Women’s Narratives of Post-Caregiving: A Gendered Lifecourse Perspective

Thèse

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Au Canada, huit millions de proches fournissent de l’aide à une personne âgée souffrant d’une maladie chronique ou présentant des incapacités. Ce rôle de proche aidant, qui est composé de tâches quotidiennes, est le plus souvent assumé par des femmes, la plupart du temps des conjointes et des filles. La trajectoire de ces femmes est affectée par leur rôle de proches aidantes, sur les plans affectif, psychologique, physique et financier. Trente ans de recherche sur les aidants, et plus particulièrement sur les femmes aidantes, ont contribué à la création d’une figure-type de la proche aidante, identifiant les principaux défis auxquels elles ont à faire face. Toutefois, la période « post-aidance », lorsque l’aidante entre dans la phase de deuil, reste peu étudiée. Pourtant, cette période peut être particulièrement éprouvante étant donné l’engagement personnel inhérent au rôle d’aidante. La recherche a déjà montré que les réactions émotionnelles des aidantes et les questions pratiques qu’elles ont à régler ne cessent pas à la mort de la personne aidée. En effet, des dynamiques complexes, tissées de prises de conscience, d’ambivalences et de tensions, caractérisent la période « post-aidance ». La présente recherche a exploré le vécu des aidantes endeuillées lors de la phase « post-aidance ». En combinant l’approche personnologique et la perspective du parcours de vie généré, cette étude de type narratif a permis de situer la période « post-aidance » comme une extension de la trajectoire individuelle. Le cheminement unique de chaque participante a été discuté en entrevue et présenté sur une ligne du temps « care-ography1 », un outil qui permet de retracer visuellement les événements et les transitions de leur trajectoire d’aidante. Trois thèmes centraux ont émergé de l’histoire de ces femmes: l’identité, la résilience et le rôle du soutien social. Les retombées que pourraient avoir les résultats de cette recherche pour les politiques, la recherche et la pratique ont été explorées. Une attention particulière a été portée au développement de programmes et d’interventions qui reconnaîtraient le deuil comme faisant partie de l’expérience de la proche aidante et fourniraient un meilleur soutien durant la période de « post-aidance ».

1 Care-ography fait référence à un outil développé pour représenter la biographie de l’expérience des proches pendant la trajectoire de l’aide.
ABSTRACT

Eight million caregivers in Canada are providing care to older adults with chronic health conditions and disabilities. Many of the daily tasks which make up the role of the caregiver are undertaken by women. These women caregivers, most of whom are wives and daughters, are often profoundly affected by their caregiving role in emotional, psychological, physical, and financial ways. Thirty years of research on caregivers in general, and women caregivers in specific, have contributed to the creation of a caregiver profile which identifies the significant challenges for this population. One area which continues to be underexplored is the post-caregiving period, when caregivers transition into a period of bereavement. This period can be particularly challenging for women caregivers given the commitment inherent in the caregiving process. Research has shown that the emotional reactions of caregivers, as well as practical challenges, do not end with the death of the care-receiver. In fact, complex realities, tensions, and responses continue well after death into the post-caregiving period. This study of bereaved women caregivers explored their lived experiences in the post-caregiving phase. Using an approach informed by personological and gendered lifecourse perspectives, this narrative study enabled a rich and compelling account of women’s experiences in post-caregiving as an extension of their individual caregiving trajectory. Each participant’s unique story was presented as a ‘careography’ timeline, which visually represented significant events and transitions throughout the process. Three central themes emerged from within the women’s stories – identity, resilience and social support. Implications for policy, research and practice were explored, with particular attention on the development of initiatives which would recognize bereavement as part of the caregiver journey and better support women caregivers during the challenging post-caregiving period.

2 Careography refers to a tool developed to represent the care-related biography of caregivers during the care trajectory.
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CHAPTER 1 INTRODUCTION

International scholarship on caregiving is abundant and more than thirty years of learning has shed light on the complicated world of caregivers and their experiences caring for family members with physical, cognitive and/or mental health issues. Early research examined the basic needs of family caregivers and the toll that providing care exacted on their lives (Guberman et al., 1991; Brody, 1985; Aneshensel et al., 1995; Lawton et al., 1991; Pruchno & Resch, 1989; Zarit et al., 1986). This research helped to popularize the use of the term caregiver and directed our collective societal awareness towards the recognition that family members and friends providing regular physical, practical, and emotional support to older adults were indeed going beyond the call of duty.

The specific aspects of the caregiving experience started to receive attention in both policy and practice as a result of the research and advocacy efforts of caregivers themselves, advocacy groups and front line practitioners. The profile of family caregivers in Canada began to emerge – that they numbered in the millions (Cranswick, 1997, Statistics Canada 2008), were mostly women (Baines, Evans, Neysmith, 1998; Hooyman & Gonyea, 1995; Pinquart & Sörensen, 2006), and suffered from physical, emotional, social, and financial problems of their own (Fast et al, 2001). Caregiving has since been termed the “unwanted career” (Aneshensel et al, 1995) in that it often involves a significant commitment of time and emotion that many are not aware of when they begin providing care.

Undisputed in the literature is the fact that women make up the majority of caregivers, and that they overwhelmingly manage the concrete tasks and emotional needs of care-receivers (Baines, Evans & Neysmith, 1998; Hooyman & Gonyea, 1995; Pinquart & Sörensen, 2006). Many women caregivers juggle multiple roles including family and work responsibilities, which
represent one of the major tensions of caregiving (Brody, 2004; Spillman & Pezzin, 2000). Eight million caregivers in Canada are juggling their work and caregiving responsibilities (Statistics Canada, 2013) and 50% of all caregivers are between the ages of 45 and 65, representing their peak earning years in the job market (Statistics Canada, 2013). Women represent 70-80% of community care for older adults (Health council of Canada, 2012) and more commonly report experiencing stress as a result of caregiving (Barusch & Spaid, 1998; Yee & Schulz, 2000). Women caregivers often find themselves “silently struggling with the balance of providing care to a loved one while internally coping with the emotional distress of their partner’s illness” (Masterson et al, 2013, p. 1459). Daughters and daughters-in-law are highly implicated as well in the challenges of juggling their lives, including families and work, in addition to caregiving. The contextual differences may influence each caregiving situation but women caregivers often find themselves balancing the demands of providing care with the challenges of emotionally coping with their care-receiver’s deterioration.

Despite the recognition that women are the primary caregivers, patriarchal attitudes about women’s roles still exist in North American society, placing low value on the role of caregivers, thus rendering this aspect of women’s work as socially invisible (Hooyman, 2015). Women caregivers are frequently at risk of economic hardship – due to the managing of multiple roles in caregiving and the lack of time to fulfill their work potential. Many of these women manage numerous roles and responsibilities of wife, daughter, granddaughter, employee, and parent to dependent children, although the greatest conflicts tend to be between informal care responsibilities and employment (Brody 2004; Spillman and Pezzin 2000).

Despite the recognition that women adapt their lives to be caregivers, the scholarship on caregiving, and on women caregivers specifically, pays little attention to lifecourse trajectories of
care – omitting in particular the important aspect of post-caregiving experiences in the exploration of caregiver realities and needs. Post-caregiving can be defined as the period of time after the caregiving has ended due to the death of the care-receiver. Post-caregiving has, to date, not been articulated as part of the landscape of caregiving, a limitation that ultimately leads to an important gap in caregiver policy, programming and research.

The paucity of post-caregiving research reflects a lack of understanding of the emotional experiences of women caregivers in bereavement. Caregivers have demonstrated difficulties adjusting to the post-caregiving period and this could be due to the fact that the death of the care-receiver is often preceded by years of challenging medical issues and intense caregiving (Schulz & Beach, 1999; Seltzer & Li, 2000). Thus, the post-caregiving experience can be complex, multi-dimensional and unpredictable, and caregivers are not homogenous in their reactions. The reactions to bereavement are often determined by the context of care that preceded the care-receiver’s death, as well as the type of caregiving experience (Schulz et al, 2008). After many years of physical, emotional, psychological and financial commitment, it is not surprising that women caregivers have difficulty transitioning out of a caregiving role. Many studies in bereavement and widowhood have examined grief reactions, few with a view on the caregiving that preceded the death. Studies have confirmed that the post-caregiving period is related to high stress levels in caregivers (Schulz & Beach, 1999). Moreover, caregivers have a high burden of chronic illness and an increased mortality when they become bereaved (Schulz & Beach, 1999). Women caregiver reactions to this phase can include depletion, depression, anxiety, hopelessness, helplessness, social isolation and relief, among others (Bernard & Guarnaccia, 2003; Li, 2005; Shulz, Haley, Mahoney, Allen, Zhang, Thompson, Belle, 2003). While there is great heterogeneity in these reactions, little is known about what factors influence women
Post-caregiving is an emerging focus strongly linked to direct practice where caregivers express great difficulty re-establishing their lives and finding meaning in the post-care period. Because we know women caregivers respond in very different ways, the study of their reactions needs to be more contextual and, by extension, qualitative. Post-caregiving has unique relevance for women who are emotionally invested and at times, compelled to adapt their lives during caregiving. This can impact women’s experiences in post-caregiving and has not been adequately addressed in the literature. The circumstances and the context of the caregiving situation prior to the death of the care-receiver have important repercussions for women during the post-caregiving period. Understanding the full context of care from caregiving to post-caregiving will allow for a better understanding of women caregivers’ reactions to the challenges faced. A qualitative inquiry into the lives of bereaved women caregivers can enable a more subtle, contextual, subjective approach. Given women caregivers’ heterogeneous characteristics and the variety of care contexts that exist, it is insufficient to discuss and plan for women caregivers as a homogenous cohort. This research will make links between caregiving and post-caregiving and argue that women’s caregiving trajectories need to be understood in reference to their lifecourse experiences.

A lifecourse perspective (Elder, 1998) connects the caregiver trajectory into a sequence of events, a process by which we can examine caregivers’ social and relational experiences. Lifecourse provides a framework for the personal and social aspects of caregiving across time and history. There is a need for a new lens to examine caregiving in order to reposition bereavement as part of the caregiving trajectory. Considering the relevance of lifecourse tenets such as transitions, role entry and exits, and significant events, this perspective is pertinent to
study women’s post-caregiving experiences. A personological and gender-informed life course theoretical framework (Arber & Ginn, 1995; Moen, 2001) is used in the current study in order to help situate this post-care period as part of the caregiving trajectory, to advance an understanding of the gendered nature of the lived experience of care in the context of women’s lifecourse, and to highlight the reality that caregivers have unmet support needs in bereavement. This perspective allows for women to assign meaning to their caregiving and post-caregiving experiences, while using their own voices to relate their stories. It is the “importance of time, context, process and meaning on human development and family life” that best defines a life course perspective (Bengston & Allen, 1993, p.471).

1.1 Objectives

This study seeks to gain a subjective and more nuanced understanding of the post-caregiving period for women caregivers. This research will use a lifecourse perspective informed by personological and gendered approaches in order to frame women’s post-caregiving experiences across the caregiver lifecourse. A narrative methodology is used to present a rich and personal account of women’s experiences, in their own voices. More specifically, this research aims to understand the impact that caregiving had on the post-caregiving experiences of women caregivers. The research question that guided my study was: *What are the lived experiences of women caregivers in the post-caregiving period?*

Using a narrative approach (Czarniawska, 2004; Elliott, 2005), this dissertation explores ten bereaved women caregivers’ experiences after the death of their care-receivers; five wives and five daughters. Investigating the impact of bereavement on women caregivers and the emotional reactions to the multiple losses in caregiving and post-caregiving will provide insight into the bereaved caregivers’ world.
What is lacking in caregiver scholarship is a better understanding of the post-caring phase for women caregivers. By asking women to map it, assign meaning and explain it in their voices, we are privileged to hear their subjective interpretations of how their bereavement is influenced by the caregiving that preceded it. Further exploration on the lived experiences of post-caregivers will enable a deeper understanding and allow for a better practical response to this underserved population.

1.2 Definitions

This section will operationalize the definitions of the terms used in this research. A caregiver is a person who takes on an unpaid caring role for a care-receiver, in this case an older adult, who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness (Carers Canada, 2016). Post-caring is the phase after caregiving has ended due to the death of the care-receiver (Schulz et al, 1995). Bereavement is “the state or fact of being bereaved; especially: the loss of a loved one by death” (Merriam-Webster, 2015). It is considered a general term that can “encompass the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one” (Christ, Bonnano, Malkinson & Rubin, 2003, p. 32).

1.3 Thesis Structure

This dissertation is presented in six chapters. The first chapter has introduced the focus of the research and presented the rationale for examining caregiving as a lifecourse trajectory. The second chapter will present a literature review that will emphasize two areas of research – bereaved caregivers and bereaved women caregivers.Thematically, the review will cover the post-caring phase in the caregiver trajectory but will as well refer to active caregiving as a lead up to post-caring. The third chapter will define and explain lifecourse theory as the
theoretical framework for this research. The fourth chapter will describe the methods and design of the narrative study. The fifth chapter will encompass a findings section divided into two parts. Findings 1 will explore individual women’s narratives which will include descriptions of their experiences alongside direct quotes. Findings 2 will illustrate the key themes emerging from the narrative data. The sixth chapter, the discussion and conclusion section, will outline the thesis results with connection to and implications for practice, research and policy.
CHAPTER 2 LITERATURE REVIEW

Chapter two explores the literature on bereaved women caregivers that has emerged over the past three decades. In order to situate this body of scholarship, the chapter begins with a brief review of the general literature on caregiving, with a specific focus on the gendered reality of care and of the challenges and strengths of women caregivers. Following a review of the general scholarship on caregiving, current research on bereaved caregivers in the post-caregiving phase, as well as women’s experience of post-caregiving, will be examined. The chapter ends with a detailed accounting of the gaps and limitations in current scholarship on bereaved caregivers.

An exhaustive review of literature was undertaken for this study. Given that there exists over three decades of work on caregiving, it was important to develop specific criteria in order to strategically identify relevant literature to examine for the current study. This was done in several phases and undertaken between 2010 and 2015. Phase 1 was concerned with the general caregiving literature and women’s care in specific. In order to gather the relevant literature for review, I used the McGill library catalogue and Google scholar to query the words caregivers, women caregivers, feminist or gendered approach, and lifecourse. For the purposes of reviewing the general caregiving scholarship and women’s caregiving experiences in order to frame the study, I narrowed my search to research undertaken in the past 20 years. This was done in order to ensure relevance to the current context and understanding of women’s care. My specific concentration during that time was on categories of literature relevant to an exploration of lived experience, to better understand the health and psychosocial impact of women’s caregiving role and responsibilities. I also focused on research that addressed the gendered nature of care with an interest in understanding dimensions of care among diverse groups of women, including wives and daughters, to situate commonalities and differences in caregiving impacts. Additionally, I
read seminal works on caregiving and women from the early 1990’s, some of which are still relevant today. I also looked at the reference lists of key articles and pursued a search into specific authors and scholars. This led to a final review of 300 articles and 20 books sub-divided along the following themes: caregivers, women caregivers, bereaved women caregivers, bereavement. In searching the literature on bereaved women caregivers during Phase 2, the focused topic of my dissertation project, I was guided by the following research question: *What are the lived experiences of women caregivers in the post-caregiving period?* Over two eight month time periods in 2010 and 2015, I used the McGill library catalogue and Google scholar to query the additional terms of bereavement, bereaved caregivers, grief after the death of a relative, post-caregiving, caregivers in bereavement, widowhood, grief, and mourning. The databases used included Ovid/Medline & Social Work Abstracts, Embase, PsychInfo, & Social Services Abstracts/Proquest. For the second article search, the number of articles found was more limited; pointing to the reality that post-caregiving among women is not a frequent topic of research. In total I found 90 articles on caregiver bereavement or post-caregiving of which 30 were about women’s experiences.

### 2.1. Caregivers

Past research has resulted in a broad-based literature on the many facets of caregiving and the subsequent impact of care on the caregiver. While research has documented the many negative aspects of caregiving, including stress and burden as well as physical and psychological morbidity (Schulz, Obrien, Czaja, et al, 2002; Schulz & Beach, 1999; Aneshensel et al, 1995), there are positive aspects as well, including opportunities for reciprocity and the development of a deep sense of meaning (Reid, Moss & Hyman, 2005), enhanced feelings of competence (Peacock et al, 2010), and overall life satisfaction (Raschick and Ingersoll-Dayton, 2004). While
caregiving can be fulfilling, caregivers often struggle to provide care while managing the changes and losses in their care-receiver’s lives. Studies have shown a significant relationship between patient health and caregiver distress – when the caregiver is distressed, it has a negative effect on the patient’s long-term adjustment (Northouse et al, 2012).

Despite subjective differences, the literature demonstrates that caregivers experience greater stress than non-caregivers (Ho et al, 2009). Cumulative stressors play a part as well, and as caregiving can span, on average, eight-ten years (Sinha, 2012), caregivers experience multiple stress and strain at both physical and emotional levels. Moreover, some studies demonstrate that stress is associated with higher mortality in caregivers (Fredman et al, 2010).

Most early studies focused on stress and coping theories to determine how caregiving influenced caregiver well-being. Several scholars in the early 1990’s reported on the tensions of role strain and role conflict in understanding caregiving stress (Marks, 1996; McLanahan & Monson, 1990; Warner & Lawton, 1991). Role strain theories viewed caregiving as the impetus for stress that influenced role restructuring. Some stressors associated with caregiving lead to role captivity, with some caregivers feeling like they had no choice in caregiving (Roberto & Jarott, 2015; Reid & Hardy, 1999). It was Pearlin et al’s early work in 1990 that expanded upon aspects of stress reactions to caregiving. This included examining the relationship between the caregiver and care-receiver, the availability of the caregiver’s social support system, and the caregiver’s feelings of self-esteem and feelings of mastery. Pearlin found that the demands of caregiving could translate into burden, due to the many obligations, responsibilities and expectations of care. Thus, caregiver burden can be seen as a “multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to the caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources”
Given et al, 2004, p.1106). Caregiving burden can mean a decline in physical health and psychological well-being, as well as difficulties in personal relationships (Roberto & Jarrott, 2014). While role overload, burden and feelings of being overwhelmed contribute to stress as well (Li, 2005), coping strategies and social support have been shown to buffer some of the negative effects of caregiving (Roberto & Jarrott, 2014). Theories of stress and coping confirm that high levels of support are associated with lower levels of caregiver distress (Schulz, Gallagher-Thompson, Haley, & Czaja, 2000). In fact, studies show that levels of caregiver depression decrease in relation to improved social support and assistance with stress management (Goode, Haley, Roth, & Ford, 1998). Social support is an important resource for caregivers as they adapt to challenging life events. Decades of studies have confirmed that strong social support can lessen the consequences of stressful life experiences and contribute to psychological well-being (Fiore, Coppel, Becker, & Cox, 1986; House, Landis, & Umberson, 1988; Kiecolt-Glaser, Dura, Speicher, Task, & Glaser, 1991; Krause, Liang, & Yatomi, 1989, Mittelman et al, 2006).

Caregivers’ sense of stress is affected by both relational factors and contextual factors. These include the ‘costs’ and ‘gains’ of care and can be broken down into factors that influence caregiving. The notion of caregiving costs and gains is subjective and can be interpreted in different ways by caregivers. A positive prior relationship could be a gain to a caregiver but the caregiving could be considered a cost as well if there was an impact on the caregiver’s physical health. A caregiver’s perception can render caregiving a burden or a privilege, which can impact on one’s subjective reactions to care (Lee, 2009). Factors that influence caregiving can be related to the quality of the caregiver/care-receiver’s relationship, the amount of family support, and financial means, among others (Hooyman and Kiyak 2008). Various factors at play influence the
The caregiving experience and it has most recently been described as an “emotional rollercoaster” (Masterson, 2015, p.1460).

Further scholarship on caregivers has focused on many aspects of the care experience beyond paradigms of stress and burden that include quality of life, identity, resilience and subjective well-being. Despite the variations in caregiver experiences, the core feature that underlines all caregiving, according to Twigg and Atkin (1994), is “the sense of being responsible for the cared-for person where the interactions go beyond usual reciprocity” (Sinding, 2003, p.153). Informal care “effectively elides the twin ideas of ‘labour’ and ‘love’ – it is both work and the expression of a relationship” (Ungerson, 1987, p. 11). While caregiving relationships are not always based on love, there is often an assumed affinity between the caregiver and the care-receiver at the start of the caregiving trajectory. Family values and inherent beliefs are aspects that support caregivers’ roles, “where the work of caring for someone is predicated on the existence of emotionally intimate social relationships” (Exley and Allen, 2007, p.2318).

More recently, researchers began to look at other ways that caregiving impacts caregivers. Montgomery & Kosloski (2007, 2014) developed a caregiver identity theory that asserts that caregiving is a dynamic process with influence on one’s identity. Based on three tenets, Montgomery & Kosloski’s 2007 theory posits that “the caregiving role is acquired in a systematic way, that it is a dynamic process that changes over time and that as caregivers experience change in their role, they also experience a change in their own identity” (p.134). Caregiver identity theory identifies ways to understand the implication of the various phases of caregiving and encourages support professionals to intervene accordingly. It is built on a theory
that speculates that caregivers are continually forced to adapt to their new roles at each stage of caregiving.

Understanding the adaptations that caregivers make during caregiving is important in order to recognize that caregiving is dynamic, fluid and unpredictable. Since social expectations to perform nurturing tasks for others place women in a caregiving position, this puts women at greater risk for psychological morbidities (Yee and Schultz, 2000). Numerous authors have connected women’s emotional and social ties, their sense of family responsibility and their nurturing characteristics as reasons that women assume most of the care (Corcoran, 1992; Gilligan, 1982; Walker et al, 1992). Tendencies to self-sacrifice, and features of commitment and altruism are also attributes of engagement for women in caregiving. Many studies have found that women experience interference and limitations in their lives due to their roles as caregivers (Sharma, 2016). The links between caregiving and gender will be explored in detail in the next section.

2.1.1 Women caregivers – the gendered nature of caregiving

Undisputed in the literature is the fact that women make up the majority of caregivers, and that they overwhelmingly manage the concrete tasks and emotional needs of care-receivers. Hooyman and Gonyea’s seminal work in 1995 brought attention to the reality that caregiving is a “women’s issue”. According to these authors, caregiving maintains gender inequity perpetuated by society – where women are deemed to be available to care at any costs. They challenged “the assumption that caregiving reflects the societal expectation and ideology that the home is women’s domain and caring a natural female characteristic” (p.3). Feminist approaches to care seek to understand the relationships of women who care and the context within which they care, identifying how responsibilities for family care across the lifespan shape women’s autonomy and
choices (Dentinger & Clarkberg, 2002; Clarkberg & Moen, 2001). The social connectedness of women caregivers to their care-receivers is acknowledged in most of the literature: “Wives’ and daughters’ greater involvement in providing more care, more personal care, and more tasks of caregiving is well-documented” (Chappell, Dujela & Smith, 2015, p. 624). Thus, many women caregivers juggle multiple roles including family and work responsibilities, which represent one of the major tensions of caregiving (Brody, 2004; Spillman & Pezzin, 2000). Women “construct their lives with the constraints of their social and physical worlds” (Roberto & Jarrott, p.198, 2014) and consequently, their lives can be significantly affected by caregiving and their social contexts can be dramatically affected. This is more frequently the case with women than with men (Hooyman and Kiyak, 2008). It has been stated that, “the two factors most consistently reported to be associated with higher levels of stress are gender and living arrangement” (Montgomery & Kosloski, 2013, p. 133). Hence, studies have shown that women spousal caregivers typically experience higher levels of stress and burden than adult children (Pinquart and Sörensen 2011). Yet, daughters living with their care-receivers can experience similar distress as spouses (Connell, 2003). Both complex and subjective, the experiences of daughters and wives as caregivers can be both challenging and rewarding. In spite of the demands of caregiving, the relational processes inherent in care can reinforce women’s family values: “Mothers and daughters are intentional in their negotiation of relationships within a socially structured context that holds them responsible for the quality of family ties” (McGraw & Walker, 2004, p. S330). As caregivers, daughters are often in a position of juggling multiple roles in addition to their caregiving responsibilities while spousal caregivers may find themselves “silently struggling with the balance of providing care to a loved one while internally coping with the emotional distress of their partner’s illness” (Masterson et al, 2013, p. 1459). In one of
the only studies to link couple identity and caregiving, Badr et al. (2007) found that identifying oneself as part of a couple helped wife caregivers to “mediate the negative association of relational deprivation, overload, loss of self, and captivity within the caregiving role“ (p. 223). The notion of a “couple identity” was highly significant for the women and served as a buffer for them as well. A study by Goldsteen et al., (2007), on daughters of mothers with dementia, related how a woman’s identity as a daughter shifted into one of caregiver. The role of caregiver was met with a great deal of struggle and ambivalence for most, as the role of caregiver between parent and child began to reverse. The shift in the caregiving dynamic corresponded to the changing responsibilities of care. However, the feelings of reciprocity acted as a stress buffer for these daughters.

Women more commonly report experiencing stress as a result of caregiving. A study by Yee and Schultz (2000) confirmed that women caregivers had higher levels of burden and depression than male caregivers. This association between gender and psychological distress or psychiatric morbidity has been established in many studies (Pinquart & Sorensen, 2006, Lutzky & Knight, 1994; Miller & Cafasso, 1992; Vitaliano et al, 2003). The feminization of caring has been facilitated by women’s socialization into nurturing roles (Aronson, 1992). Gilligan’s (1982) seminal studies on gender-role socialization asserted that gender roles are internalized from childhood and are reinforced throughout the lifecourse. She claimed that women have a deeper sense of responsibility that prioritizes connections with others. Research to date confirms that women are more likely to compromise parts of their personal and family lives to be caregivers (Yee & Shulz, 2000; Loscocco, 1997; Rosenfeld & Birkelund, 1995). Conceding certain dimensions of women’s lives limits their ability to experience respite and social support. This puts them at risk for increased stress and limited social support, two indicators of maladaptive
caregiving. Women’s commitment to caregiving can have an impact on their sense of selves and influence their ability to manage the multiple roles in their lives.

In conclusion, scholarship on caregiving and women’s care have demonstrated that caregiving is a significant challenge in people’s lives, with both negative and positive effects. Historically, studies on stress and coping, negative health outcomes and burden dominated the literature, with more recent attention to identity, resilience and strengths providing a balanced and complete view of the caregiving experience. Feminist perspectives on caregiving emerged in the late 1980’s and focused attention on the gendered nature of care, addressing both gendered socialization and the privatization of care, resulting in assumptions regarding women’s ‘natural’ role as caregiver. Feminist perspectives on caregiving have also created room for the development of research on the diversity of women’s caregiving experiences in their own voices and have highlighted distinctions and similarities between wives’ and daughters’ experiences of care, the impact of caring on labour participation and social support contexts of women’s care. This wide body of scholarship has provided valuable information to encourage both recognition and support of caregivers generally and within health and social service systems. While this abundant literature has contributed to the placement of the issue of caregiving on the policy and practice landscape over the past few decades, there continues to be a void in understanding what happens to caregivers once caregiving is over. This aspect of the caregiver journey, the transition out of care, has been far less explored in the literature. This is a considerable gap given that the reality of changes that take place during caregiving (identity, roles, relationships and social contexts) have been widely described in the literature as considerable and potentially harmful, particularly in the context of women’s lives. Difficulties associated with adjusting to the
transition out of care are present for bereaved caregivers and specifically, bereaved caregiver women. This will be discussed in the two subsections below.

2.1.2 Bereaved Caregivers

A review of the caregiving and bereavement literature confirms that losing someone after having taken care of him/her is different than losing someone under non-caregiving conditions. While the general bereavement literature asserts that the loss of a spouse or parent may have consequences on one’s health (Stroebe, Hansson, Stroebe & Schut, 2001), it is “the experiences of caregiving that are known to impact the bereavement process” (Holtslander & Duggleby, 2010, p.110). Studies have demonstrated that challenging experiences in caregiving are linked to difficult recovery and adaptation in bereavement (Brazil, Bedard & Willison, 2003; Gilbar & Ben-Zur, 2002; Kris, Cherlin & Prigerson, 2006).

Post-caregiving studies emerged in the late 1990’s as an attempt to merge the bodies of literature of caregiving, widowhood and bereavement. After years of scholarship on the psychological and sociological reactions to loss, with a major focus on depression, research began to consider the impact of caregiving on bereavement processes. It became apparent that the “aspects of the caregiver’s relationship to the deceased and circumstances of the patient’s treatment and death are important considerations for researchers and practitioners looking to predict factors that exacerbate or complicate bereavement reactions” (Bernard & Guarnaccia, 2002, p.164). Both caregiving and reactions to loss have been widely interpreted through stress and coping paradigms (Schulz et al, 2003). Similarly, many authors (Masterson et al, 2015; Masterson et al, 2013; Navaie-Waliser et al, 2002; Li, 2005; Pearlin et al., 1990; Biegel et al., 1991; Zarit 1989; George, 1990) undertaking research on post-caregiving have applied conceptual frameworks of stress and coping to understand the effects of the death of the care-
receiver on the caregiver (Schulz et al, 1997, 2001, 2005). Within the current stress-related conceptual frameworks utilized in post-caregiving, the research has found two main psychological reactions to the death of the care-receiver. For some caregivers, the death of their care-receiver is a relief, a burden removed (Norris & Murrell, 1987; Li, 2005). For others, the loss leads to significant stress and depression due to depletion of the caregiver, who has difficulties dealing with the loss (George & Gwyther, 1986; Li, 2005; Keene & Prokos, 2008). These contradictory responses are not mutually exclusive as caregivers may experience both relief and depletion. Both models are discussed below.

The relief model argues that for many people, caregiving can take an emotional, physical, financial, occupational, and social toll on their lives and when that role has ended, they feel relieved. Once the demands of caregiving no longer exist, post-caregivers are appeased and are better able to cope with the loss. Most of the post-caregiving research shows that relief is the most prominent reaction to the loss of the role (Schulz et al, 2001; Bennett and Vidal-Hall, 2000; Wells & Kendig, 1997; Mullan, 1992; Norris & Murrell, 1987). A recent study by Keene and Prokos (2008) drew upon Wheaton’s 1990 model that stated that “the prior context of stressful life events influences individuals’ experiences of those events” (p.552). Even though the loss of a family member can be difficult, if caregiving was particularly straining, the death could provide relief for some. The reasons that caregivers exhibit greater relief and less distress may be threefold: 1) the care may have been highly intense and difficult, 2) the ability to grieve prior to the death may make the after-death adjustment less difficult and 3) the caregiving situation may have initiated a support system prior to the death which has been known to mitigate the effects of the caregiving and the loss. Research found that the buffers that mitigate caregiver stress include social support, psychosocial health, subjective mastery and relational connectedness (Dilworth-

Keene and Prokos (2008) found that the longer the care situations, the greater the relief at the end. This may be explained by the “role overload” theory that states that the levels of role overload drop after the death of the care-receiver, specifically in regard to care-receivers with dementia (Mullan 1992). George and Gwyther (1986), one of the first teams of authors to examine post-caregiving, measured well-being post-loss, as compared to caregiver scores pre-loss. Caregivers in their study demonstrated a decrease in depressive symptoms and an increase in social activities. Further explaining the sense of relief, Gold et al (1995) studied post-caregivers and found that they had improved functioning compared to existing caregivers. Jones & Martinson (1992) conducted one of the few qualitative studies with post-caregivers after their care-receiver had died. The caregivers felt relief post-loss but expressed grief prior to the loss, as the care-receiver went through the final stages of illness to death. Another qualitative study, by Bennett & Vidal-Hall (2000), suggested that women caregivers experienced some relief after intense conjugal care, and appreciated the opportunity during the study to describe the intensity of their caregiving.

These factors could also be relevant to the depletion model. This model states that cumulative stress or “wear and tear” from the combined effects of caregiving stress and death depletes coping resources, resulting in negative bereavement outcomes (Schulz, Boerner & Hebert, 2008). The depletion model posits that caregivers are in fact hugely drained from all the care they have given, and are thus depleted and do not have the resources to cope with or adjust to the loss (Bonanno et al, 2002; Robinson-Whelen, Tada, MacCallum, McGuire, & Kiecolt-Glaser, 2001). It is believed that “because major life events are thought to have a cumulative effect (Holmes & Rahe, 1967; Turner and Lloyd, 1995), and because both becoming a caregiver
and experiencing a loss through death are stressful events, caregiving experiences should influence health and adjustment outcomes negatively after bereavement” (Schulz et al, 1997, 2005). The caregiving situation depletes the coping mechanisms and stress management resources, and this contributes to a more difficult post-care experience.

Bass & Bowman’s seminal works (in 1990 and in 1991 with Noelker) were among the first to point out that spouses are highly vulnerable due to the living situation as well as the provision of care 24 hours per day, whereas adult children are highly vulnerable due to life/work/care balance. Robinson & Whelen et al. (2001) found that in comparing caregivers to non-caregivers post-loss, depression levels in caregivers were higher even up to three years later. A list of authors (Thomas et al, 2014; Chentsova & Dutton et al, 2002; Bergman et al, 2010; Francis et al, 2010) support the depletion model, stating that greater care-related strain yielded greater strain during loss. Multiple stressors can limit caregivers’ coping skills and a lengthy and complicated caregiving situation can increase caregiver isolation and difficulty.

In order to understand bereaved caregivers, it is central to highlight the interconnectedness of caregiving and the period after care, post-caregiving. Despite evidence showing the association between caregiving and post-caregiving (Schulz et al, 2001), the literature mostly treats them as separate events. While “there has been extensive research conducted on caregivers during either the caregiving or bereavement phase; these phases are often treated as separate entities rather than as part of a continuum” (Masterson et al, 2015, p. 1459). Typically, caregiving literature examines active caregiving, and bereavement literature explores post-death adjustment. Pearlin (1989) was the first to regard “caregiving and bereavement as an ongoing process that exists in a chronic context” (Li, 2005, p.190). Since then, for some caregivers, scholars have noted high levels of psychological distress that begins in
caregiving and extends through bereavement (Gilbar & Ben-Zur, 2002; Aneshensel et al, 2004; Thomas et al, 2014). In fact, the links between caregiving and post-caregiving are, in essence, “reciprocal experiences, in which anticipation of loss hangs over caregiving activities, and the time spent providing care gives shape to mourning” (Masterson & al, 2015, p. 1460; Li, 2005). Moreover, the relationship between caregiving and complicated grief is also evident for some caregivers (Schulz et al, 2005; Ando et al, 2015; Lombardo et al, 2012). Complicated grief is “characterized by intense grief that lasts longer than would be expected according to social norms and that causes impairment in daily functioning” (Shear, 2015, p.154). It affects 2% to 3% of the population worldwide but can rise to 10% to 20% in those that had caregiving relationships (Kersting et al, 2011). This highlights the fact that caregivers’ support needs go beyond the end of caregiving and are closely linked to the caregiving that preceded it. The period of post-caregiving is a challenging time for caregivers, typically because it follows a period of care that may have spanned months and years of intense care and multiple losses. Post-caregiving bereavement has been associated with risks for increased anxiety, depression, and alcohol consumption, sleep disruption and mortality (Penson, Green, Chabner, Lynch, 2002). Feelings of helplessness, hopelessness, depletion and isolation are common among post-caregivers, in addition to feelings of relief (Keene & Prokos, 2008).

What we know so far is that caregivers react differently to all situations, and bereavement is no exception. Undisputed is the fact that caregiving affects the bereavement experience for caregivers, but this is reflected in a myriad of ways. Several authors have written about the impact that caregiving has on caregiver bereavement (Gilbar & Ben-Zur, 2002; Lee, 2009; Brown & Brown, 2014; Stadjuhar, 2013) and potential ways to help caregivers cope (Ando et al, 2015; Stroebe, Stroebe & Schut 2001). Others insist that it is the “caregiving intensity (a measure
of the caregiving context) that influences the caregiver’s psychological well-being, along with other aspects of the caregiving experience, the caregiver’s sociodemographic and health characteristics, and personal and social resources” (Lyons, Cauley & Fredman, 2015, p. 1019). A study by Aneshensel et al (2004) examined depressive symptoms among bereaved caregivers and found that the role overload in active caregiving was a predictor of an adverse bereavement process. They analysed bereavement as part of the emotional reactions of the caregiver, separate from the connection to the care-receiver. Other theorists have posited that caregiving takes over one’s identity and thus identity conflict can explain caregiver reactions in bereavement (Montgomery & Kosloski, 2007; 2014). The various reactions to the end of caregiving illustrates the heterogeneity of this diverse population group; each caregiving situation is unique and can affect the caregiver in different ways. Despite the possibility of complications for caregivers in the post-caregiver stage, little support or follow up is done for post-caregivers in clinical practice. Typically, most interventions for caregivers are centered on the care-receiver and thus, when the care-receiver dies, the involvement with the caregiver ceases.

A summary of the scholarship on caregiver bereavement confirms that caregivers are at a higher risk of psychological distress (Cole &Dendukuri, 2003; Zivin & Christakis, 2007; Stroebe et al, 2007). Caregivers report difficulties with caregiving roles, which can lead to distress and psychological risk over time. These feelings, despite their potential causes, can lead to prolonged grief, a disorder “coined to describe grief that continues in intensity beyond a time frame in which some form of adjustment is expected and to an extent that is significantly disruptive to a person’s life” (Thomas et al, 2014, p. 532). While it is known that age and gender impact the bereavement experience, with women caregivers having more difficulties adjusting to bereavement than men (Ferrario et al, 2004; Gilbar & Ben-Zur, 2002), research to date has not
focused sufficiently on these factors. Some studies are exploring “not only how men and women differ in performing the caregiving role, but also how gender influences the meaning, social context and consequences of caring” (Hooyman & Gonyea, 1995, p. 121; Pinquart & Sorensen, 2008). Given that women are overrepresented as the primary caregiver and that their experience of care is unique, their reactions to the bereavement phase are important to understand. This focus is presented below.

2.1.3 Bereaved Women Caregivers

This section examines bereaved women caregivers, taking into account dimensions such as the context of care, social support, and the personal impact of care. This contextual and gendered approach can shed light on women’s experiences of caregiving and the post caregiving period. Context within caregiving can “refer to the actual circumstances of the emotion-causing situation” (Francis et al, 2015, p.353). This is useful when examining bereavement as it “encompasses recognition of the circumstances of caregiving ending in death” (Francis et al, 2015, p. 353) and posits that bereavement is affected by the continual stressors within the caregiving trajectory (Gilbar & Ben-Zur, 2002). Studies that look at adjustment to bereavement should consider gendered and psychosocial differences in their analysis. Stroebe and Stroebe (1987) called for a separate research scale for women and men; stating that a “greater differentiation by gender is called for in exploring patterns of bereavement, which would facilitate an understanding of findings that show differences between the adjustment of widows and widowers whose spouse have died of cancer” (Gilbar & Ben-Zur, 2002). Studies showed that “a difficult caregiving experience has physical and mental health consequences in bereavement (Brazil et al, 2003; Grande, Farquhar & Barclay, 2004), especially for older women who have lost a spouse (Ferrario, Cardillo, Vicario, Balzarini & Zotti, 2004).
Consistent with women’s intense involvement in care, “the processes of grief and bereavement do not occur apart from the social/interpersonal context of each bereaved person” (Holtslander & Duggleby, p.110, 2010). Holtslander et al’s study on bereaved women (2014) was novel in its exploration of feelings of hope as a mediator of grief. This was one of very few studies that explored the qualitative perceptions of bereaved women caregivers. Yet, in order to mitigate psychological morbidity and promote healthy grief in bereaved women caregivers, we need to understand more about their bereavement experiences. That is, “studies that focus only on measures of functioning following loss will offer an incomplete or misleading portrait of the ways that gender and social relations shape the bereavement experience” (Carr, 2008, p. 434).

Social isolation was one of the biggest indicators of maladapted adjustment to bereavement (Kellehear, 2009; Burton et al, 2003) and social support is seen as one of the leading mitigators of complicated bereavement (Hudson et al, 2011). Ferrario et al, 2004’s study on women caregivers who had exigent caregiving experiences reported bereavement difficulties connected to their self-perceived feelings of distress and compromised well-being. The women who felt overburdened by caregiving were those that had the most difficulties adapting over the long-term (Ferrario et al, 2004; Holtslander et al, 2010). The literature states that subgroups of caregivers experience the transitions out of care with different intensity, based on the salience of their kinship relationship with the care-receiver and the timing of these transitions in the life course (Seltzer & Li, 2000). Spouses vs. adult children have different reactions, and couple relationships vs. parent/child relationships might influence the impact as well. A limitation in the post-caregiving literature is that much of the research has focused on widows/widowers without considering other family members, specifically adult children (Schulz et al, 2001; Keene & Prokos, 2008).
Caregiving strain can affect the bereavement process for women, and seems to be especially prominent when the care-receiver had cancer or dementia (Kim & Schulz, 2008). This can be explained by several factors that include an intense trajectory of caregiving, continual losses of the care-receiver’s functioning, and behavioral challenges (Lunney, Lynn, Foley, Lipson, & Guralnik, 2003; Boerner, Schulz, & Horowitz, 2004; Grant et al., 2002; Robinson-Whelen et al, 2001). Difficulties adjusting to spousal loss were explained by the prior intensity of care within the relationship and the burden of care, which often falls on women. This result reinforces prior research that states that women’s experiences of bereavement differed in intensity from those of male caregivers (Carr & Utz, 2001). A post-death study of spousal cancer patients showed that widows were more distressed and showed more grief than widowers (Gilbar & Ben Zur, 2002). Yet, as is consistent with non-gender specific post-caregiving literature, some of the research is conflicting and requires further exploration. While some studies reported that women expressed relief transitioning out of caregiving, others who cared for a care-receiver with behavioral issues felt depleted in bereavement (Li, 2005; Aneshensel et al, 1995). The scholarship on women caregivers portrays a heterogeneous picture of women who have complex feelings about caregiving and the transition out of care. Pursuing a study of women’s personal experiences in bereavement will give us a more complete picture of individual lives – to better understand the complexity of caregiver bereavement. It serves as recognition that “the process of becoming and being widowed is unique for each woman because the individual's experience of loss is rooted in the totality of her previous life course experiences” (Chambers, 2005, p. 226).

2.2. Conclusion

The current scholarship on bereaved caregivers has painted a limited picture of the context in which women caregivers live the transition out of care. One important limitation of the
current research in post-caregiving has been that the studies are mainly hypothetico-deductive and quantitative. These studies are mainly oriented to test hypotheses, have limited heuristic value and do not sufficiently explore the experience of the subjects they are studying. The two broad psychological reactions to loss discussed above are neither comprehensive nor complete in their study of the transition out of care. Caregivers are not uniform in their responses or reactions to becoming post-caregivers, to negotiating the transition out of care, to dealing with the loss of their care-receiver. While there may be commonalities among the various post-caregiving experiences, each of them is unique and is often related to the characteristics of the care situation. Thus, the meaning and impact of the care-receiver’s death for the caregiver, in addition to the caregiving that preceded this death, are all essential issues to consider for research and practice.

Another limitation is that many of the post-caregiving studies emerged from longitudinal caregiver studies and used the same approaches (conceptual frameworks, variables) common to caregiver studies (Rubio et al, 2001). That is, the research examined stress, impact on well-being, and depressive reactions after the end of caregiving. The majority of the studies, therefore, focus on depression as the most measured reaction to bereavement. These studies are limited as they do not fully consider the context of care as an indicator of bereavement adjustment.

There is a considerable need to use a different approach to understand the lived experiences of post-caregivers. There is a small but emerging body of literature related to the care-receiver’s death or how the caregiving experience has affected the transition out of care and subsequent bereavement reactions. We have seen that the context of care is highly informative regarding post-caregiving reactions. More than just knowing the objective elements of the type of care given, it is imperative to prioritize the exploration of the subjective landscape of
caregiving. Ultimately, a further elaboration of women’s experiences in their own voices is needed. As women assign subjective meanings to their caregiving experiences, their transition into bereavement helps to reposition bereavement as part of the caregiver trajectory. This allows for a more nuanced theoretical perspective that highlights a temporal and intimate context. A personological gendered lifecourse perspective can help to provide a more contextual, qualitative, retrospective approach to better understand the heterogeneity and variability in the post-caregiving experience among women. Positioning bereavement as part of the caregiver lifecourse allows for a recognition that the death of the care-receiver is a transition in the caregiver journey. This takes us beyond the acts of caregiving to understand the impact that the caregiver trajectory has on women’s experience of bereavement. This will be explored in the next chapter.
CHAPTER 3 THEORETICAL FRAMEWORK

3.1 Lifecourse Theory

This study draws on a lifecourse perspective as the lens through which to understand women caregivers’ lived experiences of bereavement. Lifecourse theory provides a framework for analysis of caregiving as a complex and subjective trajectory, accounting for both the personal and social aspects of care situated across time and history. Previous caregiver theories, especially the psychosocial theories more commonly accounted for in social work scholarship, such as stress and burden (Nijboer et al, 2000; Pinquart & Sorensen, 2006a; Pearlin, 1990), and feminist theory (Abel & Nelson, 1990; Baines et al, 1998; Gilligan, 1982) have been used to describe and/or explain caregiving as a social process (Pavalko & Woodbury, 2000) and with particular consequences for women (Donelan, Falik & Desroches, 2001). These theories, however, have rarely named the bereavement period as a component of the caregiving journey and are thus less useful in the context of the current study.

For most caregivers, the role exit out of care is a transformative significant event. During the bereavement period, the caregiver is living with complex responses emerging, in whole or in part, from the consequences of caregiving. In recognition of this, bereavement should be considered as a continuation of the caregiver journey, not as a period of time distinct from the caregiver’s personal subjective history or trajectory. Post-caregiving not only indicates the end of the primary relationship of care (due to the death of the care-receiver) but the end of the responsibility for care. This role change has an impact on one’s identity and social connections and can be seen as a consequence of caregiving. Therefore, in order to fully understand caregiving as a process and subjective lived experience which occurs over time, it is important to reconsider post caregiving and the period of bereavement as an integral part of the caregiver
journey. To this end, a more comprehensive and extended theoretical framework is needed which will enable the inclusion of the central concepts of time, trajectory and transformation into our understanding of women’s lived experiences of care and post-care.

I have chosen to employ a lifecourse perspective as the theoretical framework for this study. In particular, I draw on and integrate both the personological (Elder, 1998) and gendered lifecourse approaches (Moen, Robison & Dempster-McClain, 1995) in order to provide a theoretical lens which is both subjective and contextual, accentuating the relevance of an intra and interpersonal lens on women’s post-caregiving experiences along the caregiver lifecourse.

The current chapter outlines the theoretical framework of the lifecourse, with particular attention to the personological and gendered articulations of lifecourse theory. In the first two sections I describe the development of lifecourse theory and conclude with an exploration of the usefulness of the integration of personological and gendered perspectives for the current study. Subsequently, I address several key tenets of lifecourse theory that are relevant to my study. These include: linked lives, transitions, trajectories, significant events, time and strategic selections. The chapter concludes with final thoughts on my proposed framework.

3.1.1 History and Development of Lifecourse Theory

Lifecourse is a broad theoretical perspective used in multiple disciplines to examine life trajectories and experiences, their contexts, meanings and timing. Although current lifecourse theories are widely utilized, early sociological studies on aging did not include a lifecourse perspective. It was only in the early 1960’s that the study of humans over their lifetime was considered, to “understand how people lived their lives in changing times and across various contexts” (Elder et al, 2009, p.4). Lifecourse theories focus on human development over the

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3 Duane Alwin (2012) writes about lifecourse study in sociology, psychology, anthropology, and social history.
lifecycle, referring to events that take place over time as one develops within and across generations in a human context (Elder, 1974; Moen, 1996; Mortimer & Shanahan, 2003, Dannefer & Settersten 2010). The examination of life within a social and relational context highlights “how chronological age, relationships, common life transitions, and social change shape people’s lives from birth to death” (Hutchison, 2014, p.9). Thus, it is the “importance of time, context, process and meaning on human development and family life” that best defines a life course perspective (Bengston & Allen, 1993, p.471). The literature (Elder 1994; George, 1996; Giele & Elder, 1998; Mortimer & Shanahan, 2003) explains lifecourse as a “series of role transitions and trajectories as people move through their biographies, entering one role, exiting another over time” (Moen & Spencer, 2006, p. 127). Lifecourse has both a temporal and relational dimension as posited by decades of research on human development (Cain, 1964; Elder, 1974) and captures changes in roles and identities, social contexts and biographical histories. Linked to age related stages and also to life changes, lifecourse “emphasizes the interrelatedness of different role trajectories” (Henz, 2004 p. 853) and states that both macro and micro events in one’s life affect one’s lifecourse. Threaded through the life course are events and experiences linked by transitions and mile markers, which have subjective meaning and help to shape identities. All events can be considered pathways through the lifecourse and refer to “social patterns in the timing, duration, spacing and order of the events and roles” (Elder & Rockwell, 1979, p. 26).

In its initial articulation, human growth and change on the individual level formed the basis of the lifecourse approach, which was soon expanded to consider socio-structural, historical and temporal dimensions. Social interaction, social structure, individual agency and choice make up additions to the original lifecourse theory developed by Elder in 1974. Elder (1985)
conceptualized the lifecourse as “interdependent trajectories of social roles over time” (Macmillan and Eliason, 2003, p.530) and more recently, life course was said to be “both biologically based and also socially and culturally constructed” (Furstenberg, 2003, p. 661). Linda K. George wrote that life course is seen as “the intersection of social context and personal biography” (2003, p.672) and this view bridges two distinguishable categories of life course - personological and sociological/institutional. While certain authors spoke of a personological approach (Elder, 1998, 2003, 2006; George, 1993), others spoke of lifecourse as a feature of social structure (Kohli, 1988, 2007; Meyer, 1986; Sorensen, 1986). The two approaches are applications of lifecourse theories and have conceptual differences. Both approaches act as explanations to the phenomena of individual, collective and societal representations of the lifecourse.

3.1.2  Sociological/Institutional and personological approaches

The sociological/institutional approach to the lifecourse centres on the “macroscopic level of social institutions and population aggregates” (Mayer, 2001, p.15) and acknowledges that social forces help to shape individual biographies and trajectories. This reflects that the distinctive social and historical changes experienced by members of particular generations cannot be understood apart from the social and historical context (Dannefer, 1984; Denzin, 1989; Settersten, 1999; Cohler & Hostetler, 2003). Structural and interactional forces related to life course processes are the foci of this category. Dannefer (2013) recognized the “relevance of social change, history, cohort location, and other dimensions of social contexts as forces that influence individuals’ physical and mental health (including role and social status) over the life course and at the cultural level, shaping the very meaning and significance of age” (p. 793). Moreover, Grenier (2012) calls for a consideration of “the constraints that exist for older people,
the importance of subjective experience, and the ways that many of the transitions experienced in late life are not necessarily chosen, voluntary or reversible” (p. 35).

The personological refers to a “focus on the human being viewed as a person” (Barresi & Juckes, 1997, p.695), paying attention to both individual life course and trajectory over time (Elder, 2003). This includes any personal features as well as biographical characteristics related to human development. Context continues to have relevance but is understood in terms of how social norms and values are internalized and acted out by the individual. That is, “contextual factors that were internalized earlier, in ways that have an enduring significant for life course outcomes” (Bengtson, 2008, p.313). Personological approaches seek to explain individual subjectivity and focus specifically on individual narratives and social relations within particular groups such as they represent particular cohort responses and processes across the lifespan. Responses or impacts of experiences on individuals are interpreted as cumulative over time and in response to personal and social events and transitions that are significant to that individual. As such, both intra and interpersonal experiences are deemed central to understanding life course trajectories.

Viewed as a developmental theory (Elder, 1998), the personological life course examines individual lives as part of a process leading up to particular stages in life. It allows for “the opportunity to analyse particular experiences at different life stages and emphasizes the interplay between various life phases rather than seeing every phase in isolation” (Gunnarsson, 2009, p36). As a perspective that considers both the macro and micro influences on individuals, current lifecourse theories have expanded to consider a “context of converging divergences in age, gender, health and well-being” (Moen & Spencer, 2006). Incorporating the concept of social location within lifecourse theories recognizes that individuals are “members of a socially
constructed identity group, including gender, race, ethnicity, social class, sexual orientation, age, religion, geographical location and disability/ability” (Hutchison, 2015, p. 30). Lifecourse, then, has become a longitudinal and dynamic field of inquiry rather than a static, cohort-driven approach.

The personological lifecourse examines age-related events and their timing on individuals and their families differentially across various life trajectories. The accumulation of life experiences as one ages connects people to their families, social roles, social context, and influences their identity and sense of self. The lifecourse, when applied to families, “suggests the interlocking forces of individual, familial-generational, and social-historical structures and processes” (Bengston & Allen, 1993, p. 493). This research prioritizes the personological approach of the lifecourse, within which lives are structured by personal and contextual experiences. The subjective perspectives reveal unfolding life stories with meaning and relevance for individuals. Moreover, narratives refer to life course events throughout people’s experiences that have shaped the current interpretation of their lives.

In the following section, I introduce the gendered lifecourse approach as a means of further elaborating on gender as a significant influence on lifecourse experiences. A gendered lifecourse approach integrated with the personological provides a necessary deepening of my theoretical framework to include, as a main analytic feature, women’s subjective positioning.

3.2 Gendered lifecourse

Most relevant to the lifecourse theory is the discussion of gender, an integral aspect of lived experience across the lifecourse. “Gender is a critical social stratification factor with attendant power, privilege and status that produces inequalities and disparities throughout the lifecourse” (Arber & Ginn, 1995 in Hutchison, 2015, p. 374). Gender impacts life throughout
human development and has been viewed as “influencing the lifecourse trajectory by impacting access and opportunity, health disparities, and disparities in socioeconomic opportunities and creating a lifelong condition of “constrained choice” (Rieker & Bird, 2005 in Hutchison, 2015, p.374). A gendered view of lifecourse demonstrates how gender intersects with aging and helps us to critique women’s social roles and expectations. Within the gendered life course approach, tensions between the structural aspect of women’s lives as being constrained and shaped by social forces and expectations around them is revealed. These forces and expectations influence all aspects of the gendered life course.

The gendered life course was introduced by Arber & Ginn (1995), Moen (1996, 2001) and Moen & Spencer (2006) as an extension of lifecourse theory. Human development and the intersection of gender was influenced by the increase in women’s labour participation, the feminist movement and changes in family structure over last three decades (Calasanti & Slevin, 2001). The gendered lifecourse approach situates individual experiences within social, political, historical, biographical and structural contexts, while insisting upon a non-androcentric analysis that highlights individual heterogeneity. This lens recognizes that gender plays out “in existing, historically established institutional arrangements; in men’s and women’s strategic selection of roles and relationships over the life course, resulting in gender differences in both biographical pacing and perceived control; and in linked lives, the ways relationships produce interlocking roles and behavior” (Moen & Chermack, 2005, p.99). A feminist or gendered lifecourse perspective allows for a contextual view of a subjective topic of specific concern to women’s narratives. A feminist lifecourse approach is concerned with women’s experience in a social and relational context. Hagestad (2003) described the aim of a gendered life course approach, which is to “explore rich interdependencies between three levels: a changing society, dynamic family
Acknowledging gender influences within patterns of change, continuity, contingency and context, the gendered lifecourse examines women’s experiences within families, health care and the workplace. Gender disparities across the lifecourse due to the social construction of factors such as health, family and care have been considered from within a gendered lifecourse framework (Hooyman et al., 2008). The social expectations that women will assume care have been well documented in the literature. This aspect of gendered socialization is evident across the lifecourse, leading to the interiorization of caring as an ethical and moral stance which carries across women’s personal decisions, responsibilities and identity (Gilligan, 1982). Research has considered gendered caregiving from a psychosocial perspective in relationships of caring but has given in to the social policy concept that assumes that women will care at any cost (Czaja et al., 2003; Dupuis, Epp & Smale, 2004). This latter body of scholarship renders visible the shape of gender discrimination in the pattern of women’s caring across the lifecourse – “Women predominate not only because they are socialized to be carers but also because society devalues women’s unreimbursed responsibilities in the home as well as their paid work through employment” (Hooyman & Kiyak, 2007, p.393). A gendered lifecourse theoretical analysis provides a framework for understanding women’s caregiving in a way which is both profound and comprehensive, allowing for both the subjective and relational to emerge in women’s own voice.

3.2.1 Integrating Personological and Gendered Lifecourse Perspectives

The personological gendered lifecourse approach lends credibility to an examination of women’s caring labour and caring practices as represented through the everyday lifecourse; what they do, how they do it, what choices they make regarding care and how these choices and

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actions reflect their identities as women (intra) and their social relationships (inter) including partners, family, wider social networks and environments. Women’s lives are embedded in care relationships where dependency and need are fluid and dynamic, calling their implications into play. The everyday lives of caregivers situates “caregiving in a gendered context where care responsibilities are socially constructed as women’s issues” (Rossi, 2001, p.45). Increased health needs as people age, in combination with limited resources and a deinstitutionalization of services, render caregiving a “care at home” issue, and as such, a women’s issue. Caregiving is best understood in consideration of the gendered social and relational contexts within which it occurs.

Caregiving has been conceptualized as particularly salient for the gendered life course. Socially constructed, gender roles overlap in health and care when we see women embedded in family care, to the exclusion of other parts of their lives. It is commonly women, more than men who alter their own situations to adapt to the needs of others (Moen, Robison & Dempster-McClain, 1995, p. 270). Caregiving is a trajectory that “exemplifies the interdependency of lives, the interlocking of relationships over the life course” (Moen & Sweet, 2004, p. 213). Utilizing a personological gendered life course lens, our understanding of caregiving is expanded to include personal sacrifices, competing demands, financial and emotional risks, impact on others, age, gender, culture, family relations, and other social, contextual and ecological forces. Linking back to the personological, their subjective experiences across the lifecourse and interiorization of social norms must be understood from within a feminist discourse in order to fully capture women’s lifecourse experience as grounded in their lived identities of both the personal and social, or the intra and inter personal.

Integrating the personological and gendered lifecourse perspectives as a singular theory to
examine women’s post-caregiving bereavement experiences facilitates a rich and deep understanding of lived experience over time. This lifecourse view of the caregiving trajectory ensures that the bereavement period is conceptualized as part of the continuum of care, and emphasizes the connections between personological lifecourse narratives of women and how gendered social norms of care are acted out through everyday choices, practices and relationships. Applying a gendered personological lifecourse approach to care allows for a deconstruction of women’s roles, identities and practices as well as a rebuilding of knowledge based on gender, agency, and identity. Using this perspective, we can explore beyond the existing models to look at how “individual lives are embedded in, and mediated through, the lives of others” (Moen & Chermack, 2005; p.103). According to Moen and Chermack (2005), women’s “lives are contingent lives, shaped around the experiences of others: their husbands, children, and parents. While this is obvious around parenthood, women of all ages continue to shape their choices (involving retirement, for instance) around those of their husbands and their caregiving of children as well as aging relatives” (Moen & Chermack, 2005, p. 106). The personological gendered lifecourse approach, then, is very important in identifying the significance of timing and turning points in women’s lives when caregiving begins and ends. Working beyond a role-based approach, a personological gendered lifecourse perspective of caregiving will recognize the caregiver career as a series of transitions, at various temporal points, which make up a trajectory of change and adaptations. Moreover, it will illuminate caregiving as an integral part of women’s lives, rather than as a “problem”. This lens recognizes that caregiving has its own transitions and subjective meaning, expanding our view of personal history/biography leading up to the caregiving context and the relationships within caregiving. Caregiving can be seen as a discontinuity in one’s lifecourse process, but a continuity of
women’s social lives. This nuanced lifecourse perspective facilitates an examination of women’s life trajectories and experiences, their contexts, meanings and timing and is extremely relevant for exploring post-caregiving.

The following section explores the main analytic concepts embedded within personological and gendered lifecourse approaches. Each of these concepts is key to understanding how lifecourse theory operates at the everyday level, that is, how lifecourse theory can be applied to understanding the relationship of the personological influences in an individual’s life and how events across the lifespan influence inter and intra-personal experiences in particular contexts. For the purposes of the present study, women’s caregiving experiences across the lifecourse are theorized as influencing their post-caregiving identities, actions and relationships. These experiences of care reflect the interiorization of gender norms regarding women’s caring and are both subjective (related to the self) and relational (related to others). Caregiving is an important illustration of a gendered transition that occurs within a social and relational dimension, with its own subjective meaning and context. Caregiving epitomizes interdependency within a relational context and can best be explored by overlaying several of the main components of lifecourse theory as described in the theoretical literature: linked lives, transitions, trajectories, significant events, and time. These concepts are important to understanding lifecourse theory because lifecourse theory views events, context and timing as forces that shape and intersect with experience. A life course approach prioritizes how events are shaped by earlier influences (Moody, 1998). In addition, the concept of strategic selection, a concept introduced within the gendered lifecourse approach will also be considered. Finally, I conclude with a short discussion on how a lifecourse approach informed by the integration of personological and gendered perspectives guides the current study.
3.3 Lifecourse Concepts

3.3.1 Linked Lives

Linked lives (Elder, George & Shanahan, 1996), a concept central to lifecourse theory, illustrates that at “every step of the lifecourse, the actions, fortunes, and misfortunes of one person are likely to affect those with whom the person has close relationships” (Pearlin, 2010, p.212). The concept of linked lives highlights the inter-relationships that influence experiences and events across the lifecourse (Elder, 1994; Elder and Pellerin, 1998; Grenier, 2012). Linked lives are a dynamic concept, “recognizing that families constitute patterned, interconnected relationships over time that shift with age, age-graded expectations, and exigencies” (Moen, Lam & Jackson, 2014, p.444). Caregiving is an example of linked lives that includes not only an intersection of time and place, but also an influence on emotional and relational experiences. Through shared relationships, individuals experience their lives in relation to others, impacted by one another as they “move through time, age and history” (Kahn & Antonucci, 1980; Antonucci, 1996). Moen & Sweet (2004) have suggested that people who have linked lives share in experiences, both pleasant and painful, but can endure many changes which can be described as the ‘cost of caring’. Both objectively and subjectively, the concept of linked lives can be a source of comfort as well as a cause of stress. Further investigation of linked lives in caregiving will shed light on the experiences of caregivers in care relationships. Settersten calls for the exploration of the “significance of social relationships in time, probing the beginnings, middles, and ends of relationships” (2015, p. 217). Tensions may arise at the juncture of caregiving and other issues. Linked lives is a concept that has significance for a gendered analysis of dependence and need, concepts that are embedded with social meaning within the feminist literature on care.
From this vantage point, linked lives in the form of family care can “systematically disadvantage women” across the life course, as caregiving depends primarily on “women’s unpaid, underpaid, and typically invisible labour” (Hooyman, Browne, Ray & Richardson, 2002, p.10). Women are more likely to sacrifice their lives, careers, and responsibilities to assume care, despite the emotional and physical consequences. Women’s roles as caregivers may impact their abilities to fully engage in other roles as employees, friends, etc. during their caregiving career.

Thus linked lives are a prominent and compelling component of lifecourse as it relates to bereaved women caregivers. It depicts the connectedness of women to their care-receivers and highlights the dynamics of need and dependence. This concept is helpful in understanding women’s engagement in, and commitment to, caregiving.

3.3.2 Transitions

Transitions within the lifecourse are best understood as dynamic and fluid, with different meanings for each person. Transitions “may be defined as life changes and long term processes that influence both external (i.e.: changes in behavior, role arrangements, social and interpersonal relationships) and internal (ie: shifts in perceptions) aspects of one’s life” (Kramer & Lambert, 1999, p. 659; Cowan, 1991). Significant events, life experiences and changes make up the transitions to which people adapt and develop along trajectories in their lives (George, 1993). Through socio-cultural, relational and biographical interpretations of the meaning of each transition in the lifecourse, people decode their lives. Transitions imply movement into and out of the roles and stages of the lifecourse and transitional processes are the avenues to making meaning and experiences. Central to the concept of transitions within the lifecourse is the intersection of simultaneous multiple transitions. Thus transitions cannot be seen as singular events. Grenier (2012) speaks of ‘multiple and intersecting transitions’ experienced over the
The intersection of health and social biographies may imply multiple transitions ie: health decline, caregiving, loss of social capital, etc. Pearlin (2010) stated “if the timing and/or sequencing of a transition into or out of a role are nonnormative, there is a good chance that it will eventually result in a substantial accumulation of disadvantage and adversity over the life course” (p.211).

Transitions are considered life changes that affect families and individuals in different ways; that is, they are social changes with subjective meaning. Moreover, transitions are considered to be “socially created, socially recognized, and socially shared (Hagestad & Neugarten, 1985). Thus, we can look at transitions as markers or clues to “understand the implication of social change on individual lives” (Moen & Street, 2004, p.210). For bereaved women caregivers, transitions within and out of caregiving are subjectively measured and take on their own meaning for each caregiver. This brings to light the possible constraints that exist for women at each transition along the caregiver’s life course. Using a lifecourse perspective as a lens to examine caregiving, we gain “insights about change over time to theories and concepts about family structure and relationships” (Bengston & Allen, 1993, p. 469). Within caregiving, the meaning implied in transitions is highly significant, as caregiving is seen to be a time period of numerous changes. Both the entry into caregiving and the exit out of caregiving are transitions that greatly affect the lives of the caregiver. This perspective “shifts the discourse from one of individuals and their conflicting or enabling role obligations at any one point in time to a focus on dynamic relationships between roles and among individuals as lives unfold: over time, in tandem and in particular contexts” (Moen & Street, 2004, p. 210). Transitions are the indicators of continuity and change inherent within the trajectories of caregiving.
3.3.3 *Trajectories*

The concept of trajectories is a central component of life course approaches. It can be defined as “a change over a substantial period of life that links behavior in two or more life stages” (Bengston & Allen, 1993, p.471). Trajectories include “long term patterns of stability and change, which usually involves multiple transitions” (Hutchison, 2007, p.15). Within and throughout trajectories are the relational, historical, and socio-cultural contexts that occur in one’s biography. Replete with change and continuity, trajectories encompass subjective lived experiences, role entrance and exits, and stages/phases. Trajectories are multi-faceted and can exist among other parallel trajectories ie: occupation trajectories, health trajectories, family trajectories, etc. Within a developmental aging trajectory, caregiving can be considered a trajectory as well, or a ‘career’. Moen & Chermark (2005) speak of the “concept of career to capture health trajectories and individual biographies as they unfold in dynamic interaction with institutions, relationships and prior experiences” (p.99). Aneshensel et al (1995) refer to caregiving as “the unwanted career” or the “unexpected career” (p.22). Caregiving is a trajectory that can span, on average, 8-10 years. Within a socially influenced life, the caregiving trajectory is characterized by adaptations, health changes, dependency, shifting roles, multiple losses, identity alterations, and social networks. Both complex and subjective, caregiving is a trajectory “embedded in relational contexts” (Moen, 2001, p. 103), which can be affected by certain life choices and decisions. For example, women who choose to be caregivers may also be giving up their career plans and/or social networks. A gendered life course approach explores trajectories and their meanings for women – recognizing that caregiving may result in a new trajectory for women, at a potentially inopportune time in their life course. That said, caregiving is not always a burden or challenge for caregivers. Caregiving may necessitate a life shift or change in certain
parts of one’s life but it may be a welcome change and an opportunity for meaningful and reciprocal relationships.

For many people, caregiving is central to one’s identity and sense of self and so it should be considered a trajectory or career in the lifecourse in order to garner more attention. The lifecourse charts change and development across one’s biography, and this is highly relevant to study the role exit out of caregiving. Within the caregiver trajectory, it is the Timing, Intensity, Meaning, Experience of death and Duration (TIMED) as well as context that influence the caregiver’s adjustment to the role exit or bereavement period (Orzeck, 2014). This includes the multiple losses, transitions, identity hits, and significant events that caregivers may experience along the caregiving trajectory.

3.3.4 Significant events

As an important principle in the lifecourse, significant events are understood as indicators for change, adaptation and turning points (Cappeliez, Beaupré, & Robitaille, 2008; Ferraro & Shippee, 2009). These significant events can be considered as “life events that produce a lasting shift in the life course trajectory” (Hutchison, 2014, p.18) and as “significant occurrences involving a relatively abrupt change that may produce serious and long-lasting effects” (Hutchison, 2008, p.15). In retrospective studies with older adults, scholars remarked that most turning points/significant events related to health and family (Hutchison, 2014). Grenier (2012) puts forward the notion that “the lifecourse can be reinterpreted in relation to processes, turning points and significant experiences” (p.194), a view highly relevant for caregiving. In order to consider caregiving as part of the lifecourse, it is helpful to recognize the role entry of the caregiver as a significant event. Moreover, throughout the caregiving trajectory, changes in health status, dependencies, identity changes, etc. can be considered significant events as well.
One example could be a caregiver who is forced to retire prematurely in order to take care of her aging parents. This significant event can have serious consequences in terms of the caregiver’s family, financial status, career plans, social network, stress level, etc. For example, the personal and work spheres are often related among women, and the balance of the two can be very challenging.

3.3.5 Time

Lifecourse theory highlights a temporal dimension and asserts that the timing of each specific transition or event has significant implications for one’s biography/lifecourse. According to Hutchison (2014), “lifecourse is the relationship between time and human behavior”, “as stories that unfold over time and as we progress through life” (p.8). Time can be applied to lifecourse theory through several interpretations/notions, ie: historical time, biographical time, social time. Historical time means the era or period of time one lives in. This explains the context and the setting with which lived experiences are understood. The historical time period relates to individuals’ interpretation/significance of the life course ie: war times, poverty, experience, etc. Biographical time, as understood within the lifecourse, relates to development as people age. Early experiences, transitions, and difficulties throughout the life course of people shape their biographical time. It refers to “the biological and experiential life paths of individuals and families as they age” (Mortimer & Shanahan, 2003, p.211). Social time is the “socially constructed and institutionalized entry and exit portals into and out of various roles and relationships at various ages and stages and for particular subgroups of the population” (Moen & Sweet, 2004, p.211). Within the temporal framework of the lifecourse are other relevant themes such as agency, relationships, meaning and context. Agency is defined as “how individuals enact their own pathways in the lifecourse, make choices and negotiate roles” (Moen
& Sweet, 2004, p.212) while in relationships, we see how the connections made between family and friends are influential in decision making, beliefs and values (Moen & Sweet, 2004). To understand meaning, we see how individuals self-define in relation to core values, experiences, transitions, etc. As for context, it offers the “the multi-layered demographic, economic, technological, community, organizational and situational ecologies in which biographies unfold” (Moen & Sweet, 2004, p.212). Both time and timing, then, are important considerations for lifecourse study.

3.4 Strategic Selections

Certain scholars situate “strategic selection” as a key thread in gendered lifecourse (Moen & Spencer, 2006, Bernard et al, 2000), referring to individuals who “adapt to their changing circumstances by shifting either their roles or their role enactments”(p. 130). This refers to role entrances and role exits. This is an important concept that needs to be considered when exploring women’s lifecourse experience. The concept of strategic selection provides a contextual analysis that incorporates the previous concepts of significance to the lifecourse addressed in this chapter but which sensitizes them to women’s particular subjectivity. An example of strategic selection in the context of women’s caring labour situates timing and transitions as unpredictable. Transitions within a lifecourse approach are embedded within structural norms and expectations. For example, retirement as a life transition is contextualized within societal norms of work capacity related to ageing and is structured in North America as a chronological timed event that occurs at the age of 65. Retirement reflects a timed role transition that is somewhat predictable and structured by one’s age. However, women’s caring labour cannot be easily structured by age and time and is therefore experienced as unpredictable and represented as arbitrary. Women often have to adapt to the demands and responsibilities around them, creating dislocations in
their structural lifecourse biographies in order to accommodate the needs of others, including family members. Their choices, then, and the process of strategic selection “produce and perpetuate gender differences in roles, relationships, resources and risks at all life stages” (Moen & Spencer, 2006, p.130). Therefore ‘typical’ lifecourse events, influenced by ‘chronologically timed’ structural influences (such as represented by retirement) may obscure the lived realities of middle-aged and older women. Using a view of strategic selection is highly relevant when discussing work and retirement; yet this perspective has not yet been applied to caregiving, where both the role entrance and exit have little to do with choice or ‘typical’ life cycle events. Strategic selection critiques the notion that transitions are self-determining and chosen by women, as is evident when considering caregiving. Women’s interpersonal relations maintain a continuous and significant influence on their lifecourse. Krause (2006) references Berger and Luckman (1966) when he writes, “individuals are shaped by society and it is largely through interpersonal relationships that individuals change the social world they live in” (p.181).

3.5 Conclusion

A lifecourse theoretical approach that integrates a personological and gendered lens provides a useful framework to understand post-caregiving as part of the caregiving lifecourse of women. Moving beyond the traditional template of caregiving that ends when the care-receiver dies, it is essential to develop a lens that enables the integration of post-caregiving as an integral component of the caregiver trajectory. If lifecourse calls into question the pre-caregiving period, then the post-caregiving period is equally indicative of context, relationships, gender and social issues. Caregiving and post-caregiving are “often viewed as discrete and independent entities rather than as reciprocal experiences, in which anticipation of loss hangs over caregiving activities, and the time spent providing care gives shape to mourning” (Masterson et al, 2015, p.
Despite evidence that caregiving involvement does influence bereavement outcomes (Masterson et al, 2015, Li, 2005; Schulz et al, 2003; Collins et al, 1993; Duke, 2002), very few studies have examined caregiving and post-caregiving as a process or sequence. And while there are some studies that look at caregiving and the lifecourse process (Moen, Robison & Fields, 1994; Moen & Street, 2005), and some studies that look at late life widowhood (Chambers, 2005; Carr, Wortman and Nesse, 2005) there are no studies that examine bereaved women caregivers and lifecourse theories. This thesis will argue for caregiving to be viewed as part of the lifecourse of women in order to better investigate the implications of entering into, living within and exiting out of the caregiving trajectory. Furthermore, caregiving, and by extension, post-caregiving, is best explored through a personological gendered lifecourse lens, given the impact of societal gendered norms, the social construction of care and significance of the care relationship among and for women. Recognizing that “caregiving and bereavement are better treated as parts of a continuum rather than as isolated timepoints” (Masterson et al, 2015, p. 1460), and that caregiving is a gendered issue, this study will aim to inform practice in order to develop a more comprehensive and nuanced understanding of bereaved women caregivers. The personological perspective accentuates the personal (intra) and social (inter) contexts across the lifecourse. This allows us to examine how women create meaning and interpret their experiences within bereavement.

The lifecourse principles of linked lives, transitions, trajectories, significant events and strategic selection are highly relevant to the topic of the caregiving career. They highlight the change and continuity inherent in caregiving, while recognizing the personal impact of each principle. The current vision of caregiving recognizes the transitions into and within caregiving but not the transition out of care. This post-caregiving period can be sated with emotional and
physical reactions, high stress, and social isolation. A role-based, utilitarian emphasis on care can translate into an incomplete understanding of the caregiver’s emotional investment into and out of caregiving. To understand this transition out of caregiving, we need to look at the lifecourse of the caregiver and the series of expected or unexpected significant events in the caregiving career, including the death of the care-receiver. This will enable a new theoretical framework with which to understand the post-caregiver period women. Lifecourse theory can help us to understand post-caregiving as part of the caregiving trajectory.
CHAPTER 4 METHODOLOGY

This chapter details the narrative methodology and design of the study, and outlines the process of data collection and analysis. Reflexivity and social location are explained as influences on this research as well.

4.1 Research Question

The objective of this study is to better understand the lived experiences of bereaved women caregivers. Using a qualitative, narrative methodological approach, the main research question is: **What are the lived experiences of women caregivers in the post-caregiving period?** Further sub-questions include: How do caregivers describe the impact of caregiving on their lives? How do caregivers live the transition out of care? What are the post-caregiving experiences of both wives and daughters? The questions aim to elicit stories of the women’s post-care experiences - how they interpreted the meaningful events and transitions as they exit their caregiving trajectory.

4.2 Narrative research

This research study is guided by a qualitative methodology, a method that aims to analyze people in their “natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 1998, p.3). Qualitative methods place an emphasis on change and process, and the variability and complexity of life; they also explore the inter-relationships among conditions, meaning and action (Strauss & Corbin, 1990). In an attempt to “describe routine and problematic moments and meaning in individuals’ lives” (Denzin & Lincoln, 1994, p.2), qualitative methods seek to understand the experiences of human action on an intra and interpersonal level. Focusing on the individual life, qualitative research elicits a storied perspective that is helpful for understanding lived experiences. The choice of
qualitative methods prioritizes the contexts and meanings relevant and central to this study, namely that of the lived experiences of bereaved women caregivers.

Narrative research has enriched social science research by chronicling the use of the story in explaining lived experience. It is understood as “a spoken or written text giving an account of an event/action or series of events/actions, chronologically connected” (Czarniawska, 2004, p.17). Hinchman and Hinchman (1997) state that “narratives are discourses with a clear sequential order that connects events in a meaningful way for a definite audience and thus offers insights about the world and/or people’s experiences of it” (p.xvi). Narrative study bridges disciplines and can be applied in any domain, and is often used in the social sciences as an “interpretive approach … involving storytelling methodology” (Mitchell & Egudo, 2003, p.1). Recounting of the experience promotes learning, sharing and meaning making, constructing identity representations in retrospective reflection. The story itself “becomes an object of study, focusing on how individuals make sense of events and actions in their lives” (Mitchell & Egudo, 2003, p.1). Leading scholars in the field of narrative study (Elliot Mishler, 1995; Donald E. Polkinghorne, 1988; Amia Lieblich, 1995), agree that narrative research embodies the “living and telling, reliving and retelling of stories of the experiences that make up peoples’ lives, both individual and social” (Clandinin & Connelly, 2000, p.20). As a way to understand human experience in a temporal way, narrative research offers an opportunity for subjectivity to lead to interpretation. Narrative inquiry elicits data about how people understand their experiences, construct their identities, sense of selves, and create meaning. In essence, narrative inquiry involves the reconstruction of a person’s experience in relationship both to the other and to a social milieu (Clandinin & Connelly, 2000 in Clandinin, 2007, p.5). It is a study of the experiences of participants through life stories that uncovers the meanings people attribute to
specific experiences across time. According to Elliott (2005), “narrative methodology is based on people’s lived experiences; empowers people by looking at salient themes; focuses in process and change over time; and identifies representation of self” (p. 6).

Moreover, personal narratives tell a social story about how we interact with others. Narrative inquiry understands “lives as unfolding temporally, as particular events within a particular individual’s life. The final result is a story” (Clandinin & Murphy, 2007, p.636). In an event such as caregiving, individuals can create and recreate their caregiver story with value and interpretation, thereby developing a care biography. For caregivers, looking back retrospectively gives them an opportunity to reflect on their experiences and any lessons they may have learned. Bluck & Habermas (2001) refer to autobiographical reasoning, asserting that individuals can infer and create lessons from the stories they tell. In social gerontology, the emphasis on narratives and life stories are viewed as an integral part of late life. A retrospective narrative review of one’s life or caregiving can alter the perception of events and allow for some catharsis. Research on life review attests the fact that “meaning and positive emotions help to restore an individual’s world view and may build additional personal resources” (Schwarzer & Knoll, 2003, p.13). Some of the stated benefits of narrative research for individuals are to potentially gain a clearer perspective on the past, a renewed sense of self-esteem, validation of certain personal choices, recognized resilience techniques, and a better view of the ending (Atkinson, 2007, p.236).

Narrative research can be a strategic choice as a gender-informed method of study. Recognized as a feminist methodology, narrative research “promises a more interpersonal and reciprocal relationship between researchers and those whose lives are the focus of the research” (Bloom, 1998, p.2). This perspective on research “seeks to break down barriers that exist among
women as well as the barriers that exist between the researcher and the researched” (Bloom, 1998, p.2). The narrative approach does not evoke feminism as a call for gender equality but argues instead for an understanding of women’s perspectives in caregiving as unique and situated. Gender represents an intersection between family and society and is crucial in understanding and representing the stories of bereaved women caregivers. In looking at narrative inquiry as the study of experience, we recognize that women’s experiences are impacted contextually and temporally, and most importantly, socially. Narrative study has “human interaction in relationships as its essential area of study” (Riessman & Speedy, 2007, p.427). Moreover, the concept of sequence and consequence is particularly relevant for women, whose lives are intricately connected to others. Analysis of personal narratives can illuminate “individual and collective action and meanings, as well as the social processes by which social life and human relationships are made and changed” (Laslett, 1999, p.392).

The detailed chronological histories of people accounted for in narrative research is structured through the use of rich description of the individual life story. From a personological lifecourse perspective, attention is placed on both personal and contextual processes across the lifecourse (Elder, 1992; Bengtson et al., 2008). This rich detail of life events can help us understand how individuals make sense of their experience and create meanings and identities as they recount their personal experiences and relationships within their immediate social worlds. This focus on both subjectivity and context enables a nuanced understanding of the perspectives of participants’ life course (Elder, 1992; Bengtson et al, 2008). Narrative analysis is a strategy that recognizes the extent to which the stories we tell provide insights about our lived experiences (Sandelowski, 1991). This methodological approach is highly relevant to a study on women caregivers, whose personal identities and immediate social worlds are affected by the
transitions into, within and out of caregiving. The use of narrative inquiry informed by personological (Elder, 1994, 1998) and gendered (Chambers, 2005) lifecourse approaches will aim to capture the detailed stories and life experiences of women caregivers while at the same time paying attention to how personal life history is informed by, and informs, their immediate social contexts (family, friends and other social supports and activities). Biographical insight which emerges from a comprehensive exploration of the worlds of women caregivers can best elicit an understanding of the actions, meanings and identities of women caregivers and the relationship between these actions/meanings and the immediate social worlds in which they are lived.

The personal interpretations in narrative research accentuate the meaning and context of each event, and highlight the connections between events (Coulter & Smith, 2009). This allows participants to make sense of their experiences, recounting events retrospectively. Chase (2003) describes narrative research as “a complex social process, a form of social action that embodies the relation between narrator and culture.” (p. 274). This contextual and cultural view of narrative research recognizes the tensions that exist in people’s lives. In this study, narrative research informed by personological and gendered lifecourse theory was purposely chosen as a method for interviewing women because it recognizes the importance of meaning and interpretation in understanding the chronology of caregiving and in connecting both the notions of shifting roles and identities with the lived experience of care. The main questions of this study query women’s experience, in their own words, with their own meanings attached. The narrative approach to this study allows the women to retell their caregiving story retrospectively. Findings are presented to both display the individual lived experience told chronologically and to develop a storied connection of ideas, events and experiences across women’s stories.
4.3 Study Design

My interest in this study was to explore the narratives of bereaved women caregivers and understand how caregiving impacted their lives across the caregiving lifecourse including the bereavement period. An interview schedule was used to guide participants to share their experiences in the caregiving and postcaregiving phases of their lives and about the circumstances of the care-receiver’s death. Ten women who were in the postcaregiving phase were sought for participation in the study, a number relevant to a narrative inquiry that seeks depth and richness rather than breadth. Questions concentrated upon the transitions into, within and out of caregiving, as well as the personal impact that caregiving had on the women, in order to facilitate an understanding of how the post-caregiving period was lived and experienced. The open-ended questions focused on the impact on women’s personal life, identity, and sense of self. Questions such as: “Can you describe your life as a caregiver?”; “How did caregiving affect you?”; “In what ways did your life change after caregiving ended?” and “how did you manage your time in the post-caregiving period?” were included in the interview guide.

All of the individual interviews took place in the bereaved caregiver’s home except for one interview where the participant preferred to come to the researcher’s office. All interviews were conducted in English, except for one that was conducted in French, and all lasted between 90 minutes and 2 hours. The interviews were digitally recorded and transcribed immediately afterwards, in their original languages. Prior to the question and answer portion of the interviews, the researcher assisted participants in the creation of caregiving timelines called ‘careographies’. I invented the term “careography” to combine the terms “caregiving” and “biography” and developed the tool using computer design software called Lucid Chart. This tool served as a visual representation of the caregiving trajectory and related experiences, combining temporal
indicators within the stories recounted by the caregiver. Through the development of these timelines, participants reconstructed the significant events in the lives of their care-receiver as well as identity relevant changes for themselves. This allowed for a visual mapping of events. It allowed participants to look back and think about the changes that occurred and to link the changes in their experiences to the changes happening with the care-receiver. The timelines created tangible documents available during the interviews. This was an iterative addition to the research as it became important to develop a tool that visually displayed the significant events in a timeline format, for both the caregiver and care-receiver. Through the construction of these careographies, the researcher and participant were able to position the context of care at each transition moment. Moreover, the careographies were helpful in identifying identity-related events throughout the caregiving trajectory. Findings 1 displays each participant’s careography.

4.4. Data collection/Recruitment

Since this study sought to understand women’s post-caregiving experiences, the sample was restricted to female participants. In addition, in order to take into account the influence of the type of relationship on the experiences within the caregiving transitions, the sample included both wives and daughters of care-receivers. Five wives and five daughters who had been the primary caregivers for their husband or parent were recruited in two waves over two years. Multiple sources referred participants to the research, including social workers and group facilitators in community health care settings. Recruitment consisted of word of mouth communication with a variety of community-based sources. Participants were solicited for their involvement by the social workers and educators of the CLSC René-Cassin Caregiver Support Centre, a respite program for older adults; the case managers of the CLSC René-Cassin Palliative Care Team, a program for older adults in end of life situations; and the case managers from the
Henri-Bradet Residential Centre, a day centre for older adults. Each of these three sources are part of a larger organization called the CSSS Cavendish, a health and social service centre serving a territory within Montreal. I chose these professionals because I had a close working relationship with them and they were aware of my history of work with caregivers. The referrers verbally described the study to the caregivers and received consent to have the social worker forward their names to me. I formally invited the caregivers to take part with a detailed letter mailed to each participant, describing the nature and aims of the study, including the expected results, the interview process and the ethical considerations. I had two referred caregivers decline participation and I had to refuse one participant because her care-receiver had died over ten years ago. The other caregivers fit within the inclusion criteria. See Appendix A for the recruitment letter.

Purposive sampling was used to select ten women caregivers in the post-caregiving phase: five wives and five daughters who had recently become bereaved. A limited number of participants were selected given that narrative analysis yields an impressive amount of in-depth data. I conducted personal in depth interviews to understand the different impacts that the transition out of care had on the women as wives and as daughters. The participants were former primary caregivers of their spouse or parent. The population included caregivers who had transitioned out of the caring role in the past six months to three years. This time frame was chosen based on literature that states that some caregivers continue to feel grief and distress for up to two years after the care-receiver’s death (Thomas et al, 2014). In order to get a picture of

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4 The current Quebec health care system has since evolved (in 2015) to merge multiple organizations under twenty two CISSS’s and CIUSSS’s (Integrated Health and Social Service Networks and Integrated University Health and Social Service Networks). The CLSC René-Cassin and Henri Bradet Day Centre are two organizations under the CIUSSS de Centre-Ouest de L’Île de Montreal.
the long-term effects of caregiving, caregivers had to be involved in caregiving for a minimum of two years. This time frame assured a significant experience of caregiving. Co-habitation was not a requirement and both caregivers who lived with or lived apart from the care-receiver were sought. The care-receivers were living at home, in someone’s home, an intermediary resource or in an institution. As well, the participants were chosen to represent varied experiences, including types of illness, ie: cognitive and physical illnesses. Given the catchment area, the population base was concentrated in the Centre West area of Montreal, a geographic area which is culturally and linguistically diverse. This includes a significant percentage of Anglophone residents. In addition, the recruiting organization includes a significant number of Jewish senior clients.

4.5 Interview guide

As the researcher and interviewer, I approached the caregivers, referred by the agencies mentioned above, and personally described the project, the reasoning behind it and its relevance. I explained the consent form and obtained confirmation that they understood it clearly. Once the participants signed the consent form (Appendix B) and agreed to the interview, I conducted open ended, semi-structured interviews with the participants in the confidential location of their choice that included their homes as well as my office. The interviews took approximately 90 to 120 minutes and were audiotaped and transcribed immediately after by the researcher.

Ultimately, the interview guide focused on the subjective meanings that the caregivers ascribed to caregiving, the impact of caregiving on one’s life, how caregiving had affected them, the transition out of care and their bereavement experiences. The reasoning behind the guide was to understand how caregivers were affected by caregiving and the transition out of care through the post-caregiving years. See Appendix C for the interview guide.
The interview guide was comprised of nine main questions and various sub-questions. It was divided into two sections: caregiving and post-caregiving. In the first section, the questions focused on how the participants became caregivers and the place of caregiving in their lives. In order to best investigate the transition out of care, it was essential to comprehend their prior caregiving experiences. As well, I asked how caregiving affected their lives and themselves personally. I explored these issues to understand how caregivers lived the experiences of caregiving. Then, I questioned how caregiving affected the relationship they had with their spouse/parent and the changes they experienced. In the post-caregiving section of the interview guide, the questions were similar but were designed to evoke stories of the post-caregiving period. With a focus on the transition out of care, I asked about the last days of the spouse/parent’s life and how the caregivers felt about the end of caregiving. As well, I explored what changed about the caregivers personally after the caregiving was over, how their identities were affected. Furthermore, through questions about how their lives had changed, how their time is now managed, etc., I probed about the development, rebuilding, and renegotiation, of new or previous identities and relationships. Lastly, I inquired about what support needs caregivers had at the time and if those needs are still present. Participants were asked about their recommendations for supportive services.

The guide was open-ended and encouraged a natural flow of conversation with each caregiver. It allowed the women to talk about their experiences in the order that they felt was relevant and important. Using the stories being told, I developed a timeline with each caregiver to restory and chronologically order each significant event. It led to a shared process of charting the main details of each caregiving story.

Both wives and daughters were sought in order to understand each woman’s experience,
related to their age, life stage, and relationship with the care-receiver. I met with ten bereaved women caregivers and had follow up phone conversations with them as well. In my visits with the caregivers, nine out of ten interviews were in the caregivers’ homes. During the home visits, the caregivers displayed pictures of their care-receiver, and described the context of the photographs. As well, each caregiver presented the rooms in their house where certain meaningful events had occurred. For example, one caregiver showed me the bathroom where her husband had taken a severe fall which changed the course of his illness and subsequently, their lives. Another example was when one caregiver showed me the hospital bed that her husband had slept in, how it took up most of their living room, since he couldn’t manage the stairs in their house. This represented a rupture of their couplehood and led to an emotional disconnect between them. These are but two illustrations of how the location of the interview was part of the participants’ narratives.

4.6 Analysis

According to Clandinin and Connelly (2000), the researcher collects information about the context of the participants’ stories, situating the personal stories within their familial, social, historical and cultural contexts. In the current study, a particular focus was placed on the familial and social contexts specifically as the intent of the study was both to elicit a deeper understanding of bereaved women caregivers’ intra and inter personal worlds and to provide concrete insights for social work practice. I analysed the participants’ stories and then “restoried” them into a working framework. Restorying is the process of reorganizing the stories, analyzing them into key elements (i.e.: time, place, plot, scene) and then rewriting the stories to place them in chronological sequence. During interviews, participants may not present their personal stories in chronological order. Certain theoretical links can be established in the lived experience story
line during the restorying process. The story line may include Clandinin and Connelly’s (2000) three dimensional narrative inquiry space: the personal and social (the interaction); the past, present and future (continuity); and the place (situation). This story line includes information about the setting and context of the participant’s experiences, as well as the ascribed meanings. The data analysis elicited a description of the ten personal stories as well as themes and meanings that emerge from it. Stories are first presented as portraits of each individual participant, with relevant events recorded chronologically. Only after the reader has an opportunity to view and understand each participant as a unique individual, can the researcher connect stories to each other through the development of common emerging themes. This is a particularly useful practice for those interested in gender-informed narrative inquiry, as the process of restorying is negotiated between the participant and researcher and thus the room for power sharing in the interpretation and presentation process is enhanced. The act of restorying is part of the research design that is presented to participants at the outset, making participants aware of the role of the researcher in interpreting their narrative and in shaping their stories and voices to align with the goals of the project. This is a specific part of narrative inquiry and therefore rendered explicit in both data collection and analysis. In this study, the participants were involved in the restorying on their timelines, which were then validated afterwards by the caregivers.

The interview transcripts were read multiple times and summaries were developed for each participant. After this process was completed for each participant, common themes emerging across participant stories were considered. Narrative analysis elicits data about how people understand their experiences, construct their identities and sense of selves, and create meaning. Moreover, personal narratives tell a social story about interactions with others. This can help us
understand how individuals make sense of their experiences and create meanings and identities as they recount their personal experiences of their social worlds. Lindemann-Nelson (2001) wrote that “personal identities are complicated narrative constructions consisting of a fluid and continual interaction of the many stories and fragments of stories that are created around the things that seem most important, from either the first or third person perspective, about a person’s life over time” (p. 8).

The summaries highlighted the significant subjective events for each of the participants prior to caregiving, during caregiving, and in the postcaregiving phase. Significant events included the initial illness diagnosis, falls, hospitalizations, and any complications for the care-receiver, as well as parallel events for the caregiver such as letting go of life projects, their own health issues and limited time to pursue interests, among others. The analysis of the data helped to contextualize the narrative and detect identity-related losses and events. Part of the analysis process was to ‘re-story’ the information by analyzing key information and placing it into chronological order (Clandinin & Connelly, 2000; Creswell, 2006). This helped to associate some of the events for the care-receiver with those of the caregiver and demonstrated the impact that the physical health of the care-receiver had on the emotional health of the caregiver.

At this stage of the process, rather than looking for codes or themes, analyzing narratives refers to the chronology of events and transitions, turning points, and significant events. It is an interpretation of meaning by looking at events that influenced the caregivers’ identity, in their subjective ways, while interpreting the larger meaning of the story—i.e., shifting identities, sense of self, compromised identities, forsaken identities, etc. Presenting the narratives with a focus on identity helped to identify both unique and general features of a caregiver’s life. In this research, narratives are based on significant events within transitions where identity is the common thread.
throughout. Therefore, from data collected on subjective and contextual storytelling, the
narrative analysis in this study focused on specific caregiving events, both in their singularity
and as socially embedded phenomena. The postcaregiving narratives helped to connect the
caregivers’ stories to the interrelated world around them and assign meaning to their experiences.
After this analysis was completed, I re-read the stories to look for themes common across
women’s lived experiences in order to situate central aspects to women’s experiences and to
locate how transitions, turning points and significant events varied across stories, particularly in
relation to the experiences of wives and daughters. This was done to both deepen and enhance
the exploration of the impact of caregiving on the bereavement process of women in the study.

While the interviews were audio taped, I took numerous notes on the salient details, and
also the emotions and reactions of the participants as they told their stories. The observed
emotions and body language provided clues as to the meanings made of participants’
periences. In transcribing the audiotapes and listening to them several times, I identified
themes and specific story lines that would serve as the focus of my analysis, with a goal of
dividing the text into expressed sets of ideas. The text was dissected to look at how participants
reacted within the various dimensions of their lives. The data was coded by hand to visually code
concepts in a mapping format and allowed for comparative analyses of the participants and their
retrospective narratives. Significant events and specific transitions were noted, as told by the
women. I developed a timeline (careography) with each participant so that we could visually
map out her narrative, in a shared process. Together, the researcher and each participant wrote
out the timeline on paper, allowing the participant to visually examine their trajectories and make
any modifications. This proved to be very enlightening and informative for the participants. See
Findings 1 for the digital representations of each of the participant’s careographies.
4.7 Ethical considerations

The project was reviewed by the Université Laval research ethics committee and the CSSS Cavendish Research Ethics Committee. Given that this research included human subjects, there were consent forms signed by the participants. The participants were assured of the project confidentiality and informed that they were free to discontinue at any time. Participants were assigned pseudonyms and their names removed from all documentation to ensure confidentiality. All the materials of research, including transcripts, coding and analysis notes and audiotapes were kept in a locked cabinet accessible only by the researcher and password protected on my personal computer. All identifying information was removed on all documents prior to being saved electronically. As required, all data will be destroyed five years after the completion of the PhD thesis. All paper data will then be destroyed by shredding and all electronic data will be deleted using a data destruction software, as required by the CSSS Cavendish Research Ethics Committee.

As is frequently the case for qualitative interviews with caregivers, discussing past experiences is one of the gains of the project for the participants (Ollerenshaw & Crenshaw, 2002; Riessman, 2008). It can be helpful for bereaved caregivers to reflect on their past experiences and make practical recommendations for others in similar situations. However, a possible risk for the participants during this study was that the discussion regarding past events may bring up difficult emotions and feelings regarding their caregiving experiences. It was negotiated that the CSSS Cavendish Caregiver Support Centre short-term counselling social workers would meet with the participating caregivers, should they be interested in some short term counselling, related to any feelings that may have arisen during the interview. While all the participants found the interviews to be cathartic, there was one participant who expressed
feelings of continued depression since her husband’s death. I referred her to the social worker at the Caregiver Support Centre.

4.8 Reflexivity and social location

Reflexivity is a useful concept in feminist research, in that it insists on researchers being aware of their own subjectivity while situating themselves in participants’ realities (Rinaldi, 2013). Moreover, reflexivity encourages researchers to locate and recognize their own perceptions and the impact of these on the research process and outcomes.

My social location is that of a white, Jewish woman, Anglophone, middle-class, and educated. I am 45 years old and married with three children. I am a part-time PhD student and have worked as a social worker throughout my education. I have a strong identity as a clinical social worker and research practitioner, having spent the last twenty-four years working in a local community health and social service agency.

My relationship with my grandparents was an extremely close one and it was for this reason that I chose my career as a social worker and also for this reason that my course of study throughout my career has been focused on caregivers of older adults. I was the caregiver to my grandparents for over a decade and I understand the experience of juggling multiple roles in care. I would often have to leave work to take my grandparents to doctors’ appointments or grocery shop for them on my lunch hour. In addition, I worried about their health status and well-being on a regular basis. I understood and related to the commitments that the women in my study made, even though the extent of my caregiving paled in comparison to theirs. In my interviews, I always mentioned that I was a caregiver and I felt that it was a comfort to the participants.

Argued as a “defining feature of qualitative research” (Finlay, 2003, p.5), reflexivity is very relatable to gender issues, acknowledging the social construction of gender roles in
research. I conducted the interviews with a sympathetic tone for the caregivers with whom I met. I recognized that their situations may have been challenging and that they were in bereavement. This produced an interview process that was less objective and more flexible, perhaps facilitating the women’s levels of comfort when they were retelling difficult events. In my follow up phone calls, I questioned how the caregiver was feeling emotionally since we had spoken, to ensure that the interview did not create discomfort for the caregiver or unearth difficult feelings. The caregivers were appreciative of the follow up support and many of them invited me again to their homes.

Although this was not an action research project (McNiff, 1988; Wilkinson, 2002), my role as a practitioner-researcher (Freshwater & Lees, 2008) has enabled a degree of ‘research as action’ to be interpreted into the study design and process. Within the organization where I am an active member of a research team (CREGES\(^5\)) and the coordinator of leading practices in caregiving issues, there is institutional recognition of the importance of research to inform both policy and practice. Throughout the study, preliminary findings and insights grounded in women’s experience were brought back to the institutional hierarchy to both inform policy, create change in programming and develop tools for professional training and support at several points during data collection and analysis. This provided an exceptional opportunity to bridge research and practice as an ongoing component of the research design. Details regarding these impacts and innovative tools will be outlined in the discussion section of this thesis. It is important to note that I am employed in the health centre through which the majority of recruitment was undertaken. However, this was a large organization located at eight sites with a professional staff complement of eighteen hundred people at the time of recruitment. No

\(^5\) The Centre for Research and Expertise in Social Gerontology
recruitment was undertaken with current or former clients. The fact that I was a member of this organization facilitated trust building with recruitment sources and the uptake of findings and insights throughout the duration of the study.

4.9 Research validity

In order to ensure research validity, I pursued the techniques set out by Joseph Maxwell (2009) based on the work of Lincoln & Guba (1985). Maxwell states that long-term field involvement and producing detailed and varied data create a valid research setting. I was involved with each participant in several ways – by an initial phone call, a two hour home visit, and follow up phone call. I audiotaped each interview and took notes on each phone call and visit. Maxwell states that gaining feedback from the participants enriches the experience of validity. I reviewed the information with the participants and created a timeline of events for them to validate. This proved to be helpful for the participants as they could visually see their caregiver trajectory. In addition, major themes across stories were checked with a subset of participants to ensure my analysis was relevant to them. Moreover, it was an important opportunity to verify that the meaning gleaned from the stories told was accurate (Polkinghorne, 2007). Participants had an opportunity to expand or alter their stories in these follow up conversations. Maxwell also refers to triangulation as a process of validation and when I collected my data, I included the original information from the referral source, the information from the participants and my own field notes. In addition previous research literature was used to triangulate with stories shared. Finally, emerging ideas were shared with key experts (colleagues and supervisors) to ensure relevance to the field. Through member checking, the triangulation of sources (Patton, 1999) and the audio recording, this helped promote research validity.
4.10 Study Limitations

There are certain limitations that are important to consider. One of the limitations of the study was that the sample size was small. While this sample choice supports richness and depth in data collection, it cannot represent all caregiver reactions. A narrative approach seeks depth and subjective meaning from the collected data. The majority of the participant group were educated, Anglophone, and Jewish, with limited access to formal support services. While previous research refers to financial burden as an important area of consideration, this issue did not emerge in my study and is therefore a limitation of my findings. It is important to note that previous research has demonstrated that caregiving is a challenge that cuts across ethnicity, class, income, and education. Moreover, many of the caregivers had a connection to the health care system because of their care-receivers’ needs and this limits our understanding of those who have no connection to the health care system. Although the sample was specific and does not represent all caregivers, the issues and challenges expressed are still considered to be transferable.
CHAPTER 5: FINDINGS

5.1 Introduction to the findings section

The objective of this research was to provide a rich and detailed accounting of women’s experiences of post-caregiving, paying particular attention to their unique lived realities, personal meaning and immediate contexts, including social relationships and activities. Using a narrative approach, the women’s stories reveal the contextual nuances of post-caregiving and highlight the relevance of the caregiving lifecourse and trajectory to the bereavement process. The narrative analysis has a specific presentation that maintains the integrity and voice of the individual participant through their story, which is at first reconstructed chronologically and then interrogated for thematic connections within and across stories. Narrative stories organize human life and connect events through time, meaning and context. This research offered caregivers the opportunity to retrospectively reveal their caregiving trajectory – allowing for a unique perspective with which to disclose the personal accounts of this central aspect of their lives. The presentation of findings in the current study reflects narrative techniques of presentation, combining detailed portraits of each participant, chronological accounts through the use of timelines, and thematic analysis. By doing so, it provides a complete picture of the impact of caregiving on the caregivers’ bereavement. This can be referred to as a “narrative configuration, where happenings are drawn together and integrated into a temporally organized whole” (Polkinghorne, 1995, p. 5). Thus, analysing the caregivers’ stories as unique and whole and then interpreting common themes across stories helped to illuminate individual and shared meanings of events across the caregiver lifecourse. Identifying themes as a strategy for presentation demonstrated the caregivers’ common “values, beliefs, moral orientations, social identities, and attitudes” (Souto-Manning, 2012, p. 159). Caregivers illuminated events and choices they made
in their caregiving careers and as such, this “storied narrative… preserves the complexity of human action with its interrelationship of temporal sequence, human motivation, chance happenings, and changing interpersonal and environmental contexts” (Polkinghorne, 1995, p7). The use of both unique lifestories and common themes which emerged from these stories opened up the possibility to uncover the nature and shape of post-caregiving among women participants.

In order to pay attention to both unique lived experiences within participant stories and common themes which emerged across participant stories, the findings are presented in two distinct sections (Findings 1 & Findings 2).

In **Findings Part 1**, individual women’s narratives are presented as summary stories which include descriptions of their experiences alongside direct quotes. A corresponding visual chronological timeline of their caregiver lifecourse, identified as their ‘careography’, follows each narrative. By constructing the careography with the caregiver, we were able to see the meaning and significance of events and transitions within and throughout the caregiving lifecourse. The relevance of the careography is that the caregiver is able to subjectively and retrospectively recreate their visual caregiving trajectory. The careography is a dated timeline representing the caregiver trajectory, from the beginning of the caregiving journey into the post-caregiving period. For each caregiver/care-receiver dyad, the careography illustrates significant events during the care trajectory, over a span of time. With distinct divisions, the top part of the timeline depicts the care-receiver’s significant events related to his/her health, illness, accidents, and diagnoses. The bottom part of the timeline show the important identity-relevant events experienced by the caregiver. This tool was an iterative addition to the interview process and resulted in substantive discussions with the caregivers, as well as visual validation of their care journeys.
The individual narratives are co-constructions, with the author taking women’s stories as they were spoken during the interview process and re-storying them with attention to chronology and relative importance to the woman’s unique history. The development of distinct life stories is central to a narrative approach which seeks to represent the voices of participants in their entirety with attention placed on telling a person’s whole story in their own voice and ensuring that lived experiences are represented in a way that honours the uniqueness of each person and does not compartmentalize or ‘break down’ the story into disconnected parts. In fact, some narrative accounts do not present a thematic analysis across stories but rest entirely on an in-depth, rich and full accounting of each person’s story. This is done without interruption by the author, except to represent and confirm the story chronologically. Re-storying is a significant tool among narrative researchers because it allows researchers to find the causal links between stories told by participants. The elements found in the story are then placed in chronological sequence and within context for the participant to review (Ollerenshaw & Creswell, 2002). While in the present study I engage in thematic analysis, I first present the stories of the women interviewed as unique accounts in order to provide a full picture of each woman, their experiences and perspectives before thematic analysis is undertaken in Findings Part 2. The women’s narratives in Findings Part 1 are each organized differently, with emphasis and structure adapted to reflect both women’s stories and the way they tell them. This was done to focus on the meaning and events significant to each woman. The main ideas that emerge across all stories include caregivers’ responsibilities, experiences, feelings, relationships, work and family histories, friendships, social supports and identity.

In Findings part 2, emerging themes are presented from the participants’ stories that answer the question “what are the common lived experiences of women caregivers in the post-
caregiving period?” While each woman experienced these phases in unique ways, it is possible to uncover patterns common to both wives and daughters. These patterns are marked by several ruptures, including the onset of illness of the care-receiver representing the beginning of the caregiver role, and the death of the care-receiver marking the beginning of the post-caregiving phase. These are characterized as significant ruptures as they are events outside of the control of the participants. Whether or not the onset of illness was gradual or sudden, there was a moment in time for each woman when the activities involved in providing care represented a significant shift in identity from wife or daughter to caregiver.

Both Findings 1 and Findings 2 are connected by the events in the participants’ lives and the themes emerging from their experiences. The narratives told by the caregivers demonstrate the experiences lived during the caregiving trajectory and the transition out of care. It is helpful to comprehend the aspects of the women’s coping capacities, perspectives and negotiations of their identities across the caregiver trajectory. Thus, it is important, in the context of understanding women’s lived experiences, to pay attention to what their identity, life and relationships were like prior to becoming a caregiver, particularly in the context of reconstructing lives in the post-caregiving phase. This retrospective, chronological view of caregiving is an approach that is often not considered or accounted for in current caregiving research, practice and policy.

To provide some context to the Findings, a Demographic table (Table 1) is provided, indicating salient information for each caregiver. Demographic information was adapted to ensure anonymity and pseudonyms were assigned to ensure confidentiality. The average age of the 10 participants was 67 years old with an average duration of caregiving of 6.6 years. For the spousal caregivers, the average age was 77.6 years old with an average of 6.8 years of
caregiving. For the daughters, the average age was 56.6 years old with an average of 6.4 years of caregiving.

The table displays the wives on the top section and the daughters on the bottom section. Basic information related to the caregivers’ ages, living situation, marital status and work status are specified. This is relevant to understand the context of care for each caregiver. Moreover, understanding their living, marital and work situations can help to interpret competing demands and potential challenges. The last four columns speak to the lived experiences of the caregivers, with attention paid to the duration of the caregiving, whether the caregiver received support during caregiving or in bereavement, as well as whether they were present at the care-receiver’s death. This information was necessary to fully comprehend the impact of caregiving on each caregiver, and how they lived the transition out of caregiving. These factors played a part in the caregivers’ adaptations to the bereavement period and subsequent emotional reactions.
5.2 Participant data – Table 1

<table>
<thead>
<tr>
<th>Wives:</th>
<th>Age</th>
<th>Living situation during caregiving</th>
<th>Marital status</th>
<th>Work status</th>
<th>Duration of caregiving</th>
<th>Received formal support during caregiving</th>
<th>Was present at the care-receiver's death</th>
<th>Received formal support during bereavement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>76 yrs</td>
<td>With care-receiver until LTC placement</td>
<td>Married</td>
<td>Retired</td>
<td>11 years</td>
<td>Yes – caregiver support group</td>
<td>Yes</td>
<td>Yes, individual counseling after 6 months</td>
</tr>
<tr>
<td>Beatrice</td>
<td>75 yrs</td>
<td>With care-receiver</td>
<td>Married</td>
<td>Retired</td>
<td>5 years</td>
<td>Yes – caregiver support group</td>
<td>Yes</td>
<td>Yes, attended a bereavement group after 8 months</td>
</tr>
<tr>
<td>Charlotte</td>
<td>78 yrs</td>
<td>With care-receiver until LTC placement</td>
<td>Married</td>
<td>Retired</td>
<td>6 years</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Debra</td>
<td>80 yrs</td>
<td>With care-receiver until LTC placement</td>
<td>Married</td>
<td>Retired</td>
<td>10 years</td>
<td>No</td>
<td>Yes</td>
<td>Yes, attended a bereavement group after 7 months</td>
</tr>
<tr>
<td>Evelyn</td>
<td>79 yrs</td>
<td>With care-receiver</td>
<td>Married</td>
<td>Retired</td>
<td>3 years</td>
<td>No</td>
<td>Yes</td>
<td>Yes, attended a bereavement group after 6 months</td>
</tr>
</tbody>
</table>

| Daughters: | | | | | |
| Faith | 60 yrs | With care-receiver until LTC placement | Divorced | Unemployed social worker | 8 years | No | No | No |
| Gayle | 56 yrs | With care-receiver | Divorced | Unemployed | 5 years | Yes | No | No |
| Hannah | 50 yrs | Lived near care-receiver | Married | Employed child care worker | 8 years | No | No | No |
| Ivy | 67 yrs | Lived near care-receiver in LTC placement | Married | Unemployed | 6 years | No | Yes | Yes |
| Joanie | 50 yrs | Lived near care-receiver in LTC placement | Divorced | Employed child care worker | 5 years | No | No | No |
5.3 Findings 1

This chapter portrays descriptive summaries and direct quotes from the interview data of the five wives and five daughters who participated in this research. The summaries depict the caregivers’ responses to the open-ended questions about their caregiving and post-caregiving experiences. I have interspersed direct quotes throughout each personal narrative as the caregivers describe the events of caregiving that impacted their lives. Using a narrative approach allowed the caregivers to interpret their experiences as they retold their personal stories. Retrospectively, the caregivers were able to have insight into the events that took place as they transitioned out of caregiving. Several caregivers expressed appreciation for the opportunity to revisit their caregiving experiences, saying that it was cathartic and meaningful for them to talk about that time in their lives.

For the sake of anonymity and confidentiality, I have assigned pseudonyms to each participant in the study.

5.3.1 Alice

Alice was a seventy-six year old, white, Jewish woman. She was educated and had a Bachelor’s degree in arts. Alice was raised by both her parents, was one of three children and grew up in Montreal. She remarked that her parents were hard working people who wanted what was best for her and her siblings (line 70). Throughout the interview, Alice spoke very highly of her parents and siblings. She reported that her childhood was filled with “contentment and love” (line 72) and had many friends growing up.

Alice met her husband when she was in her mid-twenties and in her words, “fell hopelessly in love” (line 72). After they married, she worked for a short period of time as a
pharmacy clerk and then became pregnant. She stayed home with her two sons for many years until they were grown. She was involved in their “lives, their school, their homework and their social lives” (line74). After her sons had grown into young men and moved out, Alice went back to work in a pharmacy on a part-time basis until her husband became ill.

Alice was married to her husband for 49 years before he died. Alice reported that as a couple, they had a very active social life (line 81-82). They often went out with friends for dinner and to movies and enjoyed being “on the go” (line 83). Prior to her husband becoming ill, Alice reports having a very close and satisfying marriage. She stated that her husband was the “light in her life” (line 81) and that she loved spending time with him. Alice often described herself in relation to her husband, saying that he “gave her her confidence”(line 433). She stated that her role as “her husband’s wife” (line 416) was the most important one in her life.

Alice’s husband became ill in his early seventies with multiple medical problems including Parkinson’s disease, kidney disease, and familial Mediterranean fever. He faced a steady decline due to the complex co-morbidities of his illnesses, which led to a need for increased physical help. Alice became his primary caregiver and cared for him for eleven years before his death in 2009. Alice was involved in daily care including dressing, hygiene, meal preparation, feeding, and transferring as well as the coordination of his care, medication, and medical appointments. These tasks increased as her husband’s situation worsened, leading up to his relocation to a long-term care facility eight months before his death. Alice described her caregiving as “very difficult” (line 127) and felt that it “took over her life” (line 128).

Throughout the interview, Alice made comments related to the significant change in her feelings regarding her husband, due to the caregiving situation. During the caregiving period, Alice felt that her feelings about her husband, the love she had for him, changed due to the increased
demands of care (line 233-242). She felt that she went from being a loving partner to a nurse. During the caregiving period, Alice never asked for any help from her two sons, both of whom lived nearby. She said she had trouble asking for help from anyone (lines 54-56). Even when the community service worker (CLSC employee) came to do an evaluation, she did not request help. In her words, “I felt that the CLSC thought I was very strong and capable and they never offered me too much” (line 45).

When her husband died, Alice expressed feeling “relieved” immediately (line 83) but after several months, she reported feeling sad and guilty (line 438). She believed she could have “done more” (line 438). Alice felt like she had “lost her identity” during the caregiving period (line 407-408). Alice was given anti-depressants by her physician to help her deal with her feelings of sadness, guilt and loss. She felt as if people were judging her inability to “get over” her husband and therefore chose not to talk about her feelings anymore with friends (lines 421-427). Alice was having a very hard time regaining her sense of self or finding any connection with a new identity (lines 426-428).

5.3.1.1 Alice’s careography summary

When asked to talk about her life as a caregiver, Alice described caregiving as a major part of her life (Lines 135-138). She stated that becoming a caregiver was a gradual process, that things just “slipped a little and changed”, (line 12) that “you started off really slowly and then gradually, you are doing everything – that’s how you become a caregiver” (lines 20-21). Alice described caregiving as all consuming, not having the opportunity to do anything for herself (line 32-33). Her husband’s needs took precedence over her own needs and he became the full focus of her life.

“Getting him ready, if he had to go out, if he had an appointment, or if he had to go the CLSC, that was a big deal; trying to put this person together, to make sure they’re clean,
shaved, dressed. That’s a very hard job. Very difficult, it’s a lot of work. The days were full of appointments and seemed to fly by. Evenings were about getting ready for bed… your life becomes about meals and bedtimes… it’s a very hard job; it takes everything you’ve got” (Lines 125-131).

During the course of the eleven-year caregiving career, Alice described the last five years as the most intense (line 26-27). More than the instrumental tasks, Alice expressed intense emotions about the difficulties of being a caregiver (lines 153-154). Alice’s description in the next few excerpts detail the significant role that caregiving took on in her life.

“For me, caregiving meant non-stop demands, never any free time, constant medical issues… really hellish (lines 32-33). I used to hate to go to bed at night because I knew I would have to wake up in the morning (lines 113-114). You say words in your head that you don’t really mean like “he’s sucking the life out of me”, that’s how you feel. You feel like your life has been taken from you” (Lines 136-139).

“It just changes you. You’re bound to feel like this person is taking my life from me. You can’t be mean to them of course but you sometimes can end up being sort of nasty, or petty about it. I didn’t hug him as much or kiss him. They are not as attractive. There’s not that attraction still. You’re constantly caring for them. And you become… wondering when they’re going to die. It’s a terrible thing. Your life goes away; you say, I wonder what happened to my life. You’ve lost your life completely. (Lines 252 – 258).

“I used to feel like a trapped rat. Like I was disappearing, like I was going into a corner and like I had this much space left. You don’t have any space left and you have this much corner left and there’s less and less all the time” (Lines 398-401).

“There’s something that happens … when you are taking care of someone, you become entwined, like you’re one person. I felt almost masculine. Like I was taking care of him and I lost who I was. You lose your identity (Lines 405-409). My identity was one part of a couple and not the intertwined person we became. I lived and breathed for him and his needs. I didn’t even think of what I needed, besides food” (Lines 415-417).

Alice’s portrayal of her life as a caregiver helped to illuminate the intense implication involved in caregiving, and the sacrifices she made as a result. Her retrospective observations revealed the subjective and personal losses Alice experienced. Moreover, the impact on Alice’s identity and sense of self played a significant role in her caregiving trajectory, worsening
simultaneously with her husband’s deteriorating health. Alice’s husband died in the hospital after having been in a long-term care establishment for eight months. After Alice’s husband died, Alice experienced a strong “sense of relief” (Line 384). She felt like a part of her life was over and that she needed to rest and recuperate (Line 384-385). She stated that the caregiving and her husband’s suffering had gone on for too long and she was relieved for both to be over (Lines 390-393). Although she expressed some discomfort with her emotions, Alice described feeling a sense of liberation.

“I rested after and I was fine. I felt free, free at last, free at last. It was like I felt terrible but I didn’t mourn him, like cry a lot. My life had come back to me and it was like a relief in a way. It had to do with two things really, my life coming back to me and resting and him not having the pain anymore. Not having to see him suffer, I thought it was time already. Too many years, you know” (Lines 388-393).

Alice’s initial reaction to the end of caregiving shifted after some time. Her initial feelings of relief gave way to other feelings of regret and sadness.

“I still feel a part of me is gone. I miss him (crying). I try not to talk about my husband to my sister or my kids because I think they think I should be further ahead, that I should be over him. (Lines 422-424) I would like to see a therapist and talk about it. I feel like I can’t live without him (Line 428-429). I feel guilty that I should have done more. I feel my life is useless. I won’t kill myself though. Don’t worry” (Lines 438-440).”

Alice described her post-caregiving experiences as difficult. She expressed feeling depressed and guilty. Alice sought help from her general practitioner about her intense emotions and was prescribed anti-depressants, which have not proven helpful. Alice described difficulties finding a new sense of purpose and regaining her sense of self. At the time of the interview, she was seeking counseling for her unresolved grief and complicated bereavement.
5.3.1.2 Alice's careography timeline

Alice's husband gets diagnosed with Parkinson's disease

Alice's husband is very limited in his mobility and requires significant attention

Although Alice's husband wanted to remain at home, it became impossible for Alice to help him.

Alice's husband is placed in a long-term care setting

Alice's husband dies in the hospital


Alice reports that her husband's decline was immediate and she became involved in all aspects of his care

Alice felt that the caregiving was very difficult and demanding. She ceased participating in any social activities

The decision to relocate her husband was very difficult. Alice felt very guilty about it but could not maintain him at home.

Alice spent all her time at the hospital with her husband and did not pursue any of her own interests. She is exhausted from caregiving and rests for weeks afterwards.

Alice has a heart attack. Her sons help her at home until she recovers fully.

Alice is feeling sadness and guilt regarding her husband. After an interview about her caregiving, Alice is referred to bereavement counselling

Timeline of identity-relevant events for the caregiver
5.3.2  Beatrice

Beatrice was a seventy-five year old white, Jewish woman who was a caregiver to her husband for 6 years before he died in 2009. She grew up in Montreal and had “a good life” (Line 21). She stated that despite her parents’ good health, she “started out with Colitis and now she has Crohns” (Line 19). She has had multiple surgeries for her stomach issues but she “functions as best as she can” (Line 21). Beatrice worked in secretarial jobs before she got married and had an identity as a productive person. She mentioned that her health was always an issue for her.

Beatrice and her husband were married for 52 years and had two children; a daughter and a son. Beatrice described her married life as a compromise, stating that her husband had a bad temper while she was easy going (Line 111-112). As a couple, they were very social, with many friends (Line 161). Beatrice’s husband had multiple medical issues including Alzheimer’s disease, high blood pressure, chronic pneumonia, and macular degeneration. He also had a degenerative disease that made him unable to walk (Line 55-56). Beatrice was involved in every aspect of her husband’s care due to his blindness and numerous health issues. For five years, Beatrice took care of her husband at home, despite her own physical health issues and the lack of help from anyone else. Beatrice described the care as “all consuming” (Line 62) and even when he was placed 13 months before his death, she was involved in his care. Beatrice hired help once a week when her husband was at home and had help on a regular basis when he was in placement. Beatrice related that the decision to have her husband relocate to a long-term care setting was very difficult and painful (Line 36-37).
5.3.2.1 Beatrice’s careography summary

Beatrice’s caregiving lasted for six years and during that time her husband suffered from many illnesses and deteriorated steadily. Simultaneously, Beatrice had to withdraw from many social activities that she enjoyed. She recounted the intensity of the care and how it seemed all-consuming.

“I didn’t do anything for anyone, especially myself, because of his situation. I don’t even recall feeling anything… just being consumed with my husband’s health and well-being. It was like a blur in my life” (Lines 84-85).

“There were many times I was angry, I resented it. I wished I was anywhere but here. When he really needed me, I wanted to go out but I couldn’t go. It happened quite often. I found it difficult” (Lines 122-125).

While he was in placement, Beatrice found no solace or peace. She felt the responsibility of caregiving but did not have the control she wanted.

“I wasn’t with him full time at the nursing home but I always felt badly that he was there. I never felt freedom when he wasn’t with me. It was different when I knew someone was with him at home. At the nursing home, they drugged him sometimes and by that point, he was aggressive. So, those last few years were not peaceful for me”(Lines 138-141).

When her husband died, Beatrice was there with him. She found it extremely difficult to have seen his death (Line 214-215). She almost missed it and said she would have regretted that more: “It’s hard to get that image out of my head. I know, though, had I missed his death, I would never have forgiven myself” (Line 218-219). When asked to describe her life after caregiving, Beatrice described that phase as empty and difficult and lonely (Line 180).

“Sad, lost, I wish he were still here. As hard as it was, I wish he were here. It’s funny, you know. You never think it’s going to end and that you will be stuck like this forever and then one day, it’s over. And you’re left standing there, amazed that it’s all over. I think I was in shock when it was over. It was so difficult and yet, I miss him. I wish he were here again” (Lines 147-156).
Beatrice, after eight months of grieving, decided to “make an effort to get her life back” (Line 197). She joined an Alzheimer’s bereavement group that met on a regular basis and started to take a painting class. This helped her meet other widows and they started to interact as a group. They travelled and enjoyed cultural events together. This gave Beatrice a lot of pleasure and helped her to “find her way back” (Lines 176-177).

Beatrice described her post-caregiving period as challenging and without purpose, with feelings of loneliness that persisted. Beatrice joined a widow’s group that met regularly and included a lot of peer support. Unfortunately, in 2011, Beatrice died of heart failure and complications.
5.3.2.2 Beatrice’s careography timeline

BEATRICE’S CAREOGRAPHY
Timeline of significant events for the care-receiver

Beatrice's husband gets diagnosed with legal blindness and depression

Beatrice's husband becomes very demanding and dependent on Beatrice

Beatrice's husband is placed in long term care from the hospital

Beatrice's husband dies

2003

2005

2007

2009

2010

2011

Beatrice states that her role became more pronounced as the “caregiver”

Beatrice stops seeing her friends socially as her husband's daily needs increase

Beatrice visits her husband every day

Beatrice is homebound and very distressed

Beatrice begins to find new hobbies and joins a widow group

Beatrice dies from a heart attack

Timeline of identity-relevant events for the caregiver
5.3.3 Charlotte

Charlotte was a Catholic, 78-year-old white woman, born and raised in rural Quebec. Charlotte and her husband were married for 48 years prior to her husband’s death and had no children. Charlotte was a librarian by trade and had a Master’s degree in library science when she met her husband, who was an aeronautical engineer. Charlotte and her husband both worked full time and were avid skiers. Charlotte and her husband were socially active and often saw other couples for dinner or events. As they aged, Charlotte and her husband noticed many of their friends becoming ill and less autonomous. This was difficult for them, according to Charlotte, and they were very affected by the death of a couple very close to them (Lines 78-79).

Charlotte stated that her caregiving began when her husband began acting strange (having hallucinations) and when the doctor informed her of her husband’s Parkinson’s disease and Alzheimer’s disease diagnoses (Lines 10-12). Charlotte described the deterioration of her husband’s condition as rapid, and referring to her copious notes, listed the multiple falls and injuries her husband sustained as a result of the physical rigidity associated with Parkinson’s disease (Lines 8-38). One incident that occurred was when Charlotte’s husband could not get up, became “frozen” and Charlotte had to call 911 (Lines 23-27). After that incident, the CLSC became involved twice a day to help her husband into and out of bed. Charlotte said that she planned her day around her husband and his needs (Line 72) and was so busy that she didn’t have time to think of anything else (Lines 70-72). She said she “forgot about herself” and had to single-handedly deal with all the responsibilities that she once shared with her husband (Lines 48-52). Charlotte’s husband had a very serious fall in the bathroom one day and it was determined that remaining at home was unsafe. Charlotte said the decision to place her husband was very difficult but she felt it was necessary for his safety. She said she felt like a “bad wife”
(Line 57) for making that decision. Charlotte visited her husband 5 days a week, 7 hours a day and hired a private worker for the weekends. Charlotte expressed that her time was spent either with her husband or doing things for her husband, including work around the house and bills, etc (Lines 47-52).

When her husband died, Charlotte was present. She was extremely grateful to have been there when he died (Line 133-134). Charlotte described her post-caregiving reactions as being “hard to handle” (Line 140-141). She said she was “in shock” and that she held it together until everyone left after the funeral (Line 137-141). “Afterwards you really feel it”, she said, in discussing her many breakdowns for the first few months (Line 139). Charlotte said she still talks to her husband’s picture every day and visits him several times per week at the cemetery (Line 187-189). Charlotte spent almost eight months attending to her house and her husband’s financial affairs. She said she spent a lot of time feeling lonely and did not go back to her previous activities (Lines 186-187). She expressed losses related to the people at the nursing home, her private caregivers, as they were her social network (Lines 219-220). She has recently begun to meet with a widow’s group/book club and has gone back to serve on the user’s committee at her late husband’s nursing home. Charlotte said she would have appreciated a support group or some counseling but was never offered any services (Line 227-228). She would have also wanted information on death and dying; what to expect before her husband died (Lines 101-104). One year after her husband’s death, Charlotte is active again socially and has taken up exercising and socializing with friends. Her widow’s group has begun meeting regularly and this has become an important source of friendship for her (Lines 191-196).
5.3.3.1 Charlotte’s caregography summary

Charlotte’s caregiving spanned six years where she took care of her husband for three years at home and for three years in a nursing home. Her husband had multiple medical issues that progressed rapidly and for Charlotte, the caregiving began with the confirmed diagnoses of Alzheimer’s disease and Parkinson’s disease. Her husband had multiple complications, falls and hospitalizations, requiring increased care. Charlotte explained that her days focused on her husband’s multiple health needs in both settings.

“Having to look after everything and to plan my day around him. I was very very busy... I almost didn’t have time to really think too much. I forgot about myself and was so busy managing all the things in the house that we used to manage together” (70-72). When he was in the home, I went four days a week for 6-7 hours and I hired someone to do the other 3 days to cover lunch and dinner” (Lines 43-44).

“Some people would say “poor you, to have to go every day”, but you know, I loved him so much, I wanted to do it. I organized my life around him, mind you, it was difficult to have all the responsibility of the house… we have no children so it was all on me. He used to do everything. He was a handyman. He used to look after everything. I wasn’t used to calling people in to do things. I had to redo the roof and the painting; change the heating system… all kinds of stuff that I had to do while I was looking after him” (Lines 47-52).

The retrospective account that Charlotte described depicts the mixed emotions she felt during her caregiving, from not self-identifying as a caregiver to continued guilt even when her husband was in a nursing home.

“I never thought of myself as a caregiver because he was in a home. I was his wife. The caregiving part at first when he was here was very difficult... I never knew what was going to happen. He became incontinent and wet the floor… I went through all that. I would go crazy sometimes...this can’t be happening. This is my husband. I think that was the worst part... and once he was in the home, taken care of, there was more guilt feelings. I was never sure he was being taken care of sufficiently. I would ask questions … I had confidence in several of the other workers that I got to know. I thought about it a lot… there were good people and I have a lot of respect for the workers” (Lines 148-155).
After her husband died, Charlotte explained that she was in a state of disbelief and continued to feel sadness and loss, a year later. She had difficulty getting out of bed and was feeling unmotivated to attend to any responsibilities (bills, etc) (Line 141-142). Charlotte’s experiences revealed how the close relationship she had with her husband has been a source of comfort in her bereavement.

“It was hard to handle. I still cry, you know. I have crying spells. It’s not even a year. I think of him sick and well... but fond memories. I see things in the house that remind me of him. I went skiing a couple of weeks ago and we used to ski all the time together so I see him on the hill. We used to go skiing all over the world. We used to do everything together and even in the house, it reminds me of him. Little things come up. I think of him all the time, a lot” (Lines 137-146).

For the first year of bereavement, she expressed gratitude for her sister’s support and the daily phone call from a friend. Charlotte has since found solace in being active in several clubs and socializing with new friends. This has helped to buffer the feelings of loneliness and sadness she felt after her husband died. The people she met during her caregiving years became friends and she continued to see them socially.
5.3.3.2 Charlotte’s careography timeline

**Charlotte’s careography timeline**

**Timeline of significant events for the care-receiver**

- Charlotte’s husband gets diagnosed with Alzheimer’s disease and Parkinson’s disease
- Charlotte’s husband comes home. OSC becomes involved twice daily due to physical rigidity of Parkinson’s
- Charlotte’s husband gets hospitalised again and cannot return home
- Charlotte’s husband is placed in long term care from the hospital
- Charlotte’s husband dies

**Timeline of identity-relevant events for the caregiver**

- Charlotte states that this was the significant event when it all began
- Charlotte reveals that her husband’s behavior was very unpredictable at this stage. Physically and emotionally hard to handle
- Charlotte was very relieved to have CISC help so she wasn’t alone with her husband
- Charlotte is very upset by her husband’s inability to return home; feels guilty and helpless
- Charlotte withdraws from all her volunteering and her social clubs
- Charlotte has almost no contact socially with anyone anymore due to her caregiving
- Charlotte visits her husband 7 hours a day, 5 days a week
- After her husband’s death, Charlotte has difficulty getting out of bed in the morning; she is not motivated to do anything
- After one year, Charlotte is beginning to look at volunteering again, travelling and joining a widow’s group. She received support from her sister and a friend with a daily call and contact
5.3.4 Debra

Debra was an 80-year-old white, Protestant woman, born and raised in Lachute, Quebec. She grew up with her parents and her sister and had “a very normal upbringing” (Line 114). Debra and her sister were very close and saw each other often. Debra was trained as a teacher with a BA in education and worked for many years at the Protestant School Board of Greater Montreal, and then at Canadair, where she met her husband. Debra and her husband were married for 58 years and had three children; two daughters and one son, as well as nine grandchildren. Debra always maintained her personal hobbies while married and enjoyed having a career. She said her husband believed in higher education and all of her children became professionals. Debra spoke about skiing as an important part of their family lives and described the many family ski trips they would take (Line 117-119). Debra said, “her husband’s passion for skiing became her passion as well” (line 119). Debra described her marriage as “normal”(Line 108), with the occasional fight about her maintaining her independence and continuing to work (Line108-110). Her husband worked very hard as an aeronautic engineer and she was very involved with raising her three children.

5.3.4.1 Debra’s careography summary

Debra recounted that her husband began exhibiting uncharacteristic behavior in the summer of 2002, ten years before he died. At the time, she didn’t think anything of it but her husband became insecure and anxious without her near him. As well, his body was leaning one way, which was later diagnosed as a sign of Parkinson’s disease. Debra felt that this 2006 diagnosis was a turning point in their lives, and also the start of the caregiving for her (Line 22). The most significant event for her husband in relation to his health was when he had to give up driving. That was in 2006 and elicited rage and anger from him, towards her and her family and
everyone else around them. Debra realized he was “raging against everything that was happening to him” (Line 20). Her husband had a heart condition and on several occasions his heart stopped and he had to be revived. When her husband was 90 years old, the doctor insisted that he get a pacemaker (Lines 63). Debra became very involved in helping to psychologically calm her husband down and to help him deal with his anger. Debra stated that the caregiving “affected my identity in the beginning, middle and end” when she was speaking to the demands of her husband’s care (Line 3).

“After I retired, I did alot of volunteer work, I was on some boards… but I had to give it all up… you know, caregiving was a 24 hour thing” (Lines 139-140).

“As a caregiver, I think I loved him more when he was ill, not because I didn’t love him before, but it made me feel so bad to see him. He was really somebody and to see him going down and down. I would have done anything for him to try and help make him better. But you know, there’s nothing you can do” (Lines 127-129).

Debra’s husband had many serious falls, often due to blood pressure problems as a side effect of the Parkinson’s medication. Debra felt that she had to be with her husband 24/7 to prevent another dangerous fall. He showed signs of dementia as his Parkinson’s was worsening and he didn’t have the judgment necessary to prevent potential falls. On several occasions, Debra woke up to find her husband unconscious after having fainted. The CLSC became involved and an attendant came twice per week for a bath and a third time for three hours of respite. Debra was able to go shopping on those days. Debra’s husband was told to use a walker but he refused, so the CLSC arranged a customized wheelchair for him. Another significant event for Debra was a fall her husband had, in the bathroom, where he injured his head and had to be hospitalized (Line 47-53). After the hospitalization, he was sent to a rehabilitation hospital to ascertain his functioning. During all this, Debra was by her husband’s side. He wouldn’t let anyone else feed or dress him and this responsibility was difficult for Debra. One evening, Debra went home to
take a shower and was called back and told that her husband was sent to the hospital because his heart had stopped. Debra sat with her husband at the hospital while he was on the respirator, waiting for their children to come into town. The children came together and as a family, they removed the respirator. Debra says it was a “gift” that the family was together and that the children could be with their father at the end (Line 97).

Debra felt blessed that she had the opportunity to say goodbye to her husband and to tell him that she loved him (Line 91). After her husband died, Debra felt very depressed and relieved at the same time. Even though Debra described the caregiving as all encompassing and intense, she wanted her husband back (Line 156). She said, “it really affected me as a person, these ten years” (Line 175-176). Debra attended a bereavement group and revealed to the group that during the caregiving, “there was a point when she really wanted him to die” (Line 158). After he died, she felt really badly that she had said that” (Line 159). She found it very difficult to watch her husband suffer (Line 160).

After her husband’s death, Debra reported feeling depressed and hopeless. She felt very lonely and uncomfortable in her house without her husband: “I didn’t want to deal with the fact that he died” (Line 185). She said that the caregiving had changed her and she felt like a different person:

“I don’t feel like I am the same person at all... not at all... well, things that used to be very very important to me... are less. I don’t see life in the same way... I really, really don’t... there was a period that I thought, if a bus hits me, that’ll be good... I am over that now... but I feel that I am closer to my dying too. I’ve changed a lot” (Lines 204-207).

Debra depicts the post-caregiving as a complicated time with mixed emotions: “There was some relief but it varied, sometimes it was relief and sometimes I couldn’t get out of bed” (line 187).
Debra revealed that for months after her husband’s death, she continued to talk to his picture and felt “muddled” (Line 197). She cried each day as she meditated (Line 228) and when she spoke to her children. After one year, Debra expressed feeling like she has “come back to herself” (Line 190). Debra found a strong connection with other widows who have had survived similar situations. She attended a drop-in bereavement group on the weekends, which she found helpful to combat the loneliness.
5.3.4.2 Debra’s careography timeline

DEBRA’S CAREOGRAPHY
Timeline of significant events for the care-receiver

- Debra’s husband displayed uncharacteristic behaviors such as aggressivity, anger, neediness
- Debra’s husband gets diagnosed with Parkinson’s disease (PD)
- Debra’s husband has many falls due to low blood pressure related to PD medications
- Debra’s husband has a major fall and a heart attack and ends up in the hospital
- Debra’s husband is considered “unresponsive” and the family unplugs his respirator together


Debra identified this as the first signs of her husband’s dependence
Debra is involved in every aspect of her husband’s care and withdraws from her weekly bingo game as well as her book club
Debra is very fearful of leaving her husband alone due to his constant falling and accidents. She finds the constant supervision very difficult
Debra cannot handle the care and has asked the CLSC to become involved in putting her husband to bed
Debra reaches out to her three children and asks them to come in to town
Debra is depressed and relieved at the same time after her husband’s death.
Debra loss almost 15 pounds and develops high blood pressure. Debra’s sister calls her every day and insists that she get out of bed and plan something for her day
Debra joins a widow’s group and attends a bereavement group at her sister’s insistence. She is planning to go visit her children out of town.

Timeline of identity-relevant events for the caregiver
5.3.5  *Evelyn*

Evelyn was a 79 year-old white, Jewish woman, who grew up in Montreal. Raised in a two-parent family with one sister, Evelyn always remained close to her sister. Evelyn went to high school in Montreal and met her husband there. They were married for 60 years. The couple had two children and four grandchildren, all of whom live in Montreal. Both Evelyn and her husband worked in the garment industry and retired fifteen years ago. Evelyn and her husband had a nice marriage and “did everything together until the very last day” (Line 17-18). As parents, they prioritized their children and were “everyday parents” (Line 42).

In their retirement, both Evelyn and her husband were active volunteers at a local hospital. They were socially active with couple friends and went to dinner a lot. Recently, they found that their friends were all getting sick, some of them with Alzheimer’s dementia and other illnesses (Line 160-161). Evelyn described herself as “practical and sensible” (Line 161), saying, “it’s how you make your life – you can’t sit and complain because no one is going to listen to you. You have to do what you have to do” (Line 162). Evelyn mentioned that her husband was brave throughout his illness (Line 11) and that “caregiving wasn’t a problem because he wasn’t a problem” (Line 18).

5.3.5.1 *Evelyn’s careography summary*

When asked about the caregiving, Evelyn felt that being her husband’s caregiver was part of her job: “I was the wife. When you’re married 60 years, you just do what you have to do” (Line 10). When Evelyn’s husband developed liver cancer, it was the turning point in their daily activities, where their time centered on his chemotherapy treatments and medical appointments. Evelyn expressed admiration about her husband’s character:
“He wasn’t difficult to look after, he wasn’t a pest. In fact, he was amazing… and brave. Imagine, we’d go to the hospital for this chemo and he’d say let’s go out for dinner. From 7 in the morning to 5 o’clock at night” (Lines 10-12).

Evelyn reported that the caregiving was part of her life, and she never felt like it was too much for her (Line 11). Her children were involved in their lives and came to see their father often when he had chemotherapy treatments (Line 55-56). She stated that she “never had a problem being a caregiver” (Line 78) and that the experience was a “good one” (Line 84). Evelyn related the story of her husband’s last few days, when he had a leg embolism and it affected his heart. Her husband was in terrible pain from the embolism (Line 114) and he said he wasn’t interested in living this way (Line 113). Evelyn conveyed that her husband died within days of being admitted to the hospital and that she was astonished when it happened:

“It was a shock… it was a shock… it was expected that he was going to live because he was a fighter” (Line 106-107).

Evelyn felt tremendous loss and sadness when her husband died (Line 103, 121-122). She shared that “after he died, I didn’t do much, I was sad. I cry, I still do” (Line 126). For the first few months after her husband’s death, Evelyn barely went out, did not cook for herself and stayed alone a lot (Line 180-181). After about six months, her sister encouraged her to get some help and she spoke to a social worker at the CLSC who referred her to a bereavement group. Evelyn loved the bereavement group and wished it would have continued (Line 193). Evelyn revealed that she found it “very lonely coming home to an empty house each day” (Line 223-225). Recently, Evelyn had reunited with two friends, who she used to know as acquaintances, and they are both widows. The three of them “spend time together and try and get out of the house everyday” (Line 236-237).
5.3.5.2 Evelyn's careography timeline

**EVELYN'S CAREOGRAPHY**

**Timeline of significant events for the care-receiver**

- **2006:** Evelyn's husband gets diagnosed with liver cancer
- **2008:** Evelyn's husband has to undergo chemotherapy treatments 2-3 times per week
- **2008:** Evelyn's husband has a leg amputation and is rushed to the hospital
- **2008:** Evelyn's husband is transferred to another hospital, and placed in palliative care
- **2010-2011:** Evelyn's husband dies in the hospital

**Timeline of identity-relevant events for the caregiver**

- **Evelyn accompanies her husband to every medical appointment**
- **Evelyn spends all day with her husband during his treatments and they go to dinner after each treatment. She is amazed by his stamina.**
- **Evelyn is very upset about her husband's situation because the doctors said he wasn't supposed to die yet.**
- **Evelyn is extremely sad and upset by her husband's death. She rarely leaves her house.**
- **At her sister's insistence, Evelyn joins a support group for bereaved caregivers and develops a new social network.**
- **Evelyn makes sure she goes out everyday and has begun cooking for herself again. She spends most days with two other friends who are both widows.**
5.3.6 Faith

Faith was a 60-year-old, white, Jewish woman, divorced with no children. She was raised in Montreal and moved to Toronto after she got married. Faith moved back home after her divorce and lived with her mother for the last thirty years. She had two sisters, both of whom lived out of town. Faith had a very strong social network of friends throughout her life.

Faith was the caregiver for her father before he died of kidney failure and then Faith became very involved in her mother’s care when her mother had a heart attack in 2002 and was subsequently diagnosed with colon cancer. Faith described the care she took of her mother as “part of being a daughter” (Line 11). Faith and her mother were extremely close all of their lives and even though Faith had two sisters, Faith was the primary caregiver. Faith also had a partner of twenty years who had a heart condition and she ended up being the caregiver to both her partner and her mother at the same time. Faith was not working at the time her partner and mother became sick and purposely did not look for work because of her caregiving responsibilities. She stated that not working was “a choice she made” (Line 48). Faith described caregiving to the “two most significant people in her life” (line 50-51) as “all consuming” (Line 54). Faith’s partner died of a heart attack in 2009, which was a significant loss to her. Faith’s mother had broken her hip and been hospitalized during that time and Faith felt extremely helpless. Her mother became incontinent and non-ambulatory and had to be placed in a long-term care facility where she died a few months later.

Faith’s careography summary

During the caregiving period, Faith experienced fulfillment from being involved in her mother’s care and chose to stop working to care for her mother. She valued the time they had together and felt that her involvement was part of reciprocity for her mother.
“I felt wonderful that I could do it, that I could give back to her. She was a great mother to me, very involved” (Lines 21-22).

“I liked to be in charge and responsible for my mother’s care. It made me feel important, valued. I got to spend every day with my mother for the last 30 years of her life” (Lines 28-30).

“Whatever I did, I had to do for her, for me, for us. I wasn’t resentful; I did what I had to do. I did what she would have done for me” (Lines 110-112).

When asked to talk about her life as a caregiver, Faith described it as a normal progression of a mother-daughter relationship.

“So, I was always my mother’s daughter and it worked into becoming a caregiver as well as being her daughter, I mean, it’s sort of, to me, it’s one and the same. As she aged though, she needed more help” (Lines 11-14).

“I didn’t see it as caregiving as much as I saw it being her daughter. I mean, she did for me all my life and I’m going to do for her” (lines 16-18).

After her mother’s death, Faith found it challenging to cope with her new reality and needed to take some time to adjust to her loss. She explained that the multiple losses of her mother and her partner within the span of a year made her bereavement especially difficult.

After several months, Faith decided to get her life back and started exercising and looking for work. Faith now works with caregivers at a community centre and feels more empathic towards this population. Faith had an identity as a social worker, a friend, a community member. She has attempted to regain these identities that were put on hold while she was caregiving. Faith had no follow up from the hospital or CLSC after her mother’s death and felt that she would not have needed a support group or any counseling. At the time she felt that “she needed to be alone” (Line 182). Her strategy for adapting to her bereavement was to slowly integrate back into activities that were previously meaningful to her.
5.3.6.2 Faith’s careography timeline

FAITH’S CAREOGRAPHY
Timeline of significant events for the care-receiver

Faith’s mother has a heart attack and is diagnosed with colon cancer

Faith’s mother is doing well living at home with Faith’s care

Faith’s mother has a hip fracture and is hospitalized.

Faith’s mother is relocated to a long term care institution

Faith’s mother dies


Faith lives with her mother and tries to manage her care while working. She ends up resigning from her job to take care of her mother

Faith’s boyfriend is diagnosed with cancer

Faith feels torn between her mother and her partner’s needs

Faith feels terribly that her mother cannot return home

Faith is involved in her mother’s care and visits at length every day

Faith’s partner dies

Faith feels lost and alone. It takes five months before she feels ready to be with people and get involved in life again

Faith is involved in a new job, has taken up tennis and has reconnected with her friends

Timeline of identity-relevant events for the caregiver
5.3.7  Gayle

Gayle was a 56-year-old white, Jewish woman, retired and divorced. She worked in the secretarial field after she graduated from University. She was an only child and grew up in Montreal. She stated that “her parents were very good to her during her whole life and had a very nice childhood” (Lines 32-33). She met her husband in her mid-twenties and was married for ten years. After her divorce, Gayle moved back in with her mother and lived with her as her companion for the last twenty-one years. Gayle was not employed on a steady basis and her mother preferred that she not work. She was social with some friends and spent most of her time with her mother. Once her mother fell and fractured her hip, Gayle became more involved in her mother’s daily care. Gayle was involved in every aspect of care including toileting, transfers, meal preparation and puréeing her mother’s food. Gayle was a very anxious individual with her own health issues (anorexia), and she found her mother’s care to be very demanding and difficult (Lines 26-28). According to Gayle, her mother’s personality completely changed after she became ill and therefore, their relationship changed also (Lines 78-82). Gayle’s mother tried to commit suicide on several occasions due to the physical pain from which she was suffering on a constant basis (Lines 119-120).

Gayle had limited social contacts prior to her mother becoming ill and yet had spent some time with her cousin and aunt whenever possible. She described herself as a “caregiver” and often put her mother’s needs ahead of her own – “it was my whole life. It was everything” (Lines 185). Gayle found it very difficult to live her own life – “I guess we were enmeshed… like one person. A social worker once told me that. It’s very hard. I couldn’t live my own life” (Lines 179-181). Gayle’s mother went into placement one week before she died and Gayle was not present when she died. Gayle had great regret about not being there when her mother died and
felt lonely and isolated at times – “I feel horrible, guilty, even though I suppose I have nothing to feel guilty about, that I didn’t get to say goodbye. I really wanted to say goodbye” (Lines 333-335). Gayle received a follow up phone call from her mother’s social worker and had a few counseling sessions to discuss her feelings (Lines 393-395).

5.3.7.1 Gayle’s careography summary

In discussion with Gayle about her life as a caregiver, she spoke mostly of the last five years of her mother’s life as being the most challenging. This coincided with the time her mother broke her hip. Gayle’s mother’s personality changed during the course of the five years and became unpredictable and erratic. This was problematic for Gayle and she found it extremely difficult to manage. Gayle revealed the multiple losses she experienced as her mother’s condition deteriorated and her mother’s personality changed.

“She didn’t mean anything or realize it but she was very demanding. Before all this happened, that’s why I said she changed, she was the most quiet unassuming person you’d ever meet. If you wanted to start an argument with her, you could start one and she wouldn’t answer. She was quiet and very passive.. and then she became like another person” (lines 55-58).

Gayle’s caregiving was very time-consuming and arduous as her mother’s medical condition worsened. The connection between the intensifying of the caregiving and the deterioration of her mother’s medical condition was ever-present. Gayle noted that the unpredictability of the caregiving and her mother’s condition caused her great stress and left her feeling on edge.

“It was very unfair… I felt.. I was always on edge, I didn’t know what she would do next or what to expect.. It seemed like the minute I would sit down to read a book, or try to do something.. She’d call me. (Lines 141-143). Well, I couldn’t go out, to leave her alone.. I was scared.. you never knew what she would do next, and I was afraid she would try and get the walker or do something and she’d fall and really injure herself. (Lines 149-152). It stressed me out. I became a nervous wreck. I couldn’t sleep well, I couldn’t eat, as I said. It was hard until the end, right to the end” (Lines 285-286).
Gayle felt extremely sad when her mother died and had a difficult time adjusting. Gayle revealed that she felt a “void” (Line 373) for her mother and the relationship they had and that she wished she had more to occupy her time.

“We were really close. I felt like when she passed away, I was shocked because it wasn’t supposed to be. Nobody expected her to go like that. I felt like I lost not only my best friend, but I lost my companion. We were together 21 years. We always got along all our lives very well but it wasn’t good being so confined and her getting demanding when she became sick” (Lines 258-262).

Gayle’s post-caregiving experience was replete with feelings of isolation and loneliness. Gayle attended a bereavement group and sought counseling after her mother’s death.
GAYLE'S CARE-OGRAPHY

Timeline of significant events for the care-receiver

- Gayle and her mother live together x 23 years. Gayle's mother has a hip fracture and needs help.
- Gayle's mother is in physical pain and discomfort.
- Gayle's mother tries to commit suicide on two occasions.
- Gayle's mother is experiencing mood swings and has erratic behaviors including violence.
- Gayle's mother is hospitalized after increased pain and medication overdose.
- Gayle's mother dies in the hospital.

Timeline of identity-relevant events for the caregiver

- Gayle does not work and becomes more involved in her mother's care.
- Gayle is involved in every aspect of her mother's care and has limited her socialization.
- Gayle develops anorexia and has increased anxiety.
- Gayle feels that she is unable to cope with her mother's care.
- Gayle finds the care of her mother difficult and feels that her mother has become a "different person".
- Gayle is horrified that she wasn't with her mother when she died. She feels terribly guilty and upset.
- Gayle is seeking help for her anorexia and is interested in looking for a job as a companion to others.
Hannah was a 50-year-old white, Jewish woman, married with two teenaged daughters. Hannah was one of two children and described her childhood as “great – happy and fun” (Line 98) and her parents were “good to her and her brother” (Line 99). Hannah’s father died seven years before her mother and she helped her mother care for her father, who had polio. When Hannah’s mother became sick with lung cancer, Hannah and her brother convinced her to move to their neighborhood. Hannah felt that this move was a gift and that it afforded them more time together: “I’m so happy that her last two years were spent so close to us because instead of seeing her once a week, we saw her seven times a week (Lines 42-44). Hannah spoke of her mother as “an easy mother, not overly demanding” and explained her devotion and commitment: “We gave because we wanted to give because that’s what she had done for us (Lines 97-98).

Hannah was a very involved mother of two teenaged daughters who were busy with school and extra curricular activities. She valued her family life immensely and was proud to say that her daughters had a good relationship with her mother (Line 119). Hannah’s husband was very involved in helping Hannah care for their daughters and was also involved with Hannah’s mother (Lines 105-106). Hannah was employed as a pre-school teacher and worked five days a week. Prior to caregiving, she was very involved in her community and had an active social life. She exercised regularly every day and was in good physical shape. Hannah cared for her mother in the last few years of her mother’s life. Hannah managed her mother’s care with her brother and sister-in-law’s help. Hannah managed her time by getting up early to exercise before work, before her visits to her mother, before her family responsibilities. Hannah felt that caregiving to her mother made her feel appreciated:
“It made me feel valued, I knew how much she loved me, how appreciate she was. It was gratifying over all. At times, it felt like a burden because it might not have been the best time to do something but overall, I did it happily because she was a great mother. I enjoyed the time I spent with her; I enjoyed giving her my time and energy” (170-171, 143-146).

5.3.8.1 Hannah’s careography summary

Hannah was the caregiver to her mother for three years even though Hannah’s mother had been diagnosed with lung cancer ten years before. Hannah’s mother had a piece of her lung removed ten years earlier and a kidney operation as well. Following that, Hannah and her brother were involved in grocery shopping and accompaniment, but overall Hannah’s mother was independent.

“Basically the juggling act of doing errands for myself, my family and my mother. She was always in my head, what is she doing? What is going on? Is she safe?” (Lines 94-96).

“In a sense, it was the four of us. My brother and I and our spouses… we were the whole system. I was the coordinator of that system but we each took individual roles. It just kind of worked. It was out of love that we helped her, even as it became out of need too” (Lines 123-126).

Hannah reported that the last few years of her mother’s life were more challenging, where she had difficulties breathing and maintaining her independence. After a second surgery to take out a piece of her lung, Hannah’s mother became more frail and dependent. Hannah described this as the point when the caregiving became more intense and signified a turning point in her life:

“We tried to be there for her as much as possible and the needs became greater and greater as she become frailer” (Line 77-78).

“When she had her surgeries, I took off full days of work and slept in the hospital with her and then at home. And then hospital visits became many. My brother came to visit too and we were there all the time. It was a good support system of the immediate family. If things were bad or really serious, I would call my brother and say “you have to get here
now” and he knew I was there so he took comfort. He was able to work when I was there and vice versa. It was a juggling act between us” (Lines 108-113).

Hannah conveyed feeling overwhelmed with the stress of caregiving and the worry she felt for her mother. She portrayed caregiving as all consuming of both her mental and physical energy:

“It got progressively worse, her physical condition, and therefore the time that it took in my head was more. Before she got sick, I didn’t think about what she was doing all day. I knew she was fine. When she got sick, she was always in my head. It took up more headspace for me. And physically, I had to run with her more. I think I was physically more tired. I work with 3 year olds so my day takes a lot of energy. After work, I would go see my mom and help her. By the time I got home, I was tired. That’s how it changed. I was more tired, mentally and physically” (Lines 129-135).

Hannah had to give up her time with her kids, her exercise and some days of work to be with her mother. This was when she felt that caregiving was affecting her life:

“When my mother was sick after one of her surgeries; I gave up all my working out, all my exercise because I was running to the hospital all the time. That did affect me but I wasn’t resentful or anything. I was just matter of fact. This is where I needed to be” (Lines 228-231).

Hannah was not present in the room when her mother died and feels “robbed” of her mother’s presence. She often thinks of her mother and felt that “a part of her died” with her mother; that her identity as a daughter was gone.

“Being a daughter affected who I was. I was always close to my mother but it’s different when you are providing care. I am sure some people don’t give care with love but I did and so did my brother. It affected who I was for the better. I was able to help her. She raised me with love and caring and I got to give it back (crying)” (Lines 287-290).

After Hannah’s mother died, Hannah found solace in her family and friends and took some time off from work.
“I miss my mother. I miss the daily contact and her presence in my life. Sometimes I forget and think I need to go to her house after work” (Lines 217-218).

Hannah’s post-caregiving experience has been challenging. She felt that her sense of self had been compromised, that her identity as a daughter was gone. Hannah received no follow up support and felt that she would have benefitted from a support group or some counseling.
5.3.8.2 Hannah’s careography timeline

HANNAH’S CARE-OGRAPHY

Timeline of significant events for the care-receiver

- Hannah’s mother gets diagnosed with lung and kidney cancer
- Hannah’s mother has surgery to remove a kidney and a lung
- Hannah’s mother’s health is deteriorating and it is discovered that she is smoking again
- Hannah’s mother has difficulties breathing and requires oxygen at home
- Hannah’s mother dies in the emergency room of the hospital

Timeline of identity-relevant events for the caregiver

- 2001: Hannah is able to manage her job, children and her mother’s needs with the help of her brother
- 2007: Hannah has to stop exercising daily to help her mother more regularly
- 2007: Hannah convinces her mother to move closer to her and her brother
- 2008: Hannah monitors her mother’s oxygen on a daily basis
- 2009: Hannah feels exhausted from the emotional and physical strain
- 2011: Hannah expresses feeling robbed and tired. She is not ready to go back to exercising or work. She feels her identity as a daughter is gone.

At the insistence of her sister-in-law, Hannah starts exercising again and goes back to work.
5.3.9 Ivy

Ivy was a 67-year-old, Jewish, Morrocan-born woman, married and living in Montreal. Ivy had 3 siblings, 2 brothers in Montreal and one sister in Ottawa. Ivy grew up in Montreal and had a wonderful family (Line 45). Her father died twenty years earlier when he was 75 years old and Ivy and her mother were always together (Lines 43-44). She got married when she was in her late twenties and her husband travelled a lot for work. Ivy was able to spend all her time with her mother. In 2003, Ivy’s husband’s company wanted to transfer them to Toronto for two years. Ivy was very conflicted about the decision to move and asked her mother to move with them. Her mother refused to go and reassured Ivy that she would be fine (Lines 45-48). Once Ivy had left, her mother went into a terrible depression (line 30) and had frequent panic attacks (Line 32-35). Ivy felt a terrible burden, being out of town, and decided to return home to care for her mother (Lines 71-74).

5.3.9.1 Ivy’s careography summary

Ivy was the primary caregiver for her mother for six years. Ivy’s mother had hypertension, rheumatism, asthma, heart problems as well as anxiety issues (Line 98-99), which were exacerbated when Ivy moved to Toronto. Ivy’s mother was depressed and stopped eating properly, mixed up her medications on several occasions and ended up being hospitalized for a month (Lines 20-25). This event was a turning point for Ivy’s caregiving and she said her mother was “between life and death, for a month”\(^6\) (Line 23). When Ivy’s mother was in the hospital, Ivy was there “night and day”\(^7\) (Line 24). Ivy’s care for her mother was very intense and she noted that the roles had been reversed:

\(^6\) original text: “entre la vie et la mort pour une mois” - (Line 23)
\(^7\) original text: “nuit et jour” (Line 24)
“It broke my heart. It was like a baby who needed her mother. I had become her mother and she, my baby” (Lines 83-86)

Ivy felt tremendous pressure to return to Montreal but it was at the expense of her career that she made this important decision:

“That's when I asked myself: what should I do? I had proposals for work, I could have a good salary but then I decided: my mother will come first and then we'll see. It started like that and then I could not leave. It hurt too much to leave her and go and to not know if I could come in for the day, and I knew neither of my brothers could come in the daytime. I wanted her to get used to her new environment but she could not” (Lines 76-85).

Ivy’s mother’s daily care needs compelled Ivy to move home and to relocate her mother to a long-term care facility in 2008. Ivy reported that in the nursing home, her mother’s medications were mismanaged and her mother’s condition worsened after placement. Ivy became an advocate for her mother until such time as the medications were changed and her mother was better (Lines 105-128).

Ivy affirmed that she cared for her mother as a way of giving back, of reciprocity in regard to her mother.

"It came naturally, not because I was forced to do so, no, I did it in a very natural way” (Lines 307-317)

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8 original text: “Ca me faisait trop mal au cœur. C’est comme un bébé qui avait besoin de sa mère. J’étais devenue sa mère et elle mon bébé” (Line 83-86)
9 original text: “C’est le moment où je me suis demandée: qu’est ce que je dois faire. J’avais des propositions de travail, je pouvais avoir de bons salaires mais j’ai décidé : d’abord ma mère puis on verra bien. Ça commencé comme cela puis là je ne pouvais plus la laisser. Cela me faisait trop mal de la laisser et de partir et de ne pas savoir si je pouvais venir de la journée et il n’y avait aucun frère qui pouvait venir dans la journée. Ce qui faisait que je voulais qu’elle s’habitue mais ma mère ne pouvait pas”. (Lines 76-85)
10 original text: “C’est venu naturellement, ce n’est pas parce que j’ai été forcée de le faire, non, je l’ai fait d’une façon très naturelle » (Lines 307-317)
“I was there all the time, I wanted to give her breakfast, I wanted to make her happy because I knew there was not much time, and that she gave us everything when she was young, she was an extraordinary mother” (Lines 144-147).11

Despite her best intentions, Ivy says that the caregiving was extremely difficult for her and she felt overwhelmed and alone.

"It was very hard for me, very hard. There were times when I cried because I thought this is not normal that I find myself suddenly alone” (Lines 147-148).12

“I would wake up in the morning and I knew I was so tired, that I would rather stay in bed but when I thought of my mother, I said to myself, "Okay, get up!” (Lines 129-131).13

In winter, come rain or snow, I was there and sometimes when I was there, there were snowstorms, and nobody was there but I was there. I was there all the time” (Line 142-144).14

Ivy spoke very fondly of her husband and the support he gave her by accepting her devotion and daily commitment to her mother (Lines 136-138).

“I had moments of depression which I know was quite normal. My husband was there

11 “J’étais là tout le temps, je voulais lui donner son petit déjeuner, je voulais la rendre heureuse parce que je me disais il ne lui reste pas beaucoup de temps et puis elle nous a tout donné quand elle était jeune, c’est une maman extraordinaire” (Lines 144-147).

12 “Ça été très dur pour moi, très très dur. Il y a eu des moments où je pleurais parce que je me disais ce n’est pas normal que je me retrouve seule d’un seul coup” (Lines 147-148).

13 “Dès fois je me réveillais le matin et je me disais que j’étais fatiguée, que j’aimerai rester au lit mais quand je pensais à ma mère je me disais : « Ok, allez debout! »

14 “L’hiver, qu’il pleuve, qu’il neige j’étais là et dès fois quand je rentrais là-bas il y avait des tempêtes de neige, il n’y avait personne mais moi j’étais là. J’étais là tout le temps” (Line 142-144)
and comforted me. Because I dreamed of my mother when I got home, I could not sleep and relived what was happening. My son and my husband asked me to try to forget but I could not, I was living there" (Lines 281-284).\(^\text{15}\)

After three years of intensive caregiving, Ivy needed a break and had to hire help during the week, in addition to asking one of her brothers to help on the weekends.

"At some point I had to pick up. I think it was after 2 years, 3 years. It was intense. It was too much” (Lines 185-186).\(^\text{16}\)

Ivy’s mother died from heart complications at age 89. Ivy stated that she gave her mother the best care possible. After her mother died, Ivy was exhausted and depleted and had no energy to do anything for months.

“Now it’s going well but before, I did not want to do anything. It took me a few months. It took me a while to realize that I have time for myself. Because at some point, I was living at the nursing home and at home. I was missing something and I was sad” (Lines 355-357, 369-370).\(^\text{17}\)

“I would have liked a support group. A group would have suited me because at least we would share our thoughts, our feelings, our desires” (Lines 407, 427-428).\(^\text{18}\)

\(^\text{15}\) “J’avais des moments de dépression ce qui était tout à fait normal. Mon mari était présent et me réconfortait. Parce que je rêvais de ma mère quand je rentrais à la maison, je ne dormais pas et racontait ce qui se passait. Mon fils et mon mari me demandait d’essayer d’oublier mais je ne pouvais pas, je vivais là-dedans” (Lines 281-284).

\(^\text{16}\) “À un certain moment il a fallu que je découche. Je pense que ça été après 2 ans, 3 ans. C’était intense. C’était trop” (Lines 185-186).

\(^\text{17}\) “Là ça va bien mais avant je ne voulais plus rien faire. Cela m’a pris quelques mois. Cela m’a pris du temps pour réaliser que j’ai du temps pour moi. Car à un certain moment j’étais comme là-bas (à Maïmonides) et ici (à la maison). Il me manquait quelque chose, j’étais triste” (Lines 355-357, 369-370).

\(^\text{18}\) “J’aurais aimé un groupe de soutien (Line 407). Un groupe ça m’irait parce qu’au moins on partage nos pensées, nos sentiments, nos envies” (Lines 427-428).
After a year of mourning, Ivy slowly reintegrated back into her social world and now goes to movies and dinners with her husband and friends. Ivy also became involved in her helping her sister in Ottawa when her sister was diagnosed with breast cancer. Ivy had no follow up from the nursing home after her mother died. Ivy felt she would have benefitted from a support group or some counseling after her mother died.
5.3.9.2 Ivy’s careography timeline

IVY’S CAREOGRAPHY

Timeline of significant events for the care-receiver

- Ivy’s mother has an exacerbation of her heart problems, hypertension, asthma and rheumatoid arthritis
- Ivy’s mother has a heart attack and is admitted to the hospital
- Ivy’s mother requires daily care and support
- Ivy’s mother is placed in a long-term care setting
- Ivy’s mother is over-medicated and becomes very ill
- Ivy’s mother dies in long-term care

Timeline of identity-relevant events for the caregiver

- Ivy is living in Toronto and very active socially and professionally with her husband’s business
- Ivy and her husband move back to Montreal so that Ivy can care for her mother
- Ivy stops attending work functions with her husband, does not rekindle previous friendships she had
- Ivy “lives” at the long-term care with her mother. 7 days a week, 10 hours a day
- Ivy is angry and feels that her mother’s needs are not well taken care of
- Ivy is exhausted from the care and despite her limited income, hires help on the weekends
- Ivy is heartbroken and saddened by her mother’s death. As well, she is exhausted and spends months in bed recovering
- After one year of mourning, Ivy starts travelling to Ottawa to help her sister who has cancer; and resumes some socialization with her husband
5.3.10 Joanie

Joanie was a 50-year-old white, Jewish woman, divorced with a son and a daughter. She grew up in Montreal and had one brother who lived in Toronto. Joanie said that her parents were hard working, kind people (Line 108, 139) but overprotective of her (Line 302). Joanie’s father died when she was 30 years old and she was always very close to her mother (Line 6). Joanie had been divorced twice and had two conflictual marriages. A single mother, she had two teenaged children who lived with her and were dependent on her (Line 80). Joanie had a degree in early childhood education and worked for many years with children. She ran a pre-school and worked everyday until 1pm. Joanie was socially active and had many friends.

Joanie described her mother as “very warm, very kind, and very community-oriented” (Line 267). Joanie continued to say that she and her mother “had a very nice relationship; she was very close to me and would call me 10 times a day to see what I was doing” (Lines 270-271). Joanie described her mother as “a very good woman and was always very generous with her and her kids” (Lines 274-275). Joanie said that her mother “wanted the best for her and her brother, wanted us to be happy” (Lines 291-292). Joanie felt that she “did her best for her” (Line 394) and felt profound sadness that the end of her mother’s life was so unpleasant (Line 321).

5.3.10.1 Joanie’s careography summary

Joanie was always close with her mother and spoke to her on a regular basis. Her mother lived in the same building as her aunt and uncle, and would call them if she needed help. As her mother aged, she was calling on her aunt and uncle for more and more help. Joanie realized that her mother needed more care and she hired a paid caregiver to help out. Joanie’s caregiving involvement with her mother spanned five years and began when her mother was diagnosed with Parkinson’s disease. She had a difficult time viewing herself as a caregiver and did not
necessarily recognize herself in the role of caregiver. Joanie felt that her major role with her mother was that of “advocate” and that she played an important role advocating for her mother’s best health. She felt that she “was always a daughter first, then an advocate and a caregiver” (Lines 48-50).

“I didn’t identify myself at the beginning as a caregiver… I never did …(crying - I vowed I wouldn’t cry)… but then it happened. I was always my mother’s daughter – I just had to take on more of a role” (Lines 22-24).

“I don’t know if there was a feeling, it was just something I had to do… it’s something you have to do. In my case, I just had to do it… I just had to do it. She was my mother and you have to take care” (Lines 35-37).

Joanie felt tremendous responsibility as the only family member in town and she felt that her brother could not handle the emotional implications of her mother’s deterioration (Line 354). Moreover, she felt an intense emotional attachment to her mother and had watched her mother care for her father in his illness (Line 25-27). Joanie expressed that it was difficult to balance her caregiving along with the rest of her life as well:

“In my life, it was hectic. I did it without question but it was another responsibility. I was a single mother with two teen kids. They needed me too. And I am a preschool teacher, running my own preschool. A lot of people relied on me. It was another hat I had to wear, I guess” (Lines 62-65).

“Well, the worry is always, always there, constantly, you worry. When she was hospitalized, I was there for hours and hours, but when I knew she was safe, in a nursing home or with her girls, I felt better. That was 20% of my time. But when she was hospitalized, it was 80% of my time… I would work and then run to the hospital and sit there all day, try to catch doctors, try to get them involved” (Lines 96-100).

Joanie felt that a turning point in her mother’s life was when she fell and broke her hip in 2007 and had to be placed in a long term care facility. Joanie described feeling tremendous guilt and regret about her mother having to go to a long term care facility and visited with her mother for hours at a time.
“When they told me that she had to go to nursing homes, I was hysterical. I felt terrible for her because she was pretty clear but I had to place her. She used to say “I never want to go to a nursing home; shoot me first”. Going to the nursing homes, it was exhausting and emotional for me” (Lines 400-403).

Joanie’s mother died when she was 86 years old of pneumonia. Joanie felt guilty about not being there when her mother died, but felt she did everything she could to have made her mother’s life as good as possible (Line 316-321). Joanie felt saddened that the doctors caring for her mother did not do a good job, and she felt that they were “ageist” in their lack of active interventions (line 314).

Joanie is still teaching everyday and thinks of her mother often. She had no follow up from the nursing home or hospital after her mother died. Joanie felt that she would have benefitted from a support group or some counseling.

“All those last few months, I did it myself. nobody helped me. and after she died, nobody reached out to me. I don’t think I needed anything… my worry had finally happened. It’s a bit of a relief but I feel guilty saying it.. it killed me when I got the constant calls from the nursing home so I don’t have that anymore. It was pneumonia, the feeding tube, the kidney problems. It was almost a relief that it was finally over. I was waiting and praying it wouldn’t happen but then it did” (Lines 335-341).

“It was almost a relief because she was sick and suffering. It was a relief not to have to run, to think, not to feel guilty, and the phone calls were not coming. The anticipation of the death was so hard for me… is it going to happen? when is it going to happen? And then it happens and you feel badly that you’re relieved. Guilty. Because you want your parent around but it’s the other part that is so oh my god. It was a weight off my shoulders, off my head. It’s exhausting, depleting, exhausting to be a caregiver, to worry. It’s exhausting because it’s always there… and especially when there are nursing homes, hospitals, etc and you’re the only one” (Lines 344-351).
Joanie’s post-caregiving period was busy with her work and responsibilities. She did not take any time off to grieve. She had no follow up from the nursing home or hospital after her mother died and feels that she would have benefitted from a support group or some counseling. Joanie has started to be social again with her friends and is considering another move to a smaller apartment since her children have both moved out.
5.3.10.2 Joanie’s careography timeline

**JOANIE’S CAREOGRAPHY**

**Timeline of significant events for the care-receiver**

- Joanie’s mother gets diagnosed with Parkinson’s disease
- Joanie’s mother’s mobility is reduced, she is becoming less alert
- Joanie’s mother falls and breaks her hip; Joanie moves her to a private nursing home
- Joanie’s mother has multiple hospitalisations for Parkinson’s complications
- Joanie’s mother has increasing dementia and Joanie moves her to a public nursing home
- Joanie’s mother dies of pneumonia in the hospital

**Timeline of identity-relevant events for the caregiver**

- Joanie recognizes this event as the precipitator of increased responsibilities
- Joanie hires private help, recognizing that she cannot quit her job to help out.
- Joanie stays with her mother all day in the hospital and hires nighttime help. Joanie chooses a private nursing home for her mother. Joanie is there every day after her morning of work until late in the day.
- Her mother’s multiple hospitalisations mean less time for socialization. Besides work, Joanie now spends most of her time with her mother
- Joanie describes caregiving as a constant worry and said her mother became her #1 priority
- Joanie is very upset at having not been present for her mother’s death. Joanie felt relieved after her mother’s death, that her mother was not suffering.
- Joanie felt relieved and exhausted for many months. She has since moved apartments and regained some of her social life back. Joanie would have liked to talk to a professional after her mother’s death.
5.4 Findings 2

In this study, I employed a narrative method to explore the lived experiences of women caregivers in the post-caregiving period. Using a narrative approach facilitated a process of discovery of the unique portraits of the women’s lives across time. While Findings Part 1 illuminated women’s distinctive stories through the presentation of their careographies and individual narratives, this second section focuses more specifically on the thematic representation of the women’s common experiences. Through excerpts and analysis, the women’s experiences in bereavement are explored. Thematic interpretations are a typical strategy of narrative research that incorporates multiple stories in order to highlight significant events, transitions and meaning (Creswell, 2014). Findings from this study reveal the meanings that women participants gave to their caregiving experiences and the challenges they faced both during the caregiving lifecourse and in the post-caregiving period. Insights and realizations that were revealed during the storytelling were interpreted thematically in order to understand the women’s subjective experiences as a group and to link individual stories to shared experience.

The identification and exploration of key turning points across all women’s stories helped to shape thematic analysis. These included moments in participants’ narratives when they identified both challenges to their identities and strengths that helped them cope with both caregiving and post-caregiving experiences. Using a personological lifecourse perspective enabled an analysis that incorporated these key moments of identity struggle and strengths including both intrapersonal and interpersonal aspects (Elder et al, 1992). That is, women participants experienced these key moments as internal processes that were influenced by and had an influence on their relationship to others. This is seen in the three central themes that
emerged across women’s stories, identified as 1) shifting identities, 2) discovering resilience and 3) the role of social support.

Additionally, Findings 2 will elaborate upon the development of an analytic tool developed during the course of this research project which links principles central to a lifecourse perspective with the stories shared by women participants. This tool examines five aspects of care, as identified in Elder’s lifecourse theory – timing, intensity, meaning, experience of the death and duration (represented by the acronym T.I.M.E.D.). This tool can be used as both an analytic tool and a practice-based intervention that provides a methodological link to the lifecourse approach. Consistent with the theoretical framework put forth in this research, lifecourse theories focus on context, transitions, trajectories, timing, turning points and linked lives (Carr & Komp, 2011). This tool is an innovative interpretation of the main tenets of the lifecourse and can serve to illuminate caregiving as a unique but often accounted for component of the lifecourse.

The three themes and the analytic tool T.I.M.E.D. will be presented below.

5.4.1. Shifting Identities

The women’s narratives illustrated caregiving challenges and identity adaptations made along the trajectory of care. The adjustments to the caregivers’ personal time and priorities were subtle variations that occurred over time. There was a constant shifting of roles, where the amount of time and energy increased as the needs of the care-receiver increased. My findings confirmed that for the women in this study, caregiving provoked adjustments and challenges to their identities. They had to gradually shift their multiple identities to accommodate the one identity requiring the most time and energy during the transitions in the caregiving process. Thus, caregiving gradually became the dominant identity in their lives, the one that was most
demanding, both emotionally and physically. This is consistent with the literature that confirms that one’s identity is dynamic and is in constant redefinition through the interactions with others (Stryker & Burke, 2000).

Alice reflected on how her feelings about her husband changed due to the caregiving:

“It made me sad and changed how I felt about my husband. It’s a different type of love you feel for them ... whether it is love or not. You start not to be in love. You know, you don’t feel that way anymore. He was a very appealing man, a very funny man... I just started to feel differently about him. And it’s not good when your feelings change because someone gets sick. It’s sad ... awful. I didn’t think it would get to that. I didn’t expect it from myself” (Lines 227-235).

The women in the study spoke about their caregiving as all-encompassing, to the point of excluding all other roles, responsibilities, and commitments. This sentiment was common throughout the women’s narratives and revealed the intensity of the caregiving demands.

Alice, 76 years old, who was the caregiver for her husband, stated:

“Caregiving is a very hard job; it takes everything you’ve got ... well, it’s not really your life anymore. You start to feel like your life has been taken from you. And you do make a change. I mean, you can’t resist it. You make a change in your life to deal with what is happening to you. It was everything. It took over on every level. It’s all I thought about. You don’t have a life, really sometimes. It affected our lives so much.... It’s like you’re caught like rats in a corner. You feel very isolated. You’re isolated all the time. It takes over your life. You’re full of anxiety; I never knew what I was going to wake up to the next day. I was filled with anxiety and worry and that’s the way it was” (Lines 145-155, 211-213).

According to seminal research, “identity serves as the frame of reference people use to interpret personal experiences and negotiate the purpose and direction of their lives” (Erikson, 1968, p.20). This reveals how one’s identity develops over time and is influenced by relations, meanings and interactions with others. This corresponds to the dynamic nature of the caregiving trajectory and highlights the importance of the meaning that caregivers allocate to caregiving. It was evident in this study that the meaning of care was highly significant to all the women.
Referring to the concept of identity salience (Stryker, 1980), the women who found significant meaning in their caregiving roles were deeply invested and committed to that identity. The intensity and meaning allotted to caregiving can often define the care relationship for the caregiver. A caregiver’s identity is constructed from the relationship with the care-receiver and can become dependent on that relationship. From this perspective, we see that the “self is co-constructed with others and dependent upon that relationship for constitution, deconstruction and reconstitution” (Mobley, 2010, p.20). This is highly relevant to understand the challenges that bereaved women caregivers face in the post-caregiving period.

The women’s commitment to caregiving was evidenced by the challenges they faced in post-caregiving, when their active caregiving role was over. The care component added a dimension of self-sacrifice and personal loss over a significant period of time prior to the death and the women described a void in their lives when they were no longer caregiving. Debra, 80 years old, caregiver to her husband, commented on the intensity of her caregiving:

“It affected a lot. It changed my whole life for 10 years. I hadn’t really done anything else. I never really thought about it while I was doing it, I was so busy” (Lines 140-142).

All the women spoke of their identities as being affected, compromised, and forsaken due to the caregiving and that after the caregiving was over, they were left feeling alone and isolated. The caregivers had adapted their lives and abandoned their interests during active caregiving and this led to difficulties during their bereavement. In addition to the constancy of both change and loss, the women struggled with each transition, and most specifically the transition out of caregiving into bereavement.

For many of the women caregivers, the death of the care-receiver represented a tipping point, where the cumulative losses in the caregiver trajectory compounded with the ultimate loss
in death. A tipping point is defined as a) the point at which a series of small changes or incidents becomes significant enough to cause a larger, more important change (Oxford Dictionaries, 2016); and b) the critical point in a situation, process, or system beyond which a significant and often unstoppable effect or change takes place (Merriam-Webster, 2016). The emotional implications of surmounting losses culminating in a final loss seemed to define the post-caregiving period for the women in this research. It was apparent that the cumulative losses and personal changes had affected the women’s abilities to negotiate their bereavement period. The bereaved caregiver had to deal with many losses in the post-caregiving period - the loss of the person for whom they were providing care, the loss of the caregiver role, the loss of the relationship, and the loss of their caregiver identity.

These compounded losses made it difficult for the women to find the energy and strength to find meaning in their own lives again. Faith, 60 years old, describes her bereavement:

“It was an abrupt change. There was nothing. My whole life was, my whole identity, was caregiving. And then poof, it’s over. It was a lot of nothing. But I needed the time, I needed the time to lick my wounds. I wanted to be alone, I wanted time to mourn. I wasn’t myself. I needed to regain my self. I was more than depleted. I wouldn’t have talked to anybody had anyone reached out to me at that point. I wanted time to myself” (Lines 179-190).

Hannah spoke of her identity as a bereaved caregiver:

“A part of me died when she did. That’s my identity. I think of her all the time. That’s my identity. I don’t dwell, I don’t sit in the house, depressed, but she is part of me. I am happy that I got to take care of her and that she lived close and I could help her every day” (Lines 296-298).

Many women in the study noted that resuming their lives was very complicated. For those women, re-creating their previous identities or renegotiating new identities required energy and strength that they did not have. The bereaved women’s narratives highlighted the challenges:

“Caregiving became who I was, now I don’t know who I am” (Alice, Line 392)
“I gave him everything, now I have nothing” (Beatrice, Line 185)

“He needed me to survive; now I feel like I can’t live without him” (Charlotte, Line 218)

“I spent all my time putting him together, now I can’t pull myself together” (Debra, Line 214)

“I was invisible in caregiving ... disappearing day by day. Now, I am struggling to find myself, to find a purpose for my days” (Gayle) (Line 387-388).

The women in this research expressed common feelings of hopelessness and purposelessness adjusting to their new status as ‘noncaregiver’. Several women expressed feeling unable to handle the expectations of daily life. Charlotte stated that her life had changed entirely:

“When I knew the caregiving was over, I was in shock. Something chemical develops in your body and you find the strength you didn’t think you had to deal with the funeral and all the people. After you’re left alone and you really feel it. For eight months, I couldn’t do anything, could hardly get out of bed, and didn’t pay bills, fix things, or anything” (Lines 129-134).

Caradec (2004) refers to the timing of post-caregiving as important to understand the impact of transition out of care on one’s identity. A younger aged widow may feel challenged to reorganize one’s life after a spouse’s death, knowing that she has time to revisit old projects and friendships or begin new ones. An older aged person may have increased difficulty redefining her identity if she has issues of isolation, loss of autonomy, etc. Each of the women spoke about how they lost their personhood over the course of caregiving and in the post-caregiving period, they spoke of having to find themselves again. Resuming interests and rekindling previous relationships proved to be complicated. This required adapting to a new phase in their lives while simultaneously mourning the loss of their sense of purpose from the previous phase. Each woman was faced with the challenges of constructing a new sense of self, a new identity which no longer encompassed caregiving.
This focus on caregiver bereavement leads us to anticipate that caregivers need assistance in the transition out of care in order to renegotiate, reconstruct or redefine their identities. Social support can help caregivers uncover their resilience. The links between resilience and reconstruction are discussed below.

5.4.2 Discovering Resilience

The concept of bereaved caregivers’ adjustment to stress is connected to the concept of resilience and can be defined as “positive or successful adaptation, competence and functioning in the face of stressful experiences” (Gaugler, Kane, Newcomer, 2007, p. P38). The theme of resilience speaks to how participants responded to key life events exhibiting strength, capacities and resilience in the face of challenges. Influenced by the presence or absence of relationships of support, resilience is identified as both an internal and interpersonal process. Resilience can be understood in caregiving “as a dynamic interaction between biological and psychological processes” (Dias et al, 2015, p.19) but there is a need for a greater understanding in how to foster caregiver resilience within care and into bereavement.

Exploring resilience sheds light on the strengths and skills that bereaved caregivers exhibited in managing their post-caregiving lives. Since resilience for bereaved caregivers is influenced by the context of care as well as available social support, this aspect can be understood as reflecting both internal mechanisms and contextual factors that serve to enhance or limit capacity for resilience. Moreover, resilience is understood as being “influenced by three constellations of variables: context of care, status of the care recipient, and individual, family, and community resources” (Gaugler et al, 2007, p. 39). Resilience is presented with specific attention to common experiences that emerge in the bereavement period, a time period in the caregiver lifecourse journey that has previously been under-represented in women caregivers’
stories. This central transition out of care, the death of the care-receiver and the entry into the bereavement period, influences the articulation of both identity and resilience in unique and important ways.

The women caregivers in this research demonstrated resilience in various ways that revealed their strengths. Many of the women spoke of having learned to be independent and strong in the face of the adaptations in their lives. Others mentioned that they were surprised that they were able to manage their quantity of caregiving tasks while managing their sense of burden. When asked what they learned about themselves during caregiving, the women mentioned their feelings of strength and self-sufficiency. Joanie felt that she grew stronger from the experience:

“*When I was dealing with my mother, I put my emotions aside and forged on and did what I had to do. Caregiving makes you tough. It made me stronger; I had to deal with different situations; all kinds of people. It gave me strength to deal with the stuff in my life*” (Lines 186-188, 386-397).

Charlotte mentioned her resilience, as a source of pride:

“*That’s something I learned… And I don’t know where that strength came from but I still feel like I’m on top of things. I surprised myself with my strength and sometimes I feel like crying and say I can’t do this… and I talk to myself and say yes you can*” (Lines 174-178).

5.4.3 The Role of Social Support

Through the women’s narratives, it became evident that social support played a big part in recovery and reconstruction for the women in this study. Many mentioned the roles of certain friends or siblings who called them every day, encouraged them go to bereavement groups, brought them food and connected with the women on a regular basis. Several participants mentioned the potential role of formal services to make up for this absence of support networks,
stating that they would have liked to speak to a professional to discuss their feelings of depression and hopelessness during the months that followed their loss.

Many of the women felt common difficulties negotiating their bereavement and expressed interest in having some formal social support. Charlotte explained that it took many months to find her way:

“It was such a hard time. I felt so lost. I really could have used the support. I just shook the feeling of not being able to get out of bed. It took a year…” (Lines 194-196, 227).

Concern and follow up from siblings and friends was an important source of support for the women in their efforts to resume their daily lives and find new interests in the post-caregiving period. Most of the caregivers mentioned that they valued any social support they received during their bereavement. Debra mentioned feeling grateful and appreciative of her sister, who called her everyday:

“I had trouble getting out of bed in the morning and I just couldn’t face the day and my sister used to phone me every morning at 9am and I had to get out of bed for that and I was so grateful to her for that. She got me out of bed... That was a big thing she did for me. I needed my sister’s phone calls... That made all the difference” (line 182-185, 210).

Although only four out of ten women attended bereavement groups, the mention of a group where they could talk to others in similar situations was referred to several times. Joanie mentioned that she would have benefitted from some formal support:

“I didn’t have a social worker and nobody called. I dealt with the nurses but a social worker to talk to would have been nice, to talk to throughout the whole caregiving process. I didn’t even know that there was a social worker on every floor. I dealt with everything myself. It wouldn’t have hurt to sit and talk to someone after. It would have been nice to hear that it’s normal to feel this way. I felt guilty that I felt relieved. That would have helped; a group, a person to talk to” (Lines 410-415).

Beatrice shared what the group meant to her:
“I joined the Alzheimer support group – we are 8 women, we call ourselves the sexy 8. I have become good friends with all of them, I found a new group for myself, something to do” (Lines 169-171).

From a clinical social work perspective, the women’s narratives spoke to the depth of bereavement as a complex process and to the need to include formal support as an integral part of helping women to build resilience. While negotiating the transition out of care, many of the women expressed great difficulties dealing with the expectations of daily life. Some of the women spoke of the connection they had built with nurses, attendants and health workers that had been involved in their lives for years but which were lost during the post-caregiving period. Charlotte said:

“The nursing home was part of my social network... it’s another loss” (Line 219).

One caregiver was involved in a support group at the nursing home where her husband lived and when he died, she was asked to leave the group, as she was no longer an active caregiver. Alice expressed regret about this:

“I would have loved to stay with the caregiver group...my husband had died and I would have liked to stay in that group. They were friends. I couldn’t stay on... he had died. I went to that group when he was in the nursing home. That’s how I got to the group. I would have liked to stay on. You lose a spouse and then you lose a group. It’s not anyone’s fault, those are the rules, but I think it would have helped me to stay on in the group. That was another part of my social life” (Lines 510-515).

The period of bereavement can be lengthy and difficult for those without any social support or connection to the health care system. The women that received social support from friends or attended support groups seemed to reintegrate back into their lives with more ease. Feelings of isolation and loss permeated those who had minimal contact with others during their bereavement. This data corroborates the importance of follow up support with bereaved caregivers, to help them reconstruct meaning and importance in their lives. “The assumption that
support from family and friends is one of the most important moderators of bereavement outcome is widely accepted among bereavement researchers and practitioners” (Stroebe, Zech, Stroebe, Abakoumkin, 2005, p.1030). Moreover, the connections made with other bereaved caregivers in similar situations were highly significant in their identity reconstruction as well.

Rather than assume their previous social identities, it appeared the wives sought out a reinvention of them, seeking new friends in similar situations. Many of them spoke about the important friendships they had made in bereavement groups and widows groups. Debra found solace in spending time with women who have gone through similar experiences of caregiving and loss.

“I find now, when I go out, because of my age, there’s quite a few people who have lost their spouses fairly recently and I find that we’re almost a country by ourselves. There’s some kind of immediate connection and most people, go through the same things” (Lines 164-166).

Charlotte has expanded her circle of friends and reflects on the commonality of widowhood:

“I have some new friends that I made and we’re all widows. I joined a book club and I go to exercise club and we’re all widows” (Lines 191-192).

The women’s experiences of reconstruction related to their discovery of resources, social support, strengths and resilience after their complex and dynamic caregiving experiences. This corroborates the focus of this research that moves away from static stress reactions to the holistic and comprehensive view of bereaved caregivers and their care trajectory as a dynamic process. A study by Schulz et al (2003) confirmed the resilience aspect of bereaved caregivers, where high levels of depression during caregiving declined significantly within three to six months after the end of caregiving. The measure of resilience and social support in caregiver health can be valuable for professionals when working with bereaved caregivers.
Social work interventions with caregivers that incorporate the concepts of identity, resilience and social support will enable a focus on self-concept, stress and coping abilities and the subjective meaning they ascribe to their caregiving role. This information will be essential in supporting caregivers in the transition out of care and throughout their bereavement period.

5.4.4 T.I.M.E.D.

This study demonstrated that the caregiving context, prior relationships and the impact that caregiving has on the caregiver carry over into the post-caregiving period and influence reactions or responses to bereavement. In order to understand post-caregiving as a central component of caregiving and to situate caregiving as a trajectory or journey, this study applied an innovative approach, namely the lifecourse approach to data analysis. Thus, the lifecourse lens was articulated as a means through which experiences of post-care could be examined. This analytic process was facilitated by the development of the T.I.M.E.D acronym to examine the timing, intensity, meaning, experience of the death and duration of women’s caregiving as it affected their bereavement. The acronym T.I.M.E.D refers to the experiences of transitioning into, within and out of caregiving into bereavement and is reinforced in the lifecourse literature that states that timing, linked lives and human agency influence individual life courses (Elder, 1985, 1998b). These include recognition of the context in one’s life that includes the transitions, dynamic nature of roles and relationships, trajectories and transitions and experiences for each caregiver. Moreover, “the life course perspective offers a framework for exploring the dynamics of multiple, interdependent pathways in social-relational contexts” (Elder, 1994, p.5). As such, the T.I.M.E.D tool allows for a methodological connection to the theoretical basis of lifecourse theory.

These five aspects have an influence on the bereavement reactions and demonstrate the
connection between caregiving and bereavement throughout the women’s contextual and subjective experiences. These aspects can be linked to the lifecourse as explanations for the sequences that occur in trajectories. Rather than look for determinants or causes to a challenging caregiving experience, these aspects illuminate the complex interactions of events and elements that create someone’s caregiving journey. The life course focus on linked lives underscores that the expectations of the caregiving relationship can significantly affect the lives of caregivers in various ways. However, the term linked does not contextualize the relationship or resulting changes to it, nor does it consider the “nature, length, purpose, consequences” of it (Settersten, 2005, p. 217). Utilizing the personological life course perspective of the intra and inter personal can widen our view and demonstrate the significance of the five elements of timing, intensity, meaning experience of the death and duration, in the T.I.M.E.D acronym. For these aspects, the caregiver may experience both intra and inter personal reactions and impacts. “In the case of the study of life-trajectories— which are always unfolding in diverse contexts, and experience by a person through a longer period of time—change can only be explained by taking in account at least intra and interpersonal changes and their interactions” (Zittoun, 2009, p.3). This view emphasizes how the transition from caregiving to bereavement can be explored from the caregiver’s perception of herself, from the changing relationship with the care-receiver and how both unfold together.

This study revealed and confirmed the view of caregiving as a process, with strong ties between the transitions in and out of care. The T.I.M.E.D tool will add to clinical practice by promoting a comprehensive recognition of the prior context of caregiving to better understand the caregivers’ bereavement period. It will also be relevant for research as it aims to integrate theory as well. As an innovative interpretation of the key concepts of lifecourse theories, this tool
focuses on five aspects of the caregiving experience that are the most indicative factors of adaptation in bereavement.

Focusing on the timing, intensity, meaning, experience of the death and duration of care (T.I.M.E.D.), researchers and clinicians can view the transition out of care into bereavement with knowledge of the context that preceded it. It is interesting to reveal how T.I.M.E.D affects the transition out of care - each of the aspects of T.I.M.E.D. are connected - for example, the timing of the caregiving can impact the meaning and experience of the care, thus affecting the bereavement process. Another example would be if the duration of the care were over many years and may have contributed to the intensity felt by the caregiver in bereavement. Thus, the elements of T.I.M.E.D. build upon the contextual narratives of each woman’s caregiving experiences. As intersecting and cumulative, the information gleaned from examining this integrated concept illuminates the experiences of the caregiving women as they transition into bereavement. It is beneficial to have a holistic view of the caregiving trajectory, to examine each aspect in a separate and distinct way and then explore them as intersecting in order to get the full portrait of the caregiver’s bereavement. Examining the features of T.I.M.E.D. as connected and compounded help us to understand the caregivers’ lived reality. Each of the five aspects will be explored below.

5.4.4.1 TIMING:

“Life course scholars are interested in the age at which specific life events and transitions occur, which they refer to as the timing of lives. They may classify entrances and exits from particular statuses and roles as “off-time” or “on-time,” based on social norms or shared expectations about the timing of such transitions” (Settersten, 2003b in Hutchison, 2010, p.21). The timing of various events throughout one’s life course is highly significant to consider in
understanding individual and family experiences. The timing and sequence of caregiving plays a central role in understanding the women’s reactions to caregiving and bereavement. In this study, we have seen that for some, the transition into and within caregiving had an influence on the women’s transition out of caregiving into bereavement. This may have been in relation to the timing that the onset of caregiving had on work and family life and also at the age or lifestage in which this occurred. The caregiving may have occurred at a moment when the caregiver was at an opportune time of career advancement or at a time when they had looked forward to retirement and slowing down. Longitudinal studies on women demonstrated that having to care for frail relatives might result in reduced work hours or an early retirement, especially for women (Dentinger & Clarkberg, 2002).

Caregiving may have competed with family priorities or other obligations or responsibilities. Moreover, the timing of the caregiving could have been at a point when the caregiver’s own health was at risk or vulnerable. For the women in this research, timing was directly linked to the idea of “normative” life course events in which the reaction to the timing of the caregiving was interpreted through social expectations at a particular life stage. So for women who were older spouses, the social discourse of care was seen as a normal part of the life process and in line with this stage in one’s life whereas for younger women taking on caregiving tasks disrupted a normal life course trajectory and stage. This related to younger children and work lives, particular for younger women. Caregivers were compelled to make choices in the commitment of time and energy they placed into caregiving, and had to let go of other interests or responsibilities. In the quote below, Alice mentioned that her caregiving tasks superseded her valuable time with her grandson. Thus, we see that the caregiving trajectory can conflict or exist
simultaneously with the timing of other trajectories. We see below how timing and time affected this study’s caregivers’ lives.

**Spouse quote:**

**Alice:** “I would talk to my friends... but I’d have less time. I felt I had less time for everyone. I had less time for my grandson... I used to take care of him as a baby and then I couldn’t take care of him anymore. It was very sad... because I felt like I am a bad grandmother because I never spent time with him. Now I am seeing him as much as I can to make up for the time I lost with him” (Lines 483-487).

**Adult child quote:**

**Faith:** “I chose not to work at the time so I could be with her. I felt that between my guy and my mother, all my time was busy in and out of hospitals. I didn’t have the time to work, or the frame of mind. It was absolutely a choice to not work. But after, I needed the time; I needed the time to lick my wounds. I wanted to be alone, I wanted time to mourn. I wasn’t myself. I needed to regain myself. I was more than depleted. I wouldn’t have talked to anybody had anyone reached out to me at that point. I wanted time to myself” (Lines 47-49, 176-179).

**5.4.4.2 INTENSITY:**

“The life course studies the particular point in time at which an exposure occurs (a critical or sensitive period), or the particular sequence in which exposures occur (exposure trajectory), or the sheer intensity of exposure over time (accumulation), which all may be important to understanding later outcomes” (Osler et al, 2005, p. 647; Ben Shlomo & Hardy, 2002). The intensity of the caregiving was influential in the caregivers’ bereavement adaptation as well. Intensity was related to the high needs of the care-receiver and the subsequent high demands on the caregiver. The subjective burden accounted for feelings of intensity, distinct for each caregiver. These were related to challenging aspects of caregiving that may have been related to the care-receiver’s cognitive losses, behavioral issues or the stage of their illness, among other challenges. Moreover, feelings of intensity accounted for significant changes in the
relationship due to communication challenges or personality changes due to the amount of pain that the care-receiver was experiencing. Intensity could also explain how fast the disease was progressing as well as how much time the care-receiver had to live. End of life care is considered extremely intense given the acute and amplified importance of the care, pain control and comfort level of the care-receiver. The experience for the family can be highly stressful and demanding, not knowing how long the care-receiver has to live and how their lives will end. Research has consistently shown that end of life care encompasses high levels of distress and psychological burden for the family (Williams et al, 2016).

While intensity is a subjective measure and had different meaning for each caregiver, many participants spoke about how levels of intensity of care related to feelings of stress. We see below how both Alice and Faith felt overwhelmed by the intensity of the care for different reasons.

**Spouse quote:**

Alice: “It takes over your life. You’re full of anxiety; I never knew what I was going to wake up to the next day. I was filled with anxiety and worry and that’s the way it was” (Lines 360-361).

**Adult child quote:**

Faith: “So, you know, I always took care of my mother while I was with her, for the last 30 years. We were buddies. But towards the end, it was more intense. Well, it’s no longer what to eat and what to clean... it’s taking care of her as a person who’s unable to do things herself. Her bathing, hygiene, medications, appointments, etc. It was intense for me to see her suffer from cancer and a hip fracture. Would I want it all back? No. Would I want my mother back? Yes” (Lines 113-118, 208).

**5.4.4.3 MEANING:**

“Individuals construct meanings from the stream of daily experience, integrating both positive and negative chance events and expectable role transitions (Pearlin 1980; Pearlin &
Lieberman, 1979) into a narrative which itself changes across the course of life as a consequence of social and historical circumstances” (Choler & Hostetler, 2002, p.556). Elder supports this by stating that “transitions are always embedded in trajectories that give them distinctive form and meaning (1998, p.5). Related to the impact on their identities and the significance that caregiving held for them, the caregivers assigned meaning to their caregiving and the transition out of care. For many of the women, their identities were dependent upon their relationships and roles within caregiving and took on increased meaning as the caregiving continued over time. Thus, caregiving became a function of identity salience, where caregiving took on most of the caregivers’ attention. Understanding this subjective measure of meaning in their roles helps to recognize the potential needs and meaning in bereavement, when reconstruction can be challenging. It was important to recognize the relationships already held special meaning for the caregivers prior to the transition into caregiving. Moreover, caregivers spoke of meaning in their roles as caregivers and linked it to their prior relationships. Together, the meaning experienced formed the context of the caregiving trajectory. As the quotes below indicate, meaning was indicative of an intersection of the prior relationship and the existing needs in caregiving.

**Spouse quote:**

Alice: “My identity was as one part of a couple, not the intertwined person we became. I lived and breathed for him and his needs. I didn’t even think of what I needed, besides food. For 50 years, I was S’s wife. I don’t remember anything before that. Then, that was slowly taken away. I still feel a part of me is gone. I miss him (crying)” (Lines 389-396).

**Adult child quote:**

Ivy: "We had an extraordinary complicity. We were always together, when she was not at my home, I was at her home. We were the best friends. Even now, I think of her but keep
only the pleasant moments and less the unpleasant moments. I arranged my schedule to improve both my days and her days” (Lines 43-44, 292, 370).\textsuperscript{19}

\textbf{5.4.4.4 EXPERIENCE OF THE DEATH}

As we have seen in Elder’s work, the “sequences of roles and experiences are defined by transitions or changes in statuses or roles (Elder et al., 2003, p. 8). Moreover, “people bring a life history of personal experiences and dispositions to each transition, interpret the new circumstances in terms of this history, and work out lines of adaptation that can fundamentally alter their life course (Elder, 1997b, p. 957). Experience is understood more generally as a life course aspect but in this study, we highlight the relevance in the bereavement transition. Most specifically, this refers to the experience of the death from the caregiver’s perspective. Research has reported a “relationship between the quality of death and the surviving caregiver’s psychological adjustment” (Lee et al, 2013, p.38). Circumstances surrounding the death of the care-receiver affect the caregiver in a myriad of ways, including strong negative emotional reactions after a painful death. Carr (2003) confirmed, “widowed persons’ evaluations of their spouse’s end of life care are powerful influences on psychological distress six months after the loss” (p. 226). The experience of the death relates to the events or circumstances surrounding the death of the care-receiver and the transition out of the caregiving role. Since caregiving is a considerable factor in understanding caregiver bereavement, it is important to review how the end of life occurred and in what way it affected each caregiver. The experience of death has been studied in research on “the good death” (Emanuel & Emanuel, 1998, p.21), one that includes “being pain and symptom free, with patient dignity and independence, with family presence and

\textsuperscript{19} Ivy: “On avait une petite complicité extraordinaire. On était toujours ensemble, quand elle n’était pas chez moi, j’étais chez elle. On était les meilleures amies. Même maintenant, Je pense mais ne garde que les moments agréables et moins les moments désagréables. Je me suis arrangée différemment pour améliorer mes journées et ses journées à elle”.

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support, with awareness of death and good communication with care professionals” (Holdsworth, 2015 p. 835). Caregivers in this study spoke about their presence or absence at the death of their loved one – where they had feelings of retrospective guilt and regret if they missed the death. Studies on caregivers in end of life experiences highlight the conditions for a good death that point to dying as a life course process that “meets the needs of the dying person and also those of the family caregivers. Therefore, the quality of the relationship between the dying person and their family is an important component at the end of life” (Lee et al, 2013, p.44).

We see below how the caregivers had very revealing experiences in end of life care that affected their bereavement.

**Spouse quote:**

Charlotte: “He just stopped eating and was in bed and all they did was give him a little bit of oxygen in his nose. He just lay in bed and they didn’t try to feed him… just water on his lips. I spent the night with him. I saw him die. It’s very hard. And again, you think, did I do the wrong thing? Should I have signed a DNR? People were asking him did they feed him with IV … so it made me question myself… should I have done that, prolonged his life? But you know… and all these questions…they keep coming back to me now” (Lines 115-120).

**Adult child quote:**

Joanie: “I went home and this is where I’m guilty because I should have had a night nurse. When I left that night, she was up but out of it. She died in the middle of the night, I got the call. I don’t know if she suffered or not or if someone could have saved her, had I hired someone. When I saw her at 7pm the night she died, she was just lying there with oxygen. I pray that she went peacefully. When I saw her she was peaceful and that is my memory but I feel bad (crying) … I would have felt better had I had help with her. I didn’t want her to suffer. She did have a feeding tube and had had trouble in the past with pneumonia. I hope she wasn’t in discomfort when she died. She was quiet and I hope she fell asleep and died. I worry that she had a horrible death. She wouldn’t have deserved it” (Lines 315-325).

**5.4.4.5 DURATION:**

“The timing, duration, and order of life’s major events are shaped by demographic
change and individual experiences” (Quadagno, 2011, p.28). Consistent with lifecourse theory, life events over time affect the outcomes of later events (Alwin, 2009). “The timing and duration of caregiving may be important considerations in assessing its emotional impacts” (Moen et al, 1995, p. 259). A caregiving experience that had a prolonged duration may significantly affect the caregiver’s transition out of care. Consistent with the theories that state that caregivers become depleted over long periods of time in caregiving, caregivers’ abilities to cope and manage their own lives can be compromised after a long time as a caregiver. This wear and tear hypothesis highlights the duration of caregiving which could mean the length of time that the caregiving went on, the length of time that the care-receiver was ill, the length of time before and after issues of pain or helplessness, the length of time that the care-receiver was dying or in an end of life situation, as some examples. “Looking at the number of years spent caregiving helps to illuminate possible cumulative effects (Moen et al, 2005, p.267). High role conflict occurs with women who have been caregivers for a long duration, linking duration and time with emotional health (Moen et al, 2005). These are substantial elements to consider that impact the caregivers’ bereavement. Moreover, over time, caregivers can become increasingly isolated socially due to their caregiving, which can impact their bereavement as well. Thus, the time spent caregiving can put strain on the personal resources of the caregiver, ie: resilience, and opportunities for social support. Another impact of a long duration of care are the physical health effects of caregiving on the caregiver who may enter bereavement in ill health, with limited physical resources. One longitudinal study by Williams et al (2016) noted that half their sample of bereaved caregivers was managing chronic conditions for themselves. “Negative health outcomes have been documented in end of life care including increased morbidity (Zarik, 2004) and mortality for bereaved caregivers (Christakis & Owashyna, 2003)” (Williams, et al, 2016,
As the women highlight below, caregiving over time impacted their identities, their health and their ability to negotiate their transition out of care.

Spouse quote:

Alice: *I rested after and I was fine. I felt free, free at last, free at last. It was like I felt terrible but I didn’t mourn him, like cry a lot. My life had come back to me and it was like a relief in a way. It had to do with two things really, my life coming back to me and resting and him not having the pain anymore. Not having to see him suffer, I thought it was time already. Too many years, you know. But then I had a stroke and a heart attack. I couldn’t believe it.* (364-369).

Adult child quote:

Hannah: “*I didn’t have to work the summer she died so there were pros and cons about having time to grieve but with a little too much time on my hands. I knew I’d be emotional but... whoa (crying)... it was so much time and now it’s over. It was my whole life for so long and now it’s gone*” (Lines 210-213).

Summary

The three themes of shifting identities, discovering resilience and social support call attention to the multiple factors in the care trajectory that affected the caregivers’ bereavement experiences. This research has emphasized the relevance of viewing caregiving as a lifecourse process in order to better understand and intervene with bereaved caregivers. Moreover, if we understand the process as a lifecourse phase, we will recognize the dynamic nature of the caregivers’ experiences, and identify that reactions to bereavement can change over time. Awareness of the important role of social support and one’s personal resilience are also strategies to help caregivers negotiate their bereavement. Exploring identity salience and personal choices related to caregiving with caregivers can help bereaved caregivers understand and accept their care process. This may facilitate their adaptation to bereavement and reduce their complicated grief reactions. Connecting subjective and personal bereavement reactions to a theoretical base...
of lifecourse facilitates positioning the caregiving in one’s life span and understanding its impact and influence.

Examining the five aspects of the T.I.M.E.D. acronym allows for a view of caregiving that helps illuminate the caregivers’ experiences in bereavement. This tool offers an innovative perspective of the lived experiences of caregivers and a more comprehensive view of the care trajectory as a dynamic and fluid process. While each aspect of timing, intensity, meaning, experience of the death and duration can be explored independently, the intersection of the five elements in the caregiver’s journey can shed light on how caregivers will experience bereavement. Caregivers are rarely followed up after the death of the care-receiver and this may be due to a lack of understanding of the post-care bereavement process. Exploring the care trajectory through the bereavement process shines a light on the family, lifestyle, social, relational and identity transitions. It creates links to understand individual choices and subjective meaning, and associates lifecourse theories to the intersection of both practice and research.

Using the T.I.M.E.D. tool as an analytic tool brings Elder’s lifecourse theories to life in ways that help researchers and practitioners identify and then link micro and macro processes as well as intra and inter components. Using the tool with caregivers speaks to its research relevance – creating new possibilities for enacting lifecourse theory in research generally and about caregiving research specifically – enabling researchers to account for trajectory, history and subjectivity in narrative studies on lived experience.
CHAPTER 6 DISCUSSION/CONCLUSION

This thesis concludes with a discussion that first summarizes key findings, and then proceeds to interpret these findings in relation to the existing literature. Finally, it explores implications for policy, research and practice in social work. This research addressed the question: What are the lived experiences of bereaved women caregivers? It aimed to explore how wives and daughters experienced the transition out of caregiving. Using a personological gendered lifecourse approach enabled the development of a nuanced understanding of how the personal and social worlds of women along the lifecourse influenced experiences of care and post-care. Thus, bereavement is theorized as a continuation of the caregiver journey, with transitions within and out of caregiving as indicators of adaptation and adjustment to the post-caregiving period.

6.1 Summary of key findings

This study explored ten women caregiver’s experiences of negotiating bereavement after the death of their care-receiver. Five wives and five daughters were interviewed about their transition out of caregiving into bereavement. Recognizing that caregiving influences bereavement, the inquiry reflected the transitions into, within and out of care. The portraits of the caregivers that emerged described women’s unique experiences of the transition from caregiving into post-caregiving and highlighted key events, transitions and significant moments in each woman’s caregiver journey. The death of the care-receiver figured prominently in women’s stories and reflections on their relationships to the care-receiver - which were rich with examples of commitment, love, responsibility and reciprocity. Significant turning points included diagnoses, declining health, giving up of work or other activities, and limited social lives - all aspects reported by women representing the chronology of events across their caregiver
trajectory. All of these significant events were recollected as having had an important influence on the women’s post-caregiver identities and experiences. Bereavement was experienced as an extension of active caregiving, where the adaptations and losses carried over into the post-caregiving period. Turning points and significant events in each caregiver’s narratives conveyed the continual changes they had to negotiate over time. The multitude of emotional reactions to the end of caregiving combined with the loss of the loved one and the beginning of the bereavement period are important factors to consider in working with caregivers. Using the careography as a retrospective tool, this study traced the caregivers’ narratives from the beginning of caregiving to one year past the transition out of caregiving. This iterative addition of a visual timeline corresponded with the need for a wider scope with which to view bereaved caregivers. It highlighted the tensions and intersections within the experience of care. The use of this retrospective tool proved to be helpful and cathartic for the caregivers in this study. The intersections of care-receivers’ and caregivers’ significant events along the timeline were revealing for the caregivers. Moreover, they were able to find meaning in the adaptations and sacrifices they made for caregiving.

The themes that emerged in the context of women’s lifecourse accounts related to identity, resilience and social support - elements that demonstrated the impact of the caregiving journey. The theme of identity explored the reality that women’s identities were compromised as they were compelled to adapt due to the increasing needs of their care-receiver. Consequently, in bereavement, the women had difficulties reclaiming their identities. This retrospective exploration with women caregivers raised several issues and highlighted that the experience of caregiving occurs at the intersection of self and care, where an imbalance in one aspect creates challenges in the other. As the caregiving role increased, the women’s identities were affected
and were forfeited over time. Faced with choosing to prioritize their loved one’s needs or their own, the caregivers chose to surrender their identities and relinquish parts of their lives. In the post-caregiving phase, the tensions between self and care were revisited where the women’s reactions in bereavement were related to the surrendering of their identities. The women who had abdicated their social networks, time for themselves, and opportunities for respite were left with fewer social resources and limited internal resources to negotiate their bereavement. Recognizing that the caregiver trajectory required a series of adjustments for the caregiver, the death of the care-receiver can be seen as a tipping point, representing another intense adaptation in the caregiving process. This was displayed in the women’s complicated reactions to bereavement, where they expressed vacillation between emotions of relief and depletion, guilt and sadness, while expressing struggles adjusting to daily life. It was a time when the caregiver was adjusting to difficult emotions, trying to cope with their every day lives and tasks, and attempting to reconstruct their identities and sense of selves.

Resilience can be indicative of personal strength that results after episodes of adversity, and refers to “the maintenance of positive adjustment under challenging life conditions” (Luthar et al, 2000, p. 5). Resilience is a fluid process, rather than a personality characteristic and we see that the women in this study were affected by the process of caregiving. Most of the women, however, after an average of one year of mourning, were able to begin the work of reconstructing their lives again. Resilience, in the context of the current study, can be understood as the women’s abilities to rebound from the challenges of caregiving and bereavement and to enable healing. Referencing prior feelings of resilience, strength, and agency, the women resumed prior interests or recreated new social connections after several months of bereavement.
Social support was highly influential in the women’s bereavement process. Many of the women credited their friends and family for guiding and assisting them through their mourning. A study by Wilks and Croom (2008) indicated that high levels of social support correlated positively with resilience. Social support is both objective and subjective and “can be measured as the perception that one has assistance available, the actual received assistance, or the degree to which a person is integrated in a social network” (Kaur, 2014, p.338). Qualitative views of perceived support has been shown to “have more of an effect and to promote better psychological adjustment than actual support” (Thielemann & Conner, 2009, p. 84). Past research has indeed confirmed the link that perceived support is a proven defense for the damaging effects of stress (Wethington & Kessler, 1986; Morano, 2003) however, little is known about which interventions target which caregiver reactions. In caregiver bereavement, the loss of a loved one, the relationship, connected emotional support and/or companionship can be compensated for through other means of social support. While years of caregiving can lead to a “thinned social landscape” (Settersten Jr, 2015, p.221), bereavement is a time when social support plays an important role. Social support may buffer potential negative feelings or behavior and as well, helps in the emotional reactions to loss. The presence of social support to reduce social loneliness resulting from loss has been supported in the literature (Stroebe et al, 1996) as a measure of helping the bereaved in recovery. Moreover, studies show that social support provided during caregiving that continued into bereavement was most effective at buffering distress (Almberg et al, 2000). Specifically, “post death adjustment is influenced by the social support provided during caregiving, as well as during bereavement” (Almberg et al, 2000, p. 88). If we examine family caregiving and bereavement as part of a life course process, then it is clear that social support is an important aspect throughout the journey.
6.1.1 Relevance of findings to the current scholarship

The findings emerging from the current study both confirm and expand on the existing literature on women’s post-caregiving experiences. The literature states that the care component influences the bereavement context and is influenced by the events of the prior years and months of caregiving (Schulz et al., 2003; Schulz, Hebert & Boerner, 2008; Garrido & Prigerson, 2013). Many studies have demonstrated that challenging experiences in caregiving are linked to difficult recovery and adaptation in bereavement (Brazil et al., 2003; Gilbar & Ben-Zur, 2002; Kris et al., 2006). Caregivers often transition into the bereavement period feeling physically and emotionally exhausted by the caregiving experience (Stadjuhar, Martin & Carins, 2010). This places caregivers at an increased risk of psychological distress in bereavement (Garrido & Prigerson, 2013). Bereavement has been associated with high risks of anxiety and depression as well as higher rates of mortality (Penson et al., 2002, Robinson-Whelen et al, 2001). The women caregivers in this study felt similar emotions of anxiety and depression as well as feelings of hopelessness, helplessness, depletion and isolation (Keene & Prokos, 2008). It was confirmed in this study that high levels of psychological distress exemplify the post-caregiving period and despite heterogeneity in the women’s reactions, each expressed difficulties adjusting to their new realities. Studies that highlight the complicated bereavement reactions after caregiving help us to understand caregiver bereavement and ensure proper support is offered to caregivers throughout their trajectory (Aneshensel et al, 2004; Prokos & Keene, 2005; Li, 2005; Holstlander, 2008; McGhan et al, 2013).

Both intra and inter personal factors influence the context of the bereavement experience and these may include subjective levels of stress, benefit derived from caregiving and the amount of social support received (Stroebe, Schut & Stroebe, 2007; Boerner, Schulz & Horowitz, 2004).
These assertions are supported by findings in the current study. Cumulative adaptations throughout the caregiving trajectory affected this study’s caregivers in ways that led to their feelings of depletion in bereavement. This is supported by the literature on cumulative stress and role overload (Given, Given and Sherwood, 2012; George & Gwyther, 1986; Keene & Prokos, 2008). Other literature on bereaved caregivers points to relief as a main emotion after the death of the care-receiver (Keene & Prokos, 2008; Norris & Murrell, 1987). While relief is a common feeling in women caregivers, it was accompanied by guilt and regret.

This research found that women’s emotional reactions in bereavement are far more complex than can be explained by the two binary and opposing reactions of relief and depletion. It is evident that the post-caregiving reactions are mostly simultaneous and more nuanced than is understood by a single response. The notion of the tipping point is a unique way to understand this iterative experience, not as a binary reaction, but rather as a complex set of mixed emotions that accumulate and create stress. This research demonstrated that by expanding the current view of bereaved caregivers, we are able to move beyond the perspective of distress/risk or relief to include women’s multiple and diverse subjective reactions. Some of the reactions uncovered in this study included love, pride, reciprocity and resilience.

Caregiving became the identity that took up the most space and time, given the demands and intensity of care. This, over time, preoccupied the women caregivers, to the exclusion of most other roles. Retrospectively, the women described their caregiving as extremely taxing but when asked to describe how they were able to cope, spoke about the strength they found within themselves to manage challenges. They mastered new skills (nursing/medical), found energy to go on each day, and adapted to the changes that occurred on a regular basis. In discussing their feelings of strength and capacity in the role of caregiver, the women expressed pride and at
times, surprise, at their abilities to manage the challenges involved in caregiving and subsequently, post-caregiving. These strengths mentioned by the women referred to their abilities to adapt to the continual changes and losses along the care trajectory and to be able to find new meaning in their post-care lives. One study by Brandstatter et al (2014) explored meaning in a study with bereaved caregivers of palliative care patients. They concluded that interventions targeted at meaning reconstruction are helpful to caregivers negotiating their bereavement recovery.

This study’s focus on bereaved caregivers’ lived experiences has the potential to move the discourse of caregiving beyond the typical stress and coping models. It emphasized the challenges within the caregiving trajectory that influenced women caregivers’ identities. It also initiated a focus on resilience and factors that helped caregivers negotiate their bereavement period and reintegrate back into their lives. Expanding this view to explore factors that promote resilience and personal agency will improve our knowledge of caregivers. Current scholarship on resilience in bereaved caregivers is minimal (Coon, 2012; Hayslip & Smith, 2012). This study has proven the relevance of incorporating strength and resilience as factors in how caregivers can negotiate the caregiving trajectory. Moreover, this study drew attention to the personalological and gendered lifecourse as a theory to understand the complexity of the caregiving trajectory.

6.1.2 Using a lifecourse approach for understanding bereavement

This study adds to the literature by highlighting the importance of caregivers’ reactions to their caregiver journey by including, as a central feature of caregiving, the post-caregiving period. By examining the caregiving trajectory as a process and a life course event, we see the connecting links within caregiving. The findings demonstrate the importance of treating caregiving and post-caregiving as one process, as opposed to treating them as separate entities. In
fact, the links between caregiving and post-caregiving are, in essence, reciprocal experiences of care and loss.

This study demonstrated that women are significantly affected by their caregiving experiences; all participants prioritized their caregiving relationships above other activities. This is consistent with the literature that points to gender and social relations playing an important role in the caregiving and the bereavement experience (Carr, 2008). Caregiving exists within a gendered context where women assume the social responsibilities of care and are affected by caregiving personally, socially and emotionally. Linked to the dynamic changes and adaptations in caregiving and into bereavement, women experience caregiving with personal and social consequences. The literature on linked lives emphasizes the substantive impact that social and emotional relationships have on women, which carries over into caregiving and subsequently, bereavement (Moen, Lam & Jackson, 2014). The women experienced multiple impacts as a result of their connectedness with their care-receiver, their role as caregiver, and their social commitment. This contributes to bereavement strain and speaks to the social, intra and interpersonal context of caregiving and post-caregiving.

Given that women are overrepresented as primary caregivers and that their experience of care is unique, their reactions to the bereavement phase were critical to explore (Pinquart, & Sorensen, 2006; Bondi, 2008; Giesbrecht et al, 2012). Bondi (2008) describes how caring work is given to women and that this often becomes a defining characteristic of their self-identity and lifework (Giesbrecht et al, p.2, 2012). In this study, the lifecourse approach moved beyond a limited role strain model and focused on the trajectory of lived experiences throughout the caregiving lifecourse. I drew upon the dynamic, contextual principles embodied in lifecourse to explore the women caregivers’ bereavement (Moen, Lam & Jackson, 2013). Using the lens of a
personological gendered lifecourse, I explored the issues of social interdependence, linked lives, transitions and identity. Through this lens, it was clear that the multiple transitions and relational changes within caregiving affect the caregiver personally. The experience of caregiving typically has a clear beginning, often designated by a diagnosis or accident, and can continue 12-36 months beyond the death of the care-receiver. For the women caregivers, the death of the care-receivers is another transition in the lifecourse of care, which enlightens caregiving as a process, not an event. Literature on the gendered lifecourse places women in the center of vision, deconstructs experiences of power, relationships, caregiving, work and shifts away from roles of wife, mother, daughter; and reconstructs knowledge that is informed by gender and personal experiences (Baber & Allen, 1992; Stacey & Thorne, 1985).

While caregivers are heterogeneous in their experiences of care, the gender distinctions within care resonate among women. Caregiving is seen as an intergenerational and intragenerational event in women’s lifecourse where relationships take on a central importance. The lifecourse of care can be seen as a series of transitions, where personal biographies connect with family responsibilities. A gendered lifecourse approach to caregiving puts care and families in a foremost context. “Women’s life pathways tend to be embedded in, and structured by, the experience and expectations of husbands, children, and aging parents, as well as by broadly defined societal gender-role norms. Thus women’s lives are linked lives, tied inexorably to the lives of others, at all life stages” (Moen et al, 1995, p.259).

This study highlighted women’s gender roles as connected to expectations of themselves and social norms. Many of the women in this study felt it was within their role as wife and daughter to provide care to their care-receiver. The women related how caregiving affected their relationships over time and how this affected them personally. All the women spoke about their
sacrifices and letting go of personal interests and leisure time. However, despite the challenges described, the women were all deeply proud and satisfied that they had been the main caregiver to their loved one. A strong sense of accomplishment and agency was evident in their narratives.

6.2 Implications

My findings confirm the importance of viewing the trajectory of caregiving as a life course process. This will allow caregiving to be seen as a process in one’s life, with particular attention paid to life course themes mentioned above, to better understand the bereaved caregiver in the post-caregiving period. Exploring caregiving that begins at the transition into care and goes beyond the transition out of care into bereavement will help us understand how caregivers negotiate their care trajectory. This will allow for a better response to caregivers at various stages of their lifecourse through the development of better-timed policies, systematic research and best practice interventions for caregiver support.

6.2.1 Policy

Currently in Canada, caregiving issues are present on the policy agenda and embedded in home care policies to older adults (Verbeeten et al, 2015; Canadian Institute for Health Information, 2011). Although the Canada Health Act was written to ensure access to services for all Canadians, there are variations in provincial service delivery. These discrepancies relate to “health care services available to seniors, in home care, long term care and palliative care” (Verbeeten et al, 2015, p.72). Gaps in senior care across Canada result in a greater dependence on caregivers to provide much needed support.

While innovative and successful models of caregiver policies are present in the United Kingdom (Carers Strategy: Gov. UK, 2015), Australia (Carers Australia, 2010) and New Zealand (New Zealand Carers Strategy, 2014), Canada has yet to implement a national and/or provincial
policy agenda. The latest Canadian policy proposal introduced by Sheri Torjman (2015) states that caregiver needs fall into three categories: “community supports, financial assistance and accommodation at work” (p.6). Bereavement is identified as one of the areas of community supports but is not specifically tied to any action plan.

In Quebec, the discourse on caregiving has evolved considerably and now recognizes the role of family care. Caregivers are mentioned many times throughout the current home care policy and are referred to as having challenges and need for support (MFA/MSSS, 2012). A recent initiative stemming from this policy has been the development of a ten-year partnership between the Quebec government and a private family foundation to fund caregiver support programs (L’Appui National). In 2015, however, austerity measures in the Quebec health care system have led to inconsistencies in caregiver support in front line practice. This results in a diverse set of practices from agency to agency, unfortunately hindering the number of caregivers being offered services in their own right. Thus, caregivers are not systematically offered support services during active caregiving or post-caregiving.

Exceptionally, caregivers of palliative care patients are consistently offered follow up and support during their caregiving and throughout their bereavement (MSSS, 2015). This palliative care approach to family caregivers is a model that would be of great value to support caregivers with care-receivers in chronic care situations into their post-caregiving period.

Recognizing that there are long term effects on caregivers once the caregiving is over is an important consideration for government policies. Planning appropriate and timely policies for caregivers can be seen as a potential measure of prevention to help bereaved caregivers maintain their mental health. This study could help to provide key insights for the development of advocacy efforts to develop policy to support caregivers into bereavement.
6.2.2 Research

The findings of this study suggest possible avenues for future research. Firstly, expanding upon the view of the caregiving trajectory as a process would allow for research that integrates a wholistic view of caregivers. This would encourage a more comprehensive view of bereaved caregivers and move beyond the binary views of stress and coping. This study has shown that women’s experiences in bereavement were affected by their caregiving – this idea could be developed to study the links between the many transitions experienced throughout the care trajectory. The T.I.M.E.D. tool and the careographies developed in this research were study iterations that can serve to inform research methodology and design. Using analytic tools to incorporate theory into practice created a valuable perspective of bereaved caregivers. This is a key contribution of this research, to move beyond a static view of care and bereavement, and to recognize caregiving as a lifecourse process.

Secondly, further studies could develop upon lifecourse research to incorporate additional aspects of social location. For example, studies on caregiving men in different filial relationships could be an innovative line of research ie: sons, son-in-laws, grandsons at different lifecourse stages. As well, studies on culturally diverse caregivers would be enriching as well, given the diversity of different cultures and care. Finally, further inquiries in to the role of social class are warranted, particularly as previous research has indicated the important aspect of financial strain on caregivers. Although this study could not explore financial strain in any depth due to limitations in sampling, exploring the relevance of financial strain during post-caregiving would help to shed light on additional factors that may influence caregivers’ bereavement.

Thirdly, in light of my findings that describe the challenges of women transitioning out of caregiving, research that followed caregivers longitudinally across their trajectory would be
highly revelatory. Following caregivers from diagnosis into bereavement would be invaluable in regards to long-term needs and opportunities for prevention. Moreover, creating links with caregivers throughout their trajectory would be added value for them as well. Researchers could glean knowledge about this complex trajectory while clinicians could plan timely and appropriate services to support caregivers throughout their care journey.

6.2.3 Practice

From a social work perspective, women’s narratives speak to the importance of psychosocial support and follow up in the post-caregiving phase. The women in this study expressed the need and desire for follow up support due to their complicated emotions and challenges transitioning out of the caregiving role. Considering caregiving as a lifecourse trajectory compels those in clinical practice to explore caregiving as a series of transitions into and out of care. The themes of identity and resilience that emerged in this study demonstrated that caregivers are personally and profoundly affected by their caregiving role. Often, it is only after the caregiving is over that this becomes evident. As such, a focus on the intra and inter personal aspects of care are particularly meaningful concepts for social work practice. Health and social care practitioners need to recognize that caregivers experience the transitions into and out of care in diverse ways and that the context of care should be explored to understand the impact on the caregiver’s sense of self. Although not everyone needs bereavement support, caregiving adds a dimension to bereavement that can complicate the post-caregiving experience. The intense and conflicting emotions experienced by bereaved caregivers demonstrated the importance of follow up by health and social care professionals to ensure that they have access to social support and health/mental health care resources to work through the post-caregiving experience. In both individual and group work with bereaved caregivers, practitioners can
address the relevance of how caregiving affects one’s identity and the importance of fostering resilience.

My role as a research-practitioner has enabled me to observe gaps in service delivery and develop tools that would support bereaved caregivers. Early results from this study gleaned from women caregivers’ narratives helped to highlight gaps in support and emphasize the need for better intervention tools. This allowed for an extraordinary possibility to connect research with practice throughout my research design. The tools developed and described below were inspired by preliminary findings from this research. They will be developed further and tested for clinical practice in the near future. The three tools in development that emerged from this research are listed below.

6.2.3.1 *T.I.M.E.D*

The T.I.M.E.D. acronym of timing, intensity, meaning, experience of the death and duration are elements of a promising clinical tool that can be used as part of an approach to support bereaved caregivers’ in their trajectory and transition out of care. The compounded aspects of T.I.M.E.D. help to highlight the caregiving experience and the contextual and subjective elements relevant to understand the care process. There is currently no literature on the elements of T.I.M.E.D. as a lens with which to view bereavement however the lifecourse underlines various tenets that include “time, context, process and meaning on human development and family life” (Bengtson and Allen, 1993). Lifecourse can be a meaningful and significant lens to interrogate the caregiving journey, as a dynamic and contextual social process that caregivers experience over time.

The T.I.M.E.D. acronym can serve as a preventive clinical tool as clinicians accompany caregivers through their transition into bereavement. Moreover, this can also be used as a
retrospective discussion with bereaved caregivers, in looking back at their experiences and as a method to plan interventions for their bereavement period. The relevance of this tool is that it calls attention to the caregiving as a process, with lifecourse principles, with which to examine the journey. The tool can be used with the caregiver during their trajectory, in active caregiving or during their bereavement. If used during caregiving, it can be seen as a preventive tool, to identify any issues that may be pervasive in bereavement. The clinician, in building a relationship, with the caregiver, can note the particularities of the T.I.M.E.D. aspects of caregiving and work with the caregiver to prepare for their bereavement adaptation. If used in bereavement, it can be used to recognize the preceding context in developing a bereavement intervention with the caregiver. Knowing the context of how the caregiver has coped in the past, and how they have shown resilience and strengths in certain areas will facilitate the path to bereavement adaptation.

6.2.3.2 Careography

The reflexive and iterative instrument that emerged from this research was the development of an interactive careography timeline used to support reflection with bereaved caregivers regarding their caregiving experiences. The careography timeline is a practical and interactive tool that can be beneficial to social work practice. Social workers can use the timeline to better understand caregivers’ perspectives and recognize the significance and meaning of key transitions and events. This information can initiate supportive interventions for caregivers during active caregiving that would extend into bereavement. Moreover, this tool can be used as a preventive strategy that would highlight women’s strength and resilience over time. The careography was particularly useful on an individual level in this research, as a talking point with the caregivers, to have them reflect on their journey and to highlight the significant turning
points. The careography timeline can also be used in group settings where the facilitator can create an exercise for sharing and discussion among caregivers. This can create opportunities for mutual support and validation. Mapping the care journey from the retrospective standpoint of the caregiver has been revealing for clinical practice and research on caregiving and bereavement.

In the next several months, the careography will be used as a teaching tool for social work students in practice and as well in an emerging caregiver support program at the community organization level.

6.2.3.3 Post-caregiving protocol

In 2014, based on preliminary results of this study, I initiated the development of a post-caregiving protocol for bereaved caregivers of older adults (Orzeck, Freitas & Drummond, 2014). This innovative approach to post-caregiving was created in response to expressed caregiver support needs and as a response to a gap in service provision. The protocol (see Appendix D) encompasses a three-part approach that provides social work professionals with a tool that highlights potential risk factors for bereaved caregivers and proposes an intervention plan of support. As well, it emphasizes the subjective and contextual elements of the caregiving trajectory and the consequential impact on caregivers. In part one of the tool, there is a chart for professionals to complete with the bereaved caregiver in order to develop a portrait of the caregiving trajectory. The information listed corresponds to research based variables that have contributed to caregiver distress (Hudson & Payne, 2009), and are identified as characteristics of the care journey pre-death and post-death. By circling or highlighting these factors, the practitioner will gain a contextual and subjective understanding of the caregivers’ experiences. In part two, a guide to interventions with bereaved caregivers is presented with recommendations for a three step follow up intervention plan. This includes opening a caregiver health file,
assessing their factors of risk, planning a twelve-month intervention plan and prioritizing a strength based intervention approach. Part three is a validated bereavement risk assessment form to highlight complicated bereavement. If risk factors were indicated, this would impact the intervention plan and require a more frequent follow up schedule. This post-caregiving protocol is an innovative approach to bereavement support and aims to increase the clinical understanding of caregivers’ bereavement experiences, characteristics and challenges.

Future steps for this protocol include a pilot project and evaluation planned for the fall of 2017 at the CLSC René-Cassin of the CIUSSS of West-Central Montreal Health.

6.3 Conclusion

This narrative study addressed women’s post-caregiving experiences through the lens of the personological gendered life course. By doing so, it broadened and enriched the understanding of women’s trajectories of care to include the period of time after the death of the care-receiver as an integral component of the caregiving journey. A narrative method enabled a view of post-caregiving that included both a subjective and relational context. This study gave voice to bereaved women caregivers whose stories had previously been invisible in the caregiving literature; despite the reality that post-caregiving represented a time of continued struggle and transformation and was significantly influenced by their experiences of care. Examining how the end of caregiving was influenced by women’s caregiving experiences confirmed that the transition out of care is highly diverse and personal, marked by different intensities, and based upon multiple and subjective factors. This study provided an opportunity for the women participants to share their stories, make sense of their experiences and highlight meaning in the personal and social impacts of caregiving. The emotional biographies relayed by all the women told of love, loss, change, adaptation, challenges, adversity and resilience. The
women’s experiences of post-caregiving helped us to understand the importance of considering post-care as an integral part of the caregiving career and can serve as an impetus for reshaping practice and policy to better meet the needs of women as they transition out of the caregiving role and develop renewed lives. Considering caregiving as part of women’s lifecourse can encourage a holistic view of the caregiver, within the context of all the caregiving experiences that preceded the death of the care-receiver. This will allow for a greater understanding of the lived experiences of caregivers throughout their care trajectory, and create the momentum for a better clinical response to their ongoing needs.
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APPENDICES

APPENDIX A:

Information letter: for women who have previously been caring for a spouse or parent.

Research project title: Identity in post-caregiving: Exploring the transition out of care

Has someone you have been caring for recently passed away?

We are currently seeking wives and daughters who provided care to their husband or parent prior to their loved one’s death to participate in a research study regarding their caregiving experiences. This research aims to study the period following the end of caregiving to a spouse or parent. We are interested in exploring the personal changes that occurred in your life as a result of the end of caregiving and how the caregiving itself, your commitment to caregiving and your relationship with the person for whom you provided care influenced your life after their death. Moreover, this research aims to identify practical interventions that could help others who have gone through the final stages of caregiving and after the death of their husband or parent.

Participant Selection:

The participants that we are seeking offered physical or emotional daily care to their husband or parent due to physical limitations, mental health issues or cognitive losses (memory loss, disorientation, etc.). Participants’ husbands or parents died between six months and three years ago and could have lived with the participant or in any public or private setting.

What is asked of participants:

Participants will take part in a 1½ - 2 hour face to face interview in a location of their choice. Prior to the interview, participants will sign a consent form which outlines their rights in the interview process. The interview will concentrate on the following issues:

- The organization of care to the participant’s husband or parent;
- The benefits and challenges associated with the care;
- The relationship with the dependent husband or parent and other family members;
- The place that the caregiving occupied and the repercussions on the caregiver’s personal life;
- The details of the husband’s or parent’s final days and death and the caregiver’s reactions;
- The changes in the caregiver’s life after the death and the reorganization in their life;
- The challenges faced during and after caregiving, and any services or interventions that were helpful in offering support.

The interview will be audiotaped and transcribed on paper. Any and all information will be kept strictly confidential and no one other than the researcher will have access to the data.
We hope that you will take part in this research project. Your participation in this study is important to helping better understand the end of the caregiving period and its impact on caregivers’ personal lives. Our hope is that we will gain the information necessary to be able to plan support services for caregivers after their loved one has passed away.

If you would like to participate in this research study or would like more information, please contact:

Pam Orzeck, doctoral student at Université Laval, 514-484-7878, extension 1340 or by email at pam.orzeck.cvd@ssss.gouv.qc.ca.
APPENDIX B
CONSENT FORM

Research project title:
Identity in post-caregiving: Exploring the transition out of care

Researcher:
This research is being conducted as a requirement for a PhD in social work by Pam Orzeck.

Before accepting to take part in this project, please read carefully and fully understand the information outlined in the document below. This document explains the goals, procedures, advantages, risks and inconveniences of the project. You are invited to ask questions for clarification and/or further information.

Nature of the Study:
This research aims to explore how the end of the caregiving period personally affected caregiving wives and daughters. By exploring caregivers’ lived experiences and understanding the caregiving that preceded the spouse or parents’ death, we will gain a better comprehension of the transition to the post-caregiving period.

Nature of participation:
Your participation in this project involves a face-to-face interview, which will take approximately 1½ - 2 hours, and will focus on the following areas:
• Your experiences as a caregiver;
• How caregiving affected you personally;
• The circumstances surrounding your spouse/parent’s death;
• Your personal experiences after the caregiving was over;
• What help would have been useful to you at the time.

Advantages, risks, inconveniences linked to your participation in this research
Research has shown that having the occasion to discuss meaningful events with a researcher has been helpful to caregivers. In this project, you will have the opportunity to share your experiences regarding the end of the caregiving. Moreover, you will be able to suggest practical solutions for other caregivers going through similar experiences.

It is possible that the discussion of past events might bring up difficult emotions about your experiences. As such, an agreement has been made with a social worker in the short term counselling department at the CSSS Cavendish for face-to-face counselling, should you request it.
Voluntary participation and withdrawal

Your participation in this research is completely voluntary. You may reserve the right to end the interview at any time, without any consequences. Should you decide to withdraw from the study, you may choose to have your interview excluded from the data and all data destroyed.

Confidentiality and data management

The following measures will be taken to ensure the confidentiality of the information you provided us with:

- Your name will not appear on any of the data or documents;
- All data and documents will be coded for anonymity and only the researcher will have access to the lists of names and codes;
- Only the researcher will have access to the data and documents;
- All the materials of research, including data, analyses and audiotapes will be kept in a locked cabinet at the CSSS Cavendish research centre, and password protected on the researchers’ personal computer, backed up by the CSSS computer network. All data will be destroyed five years after the end of the research project. All paper data will be destroyed by shredding and all computer data will be deleted from the computer and network using a data destruction software.
- Results from the research will be presented in various ways (conferences, journal articles, etc) without you being identified by name or recognized in any way.
- A short summary of the research results will be sent to you if you specify an interest and write your address on this consent form.

Additional information

If you have any questions about this research or your participation, please contact Pam Orzeck, at 514-484-7878 local 1340, or by email at: pam.orzeck.cvd@sss.s.gouv.qc.ca.

Signatures

I ____________________ , fully consent to participate in the research project entitled “Identity in post-caregiving: Exploring the transition out of care”. I am fully aware of the nature of the research study, its risks, advantages and inconveniences. I am satisfied with the information, explanations, and answers which have been given to me by the researcher in regards to my participation in this research project.

_________________________________________  ____________
Signature of participant  Date

I would like the short summary of study results to be mailed to me at the address below.
Address to send the summary report: _________________________
_________________________
_________________________

I have explained the goals, nature, advantages, risk and inconveniences of this research project to the participant. I responded to her questions to my best ability and I confirmed that the participant understood the project.

__________________________________________  _______________________________________
Researcher signature                              Date

Complaints and criticisms

For any complaints or criticisms regarding this research project, you may contact the ombudsman of Université Laval at the following address or phone number:

Pavillon Alphonse-Desjardins, bureau 3320
2325, rue de l’Université
Université Laval
Québec (Québec) G1V 0A6
Information: (418) 656-3081
Toll-free line: 1-866-323-2271
Email: info@ombudsman.ulaval.ca

This project has been approved by the Research Ethics Committee of the Université Laval (No. approbation 2010-267, 04-11-2010 and the CSSS Cavendish Research Ethics Committee.
APPENDIX C: INTERVIEW GUIDE

Caregiving

1. Can you describe how you became a caregiver?
   1.1. What motivated you to be a caregiver?

2. Can you tell me about your life as a caregiver to your spouse/parent?
   2.1. Can you tell me about a typical day of caregiving when you were caring for your spouse/parent?
   2.2. Can you tell me about any changes you had to make or chose to make in your life as a result of being a caregiver?
   2.3. What place did caregiving take on in your life?
   2.4. How did it change over time?

3. How did caregiving affect your life?
   3.1. How did you organize your time as a caregiver with other responsibilities?
   3.2. What was your life like before you became a caregiver?
   3.3. How did you manage the competing/other responsibilities in your life? i.e.: children, family, work, friends, etc.

4. How have you been personally affected by your role as a caregiver? (How did caregiving affect you as a person?)
   4.1. Having been a caregiver, what did you learn about yourself?
   4.2. What did it change about you?

5. Can you tell me about your relationship with your spouse/parent?
   5.1. How did caregiving change your relationship with your spouse/parent?

Post-caregiving

6. Can you describe the last few days of your parent/spouse’s life?
   6.1. How did you react to the loss?
   6.2. How did you feel about the end of the caregiving?

7. How has your life changed since your spouse/parent died?
   7.1. In what ways did your life change after the caregiving ended?
   7.2. How do you organize your time, now that the caregiving is over?
   7.3. Can you tell me about a typical day in your life?

8. How have you been personally affected by the loss of your role as a caregiver?
   8.1. What did you learn about yourself looking back since the end of caregiving?
   8.2. What did it change about you?

9. What issues did you have difficulties with after your parent/spouse died?
   9.1. Have you sought any professional help?
9.2. Are those issues still present?
9.3. What services would have helped you at the time?
### Part 1:

#### Risk factors for complicated bereavement outcomes for caregivers

<table>
<thead>
<tr>
<th>Pre death</th>
<th>Post-death</th>
</tr>
</thead>
<tbody>
<tr>
<td>The caregiver:</td>
<td>The bereaved caregiver:</td>
</tr>
<tr>
<td>• Is an elderly spouse in a long term marriage;</td>
<td>• Demonstrates signs of poor initial adjustment to the death;</td>
</tr>
<tr>
<td>• lives with the care-receiver;</td>
<td>• Expressed dissatisfaction with their caregiving role during the caregiving trajectory.</td>
</tr>
<tr>
<td>• lacks social support;</td>
<td>• Is isolated after the death;</td>
</tr>
<tr>
<td>• has their own health issues;</td>
<td>• Has reduced social support due to the death;</td>
</tr>
<tr>
<td>• feels unsupported;</td>
<td>• Has a limited or nonexistent social support network.</td>
</tr>
<tr>
<td>• has an ambivalent or conflictual relationship with the dying person;</td>
<td></td>
</tr>
<tr>
<td>• has a very close/exclusive relationship/marriage;</td>
<td></td>
</tr>
<tr>
<td>• is involved in a family situation that has poor communication, lacks cohesion, has difficulty resolving conflict.</td>
<td></td>
</tr>
</tbody>
</table>

The caregiver has experienced:

<table>
<thead>
<tr>
<th>Pre death</th>
<th>Post-death</th>
</tr>
</thead>
<tbody>
<tr>
<td>The caregiver has experienced:</td>
<td>• The death was sudden or unexpected;</td>
</tr>
<tr>
<td>• Cumulative multiple losses;</td>
<td>• The death occurred in traumatic circumstances;</td>
</tr>
<tr>
<td>• Multiple stressful situations;</td>
<td></td>
</tr>
<tr>
<td>• Mental health problems;</td>
<td></td>
</tr>
<tr>
<td>• A family history of mental illness</td>
<td></td>
</tr>
</tbody>
</table>

The caregiver has:

<table>
<thead>
<tr>
<th>Pre death</th>
<th>Post-death</th>
</tr>
</thead>
<tbody>
<tr>
<td>The caregiver has:</td>
<td>The bereaved caregiver expresses:</td>
</tr>
<tr>
<td>• Few adequate coping mechanisms;</td>
<td>• Feelings of hopelessness;</td>
</tr>
<tr>
<td>• High pre-death emotional stress;</td>
<td>• Feelings of depression;</td>
</tr>
<tr>
<td>• Lived with a stigmatized, lengthy and debilitating (deteriorating) disease process;</td>
<td>• Feelings of excessive; loneliness, guilt, anger and sadness.</td>
</tr>
<tr>
<td>• Exhibits intense anger</td>
<td></td>
</tr>
</tbody>
</table>
Part 2: GUIDE TO INTERVENTIONS WITH BEREAVED CAREGIVERS:

Assessing need/risk before the care-receiver’s death:

In a meeting with the caregiver, conduct a needs and risk assessment for poor psychological health and /or prolonged grief.

Bereavement support after the care-receiver’s death:

- Contact the bereaved caregiver to give condolences and mention that you will be calling back in two weeks’ time;
- Contact bereaved caregiver at week 2 for a home visit: discuss coping and social support. Assess risk; offer resources, including grief counselling, support groups, referrals to other resources, etc.
- Develop an intervention plan for referrals to resources;
- If no intervention is planned, contact bereaved caregiver at week 4 & 6 to discuss coping skills, assess risk, offer resources, including grief counselling, support groups, referrals to other resources, etc.
- Conduct a follow up assessment of the bereaved caregiver six months post-death to assess for complicated grief reactions;
- Re-evaluate bereaved caregiver at one year.

STEP 1: ASSESS

- Open a file for the bereaved caregiver
- Assess their risk factors using a risk screen (Part 3)

STEP 2: PLAN

- Based on the assessment and the bereaved caregiver's identified level of risk; develop a 12-month intervention plan.

STEP 3: INTERVENE

- After having identified the factors that influence the bereaved caregiver's experiences of loss, develop a strength-based intervention approach (i.e.: individual counseling, referrals to support groups, psychotherapy resources, etc).
Part 3: Bereavement Risk Assessment Form to highlight complicated bereavement

Bereaved caregiver: ________________  Care-receiver/deceased: ________________
Relationship: ___________________  Date of death: ________________

<table>
<thead>
<tr>
<th>Moment of death:</th>
<th>Who was present?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sudden/unexpected</td>
<td></td>
</tr>
<tr>
<td>Calm/peaceful</td>
<td></td>
</tr>
<tr>
<td>Problematic/traumatic</td>
<td></td>
</tr>
</tbody>
</table>

Risk factors: please circle

<table>
<thead>
<tr>
<th>Emotional response to the death</th>
<th>Guilt/self-blame</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appropriate</td>
<td>None</td>
</tr>
<tr>
<td>Disorganized</td>
<td>Mild self-reproach</td>
</tr>
<tr>
<td>Highly emotional</td>
<td>Moderate</td>
</tr>
<tr>
<td>Inappropriate</td>
<td>Extreme</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Physical health</th>
<th>Financial situation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Good</td>
<td>Stable</td>
</tr>
<tr>
<td>Existing physical illness</td>
<td>Unstable</td>
</tr>
<tr>
<td>Physical concerns</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Anticipated employment</th>
<th>General anger</th>
</tr>
</thead>
<tbody>
<tr>
<td>Works full time/part time</td>
<td>None</td>
</tr>
<tr>
<td>Retired</td>
<td>Mild irritation</td>
</tr>
<tr>
<td>Unemployed</td>
<td>Moderate anger</td>
</tr>
<tr>
<td>Presently on medical leave</td>
<td>Aggressivity</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coping</th>
<th>Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well</td>
<td>Appropriate</td>
</tr>
<tr>
<td>Fair/marginal</td>
<td>Moderate</td>
</tr>
<tr>
<td>Poorly</td>
<td>Extreme (panic attacks)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current social support</th>
<th>Suicidality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Well</td>
<td>Risk</td>
</tr>
<tr>
<td>Family supportive but distant</td>
<td>No risk</td>
</tr>
<tr>
<td>Unsupported/isolated</td>
<td></td>
</tr>
<tr>
<td>Conflictual relations</td>
<td></td>
</tr>
</tbody>
</table>

Additional comments:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

(Modified tool, based on MacKinnon, C., 2013).