience. “I wasn’t ready to retire because I really liked what I was doing. I loved it there but you’ve got to do, what you’ve got do, right? So, I did it and you know, I never

looked back. You can't" (Participant 3). Participants also indicated that there were limited policies to support time off to provide care and that when they accessed such support, there was also the pressure to return to work. "There's nothing at my workplace (one of the Island's primary employers). Absolutely nothing" (Participant 5). "I was asked to come back to work ... you don't really feel like you have a choice to say no. So, I did work. ... so I agreed that I'd come but I had to be able to go home a couple of times during the day, just so I could make sure everything was okay, but I'm still really bitter about that" (Participant 4).

Advance Care Planning, Palliative Care, and Physician Assisted Death

The majority of participants mentioned, that advance care planning was something they had discussed with their care recipient.

"We're out here (hospital emergency department) waiting the many hours like everybody waits, regardless of what you come in with, and I go to the washroom after I'm here for a couple of hours. So I come out from the washroom and she said, "Well that's taken care of", I said, "What?" And she goes, "You see that dark fella sitting over there at the desk?" I said, "Oh yeah, Dr. So-and-so" "Yeah," she said, "He has my whole story." I said, "What?" and she goes "Well, he came over and he just asked me a few questions and while he was here I wanted to make sure, I wanted to make sure that he knew that there's no heroics here. That it's time, it's time – if I should do something funny here, you know, I don't want your machines on me and I don't want anything else, so don't do any fancy things, just I'm ready to go. So I told him, I'm ready to go." And I said, "Did he ask you about no code? Is that the word he used?" and she goes "Well, he said some word. She said, I'm not sure if it was no code or not, but she said, it made me think that I don't want any special stuff done." I said, "You told him that!" I said, "You never told me that." "Oh,

I'm sure I did at some point in time." "You didn't hear me." I said, "Maybe not, but I said, I'm hearing you right now." So that was the beginning of that discussion and that was the end of the discussion because it never waived after that. So she reminded me time and time again, "Now we're going back to the hospital. Remember there's nothing. There's nothing and I'm going to sign for that, because he told me I have to sign for it" (Participant 9).

A national framework, *The Way Forward* (CHPCA, 2015), was developed to guide discussions around palliative care access and quality. Participants indicated that they weren't overly familiar with existing programs provincially, or how to access them. "We haven't sold it. Nobody's educated them – they don't understand what the concept is" (Participant 6). During the research interviews, a number of participants spoke freely about physician assisted death despite the fact that the interviews took place prior to the national news around the Carter decision.

"So what's going to happen when I'm ... if I make it to 80-85 whatever ... I'm scared and between you and me, I'm not going there. No nursing home for me. I'm going to take a pill or something. You can record that, I don't care. I'm going to control my destiny, somebody else isn't going to push me in a chair and tell I'm going to go to a singing class" (Participant 6).

Systems of Policy Making

The participants mentioned that broader systems exist to develop policy and plans. These systems are comprised of various stakeholders and organizations that should be focused on supporting family caregivers. A number of participants indicated that on Prince Edward Island, individuals have easy access to our politicians and policy makers. "We have such access to policy makers" (Participant 7). Participants expressed their thoughts on how the system works and the impact of the decisions that various levels of government enact. One participant felt that physician

assisted dying would be based on pure economics. “I believe that will be a totally economical decision – they will be paying us to inject us (physician assisted death), because how the hell are we going to keep up? You can’t do it” (Participant 14). Another participant shared her views on the provincial government’s investment in homecare. “The province talking about homecare and putting more finances into homecare; that is only good to a certain point” (Participant 6). Participants noted that challenges in the health system, and the lack of planning and recognition regarding the anticipated needs of an aging population. “That’s the scary part because I don’t think we’re prepared (for the boomers)” (Participant 6). One participant noted that she feels the expectation is understood but the overall need for preparedness has not yet been recognized.

“I think the expectation is there, but the readiness is not there. They have not put into place. Yeah, the political-ness of it, is not there in terms of the resources, the supports, the 24/7 – I’m talking about the 24/7, the respite care for the providers that take on the 24/7. There’s a lot of infrastructure, a lot of infrastructure that has not been anticipated and some that has been anticipated, has not been implemented yet” (Participant 9).

Other participants recognized the current state of the health care system and the inappropriate use of Island hospital emergency departments. “The health care system...it’s in rough shape and there are so many that are using that hospital for a clinic” (Participant 5). Participants also referred to the economic challenges of providing care to an aging population. “No government’s going to be able to afford to provide the paid care for and the paid respite that people are going to need” (Participant 10). One participant noted, that with the increased financial costs to the system, the reality may very well be, either you pay for services or you provide them, yourself. “No, there will be the economic pressures too of the reality of ‘do you want to pay for it’ or ‘can you handle it within your family’” (Participant 14). Participants also recognized that we

can't expect the government of the day to address every single issue, without being engaged ourselves. "We as individuals can't expect the government to do everything" (Participant 5). One participant mentioned that front-line government employees and health care staff probably feel defeated in addressing the challenges of the health care system. "I suspect that they see all kinds of flaws in the system and probably feel that there is nothing much they (front-line staff) can do" (Participant 1).

Participants also expressed concern about access to long-term care and the number of beds available. "They built the same number of beds! Are they crazy? There's going to be a crisis. There were no beds and that's the problem. There are not enough long-term beds. I am terrified what's going to happen, like I'm a baby-boomer and there's a lot of us that are in our sixties. I'm a stroke away from going out to Beach Grove or wherever" (Participant 6). Participants also spoke about government investment in home care, as part of the model of care.

"Now they're putting great store by the homecare, I know that, that's very much a part of the new model of care" (Participant 1). Participants agreed with this approach, to an extent. "Government's making a lot of their investment in home care, which I agree with" (Participant 10).

The issues with the system also extend to municipal levels of government, with caregivers facing challenges in accessing building permits to provide support for the caregiver and care recipient.

"When I first called city hall about it, they told me it didn't matter who lived in the in-law suite and I was so relieved, you know, thank heavens we can stay in our home. The last thing was yesterday when they said, 'We need a copy of your deed.' I said, 'Well, I'm pretty sure you must have one. How do you know I own the property? Like how do you

know we own this property and that we're residents here? You bill us every year so you must know!', "Well we just need a copy of the deed" (Participant 4).

Recognition

The participants also m how they were, and were not, recognized in their role and equally as important, how they recognized themselves. "When I take her for a nursing appointment, health appointments, they ignore me; you know, 'Who are you and what are you doing here?' and sometimes that literally what is asked, not in a pleasant way" (Participant 14). One participant shared that her family recognized the commitment she had made in caring for their parents. "We (family) want to thank you for all you've done for mom and dad. All through the years and you're the one that did it all' and they... I was blown away and to have that acknowledgement didn't make up for it all, but it was so nice to realize that they knew that I had put everything that I could to do for mom and dad" (Participant 5). One participant shared the growth and self-development that came from her caregiver role and how little the experience is recognized in social and professional circles. "It's a time of incredible self-reflection on what life means and not only the, as we were talking about earlier, the coming in and the going out and how important that is and how little value society places on that and I now put on my resume "caregiver" (Participant 7).

Prince Edward Island Context

Participants also touched on Prince Edward Island culture and what makes caregiving on PEI unique, suggesting that women raised on PEI and Islanders in general, have the feeling that: "They're so, 'that's the way my Mom did it, that's the way we did it for generation' I think in other generations for our culture, it was an expectation that you looked after your aging parents or the aging family members" (Participant 6). Participants also indicated a shift in our rural Island communities and the impact that is having on health care delivery, community connectedness, and

engagement. “This community has changed. There’s a lot of new people in it” (Participant 11). They also noted the decline of traditional community-based engagement. “There aren’t nearly as many Women’s Institutes anymore as there was 30 years ago” (Participant 1). The Women’s Institute movement on Prince Edward Island has been rather significant over the past number of generations, as it served to bring women of the community together. As their tagline suggests, they are “an educational organization focusing on the family, personal growth and community action”.

Physician access. Participants also mentioned how these shifts have affected the delivery of health care in rural areas and how their relationships with physicians and other healthcare providers have changed. “You don’t have that 24 hour crutch to lean on, that you know that if something unforeseen happens or you don’t know what to do, all you had to do was call your doctor” (Participant 10). Participants were also very vocal about the perceived lack of family physicians. “We’ve got all these people that don’t have primary care physicians. We’ve been here for two and a half years and we do not have a doctor” (Participant 7). Participants also noted the effect that this is having on primary care and acute care delivery. “I’d say they’re (those without family docs) falling through the cracks and they’re in emerg and taking up beds in emerg or they’re going to clinics” (Participant 6).

Government and systems. Participants expressed their thoughts around our elected officials and what they expect of them. “I feel very frustrated with our provincial politicians maybe, I just feel like, you know, ‘I don’t think you have an older Mom or Dad, who’s in an institution. I don’t think you know what it’s like to walk through those doors and see people tied into chairs, with bibs around their neck...’”(Participant 6). They also referred to the richness of the experience in forming understanding.

“They’re all educated people but aside from actually experiencing it, I don’t actually know

if there's ... I don't know. I think you have to rely on the people that are in the departments that are responsible for these things, to put the message up there and make sure that if it's a priority, then they need to make sure that everybody understands that it's a priority and those people have to trust them, that they know what they're talking about. I don't have a lot of faith in the big guys" (Participant 3).

A number of participants cited frustration with how the system operates and the lack of communication that occurs. "It was beyond me the excuses they were giving me. So you know, you're frustrated with the government system. You're frustrated because you can't get your mother looked after and you're trying to live a life and look after your father at the same time" (Participant 5). These frustrations weren't experienced solely by those who experience the system from the outside. "I worked in 'the system' When my husband had a stroke, not one person in my office said, 'Why don't you apply for disability support?'" (Participant 4). Participants also expressed concerns between public and private long-term care institutions. Participants noted discrepancies in the training required by staff in public versus private long-term care facilities:

"It's just like there's so many of them (staff) coming through and none of them in the private nursing homes, they don't have to have the course, right. They don't have to have the RCW course and that's huge. They take people in there off the street and they train them for three weeks and they hit the floor. The thing of it is with a government run nursing home their accountable to the public because it's a public institution, right? So I think they're probably a little more careful about ..., well they're careful about who they hire, right? I mean their people all have the appropriate credentials and stuff like that" (Participant 3).

The same participant mentioned that quality of care and respect for the individual were being cast

aside based on budgetary restrictions.

“It’s all about financial responsibility and budgets and all that kind of stuff. They have to have an inspection every year for their license...so they didn’t get their license. They got a temporary license for like three months until they cleaned up their act, sort of thing. The edict came down back a while ago that each resident who is incontinent was only allotted five pads per day, and it’s just, it’s all about the money, right” (Participant 3).

Participants also referred to the changing dynamics of healthcare. “The doctors are looking for any option because the beds are full, so if you’re willing to give an inch or if there’s another road through one of the family members, that’s the route you’re going, even if it’s not in the best interest of ... it’s going to cost health care in the end, to look after me” (Participant 14). The shifting role of acute care was mentioned by participants. “We’re no longer all about acute care. Acute care is just one little episode of our lives” (Participant 9). Participants also mentioned the move toward inter-disciplinary teams in care provision. “If we’re going to have teams working in medicine, then we need them to really work and work for the patient” (Participant 1).

Ageism and advocacy. Participants also indicated that there were issues with ageism and dignity. Participants identified ageist behaviours toward their care recipient and, in some cases, themselves. “All of a sudden, you don’t have a voice anymore once you get 60 or 65 in this province. Yeah, that’s the appearance, it’s when you speak to a lot of seniors in my experience anyway” (Participant 9). Participants also witnessed evidence of this type of behaviour in health care delivery. “When I went in saw Mom with a bib around her neck – shit! This is not my mother. Why are you doing that? I’d rather you tuck a napkin under her shirt but don’t put a bib around her neck. That’s demoralizing. You know, that’s awful” (Participant 6). As one participant stated, “It was terribly humiliating and it was so unnecessary for him (care recipient) who at that time had

perfect bowel control but you can't wait a half an hour and it was exactly a half an hour" (Participant 15). Participants stated that there are certain elements of dignity and respect that can be maintained, despite significant shifts in how care is provided. "We're putting you in the tub, we're going to take your silver bracelet off which you never take your silver bracelet off and they take it off and guess what? Somebody put it in their pocket. That was not good. That was demoralizing and that was total disregard for Mom and that was something that was very important to her" (Participant 6). One participant clearly articulated the need to understand and normalize the aging process. "It's that refinement of that dignity and integrity between one another and that we're not always going to be youthful and we're not always going to have curves. You know, and so we make – we normalize that." (Participant 9)

Participants were unanimous in identifying the need for advocacy, usually for their care recipient. They also mentioned that their efforts weren't always well-received. "You have to be that advocate for them because my mother would never speak up" (Participant 5). Participants also referred to the value of being able to advocate effectively. "If you can't advocate for yourself in the present day medical system, you're not going to have good luck and many people recognize that now" (Participant 1). Participants also expressed concern for those who did not have a family caregiver who could help support their advocacy efforts. "What do the people do that have no family or no friends, nobody to help them?" (Participant 6). Participants noted the importance of being an advocate. "You know, there's so much that we have to do, so much work to be done" (Participant 6). They also mentioned the demands that advocacy places on caregivers. "All of that takes energy and if you're not getting enough sleep, you can't really accomplish very much of anything" (Participant 7). One participant indicated her hopes for this research: "I think with what you're doing it will add to shifting and shaping some of the care provisions, like in the years to

come. And people may be will look at it in a different way, once they see someone, the reflections of the voices that you interviewed” (Participant 9).

The participants laid bare their thoughts, feelings and experiences on caregiving. The aforementioned themes demonstrate the depth and breadth of family caregiving – the challenges, the opportunities, the demands and the growth. In the next Chapter, I will discuss these findings in relation to the research questions that have been posed. I will explain the meaning and importance of these findings for policy makers, service providers and other family caregivers.

Chapter 6 - Discussion of Findings and Conclusion

This chapter will discuss the research findings as they relate to the research questions and explain the meaning and importance of these findings. The findings will be examined in relation to the previous literature and studies on caregiving. It will also examine the implications for social work practice as well as the limitations of this research. The purpose of the study was to address three key questions:

1. What is the experience of older female caregivers living on Prince Edward Island?
2. What does it mean to be caregiver?
3. How do Prince Edward Island women describe caregiving?

Caregiving has become an important topic for research and this qualitative study explored the experiences and meanings, older female adults on Prince Edward Island ascribe family caregiving. The major findings from this research included how these experiences shape women's lives, the challenges and positive outcomes of family caregiving, and the need for timely access to quality health care services, programs, support, and education. The population of Atlantic Canada is aging faster than the rest of the country and this has significantly impacted the need for family caregivers (Keefe, 2012). The participants in this study also noted that there are significant communication gaps between professional services and the Island community, with caregivers having very little information on where to turn for support and guidance. Participants who work or have worked within the system also mentioned these challenges. Giosa et al. (2015) indicated that some of these gaps in communication could be mitigated by care recipient and caregiver assessment, particularly within the acute care setting. The 2015 study by Ceridian also noted that a significant number of public service employees could not identify support organizations for caregivers, when asked. These existing gaps in communication were also mentioned in the Health

Quality Ontario (2014) report as well as the Government of Canada's Action for Seniors report (2014). The work of Jacelon and Henneman (2014) noted the positives associated with keeping family caregivers informed and involved. As their research found, caregivers felt a greater sense of dignity in their role.

As part of the province's health care restructuring, investments are being made in homecare which means that family caregivers are, and will be, shouldering the economic, physical, and emotional burden of family caregiving. The Romanow Commission report (2002) indicated that 80-90% of homecare is provided by family caregivers, and I strongly suspect that this number will continue to climb as the population continues to age and aging in place becomes the preference of many older adults and governments. The commission heard concerns about the effects of family caregiving on women especially the sacrifices made to their economic security, health, and well-being. As Poirier (1998) noted, the care of older adults falls first to the spouse, daughter and daughter-in-law; a pattern that was repeated in the research findings. Participants in my study also acknowledged that there were gender differences in care provision, as well as family and social expectations to provide care. These gender divisions were readily referred to in the works of Bozalek and Hooyman (2012), O'Connor (2007) and Brewer (2001). In the next section, I will discuss the experiences and meaning assigned to caregiving by the participants. This will be followed by a discussion on the policy implications and need for recognition of family caregivers.

Caregiver Experiences

Participants affirmed the work of Pope, Kolomer and Glass (2012) in that they either became a caregiver as the result of a significant event or gradually fell into the role by virtue of additional tasks for the care recipient. Brewer (2001) also noted that identifying as a caregiver is often a challenge for women, as they continue to perform duties they've always carried out such

as meal preparation, laundry and housework. O'Connor (2007) also indicated that once immersed in the caregiving role women had little time to reflect on how it was shaping them. My research provided a conscious opportunity for the women to reflect on their approach and the meaning they give their caregiving. Participants also affirmed the work of Stuifbergen and Van Delden (2011) in identifying that there is an expectation across cultures to care for older adults, which was also mentioned in the work of Ting and Woo (2009) and Lakra (2002). The work of Theixos (2013) was also demonstrated in the findings with caregivers expressing concern about how they were perceived and the need to fulfill a filial obligation to care.

Advocacy was identified as major issue for participants, with some not feeling comfortable in their abilities and others expressing the sheer exhaustion related to caregiving and the effort involved in being an effective advocate. It was suggested that a coalition or caregiver association be struck to advocate and support family caregivers. I would see this as an important step in providing the necessary education and support to family caregivers; one which would have little if any cost to government. The not-for-profit sector has provided other services for family caregivers, namely support groups, day programming, and equipment loans/purchases. As noted in Struthers (2007) the changes to the Veterans Independence Program (VIP) came about as the result of the advocacy work of front-line counselors and senior officials within Veterans Affairs Canada. This awareness and change in programming was designed to provide lifetime eligibility to veterans' widows in recognition of their years of unpaid caregiving.

Participants indicated that they received little support in their caregiving role and were often encouraged to return to work. As Day and Brodsky (2007) suggest women are more apt to take leave or accept part-time jobs in order to accommodate caregiving responsibilities. This was also support by the work of Neumann and Amaratunga (2006). The Employer Panel for Caregivers

(2015) noted a lack of awareness amongst employers, that employees had assumed a family caregiving role. The Ceridian (2015) study indicated that only 12% of workplaces have formal caregiving policies in place, with most employers choosing to deal with employees on a case-by-case basis. Even with policies in place, caregivers often feel as though they need to return in order to secure their income. One benefit of continued employment and/or retirement benefits is access to services, such as EAP, which one participant mentioned was of tremendous benefit.

The Island workforce is experiencing significant shifts with individuals still seeking employment off Island. We are also an economy based on a number of seasonal industries, with workers being employed for periods of time, which hopefully is long enough to qualify for EI benefits. Our one saving grace has been the influx of immigrants who are establishing businesses and securing employment in the seasonal workforces of farming, fishing, and tourism. As aforementioned, PEI has a significant older adult population and high chronic disease rates. This is placing family members in caregiving roles while oftentimes trying to juggle labour force participation. As Sawatzky and Fowler-Kerry (2003) noted, family caregivers can be forced into retirement to provide care, something that was confirmed by research participants.

Participants referred to the need for education in supporting them in their role. However, participants also mentioned that most sessions were often difficult to attend due to timing or care demands. As noted in the work by Giosa et. al (2014) there needs to be an assessment of caregiver knowledge, particularly when sending care recipients home from acute care or when managing multiple chronic conditions. Equally as important is education for front-line professional staff in recognizing the valuable contributions of family caregivers, and their specific needs to support and services. As Stall (2012) indicated, medical professionals need to be made aware of their ageist

attitudes and educated to support older adult patients and their families. This was affirmed by the work of Battams (2014).

Each participant mentioned her challenges with “caregiver burden” – physical, emotional, social and financial challenges associated with caregiving. The research material on this topic has been plentiful, particularly from a quantitative approach (Ceridian, 2015; Adelman et. al, 2014; Beach et. al, 2005). My research demonstrated the value of hearing the voices of these women and their experiences.

Policy Implications

Previous research on the gender-based provision of care indicates that there is a need for gender-sensitive policy development (Gahagan, Loppie, Rehman, MacLellan & Side, 2007; Sims-Gould & Martin-Matthews, 2008) and the women who participated in this study reiterated that need. They felt that if their male counterparts were in this situation, there would be a far greater outcry for policy that addresses issues related to family caregiving. The current federal Liberal government’s commitment to a new multi-year health accord is raising expectations around the delivery of homecare, palliative care and mental health services. It is hoped that those provinces with a higher percentage of older adults will receive increased health care transfers to support delivery of existing services.

As part of the research for this study, various provincial strategies were reviewed and participants offered comment on the need for a provincial caregiving strategy. Participants felt that the strategy needed to be comprehensive, include front-line stakeholders and those who have experienced family caregiving, and have a definitive action plan and measureable goals to ensure that the needs of family caregivers are being met. The findings captured the need and value of hearing the experiences and voices of family caregivers. As Stadnyk’s (2006) work highlighted,

caregivers need to be involved in policy and program development. At present, the province has engaged consultants to draft a comprehensive seniors' strategy, which will hopefully be far more inclusive and comprehensive than the 2009 Healthy Aging strategy as discussed in the literature review. It was noted that the strategy had numerous gaps in relation to the issues of older adult Islanders as well as limited support and recognition of family caregivers. The province is also in receipt of a provincial palliative care strategy that has yet to be rolled out or communicated to Islanders. It is hoped that these strategies will recognize and support family caregivers, by offering concrete, evidence-based programs and services.

In 2014, Dr. Lori Weeks conducted research with family caregivers, recipients, and other stakeholders that identified key issues in lack of knowledge and information about health services; caregiver support and respite, quality of services of available and attitudes toward older adults and their value in society. We need to move from identifying these issues to creating a knowledge translation piece, whereby research and policy combine to create improved situations for family caregivers as suggested by Martin-Matthews, Tamblyn, Keefe and Gillis (2009). Caregivers have bared their souls in sharing their experiences but have limited power to translate these experiences into policy that would support family caregivers Island-wide. I would encourage the provincial government and educational institutions on Prince Edward Island to foster continued research in the area of family caregiving.

Benefits and Tax Credits

The existing federal benefits and credits have little impact on older female caregivers, as most are tied to the EI program, or only one credit can be claimed per year. There have been repeated calls for a refundable tax credit which provides cash to family caregivers (Torjman and Makhoul, 2010), although, from my perspective, it seems to be a matter of optics and the

prospective refund would do little to offset the overall costs to family caregivers. The CCB, although a wonderful program, is all but moot to older female caregivers. The recently announced expansion to the program is still only available to those who qualify for employment insurance programs and who are providing care to those who are gravely ill. As Torjman (2015) indicated, it does not include the often lengthy caregiving required to support an individual with a chronic condition. It is hoped that it will be extended to cover care for chronic conditions so that family caregivers may access it early in their caregiving careers while most are still working and eligible. Warrick et. al (2014) also noted other benefits associated with engaging family caregivers earlier in their caregiving career. The economic value associated with supporting family caregivers with resources and information was mentioned as beneficial, but greater autonomy for both the care recipient and caregiver is also a boon.

Recognition

The recognition of family caregivers is something that needs to become part of our public dialogue. Despite federal and other provincial efforts, little has been done locally to recognize the tremendous impact of family caregivers. As Keefe (2011) stated “more public support for caregivers would not only demonstrate greater recognition of caregiving, it would also reduce the need for formal care, delay institutionalization and relieve the cost pressure on home care and health care systems” (Keefe, 2011, p. 1). Warrick et. al (2014) also called for the formal recognition of caregivers as part of the unit of care, indicating that Manitoba’s Caregiver Recognition Act (2011) provides a framework to guide this recognition on a broader scale. As Torjman (2015) noted, the caregiving work assumed by family caregivers is invaluable and invisible, with the caregiver voices rarely heard. As one participant mentioned, it was her hope that this research would serve to give voice to family caregivers and their experiences in providing

care on Prince Edward Island. As a social worker, I see tremendous merit in organizing a non-government organization to support and advocate for family caregivers across the spectrum of caregiving.

System Issues

The seamless integration of health care services is being widely touted as providing patient-centred care and support, but it also has economic benefits as well. There is no need to recreate systems and processes, when timely and accurate communication and infrastructure can ensure that integration takes place. One prime example of this is the transition between various types of care. It has been suggested by the Ascent Strategy Group's (2008) report that the province look to private industry to create the additional long-term care beds required to support our aging population. At present, community care facilities are at the ready to respond with additional advance level care beds, should a request for proposals be issued. However, the province has not issued any new requests at this time. Integration of health care services should be imbedded in professional human resources as well. The caregivers noted that the transition to long-term care resulted in the loss of one's family doctor, as well as the introduction of a hospital list when transferred to acute care.

Participants were very candid in their experiences with acute-care and the fact that Islanders are dying in acute-care facilities while waiting for long-term care placement. Giosa et al. (2015) found distinct benefits for caregivers during the acute care phase, allowing for assessment and knowledge building should the care recipient be returned home. This "home first" approach is gaining momentum in an attempt to free up acute care beds. It has been stated that there are distinct benefits to this program including the fact that the individual is in a more suitable environment and can make life-changing decisions surrounded by family and in the comfort of their own home.

When that option is not available, care recipients are being transferred to rural health care centres to make room at the primary referral hospitals. While this sounds good in theory, it is known to create issues for families and care recipients. No one is debating the quality of care provided in rural Island health care centres, but when family are not nearby, the quality of life for the care recipient and family is diminished.

The ineffective use of acute care centres was widely discussed in the CSI Consultancy (2010) report but without effective and accessible primary care programs and services, caregivers feel that they are left with little choice but to turn to the emergency department of the nearest hospital. The economic impact of this is staggering. The need for strong, primary care centres designed with specific programs and services to address the issues of an aging population and its caregivers is required. At present, case management services are at the centre of providing support to family caregivers – i.e., the ones who access primary care services in the first place. CSI Consultancy (2010) sees primary care and homecare renewal as the foundation for shifting Islanders perceptions around what constitutes health care. The need for well-trained, interdisciplinary staff teams is crucial if primary care is to be successful in addressing the challenges of health care delivery on Prince Edward Island. In an effort to stem the tide, and re-educate Islanders on health care delivery, there has been a concerted effort to move care away from the acute care and long-term care settings. One of the main reasons for this shift is purely economical, but it also meets the majority of individuals' wishes to remain at home and independent as long as possible.

The province has begun to strategically invest in homecare services since various reports have cited that homecare was grossly underfunded on Prince Edward Island. The majority of participants in this study accessed homecare during their career, but faced a number of obstacles

in doing so, including the amount of homecare support they were able to access as caregiving progressed. However, since those investments have begun, there has been an overall decline in the number of Islanders accessing homecare services, with a drop from 4677 clients in 2010-11 to 4192 in 2014-15. The average spent per homecare client declined in the 2014-15 fiscal year, from an all-time the previous year, bringing it in line with spending from the 2010-11 fiscal year. The province's approach to homecare as outlined in the 2009 Healthy Aging strategy, was negligent in including the voices of Island caregivers or recognizing their contributions in supporting the homecare program. An example of a program that works that could be considered by the Island is the Veterans Affairs Canada VIP program. This program illustrates distinct advantages in their delivery of homecare services to Canadian veterans, a point that was quickly collaborated by participants. The VAC recognized that in order for a homecare program to be successful long-term it needed to shift from a client-centred perspective to a family-centred perspective, with the health of the family caregiver paramount to providing quality care. The recognition and importance of the family caregiver was demonstrated by mandated caregiver assessment; something that does not occur on Prince Edward Island and is at the discretion of the individual caseworker. The VAC also stressed human resources in the fields of social work and gerontology. As participants mentioned, they were not asked to evaluate homecare services nor were they engaged in a meaningful way. Some participants indicated, that the skills they developed and their creative approaches to care were recognized by homecare staff. One participant in particular noted the value of their visits in lifting her spirits.

Participants shared their experiences with long-term care, from dealing with a challenging wait-list process, to the emotional and challenging transition to care, the types of programming available, and the philosophy of care demonstrated by some facilities. They were very frank in

their assessment around the discrepancies between public and private facilities, something that was also referred to in Weeks (2014). With no single legislative framework for public and private facilities, it is unlikely that any significant change to the status quo will arise. The government also indicated that they would release inspection reports, and have gone as far as to create a website, without one single report uploaded. The majority of concerns expressed by participants hinged on the available human resources and their training levels. With increased complexity of care required as suggested by CSI Consultancy (2010) it is hoped that quality mandatory training will be implemented.

One significant improvement is the introduction of social work services to Beach Grove and Prince Edward Homes (the Queens region two publicly funded facilities). It will be interesting to see what, if any, evaluation is done regarding the need for gerontological social work, and if plans for expansion to other public facilities are in the works. Given the aforementioned discrepancies in services between public and private facilities, one has to wonder if the province will change the frameworks to include interdisciplinary staff teams, and in turn provide additional compensation to private facilities to ensure a full range of services are provided. The geography of the province also contributes to service delivery, with programs usually rolled out in the Queens region (central Prince Edward Island, including the province's capital city, Charlottetown). The recently announced expansion to the seniors' mental health program has demonstrated this, with Charlottetown having received these services for a number of years and Prince County's program established in May, 2016. It was noted that Kings County will be welcoming a seniors' mental health team later this calendar year.

The 2009 Healthy Aging strategy laid out plans for long-term care facility replacement. To date, four of the five facilities have been replaced, with the Riverview Manor in Montague still on

the list. Ground has yet to be broken and despite promises that the facility would have been completed in 2016, it now appears as though construction will not begin until sometime in 2017. This particular manor was mentioned by one of the participants as being in need of repair, to the extent that her care recipient who was diagnosed with dementia, managed to leave the premises. The strategy actually called for the replacement of the identified facilities within a five year time period, i.e. by 2014. However it was noted that the delay was due to expected federal infrastructure funding to support the project.

Finally, as aforementioned, a provincial palliative care strategy has been prepared but not yet released. As identified by the CHPCA Harris Decima poll, 75% of Islanders want to die at home, with only 19% being able to achieve this personal health care desire. Participants also referred to the importance of advance care planning discussions, something that is widely touted in the research (CHPCA, 2015; CMA, 2015). The province is slated to introduce policy in this area.

Limitations of the Study

As with any research study, there are limitations. My research sought to explore the experiences of older female caregivers on Prince Edward Island, therefore no males were included, or women under the age of 60 years. The research also focused on care of older adults and did not include children or adult children with developmental or mental health issues. The sample size was suitable for the design, but a larger scale study could also be mounted. The participant sample was relatively homogeneous with no ethnic minorities or Aboriginal participants, as well as no individuals within a same-sex, intimate dyad. The setting for my research was also relatively small, given the population of Prince Edward Island when compared to other provinces and territories. The approach to data analysis, including the feminist lens

might also be viewed as a limitation in that it views the experiences of women as something solely related to women and does not include a broad, more holistic view of the caregiving experience. This being said, the findings of this study could be useful in shaping future policy, programs, and services.

Implications for Social Work Practice

The implications for social work practice are significant. The population is aging, and the need for well-trained gerontological social workers should be a priority. It will also be important for social workers to have professional training in hospice palliative care services. Social workers are obligated to advocate for their clients and to address pervasive ageist behaviours and beliefs. It is essential that support systems change to benefit our clients, to help empower them, to support their advocacy efforts, and to provide necessary training to help them achieve their goals. We are also called upon to establish our profession in the public, and to draw attention to the various skills and services social workers provide to our Island community. It is imperative that our professional bodies communicate clearly with the public so as to address any myths or misconceptions about our scope of practice.

I also believe that social workers need to play a role in the development of non-government organizations that can work in collaboration with existing public and private services to provide timely access and quality services to clients. We could do this through the use of anti-oppressive practice tools, combined with cultural competence. Social workers would be required to develop, deliver, and evaluate programs to provide an evidence base for skilled practice. This would include being a vital member of interdisciplinary care teams across the health care continuum, designed to promote a family-centred approach to care.

This research experience as a social work student has resulted in a number of new insights that I will carry forward in my work as a social worker and volunteer. I think particularly of the discussions around our roles as women, the attempt to balance our competing demands, and the priorities such as work, family, and intimate relationships. I continue to be awed by the strength and resilience shown by participants as they journey forward in their caregiving roles or define a new path, post-caregiving. The loss of a participant during the research study was particularly emotional for me as the researcher. This woman had given voice to her experiences that covered a life time of caregiving. She expressed the desire to fulfill one of the key transitional life roles most women get to experience with such eloquence and desire. To know that she is no longer able to participate in that role, in a way in which she had hoped, has been emotionally painful as often times women do not have the opportunity to fulfill certain roles based on limitations or other intervening factors. As women, we are socialized to provide care, and this is usually tied to our roles as daughters, wives, mothers, and grandmothers. When circumstances of life intervene to circumvent these traditional roles, we often carry emotional hurts and feelings that affect our perception of self and our abilities.

The consciousness-raising that has arisen from this research has only helped to affirm my commitment and dedication to caregivers and their issues. These women have demonstrated advocacy at its finest, resilience on a daily basis, and an unmatched commitment to love, care, and the support to their care recipients. This research has informed my own advocacy efforts and has challenged me to lend my voice to the issues encountered by family caregivers. The identification of gaps in services and supports, serves as a reminder to first listen to the experiences that are being shaped by unmet needs and then to act in support of those in the midst of their caregiving experience and future generations of caregivers. For me, this is the heart of

feminist research – to raise the consciousness of our society about issues that affect women and in turn affect all peoples. It is an integral part of effective social work practice and reminds front-line social workers to advocate with and for clients.

Conclusion

In conclusion, the findings of this study demonstrated the need to listen and act upon the experiences of these caregivers. It is the economic, moral, and ethical direction in which to move. As the population continues to age, with Atlantic Canada aging faster than the rest of Canada (Keefe, 2012), it is imperative that all levels of government, the not-for-profit and public sectors and individuals, work together to assume a shared responsibility for the care of older adults and their family caregivers. Should we choose to ignore the vast findings on family caregiving research, it will be to our own detriment. The evolving health care system will not meet the demands of recipients or over-burdened caregivers. The economic impact of family caregivers on the workforce will create an unstable economy and family caregivers will not be recognized as valuable members of our society. As former first lady Rosalyn Carter stated, “there are four kinds of people in the world: those who have been caregivers; those who are currently caregivers; those who will be caregivers, and those who will need a caregiver”.

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Appendix A – Research Ethics Board approval



APPROVAL FOR CONDUCTING RESEARCH INVOLVING HUMAN SUBJECTS

Research Ethics Board – Laurentian University

This letter confirms that the research project identified below has successfully passed the ethics review by the Laurentian University Research Ethics Board (REB). Your ethics approval date, other milestone dates, and any special conditions for your project are indicated below.

TYPE OF APPROVAL / New <input checked="" type="checkbox"/> / Modifications to project / Time extension	
Name of Principal Investigator and school/department	Jodi Swan (Social Work) Diana Coholic, Leigh MacEwan (Supervisors, Social Work)
Title of Project	Beyond the Sandwich Generation: The Lived Experiences of Older Prince Edward Island Women Caregivers Caring for an Older Adult
REB file number	2014-2014-04-07
Date of original approval of project	May 10, 2014
Date of approval of project modifications or extension (if applicable)	
Final/Interim report due on	May 10, 2015
Conditions placed on project	Final report due on May 10, 2015

During the course of your research, no deviations from, or changes to, the protocol, recruitment or consent forms may be initiated without prior written approval from the REB. If you wish to modify your research project, please refer to the Research Ethics website to complete the appropriate REB form.

All projects must submit a report to REB at least once per year. If involvement with human participants continues for longer than one year (e.g. you have not completed the objectives of the study and have not yet terminated contact with the participants, except for feedback of final results to participants), you must request an extension using the appropriate REB form.

In all cases, please ensure that your research complies with Tri-Council Policy Statement (TCPS). Also please quote your REB file number on all future correspondence with the REB office.

Congratulations and best of luck in conducting your research.

A handwritten signature in black ink that reads "Susan James". The signature is written in a cursive style with a large initial 'S' and 'J'.

Susan James, Chair
Laurentian University Research Ethics Board

Appendix B – Consent form

Consent Form

Beyond the Sandwich Generation: The Lived Experiences of Older Prince Edward Island Women Caregivers Caring for an Older Adult

Investigator: Jodi Swan, M.S.W. student ja_swan@laurentian.ca

Supervisors: Dr. Diana Coholic and Dr. Leigh MacEwan

Before agreeing to participate in this study, it is important that you read and understand the proposed structure and procedures. You are asked to sign this consent form which indicates that you understand the benefits and risks of participating in the study.

Purpose: The purpose of the study is to gain insight into the experiences of older female caregivers in order to better understand what meaning is given to your role as a caregiver providing care for an older adult on Prince Edward Island.

Objectives: By sharing your experiences with me, it is possible that you will help me understand what situations caregivers are facing on Prince Edward Island; what supports might be beneficial and how your definition and understanding of your role as a caregiver can be used to highlight issues and concerns of Island caregivers.

Procedures: If you decide to participate in this study, you will participate in two interviews. The interviews will take place in person and will be audio-recorded so that I can look back at your responses and understand their meaning in relation to your caregiving experience. The first interview will take approximately 60 minutes to complete. After I have had time to read through your responses, I would like to conduct a second interview to ensure that I have understood what has been shared and allow you an opportunity to share any additional thoughts since our first interview.

Risks: As a caregiver participating in this study you will be asked to share your experiences and thoughts on providing care to an older adult. There is a possibility that as you reflect on your experiences you may encounter some upsetting memories or concerns. I am prepared to help you confront difficult emotional issues by directing you to a qualified professional should you wish to speak with someone. There are no other significant risks to participating in this study.

Benefits: You may benefit from sharing your experience to an attentive listener. Although you may not directly benefit from the results of this study, you may benefit from knowing that your experiences may assist others who are providing care.

Confidentiality: The information that is collected for this study will be kept in a locked and secure area. Only my supervisors and I will have access to what you share. Once the research project is completed, my supervisor will keep your information and signed consent form in a locked filing cabinet at Laurentian University for 5 years; after 5 years this information will be shredded. I will erase any and all information from the digital recorder used as well as from any computer hard drive or USB key.

Participation: Your participation in this study is voluntary. You can choose not to participate or refuse to answer a question or withdraw at any time.

Should you have any questions about the study, you may call or email my supervisors:

Diana Coholic dcoholic@laurentian.ca 1-800-461-4030 ext 5053

Leigh MacEwan lmacewan@laurentian.ca 1-800-461-4030 ext 5059

If you have any questions about the research ethics, please contact the Research Ethics Officer, Laurentian University Research Office, telephone: 705-675-1151 ext 2436 or toll free at 1-800-461-4030 or email ethics@laurentian.ca

My contact details are:

Jodi Swan ja_swan@laurentian.ca 902-394-0490

Consent: I have had the opportunity to discuss this study and any questions that I had have been answered. I consent to take part in this study. I may withdraw at any time.

Participant's Name _____ Date _____

Address _____

Telephone _____ Email _____

Witness _____ Date _____

If you would like a copy of the results of this study, please advise me and will see that a copy is mailed to your attention. The report will be sent once the project requirements have been completed.

Appendix C – Interview Guide

Interview Guide Initial Interview

1. What is your experience as a caregiver?
2. What meaning do you give your care giving?
3. What makes it meaningful for you?
4. What does it represent for you?
5. Do you face any barriers in providing care?
6. Do you work outside the home?
7. What are the positives of care giving? What are the challenges?
8. Do you feel you have support in your role as a caregiver? If so, please provide some examples. (other informal care support/formal support) If not, what type of support would you appreciate?
9. Did you have any options when it came to providing care?
10. Where do you provide care? (urban/rural setting, home or other environment)
11. How many people do you provide care for? How many hours in a week do you spend care giving?

This semi-structured interview will allow the researcher to ask additional questions based on the direction the participant may take the interview.

Appendix D – Participant recruitment advertisement



Recruitment Flyer

Are you a caregiver?

- Do you provide short-term or ongoing care and assistance, without pay, to those in need of support due to physical, cognitive or mental health conditions?
- Are you willing to share your experiences of caregiving?

If you are a woman, age 60+ years providing care (or has provided care in the past year) to an older adult (partner, parent, sibling or friend) and interested in sharing your experiences, you qualify to participate in this study.

Beyond the Sandwich Generation:

The Lived Experiences of Older Prince Edward Island Women Caregivers

Caring for an Older Adult

What do I have to do?

Participants are asked to participate in two private interviews which will be approximately 30-60 minutes.

Why is this study important?

The aging of the baby boom generation and current healthcare reform is creating an increased demand on informal caregivers, the majority of whom are women. This study will provide us with your first hand experiences of providing care to an older adult on PEI and highlight the issues you are facing and any gaps that may exist in supports and services.

I want to participate!

If you are interested in participating, please contact MSW student Jodi Swan at ja_swan@laurentian.ca or call 902-394-0490