

**NAVIGATING FAMILY CAREGIVING FOR DEMENTIA:
THE JOINT ACTIONS AND PROJECTS OF FAMILY MEMBERS**

by

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Abstract

As the “baby boom” generation ages and the population shifts over the next two decades there will be an unparalleled number of individuals in need of care and a significant gap in resources to meet the demand. With this shift, family members, though often unequipped and lacking in resources, are expected to shoulder the financial, medical, and other care needs of the aging population (Barnett, 2015). Though one individual often serves as the main caregiver, all family members can be impacted and experience stress due to the complex caregiving process. This study explored the joint goal-directed processes that occur in the caregiving process for a family member with dementia. The research question that guided the study was, “What are the goal-directed actions and projects that family members construct, express and participate in together, relevant to the caregiving process for a family member with dementia?” The method used to explore this research question was the action project method that examines the internal thoughts and feelings, manifest behaviours and social meaning behind joint actions. Three family dyads (six individuals) who are involved in family caregiving for an individual with dementia participated in a joint conversation and self-confrontation interview. The study was examined from a multicase perspective following in-depth analysis of each case using the action project method. Qualitative analysis revealed that family members engaged in joint goal-directed actions that facilitated caregiving projects for the three participating families. Although there were processes unique to each family, common processes amongst the three families included relative unwillingness to vocalize internal thoughts and feelings, a focus on the primary caregiver, having different perspectives on caregiving, prioritization of physical needs of the caregiver or care receiver, and grieving the loss of normal. This work represents the first attempt to explore family caregiving processes (i.e. conversations) as they occur between family members and adds to the

growing literature on the family caregiving experience. Implications for counselling practice working with individuals navigating the complex process of family caregiving are also drawn.

Lay Summary

The purpose of this study is to gather information about the process of caregiving as it occurs between family members providing care for a relative with dementia. The research is focused specifically on families with a relative diagnosed with dementia who is still living at home. Sessions were guided by the action project method framework that allows for family members to have conversations together without the presence of the researcher. Family members were found to engage in different projects together but the following processes were found to be common amongst all families: relative unwillingness to vocalize thoughts and feelings, a focus on the primary caregiver, having different perspectives on caregiving, prioritization of physical needs of the caregiver or care receiver, and grieving the loss of normal.

Preface

This dissertation is the original intellectual work of the author, V. Silva. The research activities outlined in Chapter 3-5 were covered by the University of British Columbia, ethics certificate number H18-01169. Ethics approval was also obtained through Vancouver Coast Health Authority and Vancouver Coast Health Research Institute, ethics certificate number V18-01169.

Participant interviews were completed by the author in collaboration with two research assistants, M. Chiang (Masters Student, University of British Columbia) and S. Rosario (Masters Student, University of British Columbia).

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Glossary

Contextual Action Theory Terms

1. **Action:** The intentional goal-directed behaviour of persons. Can be considered from the three perspectives of manifest behaviors (verbal and nonverbal behaviours that can be observed), internal processes (thoughts and emotions that the actor has while engaging in the action), and social (how the action is understood in the social, cultural and language context of the actor and others).
2. **Career:** The construction of meaning from a range of projects over a long-term period of time. Holds significant meaning in an individual's life.
3. **Elements:** Specific coded units of manifest behaviour (set of defined actions or expressions)
4. **Functional Steps:** The steps that actors take to reach the goal of an action
5. **Joint Action:** Action as it occurs between two or more actors (socially embedded)
6. **Joint Goals:** What actors hope to accomplish or are working towards
7. **Joint Project:** When several discrete actions, having common goals, occur over a mid-length period of time.

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Dedication

This thesis is dedicated to my family, and the countless other families out there, who are trying to figure out how to do caregiving. It is messy, it is never ending, it is full of grief but there is also passion, love, and purpose. This work was done for each and every family member in the thick of it all.

Chapter 1: Introduction

1.1 Research Problem

There will be a significant demographic and parallel social shift in the West as the aging “baby boom” generation needs care over the next two decades. Between 2006 and 2011, the number of seniors increased nearly five million, or 14.1%, based on data collected by Statistics Canada (2012). However, the Canadian population is disproportionately aging as the number of those between the ages of 15 to 64 increased by only 1.2 million, or 5.7% (Statistics Canada, 2012). Providing further evidence of this shift, Statistics Canada census data demonstrates that fewer people are entering the work force than leaving it (2012). This shift is occurring across the globe; there is a growing population of aging adults requiring either formal or informal care as the average life expectancy increases in developing countries (Watt, 2014). With this impending shift over the next two decades, “Generation X” will shoulder the financial, medical, emotional, and other caregiving needs of their aging parents (Barnett, 2015).

In the United States alone, it is estimated that almost 60 million individuals living with disabilities, of whom ~70% are severely impaired, do not receive institutionalized care (Barrio, Hernandez, & Gaona, 2016). These disabilities cover a significant range including neurodegenerative diseases, developmental disabilities, or severe mental illness to name a few (Barrio et al., 2016). Based on a United States national report, statistics indicate that 85% of caregivers are family members (National Alliance for Caregiving & AARP Public Policy Institute, 2015). For individuals with intellectual and developmental disabilities in the US, it is estimated that approximately 80% live with their families (Hodapp, Burke, Finley, & Urbano, 2016). This trend is mirrored in Canada where there is a rapidly expanding population providing

informal, or unpaid, care to family members. In 2010 alone, an estimated 4-5 million individuals in Canada served as informal caregivers for a family member or friend with a disability (Shooshtari, Duncan, Roger, Fast, & Han, 2017).

In order to fully appreciate the caregiving process, one must examine the influence and interaction of the larger systems within which the family exists and the ways that these systems support or hinder the caregiver's development. For example, in an effort to limit public costs in Western Europe and despite expanding social services, increasing pressure is being placed on individuals to serve as caregivers for family members (Leinonen, 2011). In Canada, recent statistics have indicated that over 3 million individuals provided care for a parent with a long-term health condition or problems associated with aging, yet only 5% of these caregivers received government financial assistance (Statistics Canada, 2013). In the West, as a result of the growing responsibility of families to provide caregiving, social pressure has normalized the transition to parental caregiver (Leinonen, 2011).

Governments help foster individual development through the establishment and enforcement of social systems, economic regulation, and legislation (Mayer & Schoepflin, 1989). However, this framework could hinder adult development and life transitions if the state endorses responsibility of families to care for individual members yet restricts funding for the appropriate supports. Other contextual factors that may influence the caregiving process include socioeconomic status (SES) and race (Cassie & Sanders, 2008). For example, middle class families adopt more of a care managing role while lower-class SES families tend to provide more direct care (Merrill, 1996). Further, Merrill (1996) reports that, along with influencing what caregiving entails, SES can influence when during the adult life course the caregiving transition occurs.

Though social systems help shape the nature of family caregiving, the dynamics of the family microsystem also play a significant role. Family members need to navigate both adaptive and hindering microsystem dynamics in the caregiving process (Merrill, 1996). According to Merrill (1996), caregiving roles reflect family patterns that have been ingrained over the course of the family life-span. These patterns determine which family members have the motivation and capacity to participate, and to what degree, in caregiving responsibilities. The sharing of responsibilities amongst family members is essential for the adaptation and coping of individuals providing caregiving (Davey & Szinovacz, 2007). Primary caregivers experience greater stress and negatively impacted health when they do not have support from other family members or if there is increased microsystem conflict (Kwak, Ingersoll-Dayton, & Kim, 2012).

As the number of adult children without siblings increases, there is little option for available family members who might take responsibility for the caregiving role (Leinonen, 2011; Lin, Fee, & Wu, 2012). Further, cross-cultural studies indicate a gender bias as female adult children primarily take on responsibility for caregiving of elderly parents (Leinonen, 2011; Lin et al., 2012; Merrill, 1996). Depending on the caregiver's gender, the specific caregiving tasks have also been found to vary significantly, leading to asymmetry in family caregiving (Kwak et al., 2012). Due to factors such as the unequal distribution of caregiving tasks, relation to the care receiver, or stressful interpersonal dynamics, caregiving can lead to high conflict and tension within the family (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Connidis & Kemp, 2008; Lin et al., 2012).

For family caregiving, the process can be an incredibly stressful one, with caregivers reporting physical and emotional problems, financial difficulties, decreased recreational hobbies, and social isolation, to name a few issues (Barnett, 2015). Caregiver health outcomes can be

bleak, with various studies reporting onset of depression, anxiety, and reduction in physical health and general well-being (Barnett, 2015). In describing the caregiving process, Blando (2011) outlines feelings of anger, anxiety, guilt and isolation that are typical in primary caregivers. Mounting research into the effects of caregiving also demonstrate that caregivers experience a range of psychological and physiological health impacts such as an impaired immune system and increased risk of heart disease, compared with non-caregiving adults (Gouin, Hantsoo, Kiecolt-Glaser, 2008; Lee, Colditz, Berkman, Kawachi, 2003). Ultimately, the caregiving relationship and the quality of care provided can suffer as the caregiver experiences multiple, overlapping stressors (Watt, 2014; Leinonen, 2011).

Though a significant amount of research has been conducted on the adverse health outcomes of individuals who provide caregiving for an elderly family member, this work is largely based on cross-sectional observations collected well into the caregiving role (Barnett, 2015). Further, a majority of the research focuses on a single caregiving individual and fails to address the dynamic and interactional process of caregiving as it occurs over time. Some research highlights the experience of conflict in family caregiving due to challenges in negotiation with siblings (Leinonen, 2011; Tatangelo, McCabe, Macleod, & Konis, 2017). However, this work was based on individual respondents and failed to describe how the process of negotiation occurred between siblings.

In a recent study, authors highlighted how the majority of dementia family caregiving research is dyadic focused and primarily centered on the spousal caregiving relationship (Esandi, Nolan, Alfaro, & Canga-Armayor, 2018). Seeking to develop a more holistic understanding of the family caregiving experience, the authors used semi-structured interviews to explore the experience of family units living with Alzheimer's disease (AD) (Esandi et al., 2018). Through

joint interviews with family units, researchers guided family members to talk about how relationships, interactions, and dynamics were impacted as a result of caregiving (Esandi et al., 2018). Though this work identified social processes that occur in family caregiving not previously explored, including that of noticing, suspecting and confirming changes with the individual with AD, the research did not capture how these processes actually played out between family members.

Informal family caregivers are becoming a crucial part of a multifaceted health care system as a result of this demographic and parallel social shift (Bevans & Sternberg, 2012). Though one family member often serves as primary caregiver, all family members are ultimately impacted and experience stress as a result of family caregiving. The greater the support and more balanced the sharing of caregiving responsibilities within the family, the better the health outcomes for each family member involved (Davey & Szinovacz, 2007). Not only is it necessary to better understand the caregiving process in an effort to mitigate negative health outcomes for the caregiver, the caregiver's well-being can also have a significant impact on the health outcomes of the individual receiving care (Barnett, 2015). Uncovering the ways family members engage in the caregiving process and identifying growth promoting patterns have the potential to help the countless others who face the caregiving transition in the future. More specifically, by revealing some of the implicit and explicit actions in caregiving conversations as they occur between family members, we can increase our understanding of how the process occurs and better support these families in the future.

Chapter 2: Literature Review

Before exploring the actions in which family members engage in the caregiving process, a comprehensive picture of caregiving in the context of the family must first be established. In this chapter I begin by providing an overview of the family life cycle and detail the family caregiving process including the documented negative impacts caregivers experience over time. I highlight caregivers for family members with dementia or Alzheimer's disease (AD) and explore the different experiences these individuals face compared to other familial caregivers. To provide context for exploring the dynamics that may be present between family caregivers, I describe some of the reported expectations and exchanges between family caregivers. Lastly, I suggest the conceptualization of caregiving as goal-directed action to address the gap around current understanding of the action processes that family members engage in relative to caregiving.

2.1 The Family Life Cycle

Just as theorists have determined normative individual developmental stages, similar work has been done to define life cycle models for families. A foundation of family stage theory, Carter and McGoldrick (1988) outlined the following six stages through which a family typically progresses: (a) leaving home: single young adults, (b) the joining of families through marriage: the new couple, (c) families with young children, (d) families with adolescents, (e) launching children and moving on, and (f) families in later life. As families transition from one stage to another, they experience increased system tension and psychological impairment (Carter & McGoldrick, 1988). According to systems theory, families often resist change, struggle with adapting, and feel unprepared for the next stage in the cycle.

A foundational tool for understanding family development, the family life cycle can inform conceptualization of the numerous issues that families experience in the different stages.

In each stage, critical developmental tasks must be undertaken in order for families to effectively transition on to the next one (Ballard, 2012). In fact, each stage is defined by key transition principles and second-order changes that must be met in order to proceed developmentally. For example, in the third stage, families with young children are expected to accept new members into the system by adjusting the marital system, realigning relationships with extended family, and sharing childrearing tasks (Carter & McGoldrick, as cited in Ballard, 2012). However, families in the sixth and final stage of the family life cycle have the key developmental task of accepting shifting generational roles which involve the secondary changes: (a) maintaining function despite physiological decline; (b) supporting older family without over functioning; (c) allowing for increased role of the middle generation; and (d) dealing with the loss of spouse, other family, and peers (Carter & McGoldrick, as cited in Ballard, 2012).

Not only are developmental tasks different for each family stage in the life cycle, the patterns and dynamics of families can vary drastically from one stage to the next. One noticeable difference is that young adults in earlier stages rely more on friends for emotional support while dependence on family members tends to increase in later stages of the life cycle (Fuller-Iglesias, Webster, & Antonucci, 2015). Another difference between stages is that as individuals age, their reliance on structural supports increases. However, while in earlier stages, individuals may be focused more on the qualitative or emotional nature of relationships (Fuller-Iglesias, Webster, & Antonucci, 2015). Other factors, such as emotional regulation, change as the individual and family progresses over time, contributing to the different characteristic needs, patterns, and tasks of each stage.

Depending on an individual's current life stage, family members may not be as willing to engage in certain activities or challenging conversations with others if those activities interfere

with their own developmental tasks or life demands (King & Wynne, 2004). Family members can remain fixed in old patterns of communication that no longer serve current life cycle stages (King & Wynne, 2004). These maladaptive patterns and old roles may lead to increased tension and separation between family members and actually prevent individuals from successfully engaging in or passing through certain developmental tasks. In the case of family caregiving which often occurs in the families in later life stage, some of these tasks could include accepting shifting generational roles or supporting increased responsibility of the middle generation (Carter & McGoldrick, as cited in Ballard, 2012). Understanding the family life cycle and the key developmental tasks for all family members involved is essential to provide the appropriate support for families in the midst of negotiating caregiving.

2.2 Family Caregiving- Shifting Norms

Family caregiving can be considered a value embedded within the family structure for a vast number of societies around the world (Bailey & Gordon, 2016). The ways that individuals within a family engage in caregiving is largely dependent on embedded schemas such as beliefs and cultural norms (Bailey & Gordon, 2016). These norms, both spoken and unspoken, are passed down in the family but also shaped within and by the greater social context. This is especially relevant as services to care for the elderly are overwhelmed with the aging demographic- there is increasing social pressure on family members to serve as caregivers in order to reduce public costs (Leinonen, 2011). Though the caregiving process is engrained in the fabric of the family, it is also largely influenced and limited by the “social policies and norms that reinforce the obligation of family caregivers” (Bailey & Gordon, 2016, p. 227). Family members are expected to serve in caregiving roles for which they have limited resources,

supports, skill sets, and knowledge, in order to bridge the rift in the formal health system (Bailey & Gordon, 2016).

As a result of the significant health care gap family members are expected to fill, informal caregiving can have significant negative impacts in almost all facets of the caregiver's life. These impacts can manifest in countless ways at the physical, mental, social, or emotional level and are mediated by a "complex web of background characteristics, such as the caregiver's physical, social, and economics status, and available internal and external resources" (Amirkhanyan & Wolf, 2003, p. 818). Studies have also shown that the influence of caregiver burden is partially mediated by the caregiver's appraisal of various factors as stressful (Litzelman et al., 2015).

2.2.1 Financial

Caregiving takes a substantial toll as family members balance the cost of caregiving with other financial responsibilities (Roberto & Jarrott, 2008; Shooshtari et al., 2017). Even in Canada where primary health care is funded, family caregivers face significant financial burdens in order to cover medical and other care related costs (Longo, Fitch, Deber, & Williams, 2006). These families are put in stressful situations as they are forced to choose between essential caregiving expenses and personal or household costs, such as investments or house improvements (Shooshtari et al., 2017). Likely due to the financial burden of caregiving, studies have shown that those with a lower income have more pronounced negative physical and psychological impacts (Marks, Lambert, Jun, & Song, 2008).

2.2.2 Physical/Psychological

The physiological and psychological impacts of caregiving have also been well documented. In a study conducted by Schulz and Beach (1999), caregiving spouses experiencing

strain were found to have a higher mortality rate than those who were non-caregiving. An almost 40% decrease in physical functioning was found in caregivers of family members recovering from heart failure (Bakas, Pressler, Johnson, Nauser, & Shaneyfelt, 2006). In a study looking at allostatic load, individuals who contributed the most hours towards caregiving reported higher levels of physiological dysregulation (Dich, Lange, Head, & Rod, 2015). Another study found that family caregivers that were “non-White, less educated, lower income, not married, and/or not working” suffered from worse psychological and physical health overall (Barnett, 2015, p. 248). Research indicates that family members who enter into the caregiving role experience psychological distress, such as depression, (Roth, Perkins, Wadley, Temple, & Haley, 2009) and deterioration in the overall quality of the individual’s life (Rafnsson, Shankar, & Steptoe, 2017).

2.2.3 Social Isolation

One of the most adverse impacts on their daily functioning - caregivers’ disrupted schedules - resulted in a significant decrease in their own free time (Liu & Huang, 2018). As a result of their caregiving tasks and responsibilities, individuals experience greater feelings of isolation as they participate less frequently in their social circles (Liu & Huang, 2018).

Relational isolation can also arise from a decline in social connections over time (Roth et al., 2009) as well as a loss of normative roles (Roberto & Jarrott, 2008). Shooshtari and colleagues (2017) found that in order to meet caregiving responsibilities, one-third of the family caregivers interviewed limited their social engagements while one-fifth abandoned their vacation plans.

2.3 Dementia/Alzheimer’s Caregiving

2.3.1 Prevalence

In the United States it is estimated that one in nine individuals over the age of 65, or more than five million people, suffer with AD (Alzheimer’s Association, 2016). Projections in Canada

indicated that in 2016, over 560,000 individuals were living with a form of dementia (Alzheimer Society of Canada, 2016). As the average life expectancy continues to rise and as the baby boom generation ages over the next two decades it is expected that the prevalence of age related diseases, including AD and related dementias, will exponentially increase (Hebert, Weuve, Scherr, & Evans, 2013). It is estimated that in the United States over seven million people will be living with AD by 2025 with that number nearly doubling by 2050 (Hebert et al., 2013). Meanwhile in Canada, it is projected that in just fifteen years, nearly one million people will be diagnosed with AD (Alzheimer Society of Canada, 2016).

2.3.2 Differences in Caregiving

On average, individuals caregiving for those with AD and related dementias spend a longer period of time providing care compared with other caregivers (Alzheimer Society of Canada, 2016). Further, though the tasks that are carried out by family caregivers for those with AD overlap with the tasks typical for those having other conditions, such as assistance with Activities of Daily Living (ADL), there are additional, significant differences (Alzheimer Society of Canada, 2016). Family caregivers for those with AD and dementias are more likely to handle finances, manage health care, advocate with government and other service agencies, and provide other essential life tasks (National Alliance for Caregiving and AARP, 2015). One of the most striking challenges specific to these caregivers is, over time, navigating the progressive behavioural and neuropsychiatric symptoms that are characteristic of AD and related dementias (Alzheimer's Association, 2016).

2.3.3 Relationship Changes

Due to the progressive nature of dementia and AD, neuropsychiatric and behavioural symptoms increase steadily over time. As the disease progresses, the affected individual is less

able to independently function and make decisions, resulting in family members needing to take on more tasks and responsibilities; this results in a “transition from a reciprocal, egalitarian relationship, to one of caregiver and care recipient” (Adams, 2006, p. 22). For family caregivers and other family members, some of the most difficult changes faced are those that occur in the relationship dynamic with the loss of joint activities, goals, familiarity and intimacy (Adams, 2006). In reaction to these significant relational shifts, family members experience feelings of anger, grief, frustration and impatience (Adams, 2006).

Changes are experienced differently by all members within a family when a parent is diagnosed with dementia. For children, there is a profound anticipatory and ongoing grief over the loss of their parent and normative roles (Cabote, Bramble, & McCann, 2015). For an adult child who steps into the caregiving role for a parent with AD, change is also experienced in role reversal as children take on responsibilities for their parents (Cabote et al., 2015). For spouses, there is a significant experience of loss and uncertainty as well as stress and conflict from weakened relationship reciprocity (Bakker et al., 2010).

Numerous studies have demonstrated a wide spectrum of negative impacts experienced by family caregivers of individuals with dementia, including social isolation, depression, anxiety and other mental, emotional and physical concerns (Roth, Mittelman, Clay, Madan, & Haley, 2005). In one study, the younger a child caregiver, the more anxiety, guilt and lower life satisfaction were reported (Hayslip, Han, & Anderson, 2008). Younger caregivers also reported more anxiety around aging and having less social support (Hayslip et al., 2008). In the same study, findings also showed that the greater the knowledge of the disease, the greater the caregiver burden- this was contrary to research done in the past; this may be related to the progressive nature of dementia and the greater demands over time (Hayslip et al., 2008). Further,

caregivers that had greater perceived social support reported fewer feelings of depression and greater overall well-being (Hayslip et al., 2008).

2.4 Family Caregiving

When a family member requires caregiving support, each individual in the family experiences ramifications as a result of the shift within the family system (Aneshensel et al., 1995). Most notably, the caregiving process can create family tension and conflicts over the distribution of caregiving responsibilities (Aneshensel et al., 1995). In families where there is well established, open and collaborative communication, individuals in the family, whether caregivers or care receiver, fare better and are more equipped to adjust to the transition (Bailey & Gordon, 2016). Further, in caregiving relationships with higher levels of mutuality, individual well-being improves and family members experience increased levels of attachment (Lyonette & Yardley, 2003).

2.4.1 Spouses as Caregivers

Though a challenging transition, individuals perceive spousal caregiving as a more normative process than in non-marital relationships (Lin, Fee, & Wu, 2012). In their analysis of measures carried out in a longitudinal study, researchers found that spousal caregivers reported less negative experiences than did adult-child caregivers (Lin et al., 2012). In the same study, male spouse caregivers were also more likely than others to find positive meaning in caregiving (Lin et al., 2012). However, conflicting research has demonstrated that spousal caregivers reported decreased levels of self-efficacy and increased levels of stress (Braun et al., 2009). Another study looking at the spousal caregiving and care receiving relationship found a correlation between caregiver well-being and the occurrence of joint activities enjoyed between both individuals (Searson, Hendry, Ramachandran, Burns, & Purandare, 2008).

2.4.2 Adult Children as Caregivers

For adult children who engage in family caregiving, it is a particularly stressful time as, typically, individuals do not intentionally plan to provide care for their parent (Aneshensel et al., 1995). Some research points to more adverse physical and psychological health outcomes for adult children having to serve in the caregiving role for a parent (Amirkhanyan & Wolf, 2003). Another study found that compared to spousal caregivers, adult child caregivers experienced more family conflict (Tatangelo et al., 2017). Though there is literature on the prevalence and outcome of informal family caregiving, there is a gap in the literature on the ways that adult children “perceive, anticipate, and negotiate support to their parents” (Connidis & Kemp, 2008, p. 229). The transition of adult children to parent caregiver is seen as a momentous life stage transition which can result in unearthing system patterns and parent-child relational dynamics (Connidis & Kemp, 2008).

2.4.3 Gendered Caregiving

Studies across cultures also show a disproportion in the gender of the child who takes on the caregiving role, with daughters primarily providing care for their elderly parents (Leinonen, 2011; Lin et al., 2012; Merrill, 1996). Further, the very nature of caregiving work has been found to vary depending on the caregiver’s gender (Matthews, 1995; Kwak et al., 2012). Daughters are more involved in direct-care needs, such as assisting with meals and medical necessities, while sons take on more indirect forms, such as managing financial matters (Matthews, 1995). In a narrative inquiry by Hequembourg and Brallier (2005), in caregiving sibling pairs interviewed, the adult daughter were found to be in charge of care coordination. In line with previous research, an unequal division of caregiving responsibilities between siblings was reported, as daughters were more likely to engage in a wider spectrum of responsibilities, while brothers

engaged in a narrower range, with more defined tasks such as house maintenance and lawn work (Hequembourg & Brallier, 2005).

In families where there is an unequal division of caregiving responsibilities or where there is disagreement over care related decisions, the family can become a significant source of stress (Kwak et al., 2012). In fact, many of the negative psychological outcomes that occur, such as distress and depression, can result from relational tension and role conflict as caregivers cut back on external relationships and social supports while navigating stressful divisions of family caregiving responsibilities (Roberto & Jarrott, 2008). Asymmetrical caregiving, where one family member carries the bulk of the responsibilities, can result in the loss of normative roles, emotional stress, and negatively impacted family dynamics (Roberto & Jarrott, 2008). When unequal sharing of caregiving responsibilities occurs in the family system, the sibling that provides more caregiving support may become resentful while other siblings could feel increasing guilt (Leinonen, 2011). Strained microsystem dynamics can also result in families where an adult child caregiver harbors anger towards their parents due to childhood attachment injuries; the adult then carries the difficult task of weighing their family obligation when considering their involvement in caregiving responsibilities (Leinonen, 2011).

2.5 The Dynamics of Caregiving

Though many studies have focused on the psychological and physiological health outcomes of family caregivers, little research has identified the ways in which individuals navigate the caregiving process. Further, a significant part of the literature is focused on individuals well into the caregiving role without highlighting the dynamic and collaborative nature of family caregiving (Barnett, 2015). For example, one study by Amirkhanyan and Wolf (2006) used cross-sectional retrospective demographic data from the Health and Retirement

Study (HRS) conducted in 1992. Using the demographic data, they examined the differences in mental health consequences to comment on the impact that various caregiving arrangements for parents and/or in-laws had on heterosexual spouses (Amirkhanyan & Wolf, 2006). In a separate study, researchers conducted quantitative analysis on retrospective demographic data from the HRS and found that adult children caring for fathers experienced more depressive symptoms compared to adult children caring for mothers (Chumblor, Pienta, & Dwyer, 2004). Yet another study using retrospective statistical data from the HRS, Barnett (2015) found that over the adult life course, additional roles such as marriage and employment played contributing additive factors on caregivers' psychological and physical health outcomes.

In a different study attempting to understand the dynamic nature of the caregiving process, researchers conducted a three-year longitudinal telephone survey of wives and daughters serving as family caregivers (Seltzer & Wailing, 2000). The study found that wives experienced greater impacts from taking on the caregiving role, however daughters were more likely than wives to become caregivers (Seltzer & Wailing, 2000). In a phenomenological study looking at the adjustment experience of caregivers looking after family members with dementia, researchers conducted semi-structured individual interviews for 20 spouses and adult daughters (Adams, 2006). In a similar phenomenological study, Czekanski (2017) conducted 10 semi-structured individual interviews to uncover the experience of family members transitioning to the role of caregivers for an individual with AD or related dementia.

Although these studies provide essential information on the individual experience of familial caregivers and some aspects of the caregiving process, this research fails to address the joint nature of family caregiving. There is some literature that explores how family members negotiate or engage with each other in the caregiving process though this is from an individual

perspective. Matthews (2002) found that when it comes to caregiving for an older parent, adult sons are more likely to consult with parents while daughters consult with both siblings and parents. Looking further at the gendered nature of caregiving with families, one study found that caregiving daughters took responsibility for the primary coordination of care while sons took one of two roles: helper-brother, relying primarily on the sister to delegate tasks, or co-provider, playing more an equitable caregiving role (Hequembourg & Brallier, 2005). Adult siblings who serve as primary caregivers expect their other siblings to feel similar obligations and are disappointed when help is not demonstrated (Merrill, 1996).

In a study looking at inequity amongst siblings serving as parent caregivers, Ingersoll-Dayton et al. (2003) found that siblings that were distressed at the asymmetrical distribution of caregiving employed “behavioral strategies to forge actual equity and/or used cognitive strategies to forge psychological equity” (p. 210). Some examples included focusing on other family responsibilities as an excuse to avoid attending to caregiving tasks or minimizing and/or maximizing the value of different caregiving contributions (Ingersoll-Dayton et al., 2003). Primary caregivers tend to use both cognitive and behavioural strategies to correct these inequalities while siblings who were less involved utilized cognitive strategies such as concentrating on their own employment or attributing the inequality to a difference in personalities (Ingersoll-Dayton et al., 2003). The same study found that as with the dynamic nature of caregiving, siblings’ assessment of the caregiving distribution changed over time; however, compared to initial attempts, efforts to address asymmetrical caregiving amongst siblings may not be as successful as time goes on (Ingersoll-Dayton et al., 2003).

In a qualitative research study involving questionnaires and semi-structured interviews, researchers worked with caregiving families to explore “actual and anticipated exchanges of

support with and across generations” (Connidis & Kemp, 2008, p. 231). Results from the family case study showed that the distribution of caregiving within the family was fluid and evolved depending on social, family, and individual situations (Connidis & Kemp, 2008). One key factor that emerged in the negotiation of caregiving tasks was emotional closeness- the greater the emotional intimacy, the greater the attempt at symmetrical caregiving among siblings (Connidis & Kemp, 2008). Another key finding of the study was that only in the case of a specific incident requiring immediate attention were siblings explicit in their planning and negotiation of parent care; under normal circumstances, discussion or negotiation of caregiving was negligible (Connidis & Kemp, 2008).

2.6 Goal-Directed Joint Action in Family Processes

Though there is some research around the experience of family members as they navigate the caregiving process (Esandi et al., 2018; Leinonen, 2011; Tatangelo et al., 2017), there is no literature that discusses the explicit actions family members take, either as individuals or jointly, to facilitate this. One way to uncover the individual and joint processes of family caregiving is to conceptualize human action as intentional and goal directed. In a report by Valach, Young, and Lynam (1996), action theory was proposed as a conceptual framework to unpack the processes of health-promotion within the family unit. Health, understood as meaningful in most families, orients the family towards the generation of health promotion projects such as nutrition or physical exercise (Valach et al., 1996). These family health-promotion projects are driven by shared goals and carried out through the joint actions between family members over a period of time (Valach et al., 1996).

Other studies have used action theory to uncover the individual and joint processes within families by examining conversations about specific issues as they occur between family

members. In one study looking at how families develop sun-protection attitudes, researchers used action theory to better understand the goal-directed behaviours of family members (Young, Logan, Lovato, Moffat, & Shoveller, 2005). Through a conceptualization using an action lens, researchers were able to uncover the ways in which adolescents and parents jointly navigated sun protection practices in their conversations with one another (Young et al., 2005). In a different study, researchers used action theory to understand how parents of young people with intellectual and/or developmental disabilities (IDD) were active agents relative to their child's transition to adulthood (Young et al., 2018). Using a goal-directed perspective, researchers analyzed conversations between parents, and described the explicit ways the participants identified and attempted to resolve problems in their child's transition as well as the associated challenges in their own lives (Young et al., 2018).

2.7 Research Question

There is a vast amount of research on the health outcomes for individuals in the caregiving role. In regards to family caregiving, there is also much literature on family dynamics, conflict, role sharing and responsibilities. However, a significant majority of this research has been drawn from the perspective of the individual with no input from other family members. In fact, there exists a significant gap in the literature addressing the ways in which family members jointly navigate and engage in caregiving over time (Barnett, 2015; Braun et al., 2009; Connidis & Kemp, 2008). More specifically, no research has examined the joint actions that individuals within a family engage in together, to facilitate the caregiving process. Family caregiving is not a process that occurs in isolation but one which is largely impacted by the actions, both implicit and explicit, taken jointly by those within the microsystem. As it has done for the examination of family processes in previous studies, action theory may provide a framework by which we can

better understand the joint interactions between family members as they navigate family caregiving. For this reason, the proposed research seeks to address the following question: What are the goal-directed actions and projects that family members construct, express and participate in together, relevant to the caregiving process for a family member with dementia?

Chapter 3: Methods

Much of the research that exists on family caregiving for an individual with dementia or AD has been conducted from the perspective of a single family member. However, as outlined in Chapter 2, literature clearly demonstrates that family caregiving is a systemic process that involves and impacts all members of the family in various ways. Previous research includes both qualitative and quantitative methodologies that cover a range of topics from the experience of individual caregivers to the resulting physiological and emotional health outcomes. In this chapter, I outline my epistemological framework, situated in the social constructionist tradition, and use this framework to conceptualize the topic of family caregiving. I propose the use of the Action Project Method (APM) as a means to further examine the ways that family members engage together in the joint process of family caregiving.

3.1 Social Constructionism

According to the constructionist tradition, “knowledge, reason, emotion and morality” (p. 109), exist within the relational context, not the individual (Gergen, 2011). The psychological self, as seen through the social constructionist lens, is one that emerges through relationships and the interactional process (Gergen, 2011). Not only is the self constructed through relationships, an individual arrives in a world where “conceptual frameworks and categories used by the people in our culture already exist” (Burr, 2015, p. 10). Therefore, knowledge is not an innate quality, but “something that people create and enact together” (Burr, 2015, p.11) within these cultural frameworks.

Social constructionism traditionally places emphasis on language as the route to knowledge, and ultimately meaning- it is the exchange between individuals that creates meaning.

With contextual action theory (CAT), language and action are viewed as being intricately intertwined (Young & Valach, 2016). Language is itself considered a manifestation of action, the meaning of which is determined and agreed upon by individuals within a social context (Young & Valach, 2016). Though language plays a predominant role in the social constructionist paradigm, there are other joint processes, conscious and unconscious, that are often unattended to (Young & Valach, 2016).

In CAT, equal emphasis is placed on both the verbal and nonverbal actions that make up human behaviour. It is based on the idea that much of an individual's behaviour can be conceptualized as goal-directed action (Young et al., 2011). Instead of looking at causal explanations for human behaviour, CAT looks at the goals of action processes (Young et al., 2011). By analyzing the manifest, cognitive, and social aspects of individual and joint actions, CAT provides a conceptual framework for understanding the dynamic and relational processes that individuals engage in together.

3.2 Rationale for Choice Method

Most research frameworks fail to address action explicitly, nor do they account for an understanding of “human action as intentional and purposeful behaviour” (Young, Valach, & Domene, 2005, p. 215). To compensate for this gap, the action theory based Action Project Method (APM) focuses on uncovering the intentional, goal-directed behaviour of individuals (Young et al., 2005). The APM has been utilized to explore a wide range of human interactions and transitions including suicide (Valach, Michel, Dey, & Young, 2002), parenting as children transition to adulthood (Marshall, Zaidman-Zait, Logan, Lee, & Young, 2011; Young et al., 2018), family and health (Valach et al., 1996; Young et al., 2001), and career development (Young et al., 1999).

The caregiving process is collaboratively driven by individual and joint action, in both salient and subtle ways. With the APM, there is the potential to produce thick data describing the manifest behaviour, cognitive processes, and social meaning within the context of complicated and multifaceted social processes. Therefore, the diverse application of the APM to describe social interactions makes it an ideal method for describing how different family members engage in the caregiving process.

As identified, most literature does not examine the dynamic and interactional process of the caregiving transition as it occurs within the family. Much of the literature on informal caregiving for a family member with AD or related dementias is based on cross-sectional observations from the perspective of a single caregiver. With the APM, there is the potential to systematically examine the relational process of caregiving by examining the joint actions and projects that individuals engage in together.

3.3 The Action Project Method

According to CAT, action is defined by its goal and is the foundation for explanation of intentions (Young et al., 2005). Unlike causal frameworks that seek explanation through examination of antecedents, action theory undertakes a contextual approach where explanation occurs through examination of the “processes in which the action is embedded” (Young et al., 2005, p. 216). A key component of the APM is its focus on joint action, defined by the common goals that drive the intentional behaviours of a group of individuals and seen as central to human agency (Young et al., 1999). The APM allows for analysis of a social or joint process (i.e. a conversation) between individuals as well as the exploration of an individual’s cognitive and emotional processes during the interaction (Young et al., 1994). A distinguishing feature of the APM, the video self-confrontation method is used as a way to reveal the “conscious cognitions

that the participants in the action had while the action was taking place” (Young et al., 1994, p. 186). This allows for insight “into influences of which one is not aware and which become visible in the course of action” (p. 186). The premise of the self-confrontation is founded in the belief that the individual has the largest available data repository regarding his or her own experiences, insights that often remain untapped in typical interview methodologies (Hermans et al., 1990).

3.4 Basic Tenets of the Action Project Method

According to the CAT framework, action can be considered from three perspectives which include (a) the perspective of manifestation (visible verbal and non-verbal behaviours), (b) the perspective of internal processes (action is guided by emotions and cognition), and (c) the perspective of social meaning (action is understood in a social context) (Young et al., 2005). Key to the APM, action can be organized into three different levels (Young et al., 2005). At the first level, action elements are described as “structurally defined features of an action” (p. 217) which can be observed and measured methodically (Young et al., 2005). Elements build to establish the second level, functional steps, which are understood in functional terms and which contribute to the sequential nature of action (Young et al., 2005). At the third and highest level, functional steps contribute to overarching goals which “represent the meaning of action processes” (Young et al., 2005, p. 217) and are end states individuals are moving towards.

Using the CAT framework, the APM further organizes action into four systems: (a) individual action, (b) joint action, (c) project, and (d) career (Valach, Young, & Lynam, 1996; Young et al., 2005). Considered short-term phenomena, individual and joint actions are the basic units that are socially, contextually, and cognitively embedded in the fabric of everyday (Young et al., 2005). Projects are seen as forming over a midrange length of time and are constructed by

a sequence of actions (individual or joint) that share an overarching goal (Young et al., 2005). Careers, the fourth and overarching system, can be described through the construction of projects over a longer span of time (Young et al., 2005). The understanding of career within the APM framework extends beyond the concept of occupation to encompass the significant guiding goals in an individual's life (Young et al., 2005). Unlike other theoretical frameworks that are more static in nature, action theory provides a dynamic framework for understanding how action plays out over time (Young et al., 2005).

3.5 APM as a Case Study Method

Case studies offer a chance for a multifaceted and holistic description of complex processes or phenomena (Stake, 1978). In multicase research, the phenomenon that is being studied is called the quintain (Stake, 2003). Stake claims that, for multicase research, each individual case is significant as it belongs to a set of cases that share particular characteristics. In order to understand the quintain, or phenomenon of interest, for a set of cases, the researcher must understand each case. In this research, the quintain, or phenomenon, being studied is laid out in the research question: What are the goal-directed actions and projects that family members construct, express and participate in together, relevant to the caregiving process for a family member with dementia?

Stake (2003) also addresses the competing interests of uniqueness and generalization inherent in the multicase research approach. He states that this approach can damage the case, “when the commitment to generalize or to theorize runs so strong that the researcher’s attention is drawn away from features important for understanding the case itself” (Stake, 2003, p. 141). The researcher must adequately present the cases so that readers can understand and draw conclusions, understanding that these “may differ from those of the researchers” (p. 140).

3.5.1 Assertions

In a multicase study, the researcher can assert what they find significant in the data as a result of their inquiries and analysis (Stake, 2003). Stake writes that these assertions are conclusions drawn by the researcher who, grounded in the data, relate the findings to the original research question. Though the researcher seeks to uncover the perspectives of the cases being studied, it is also understood that the researcher's assertions may differ from other valid interpretations of the same data (Stake, 2003).

3.6 Research Team

The research team for data collection included the primary researcher and two research assistants (Masters graduate students in counselling psychology). The primary researcher worked with the two research assistants on a previous qualitative APM counselling research study. All team members involved in collection of participant data were experienced in the research interview process as well as the APM protocol. The primary researcher met with the research assistants prior to the participant interview in order to go over procedures and set up the research space. Research interviews and video self-confrontations were conducted by the primary researcher and one of the research assistants.

The research team for data analysis included the primary researcher as well as the research supervisor (Dr. Richard Young). The primary researcher worked with the research supervisor on a previous qualitative APM counselling research study. The primary researcher has almost three years of research experience using the APM procedures for data collection and analysis under the supervision of Dr. Richard Young. She also has four years of experience running a clinical genetic study with families having Parkinson's disease and related disorders.

The primary researcher has counselling training with the general adult population along with specialized training in grief and loss and post-secondary counselling.

The research supervisor is a registered psychologist and a professor in Counselling Psychology at the University of British Columbia. A co-developer of the APM, he has many years' experience applying the qualitative research method to a variety of issues and populations including youth transition to adulthood, family transition in illness, career development, suicide, and many others. The research supervisor was engaged in every step of the study from the proposal, data collection, and data analysis stages to the organization and presentation of findings.

3.7 Participants

3.7.1 Eligibility Criteria

Prospective participants were dyads (two individuals) in a family who identified as serving in a caregiving role for another family member diagnosed with dementia. Participation was open to include any two immediate or extended family members. Eligibility criteria for participation included the following:

1. Over the age of 18
2. Spoke fluent English
3. Identified as playing a role in family caregiving
4. Had a family member with dementia or AD who was not in residential care
5. Willing and able to participate with another family member

Participation was open to individuals in any stage of the caregiving process for a family member with dementia currently living at home (not in assisted living). No limitation was placed on families accessing additional formal support services including adult day care, support

groups, respite care, or other forms of support. All family dyad combinations including spouses, adult children, and grandchildren were considered to ensure that the typical dementia family caregiver population (Nichols, Martindale-Adams, Burns, Graney, & Zuber, 2011) was captured. Though the issues experienced by different family members providing caregiving vary, I was interested in the joint action relative to caregiving as it happened within families, so welcomed any combination of dyad.

3.7.2 Recruitment

Recruitment was broad based and largely carried out through advertisements with the Alzheimer Society of BC, Family Caregivers of BC, the Clinic for Alzheimer's Disease and Related Disorders (CARD) at the UBC hospital, and through social media. Depending on the organization, study posters (Appendix A) and a research introduction letter (Appendix B) were placed in monthly newsletters or in waiting areas of affiliated clinics. Notifications were circulated about the study through the Facebook and Twitters accounts of the Family Caregivers of BC and the Alzheimer's Society of BC. Interested family members were invited to email the researcher to establish contact and request further information if interested in the study.

3.7.3 Participant Selection

In total, 10 prospective participants expressed interest in learning about and potentially participating in the study. Only six met all requirements in the inclusion criteria described above and agreed to participate in the study. Four individuals were not included in the study as they did not meet the following criteria: (a) currently serving as a family caregiver ($n= 2$) and (b) willing and able to participate with another family member ($n= 2$). Due to time restraints, limited resources and challenges in recruitment, only three of the original sample target of four dyads was reached. As a case study approach using the APM framework was chosen for this research,

data analysis could continue despite the small sample size.

In total, six individuals (three dyads) serving in some caregiving capacity met all inclusion criteria and were willing to participate in the study. One family member from each of the three dyads responded to posters (Appendix A) advertised through social media and shared the information with their family member. Though they did not meet the inclusion criteria, other individuals who responded to the research did so through the posters advertised with the Alzheimer's Society of BC and through social media. All family members were from the Greater Vancouver Regional District in British Columbia, Canada.

Of the three dyads, two lived in and provided caregiving together in the same house as the family member with dementia. Of these, one dyad consisted of a wife and husband with the wife serving as primary caregiver. The other dyad consisted of a mother and daughter with the mother serving as primary caregiver. For the third dyad, two adult siblings serving as secondary caregivers, neither sister lived with their parent who had dementia. Two dyads identified as Caucasian with the third identifying as South Asian. Due to the intense caregiving demands on family members, particularly those serving as primary caregivers, individuals were given the option of participating in their homes. Two dyads, both of which included a primary caregiver, chose to participate in their home so as not to disrupt their caregiving schedule.

3.8 Procedures

3.8.1 Participant Screening

Participants were screened to ensure that all individuals met the following basic inclusion criteria: (a) over the age of 18, (b) identified as a caregiver for a family member with dementia who lived at home, and (c) had an additional family member who served as caregiver potentially willing and able to participate. Following this, individuals were emailed a copy of the informed

consent (Appendix C) and the introductory letter (Appendix B). Individuals were asked to pass the information on to their family member to assess level of interest. Once both individuals responded to confirm willingness to participate in the study, researcher and participants made arrangements to find a convenient time and place for the initial interview.

3.8.2 Data Collection

3.8.2.1 Initial Session

The initial session took place at locations accessible and convenient for the participants and included participant homes ($n = 2$) and university research space ($n = 1$). The primary researcher and research assistant were both present at this stage. Each participant was given a copy of the informed consent, which was read aloud by the researcher. Participants were invited to take time during the initial session to ask any questions about the procedures which were then answered by the researcher. Each individual who participated in the study was given an honorarium of \$25.

3.8.2.2 Warm-Up Interview

Following informed consent, the researcher guided participants through the warm-up interview that last approximately 15 minutes (Appendix D). The primary researcher and research assistant were both present at this stage. The warm-up interview served to establish rapport and orient the participants to the topic of their engagement in family caregiving. The researcher tracked significant issues specific to the dyad's caregiving process that surfaced in the course of the conversation. With the use of questions, the primary researcher guided the conversation so that participants were in dialogue with each other rather than focused on the interviewer. The warm-up interview ended when the participants were mostly in dialogue with each other speaking about their joint caregiving process. The dyad was invited to continue their discussion

at greater length during the subsequent joint conversation as the primary researcher and research assistant left the room.

3.8.2.3 Joint Conversation

Immediately following the warm-up interview, the dyad continued to have their joint conversation (JC) focused on a salient topic related to the research that came up over the course of the warm-up interview (Marshall et al., 2012). Participants engaged in a videotaped self-directed JC for approximately 15 minutes without the presence of the researchers. Directly after the JC, participants simultaneously engaged in the separate video self-confrontation procedure with either the primary researcher or the research assistant (Marshall et al., 2012). Participants were separately shown a 7-10-min segment of the filmed JC and asked open-ended questions in order to access the participants' internal thoughts and feelings. The interviewer stopped the tape every minute, or when appropriate, and asked the participants to describe their feelings and thoughts during that short interaction segment. The participants were able to share without apprehension of the other dyad member's reaction (Marshall et al., 2012).

3.8.2.4 Narrative Feedback

Data from the orientation, dyad conversation, and participant video self-confrontations were transcribed and the first phase of analysis was performed (Marshall et al., 2012). This analysis took approximately two months and was used to create individual and joint narratives based on the identified caregiving project. The narrative summaries were generated in such a way as to highlight the individual and joint actions that contributed to the project the dyads engaged in related to family caregiving.

Participants were given the option of a follow-up session to have their narratives presented in person or to receive them via email. Due to time restraints as a result of work and

caregiving, all participants opted to receive their narratives over email. Participants were invited to share feedback concerning the analysis and interpretation of the narrative, the identified joint project, and make any suggestions they deemed appropriate (Marshall et al., 2012). After reading the narratives, participants opted to give feedback through email ($n= 3$), over the phone ($n= 1$) and in person ($n= 1$). One participant was unresponsive and did not give feedback at this stage. At their own discretion, participants were given the choice to share their individual narrative description with the other member of the dyad.

3.8.3 Data Analysis

All data collected were analyzed using the action theoretical based APM framework as described by Young, Valach, and colleagues (Valach et al., 1996; Young et al., 2001; Young et al., 2005). There were three phases of data analysis: (a) creation of the narrative descriptions based on the joint conversations, (b) within-case analysis of dyad data from in person sessions and narrative feedback, and (c) cross-case analysis based on within-case analysis.

3.8.3.1 Phase 1

- i. All data (initial orientation, dyad joint conversation, video self-confrontations) were transcribed and checked against original recordings.
- i. Transcripts were read and video self-confrontations reviewed to determine an overall intentional framework at both the individual and dyadic levels (Marshall et al., 2012).
- ii. Individual and joint goals were determined based on the initial reviewing of transcripts and video self-confrontation data. From this a preliminary joint project was determined and individual and joint narrative descriptions created.
- iii. Narratives were submitted to participants for review and feedback was elicited to determine whether any changes should be made to the determined joint project, individual goals

and joint goals. Of the six participants, five responded with feedback. No participants suggested changes at this point in the feedback.

3.8.3.2 Phase 2

iv. At the lowest level of abstraction, using a limited set of previously identified elements (actions or expressions), the primary researcher coded the manifest verbal and non-verbal behaviours of each participant in the joint conversation transcript (Marshall et al., 2012; Wall et al., 2016). The set of coded elements is included in (Appendix E).

iv. At a higher level of abstraction, functional steps were identified in the self-confrontation procedures which “encompass movement toward the goal ... informed by participants’ internal processes” (Wall et al., 2016, p. 32). Unlike coding of elements, which utilized a set, predetermined list of elements, the assignment of actions steps involved a process of “flexible emergent coding” (Marshall et al., 2012, p. 167).

v. For each 1-minute segment of dialogue, individual goals were then determined based on the resulting elements and functional steps (Marshall et al., 2012).

vi. Following analysis of each participant’s use of elements, functional steps, and goals, the researcher assessed dyad interactions by examining how actions steps and goals are linked (Marshall et al., 2012). This resulted in the formulation of joint goals for each minute followed by grouping of goals to find emerging constructs for each dyad.

vii. The joint project was revised at this stage according to the resulting joint goals.

3.8.3.3 Phase 3

i. A summary report of all conversations and filmed self-confrontations was made for within-case analysis (Marshall et al., 2012). This data was compiled together in an overall analysis sheet for each dyad (Appendix F).

- ii. The primary researcher and the research supervisor looked across data gathered for each dyad until consensus was reached on emerging themes. Joint goals and joint projects were reevaluated in light of the emerging themes and modified as necessary.
- iii. The primary researcher and the research supervisor compared themes, joint goals and joint projects across dyads until consensus was reached on commonalities across cases.
- iv. A summary of the joint projects, joint goals and a description of the actions participants engaged in to reach these goals were submitted to participants for further feedback. Participants were invited to share feedback or make any suggestions they deemed appropriate. Participants were also asked whether they had any concerns regarding the presentation of their case and use of JC and SC quotations. Of the six participants, five responded with feedback. Only two participants suggesting minimal changes to the summaries which were addressed accordingly in the Findings chapter.

Using a small sample size of three dyads, I present in greater depth the goal-directed actions that surround the complex nature of caregiving for a family member with dementia. In keeping with the multicase study approach, following in depth analysis of each individual case using the APM framework, cross-case analysis was conducted across the three dyads. Through this process, I uncovered the implicit and explicit ways that family members engaged in conversations around caregiving. Though each of the caregiving dyads represented different family configurations from unique contexts and at various life stages, within-case analysis revealed common processes across cases. Though commonalities existed between family caregivers I also present the processes that were unique to each of the individual cases. This work adds to the gap in literature on family caregiving for individuals with dementia by

specifically describing, from the three perspectives of action, the joint processes that family members engaged in to facilitate caregiving.

3.9 Criteria for Evaluation

3.9.1 APM and Validity

Researchers who utilize the APM speak to various procedures that hold the method to a high standard of validity. Some of these measures include: (a) the use of data from “three different perspectives on the same action” (Young et al., 2005, p. 221), (b) systematic data gathering and analysis, and (c) feedback sessions with participants. To ensure that the researcher’s interpretation lines up with the dyad’s experience, the narrative feedback session and video self-confrontations were especially important (Young et al., 2005). The APM uses a comprehensive coding system (elements and functional steps) as well as review and consensus to ensure a rigorous analysis procedure (Young et al., 2005). Proponents of the APM also claim that use of the method satisfies the requirement for reasonable interpretations as the method “generate(s) findings that resonate with human experience” (Young et al., 2005, p. 221).

Using the APM as a research framework, sufficient evidence is acquired through the multiple data sources including recordings from the warm-up, joint conversation and video self-confrontation. Additional data sources also arise from the initial screening and member check interviews at the initial narrative and final analysis stages. Having multiple data sources allowed for suitable interpretation of the data for this multicase qualitative study.

3.9.2 Validity Criteria Action Steps

Member checking was used at various stages of the research in order to address the trustworthiness and comprehensiveness of the analysis. Immediately following the joint conversation participants engaged in the video self-confrontation, which also serves as a member

check. Participants were able to vocalize their internal thoughts and feelings rather than have the primary research make an educated guess. All participants were also invited to comment on the representation of what has been produced at the initial narrative presentation stage and at the project completion. These verification steps were used to confirm that participants' voices were adequately represented in the analyses.

I solicited feedback from my thesis committee when needing to modify my study protocol to open criteria to family members with dementia as well as decrease my sample size to three dyads. I also worked with my research supervisor regularly when I analyzed data, formulated theories or made conclusions about my data. I solicited guidance from professionals in the health care field including the Alzheimer's clinic, the Alzheimer's Society of BC and the Family Caregivers Association of BC.

I verified resonance of my findings with study participants in order to determine whether the findings meaningfully reverberated with individuals' experiences. This helped contribute to ensuring that the study's findings are both applicable and valuable.

Use of the APM provided rich, valid data through the combination of filmed interviews, audio recordings, video self-confrontations, and narrative feedback all with the integration of various validity standards to ensure as high a level of trustworthiness and reflexivity as possible.

3.10 Ethical Considerations

As previously described, caregivers are often faced with multiple stressors and experience a myriad of difficult emotions as a result of their caregiving responsibilities. Having individuals discuss their caregiving process for a family member with dementia may likely be a vulnerable experience and result in distressing emotions during the session. The nature of the topic discussed may also be a tense relational issue between participating family members, and

result in upsetting emotions during the session. For these reasons, study participation may result in individuals needing additional support outside of the study. A list of external supports and counselling resources (Appendix G) was made available to all participants. However, no individual requested the counselling resources nor did the primary researcher deem it necessary. Participants were given the option to withdraw at any point, without explanation, if they found study involvement too distressing.

One significant stressor for caregivers of those with dementia is the challenge of safely leaving the care receiver at home alone. In order to ensure equal access to study participation, we accommodated for these families by facilitating research sessions within the family's home. We also recognize the ethical consideration of those individuals who were absent from the conversation and unable to speak for themselves. The process of family caregiving impacts all individuals within a system. Due to study limitations, not all of these voices can be represented. In order to avoid discussion of family members who have not consented to be part of the study, effort was made in the initial warm-up conversation to direct the conversation towards the actions and projects shared between the two family members who have consented to the study. Effort was also made in the initial warm-up conversation to direct the conversation towards the process of caregiving between the two family members participating in the study rather than on issues with the family member receiving care. Though efforts were made to address these ethical issues in the design and operation of this study, it was also recognized that study participation may have been beneficial to the participants as it provided the space to deal with specific caregiving issues and access their internal thoughts and feelings.

Chapter 4: Findings

The research question we sought to address was: “What are the goal-directed actions and projects that family members construct, express and participate in together, relevant to the caregiving process for a family member with dementia?” All family members involved in this study were either primary or secondary caregivers involved in the care of a loved one with dementia. As part of this research, in-depth within-case analysis using the APM framework was conducted for three cases in order to address the research question and uncover the ways family members engaged in the caregiving process together. Subsequent cross-case analysis was used to determine the commonalities across cases as well as the particularities unique to each case.

4.1 Summary of Findings

Within-case analysis revealed three projects undertaken by family members as they engaged in the family caregiving process for a loved one with dementia. An overview of these projects and their associated joint-goals is presented in Table 1. A thorough description of the joint actions family members engaged in to facilitate their caregiving project is further detailed within this chapter. Overall, findings indicated that family members conceptualized caregiving as a joint process, as they participated in goal-directed actions and projects that supported or hindered their overall process of family caregiving.

Cross case analysis revealed five commonalities in the projects in the three cases: (a) relative unwillingness to vocalize internal thoughts and feelings as they engaged in the joint action, (b) focus on the primary caregiver, (c) different perspectives on caregiving, (d) prioritization of physical needs of the caregiver or care receiver, and (e) grieving the loss of normal. These commonalities further illustrated how family members constructed, expressed and participated in the caregiving process together for a family member with dementia.

Table 1. Key Projects and Joint Goals for Each Case

Case	Key Project	Joint Goals
1	Trying to be functional amidst the challenges of the context of their father's caregiving, while holding in abeyance the contrasting emotions they both had	<ul style="list-style-type: none">• To discuss how to navigate caregiving conversations with their mother• To share about and process each other's recent interactions with their mother• To discuss strategies and next steps for their parents' welfare (e.g. housing and health care)• To share the impact their dad's health changes have had on them
2	Coming up with alternative care supports while also negotiating the limits to caregiving for their grandfather	<ul style="list-style-type: none">• To express frustration and compare previous experiences with various health care supports• To explore additional supports they need and could utilize to help with caregiving• To negotiate how and when they each could take a break• To talk about what their caregiving limit is
3	Emphasizing their individual caregiving role in order to challenge and clarify the other's caregiving role	<ul style="list-style-type: none">• To explore their differing perspectives on how to approach caregiving tasks• To discuss the impact that experience and knowledge have on caregiving• To negotiate the caregiving role a family member has

4.1.1 Presentation of Detailed Findings

In keeping with the case study approach, within-case findings are first presented in detail in order to communicate the depth and uniqueness of the individual cases. Each case was analyzed according to the APM, which served as a framework to uncover the joint actions and projects that family members constructed, expressed and participated in, to move towards their joint caregiving goals. Cross-case findings are presented in the subsequent section of this chapter.

Each case was organized and presented according to the structure presented in Table 2. Starting with background information, some basic demographic information, including gender,

participant relationship and caregiving duration, is used to introduce the participants. Following this, a description of the caregiving context is given along with the caregiving project in order to lay the framework for the case presentation of each dyad. The rest of the chapter contains a summary of the analysis of the dyad processes including a summary of the dyad joint goals identified in the conversation. A thorough description of the main joint actions in which family members were engaged, in order to facilitate their identified family caregiving project, is then presented. In order to highlight the researcher’s key findings, each case concludes with a presentation of assertions.

Table 2. Structure of Within-Case Findings

Case X: Individual A and Individual B
Background Information
Caregiving Project
Description of Joint Goals
Assertions

To protect the identity of the participants involved, pseudonyms are used. In order to specify which interview conversation a participant’s quote is taken from, the following abbreviations will be utilized in this chapter: JC= Joint Conversation, and SC= Self-Confrontation. For each participant quote used in the chapter, a number will be included to indicate the line in the transcript from which the quote was taken.

4.1.2 Within-Case Findings

Here we present three different cases in depth. Each case represents a different family configuration: (a) two sisters, (b) husband and wife, and (c) mother and daughter. Each case resulted in uniquely different joint projects and specific actions that facilitated those projects. However, we also found similarities across the three cases. Overall, the findings indicate family

members conceptualize caregiving as a joint process that involves not only the individuals who participated in the study, but extends to many outside the study as well (i.e. other family members, health care workers, etc).

4.2 Case 1: Amy and Becky

4.2.1 Background information

Amy and Becky are cis-women and sisters who chose to participate together in the study. Both in their mid-40's, Amy is married with two children while Becky is single with no children. Amy and Beck identify as serving in secondary caregiving roles for their father who has Alzheimer's disease. Both women work full time and reside in separate homes from their father and mother, the primary caregiver. Amy and Becky attended the session which was broken into four parts: i) a warm-up interview with the researcher and a research assistant, ii) a 16-minute joint conversation with just the participants about caregiving for their father, iii) a separate video self- confrontations with either the researcher or research assistant, and iv) a short debrief. Participants also gave narrative and final summary feedback several months after the first session.

4.2.2 Caregiving Project

In the warm-up interview and joint conversation, the participants reported that their mother was the primary caregiver for their father. Both sisters spoke of their uncertainty and attempts at engaging with their mother to address caregiving concerns for their father. They also spoke of their concern for their mother and the caregiving load that she carries. The sisters outlined their different perspectives on how to approach caregiving conversations with their mother. The sisters shared their most recent interactions with their parents and other family members. Both also addressed their immediate caregiving concerns regarding their father's care

and attempted to engage in planning next steps to address his future care. Out of this discussion and following analysis of elements, functional steps, internal processes and goals, the following project was identified: *trying to be functional amidst the challenges of the context of their father’s caregiving, while holding in abeyance the contrasting emotions they both had*. This project captures the manifest behaviours the sisters engaged in throughout the conversation as they attempted to communicate the challenges of supporting their mother, the primary caregiver, while also acknowledging their own unexpressed and contrasting emotions.

The following section outlines the overarching joint goals (Table 3) Amy and Becky engaged in together that contributed to their caregiving project. Specifically, this section describes in more detail some of the goal directed actions that Amy and Becky took towards each of the four joint goals identified in their conversation. For full details of the individual and joint sub-goals for this case, see (Appendix F.1).

Table 3. Key Project and Joint Goals for Case 1

Key Project	Joint Goals
Trying to be functional amidst the challenges of the context of their father’s caregiving, while holding in abeyance the contrasting emotions they both had	<ul style="list-style-type: none"> • To discuss how to navigate caregiving conversations with their mother • To share about and process each other’s recent interactions with their mother • To discuss strategies and next steps for their parents’ welfare (e.g. housing and health care) • To share the impact their dad’s health changes have had on them

4.2.3 Description of Joint Goals

To discuss how to navigate caregiving conversations with their mother

Becky engaged in this goal by describing her strategy of timing her caregiving conversations with their mother (“Where dad can hang out with the kids, and that’s actually,

sometimes, when I can talk to mom” JC10). Amy responded by describing her own strategy for navigating caregiving conversations with their mom (“The times I do talk to mom it’s when I’m driving in the car, on the way home, ‘cause dad’s usually asleep” JC11). Becky shared her perspective that their mom didn’t create space to have these conversations and Amy affirmed this by describing how their mom will avoid the conversation, attempt to change the subject, or remove herself from the situation.

In an effort to describe their approaches to speaking with their mother regarding their father’s caregiving, Becky shared her perspective of their different communication styles:

Yeah, I feel like you and I balance ... I don’t want to say good cop, bad cop but you, you’re the up front, and I do, I don’t want to say ‘damage control’, but I use a different way of talking with mom, like a more sensitive approach, so that she will stay a little bit more open. (JC5)

Responding to how, or even whether, they should approach their mother together to discuss their caregiving concerns, Amy repeatedly expressed her uncertainty (“I don’t know if it’s even worth it to do it together” JC22). She then shared her perspective of the impact their different communication approaches would have on their mom:

But I don’t think it’s necessarily a bad thing if we’re doing things separately, and having different approaches to it either, ‘cause she might be more comfortable saying something to you, without me around but as long as we’re saying the same. (JC29)

Reflecting on having said this, Amy revealed in her self-confrontation that she had felt guilty that they hadn’t yet had a conversation with their mother. However, she also expressed relief to be talking about things with Becky and to know that these issues were also concerns for her sister (“sometimes I wonder if she’s worrying about things as much as I am” SC11).

As Becky continued to engage in actions to discuss how to navigate caregiving conversations with their mom, she felt conflicted. On one hand, she felt overwhelmed with all the expectations that were placed on them and the limited time they had (“we can’t always do the things we say we’re going to do either” SC18). However, as Amy shared her perspective about how to approach their mother while remaining on the same page, Becky also experienced relief. Similar to Amy, this relief was never openly expressed to the other during the joint conversation but was revealed during the self-confrontation:

Getting a chance to talk through some things you don’t always get the time to and come up almost, now with solutions, but ... some ways of dealing with it, when it feels overwhelming. So just having the chance to talk it through. (SC23)

To share about and process each other’s recent interactions with their mother

Amy engaged in this goal by describing how she confronted her mother about their parents’ living situation and discussing what kind of facility to look for. While recounting how she was “frank” in her confrontation with their mother, she had thought about how difficult it was to communicate without being too blunt in her personal life (“it’s part of my occupation ... it’s hard to cut that off from work” SC4). However, she also revealed that she didn’t want to get overly emotional either (“when you’re having the discussions, even with my sister, it’s still good to kind of keep it all together” SC4). She recounted exactly what she had told her mother regarding the impact either parent’s death would have:

I said: ‘But it is something I want you to consider, it’s something that I’ve been thinking about a lot, I’m worried if you pass away, we’re now going to have the whole condo to deal with, and dad ... who’s just going to beside himself, right. like?’. (JC16)

While Becky responded by encouraging Amy that these conversations take small steps, in her self-confrontation she shared her realization that she hadn't thought of the practicalities involved with either parent dying. Though she never communicated this with Amy, with this realization she felt relief being in the "in between" period where their father did not need to be moved to a care home yet. At the same time, because this was not just affecting their parents, Becky believed they had the motivation to "move to the next level" in considering planning for their father's caregiving ("Yeah, a step, some reasoning behind it, I think ... to give, to give my mom, like an impetus to move forward, because it's not just about her" SC12).

To discuss strategies and next steps for their parents' welfare (e.g. housing and health care)

Amy engaged in this goal by sharing with Becky the hypothetical situation of their dad being moved to a temporary facility if they were in a crisis situation. Becky responded by describing a potential care facility that could be a good fit for their father. She described a past experience with another family member who relocated closer to AD support and resources and expressed her perception that they should be "trying to be a step ahead" (JC38) when considering their father's future care. She elaborated by discussing their parents' past living situations and shared her opinion of what would be best for her mother to consider when preparing for a future move ("If she's not seeing her friends that often, then is it better to be around family, kind of like the decision everyone had to make when grandma moved, right?" JC35).

When Becky described herself as "the one that kind of puts in the subtle hints" (JC39) and shared how she suggested that their parents get flu shots, Amy explained she had already checked flu shot availability and described her own strategy for reminding their mom about vaccinations ("So yeah, I just go and say: 'Oh, by the way, your flu shot here at the Rexall on October 23rd'. Done." JC42). As they continued to engage in the joint goal of discussing

strategies, Becky described how she checked in on their parents, by calling and acting like an “undercover detective”:

I try and get an idea of what they’re eating, too, when I call ... Well to me it’s just, it just is indicative of how they’re living. Like, if it’s getting to be too much, mom’s not going to be cooking much, or I can just tell from her receptiveness anytime to want to come out, ‘cause she’ll, like, drop the hat if I invite her... (JC50-52)

Becky also expressed uncertainty over how to approach health care conversations with their mother and asked whether Amy had attended their father’s recent medical appointments. Amy answered that their mom had been unable to contact their father’s case manager and admitted that she had not followed up on things. In her self-confrontation, Becky revealed that she inquired about their father’s last appointment as she was thinking how to best use the conversation to address any concerns regarding their father (“we have a bit of time, what can we actually talk about and make use of this time ... just trying to stay on top of everything” SC40).

Amy also described how she had offered to look into care homes with their mom, but she had refused the offer. Becky responded by sharing her perception, “Yeah, she probably doesn’t want anyone pushing” (JC47). In her self-confrontation, Amy said that she had her “back up a little bit” at this point, thinking she had overstepped her boundaries. She reflected on how she wanted her mom to know it was not a burden to help out, however, she was also uncertain about how much to be involved.

Addressing the impediment to engaging in the goal of discussing strategies and next steps for their parents’ welfare, Amy expressed her frustration at the communication issues between her mom, Becky and herself (“like mom didn’t even say anything to her” SC28). In her self-confrontation, Amy shared her thinking that she wanted to spend time with her parents but her

mom believed she was a burden to Amy and Becky (“so it’s trying not to be too pushy ... but at the same time making her realize we want to be helping” SC32).

To share the impact their dad’s health changes have had on them

Amy and Becky both engaged in actions to facilitate this goal towards the end of their conversation, as they spoke about the impact their father’s diagnosis and deterioration had on them. Amy shared how difficult it was to know what to talk with their dad about, saying, “what do you even say to dad about stuff half the time, either, right?” (JC55). She described her observation of how he struggled to concentrate in group settings and tended to shut down. Becky explained how she was learning to interact with their dad by engaging him in tasks rather than talking as he “just wants to help” (JC60). She acknowledged that he struggled or got tired doing tasks, but gave her opinion that their father helping out was what he was most happy doing.

Though it was never communicated, Amy felt frustrated as she believed she and Becky were on different wavelengths as they discussed the impact of their dad’s condition, stating, “I worry about communication a little bit sometimes and where dad is really at, and where mom and Becky think he is sometimes” (SC35). She reflected on how difficult it was to be around their father in groups and how hard it was to see how much he’s changed. In the joint conversation, both Amy and Becky described the past and reflected on when it was that they noticed things start to change with their father. Amy shared her memory of when she first approached her father about the changes:

I would say it was around the time I turned forty, for sure, ‘cause I remember having an argument with dad one day. About four years ago, and I remember saying to him: ‘I’m worried that this is what you have, and I’m saying it to you so we don’t’. (JC64-65)

4.2.4 Assertions

Overall, the focus of the caregiving project was on supporting the primary caregiver rather than on the family member receiving care. Family members recognized that supporting the primary caregiver was essential for the care receiver to be well looked after. Accepting each other's different communication styles and roles was key to remaining practical in the context of family caregiving. Further, in order to have functional caregiving conversations, family member's underlying negative emotions (e.g., fear, anxiety, apprehension) were not conveyed openly or expressed through manifest behaviours. Though family members openly expressed their differing opinions on how to approach caregiving conversations, individuals experienced apprehension in regards to how their opinion would be received or the impact their opinion would have on the other.

4.3 Case 2: Christina and Dan

4.3.1 Background information

Christina and Dan are wife and husband who chose to participate together in the study. Both in their late 40's, they have been together for over 20 years and have one child, an adolescent, together. Christina identifies as the primary caregiver for her maternal grandfather who has AD while Dan, who works full time, serves as a secondary caregiver during the evenings and on weekends. As their grandfather lives with them, they provide caregiving in their home. The initial session was held at the participants' home due to the intense demands of caregiving and lack of respite care. The session was broken into four parts: i) a warm-up interview with the researcher and a research assistant, ii) a 16-minute joint conversation with just the participants about caregiving for their father, iii) separate video self-confrontations with

either the researcher or research assistant, and iv) a short debrief. Participants also gave narrative and final summary feedback several months after the first session.

4.3.2 Caregiving Project

In the warm-up interview and joint conversation, the participants reported that Christina became primary caregiver for her grandfather when her mother passed away almost four years ago. They utilized care support, such as government subsidized health care aids, however Christina carried the bulk of the caregiving load and often felt like she couldn't take a break even with the respite care. Christina and Dan spoke about the challenges they experienced in accessing subsidized care as well as the challenges they faced balancing caregiving and other life demands. They each outlined their different perspectives on a "caregiving line" and discussed what their limits to caregiving were. They both also addressed their immediate concerns regarding their capacity to provide caregiving and brainstormed future steps to access additional resources for their grandfather's care.

Out of this discussion and following analysis of elements, functional steps, internal processes and goals, the following project was identified: *coming up with alternative care supports while also negotiating the limits to caregiving for their grandfather*. This project captures the manifest behaviours the couple engaged in throughout the conversation as they attempted to communicate the challenges of providing caregiving for their grandfather while also supporting Christina, the primary caregiver.

The following section outlines the overarching joint goals (Table 4) Christina and Dan engaged in together that contributed to their caregiving project. Specifically, this section describes in more detail some of the goal directed actions that they took towards each of the four

joint goals identified in their conversation. For full details of the individual and joint sub-goals for this case, see (Appendix F.2).

Table 4. Key Project and Joint Goals for Case 2

Key Project	Joint Goals
Coming up with alternative care supports while also negotiating the limits to caregiving for their grandfather	<ul style="list-style-type: none"> • To express frustration and compare previous experiences with various health care supports • To explore additional supports they need and could utilize to help with caregiving • To negotiate how and when they each could take a break • To talk about what their caregiving limit is

4.3.3 Description of Joint Goals

To express frustration and compare previous experiences with various health care supports

Dan engaged in this goal by expressing his frustration with their experience of care aids in the past. Specially, he highlighted their refusal to read the care plan they created that gave detailed instructions for their grandfather’s care:

If they don’t read the care plans, then what do you want to do? Like, you can’t make them, obviously. You tell them every night when they come here to read that book, and they don’t. They say they do, they sit down there and look at their phones instead of reading the care plan. (JC19)

He also shared his opinion that newer care aids reverted to their school training as they lacked common sense unlike the caregivers that have been around a long time (“experience is what it takes” JC21). Christina agreed with Dan and shared her own perspective that new care aids were doing jobs they didn’t want to do but had to, for the money. While talking to each other, both of them had been thinking that this topic was one they had talked about repeatedly. In her self-confrontation, Christina also revealed she had thought that it was good to be speaking about their frustrations when they weren’t in the heat of the moment.

As he continued to engage in actions to express his frustration about health care support, Dan was thinking that the issues they had with care aids had a greater impact on Christina as the primary caregiver (“she’s here all the time dealing with all this stuff and she tried to make it as simple as humanly possible for the people that are coming in to give her a break” SC8). Though he did not explicitly state this in the conversation, he felt concerned for her and wondered how she could get more support not only for her grandfather but for herself (“she has her own life to live too” SC11). Dan also thought that the way respite support was structured, didn’t leave Christina with time to actually take a break and do things for herself.

Christina expressed her wish for more subsidized care supports offered through other companies while Dan agreed and expressed his frustration with the current system of monopolized care available through their Health Authority. They both expressed frustration and uncertainty with how the Healthy Authority works:

Christina: I don’t even know what the changes were, that they made ... it doesn’t really make sense though. Well, it’s a huge business, corporation, a lot of organizing to do.

Dan: Why, why can’t they just shop it out? That’s what other government agencies do. They don’t have to do it, they just have to direct it to another company ... why do they have to use only one company? I don’t know. (JC26)

While they continued to talk about their frustration with how their Healthy Authority was set up and their limited access to caregiving resources, Christina was thinking that offering subsidization for more than one company was a great idea. She also revealed in her self-confrontation, that though she was initially resistant to the idea (“hard to give up my child kind of thing ... especially when he’s not well” SC8), she was more on board with trying out other companies and paying for private care. She felt bad thinking about the free time that additional

private care support would afford her (“I’m like come on, I have all this extra time, but it’s not as much extra time as a person with a normal job would ever get, but I feel grateful for it.” SC8).

While Christina felt guilty about getting additional help, Dan was concerned for her and all that she had to deal with (“Look at her hand ... it’s hurting her head just thinking about all this stuff” SC19). He also felt frustrated thinking about how they were trying to figure out how to navigate not just the health care system with their grandfather, but other government systems (i.e. taxes) as well:

And you try to get help, like you try to get help, like you know, when they first come to talk to you about all these things, they give you so much information at once, and then you never see them again. (SC17)

Dan compared previous care supports by describing a past caregiver who was very good at providing care for patients on the job. He stated that this caregiver helped with all the necessary ADLs and provided companionship by sitting and talking with her clients. He compared this caregiver to others who spent their time on the phones instead of connecting with their grandfather. Though he didn’t communicate this directly, as Dan expressed his frustration with caregivers who did the bare minimum, he had thought about Christina’s extended family who managed their grandfather’s money but were not involved in direct caregiving:

You always feel like (uncle) and his kids are always looking at us like, ‘Why are you guys doing this, how come you’re spending all this money’ ... they don’t come around and you get the feeling that, well, they’re not coming around because they think that we’re stealing from them or something. (SC64)

To explore additional supports they need and could utilize to help with caregiving

When Christina talked about the struggle of finding caregivers who were willing and able to come at night, Dan responded that there were companies that provided 24h caregiving. He acknowledged Christina's frustrations with trying big caregiving companies then asked why she didn't have a list ready of different private care companies to choose from as needed ("somebody's got to be able to do it" SC17). Christina responded by partially agreeing then shared her apprehension with the level of training and lack of experience of other caregivers. When they talked about how helpful an experienced occupational therapist would be for their grandfather, she had been thinking they had no control over the health system:

It's probably impossible. I mean, and that's what I even said, it's cost, it's not cost efficient. Like, they're going to send in the lowest paid worker the most, it's business, unfortunately. (SC20)

As the conversation continued, she acknowledged the need for a caregiving list and then redirected the conversation to highlighting the need for additional meal supports ("we get a list of people that we can phone but meals, like all these places we've never tried" JC27). Dan and Christina then clarified with each other the types of meal supports that were available and how they were limited by the care aids that were on shift:

Dan: It's only just like frozen, microwave and serve stuff, and it's not portioned so.

Christina: But that's what the carers are supposed to do.

Dan: Yeah, but you know they won't do it. They're just, they can barely date it. They don't understand, they don't know what to do. (JC31-33)

As they brainstormed different options for meal supports, Christina felt supported by Dan and was happy that they were coming up with a solution ("that's been kind of a battle too,

because I'm having to cook two meals" SC10). Whereas she was reluctant to give up caregiving responsibilities before, she felt more open to getting additional support:

I guess when I think about it all in general now I feel like I'm able to give up, I'm not giving up anything, it's bettering if I don't keep it all on my plate, on my 'to do' list and delegate accordingly, as best I can. (SC12)

Though Christina felt that they were having a supportive conversation and was relieved to be problem solving, Dan was frustrated thinking about the process of getting meals ready for their grandfather and how labour intensive it was ("His throat doesn't work anymore, everything has to be pureed, and it has to be done a certain way" SC21). He had also reflected on how he had encouraged Christina to switch caregiver shifts so they would have support during dinnertime:

She wants him to feed himself, I don't want him to feed himself anymore because he shovels it in so fast and then he throws up all over the table. He doesn't want to be doing it either. I want her to get rid of the two o'clock and switch it to a dinner, so that there could be (care aids) here to do that. (SC23)

Towards the end of the conversation, Christina, engaged in actions to redirect the topic back to finding meal support, as she stated: "I'm going to look into food for grandpa, because I've been finding that's a bit of a challenge at times" (JC83). They continued brainstorming alternate options and discussed which meals could be readily prepared and pureed for their grandfather. Christina suggested that Veterans Affairs (VA) could cover the cost of meal service to which Dan encouraged her to set something up. She then clarified her understanding of VA and the process of getting approval for and billing their grandfather's meal service through the agency. Christina shared her opinion that having the VA cover the cost of their grandfather's

food could work out well (“This way, grandpa will be paying for his food, which he likes, he wants to” JC105).

To negotiate how and when they each could take a break

At various times in the conversation, Dan stated his opinion that Christina needed to take a break and then asked her how she was going to get one. Christina expressed her uncertainty with taking time off and Dan continued to draw her reasoning out by asking why she couldn't take a break. He suggested different times that she could arrange for respite care (“Every weekend, what's wrong with that? No, ok, well how about couple of weekends?” JC59). Christina continued to engage in manifest behaviours that conveyed her uncertainty and reluctance to take a break:

I don't know, I don't like it, it makes me nervous. When I put him away, when I put him in care, I don't want him ever to feel like I'm, like 'go'. Like, I don't know. (JC61)

Dan encouraged Christina to take a break and shared his perception that their grandfather did not have the state of mind to comprehend being sent to respite care for the weekend. He attempted to persuade Christina, sharing that the break would be not just for her but was necessary for their own family, especially their son. Dan also shared his opinion about the unrealistic expectations she placed on herself, stating, “You can't be working twenty-four hours a day, nobody would expect you to do that, except you” (JC65).

As they continued to negotiate how Christina could take a break, she expressed her uncertainty with when she should have one saying, “Like soon? I feel ok right now, like, I don't feel stressed” (JC65). To encourage Christina, Dan reminded her of the last time they took a vacation. They both described their last vacation and how they did not need to provide 24/7 caregiving for their grandfather. Christina shared her perspective on how “strange” it was to not

get up in the middle of the night to check in on their grandfather or have any responsibilities during the day. Dan restated his opinion that Christina needed a break and that she should do things that made life easier for herself. He also shared that he needed to find a way to arrange a vacation for himself.

As Dan repeatedly stated that Christina should take a break, she felt defensive and didn't believe that she actually needed the time off. As the conversation continued, Christina softened to the idea, but also felt stuck:

But how do I make it happen? That's the big one. That's always the question, how do you do it? You get thirty days a year ... I don't even like putting him in a home. I can't take him with us and we have a good time when he's not with us of course. (SC40)

Though Christina initially felt defensive thinking that she didn't like to be told how and when to take a break, as they continued to talk she felt very supported by Dan ("I felt good because he acknowledged: 'You should do things to make it easier on yourself' ... I think we worked it out" SC44). Christina also revealed a deep tension that she did not articulate directly to Dan:

I'm pulled. I want to do so much for grandpa, I want to be there for Dan and my son, always somebody has to feel left out. It doesn't have to be that way, it's mom talk.

Nothing ever comes easy ... just try to keep everybody happy. (SC46-47)

While Christina felt pulled by her desire to take care of both her grandfather and her own family, Dan felt concerned for Christina and the weight of responsibility she carried. He felt frustrated trying to convince her to take a break, but he also knew that she would continue to do whatever she wanted to do ("She wants to but then she feels guilty. I don't know if she even recognizes that. She probably does but doesn't want to say it, that she feels guilty." SC53).

Though neither explicitly expressed this in their joint conversation, both were aware that guilt was the biggest obstacle to Christina taking a break from caregiving. As he tried to convince her that she needed a break, he thought to himself how she didn't like not being in control of what happened to her grandfather ("You can't blame yourself because you went out one night and he fell and died. I mean, you, you can't blame yourself for that." SC52).

To talk about what their caregiving limit is

Motivated by this last goal, Dan and Christina discussed and negotiated what the caregiving limit, or stopping point, for them was. Dan directly asked Christina what she believed her caregiving limit was. Christina and Dan discussed how the line that they set seemed to change depending on the day and how things were going with their grandfather. When it came to a caregiving limit, Christina emphasized that it was not as simple as creating a timeline ("you can't really pick an expiration" JC11). She elaborated by stating that she would know only when they had reached their caregiving limit ("we'll know when we get there, that's how I feel" JC12). On the other hand, Dan clearly expressed his opinion that his caregiving limit was when they reached the point of needing twenty-four hour care support for their grandfather.

At a later point, Dan brought the conversation back to negotiating what the caregiving limit for their grandfather was ("so yeah, you know, where's the line for grandpa, I don't know" JC47). As Dan expressed his uncertainty, Christina stated that an obvious limit for caregiving would be when their grandfather needed a wheelchair for his mobility ("this house is not suitable ... he couldn't, he'd tear it apart" JC49). As they discussed their grandfather's mobility and how he needed a walker or wheelchair depending on the situation, Dan stated his opinion that Christina should do whatever she could to make things convenient for herself ("you can't hurt your knee or your back or anything like that trying to pick him up" JC53).

Even though Christina had stated what a caregiving line for her might be, she had been thinking that the line she chose was arbitrary (“I just threw out ‘wheelchair’, well that’s a no brainer, we can’t have a wheelchair here” SC35). As they negotiated their limits to caregiving, Christina thought about the times her grandfather had had strokes and how his health deteriorated when he was in the hospital. She reflected on how, during his last stroke, she had nursed him back to health in their home:

And here, I can just take care of him, so yeah, I don’t know. I get it, I’m rational, reasonable about the fact there’s going to come a time and it just keeps bumping a little bit. He’s not there right now, we’ve both agreed to that, like he’s not. (SC35)

As they discussed how their grandfather’s need for a wheelchair could influence their caregiving limit, Dan felt concerned for Christina’s health and safety. He was thinking about what could happen to her if their grandfather had another stroke, fell, and accidentally knocked her down in the process. As they discussed the difficulties they would have maneuvering a wheelchair, Dan had imagined all the different scenarios in which Christina could get hurt (“you know, we’re always, always worried about her safety for getting hurt, physically hurt” SC50).

4.3.4 Assertions

The focus of the conversation was on supporting the primary caregiver as they struggled to balance the demands of caregiving, family, and other roles. Despite having different expectations of what a caregiving limit was, family members engaged in joint actions to negotiate the boundaries of caregiving they could provide as a family for their loved one. One of the biggest contributing factors to a family member’s caregiving limit was the challenge in accessing Health Care resources and information. In their self-confrontations, participants revealed how they grieved the loss of what was ‘normal’. This was expressed through their

sadness and frustration as well as their reflections on how their lives had drastically changed (i.e. unequal balance of family, caregiving and rest). In order to facilitate the caregiving process and to avoid being overwhelmed, family members focused their actions on addressing their physical needs as opposed to their emotional ones.

4.4 Case 3: Eveline and Fiona

4.4.1 Background information

Eveline and Fiona are mother and daughter who chose to participate together in the study. Eveline is a single mother in her 50's and her daughter, Fiona, is in her mid-20's. Eveline identifies as the primary caregiver for her mother who has AD and who also lives in the home. Eveline works full-time on top of being primary caregiver for her mother. Fiona, is a university student and identifies as being a secondary caregiver for her grandmother. As Eveline and Fiona live in the same home, along with the care receiver (identified as grandmother), they provide caregiving in their home. The initial session was held at the participants' home due to the intense demands of caregiving and lack of respite care. The session was broken into four parts: i) a warm-up interview with the researcher and a research assistant, ii) a 12-minute joint conversation with just the participants about caregiving for their father, iii) separate video self- confrontations with either the researcher or research assistant, and iv) a short debrief. Participants also gave narrative and final summary feedback several months after the first session.

4.4.2 Caregiving Project

In the warm-up interview and joint conversation, the participants reported that Eveline became primary caregiver for her mother as her other siblings were unable to take up the role. She reported that her home country did not have the same resources available in Canada and she thought it was best for their mother if she were supported here. Since that time, five years ago,

Eveline has been the sole caregiver and reported little support from other family members. Fiona recently moved into the home so that she could help her mother provide caregiving for her grandmother though this reasoning was not explicitly communicated to Eveline. They utilize additional care support, such as government subsidized health care aids, so that Eveline is able to maintain her full time job. Eveline carries the bulk of the caregiving load and is responsible for arranging any respite care. Eveline and Fiona spoke about the challenges they experienced in negotiating the sharing of caregiving roles. In particular, each outlined their very different perspectives on what their caregiving roles were and how they believed the tasks should be balanced. They both also addressed needs in their caregiving roles in relation to the other and issues they had in communication.

Out of this discussion and following analysis of elements, functional steps, internal processes and goals, the following project was identified: *emphasizing their individual caregiving role in order to challenge and clarify the other's caregiving role*. This project captures the manifest behaviours the mother and daughter engaged in throughout the conversation as they attempted to clarify and establish each other's role in providing care for their grandmother.

The following section outlines the overarching joint goals (Table 5) Eveline and Fiona engaged in together that contributed to their caregiving project. Specifically, this section describes in more detail some of the goal directed actions that they took towards each of the four joint goals identified in their conversation. For full details of the individual and joint sub-goals for this case, see Appendix F.3.

Table 5. Key Project and Joint Goals for Case 3

Key Project	Joint Goals
Emphasizing their individual caregiving role in order to challenge and clarify the other's caregiving role	<ul style="list-style-type: none">• To explore their differing perspectives on how to approach caregiving tasks• To discuss the impact that experience and knowledge have on caregiving• To negotiate the caregiving role that Fiona has

4.4.3 Description of Joint Goals

To explore their differing perspectives on how to approach caregiving tasks

As soon as their conversation began, Eveline engaged in this goal by directly asking Fiona what she believed her perception of caregiving was (“What is your idea of helping? It seems like we both have two different ideas” JC3). Fiona responded by expressing uncertainty and assuming a defensive posture (“Well, you always get mad at me whenever I try to” JC5). In her self-confrontation, Fiona revealed that she had felt as though she were ten years old. As she attempted to describe the ways she tried to help, Eveline disagreed with what Fiona shared and explained her own approach. She stated, “I know what to do with grandma ... I’m doing all those things which she knows how it’s done, instead of teaching you, and of course, you do it a different way right?” (JC7).

Eveline described how Fiona’s approach to helping with her grandmother’s ADLs could be disruptive (“You have a different way of brushing her teeth or other things, because she gets confused” JC7). She elaborated by describing how her own approach to brushing grandma’s teeth ensured safety and minimized choking hazards while reiterating how Fiona’s approach was disruptive: “So the way you’re doing it, she’s not used to it, so of course she’s going to get confused” (JC9).

As Eveline attempted to explain how Fiona's approach was disruptive and suggested other ways of helping out, in her self-confrontation, Fiona revealed that she struggled with many contrasting emotions including anger and exasperation at being told the same thing many times before. She revealed her longing to be heard and a desire for change ("She has her opinion and it's not going to change" SC27). At the same time, Eveline had been thinking how hard it was to explain things to Fiona. She had been reflecting on how the suggestions Fiona made wouldn't work well ("For me, after doing this so many times, I get to know which way is easier" SC39). Though she believed she figured out the most efficient approach to caregiving tasks, she couldn't seem to convince Fiona to use the same strategies. She stated, "That's the most important thing. I think for me to get her to understand ... I don't know. For me, it's very hard to get her to understand" (SC34).

As they continued to discuss exactly how brushing teeth should be approached, Fiona shared her own opinion that, though it was a caregiving task, they should still communicate with grandma throughout ("Right, but she'll speak to you too. Like she listens too" JC16). Eveline disagreed with Fiona and expressed her opinion that it was not necessary to talk to grandma while brushing her teeth ("I can speak to her when it's needed, but when it's brushing her teeth, I don't need to speak to her" JC18). When Eveline tried to redirect the conversation back to her own approach of minimizing choking hazards, Fiona restated her opinion about how to approach things: "Just tell her: 'I'm brushing your teeth'" (JC20). They continued emphasizing their own perceptions of the same task, with neither fully agreeing with the other:

Eveline: For example, she needs to have medication, she needs to take it

Fiona: If they can listen, I think she just, it's nice to know, too

Eveline: Yes, nice to know, but then...

Fiona: Sometimes she doesn't, I'm not saying that grandma will always know

Eveline: Not sometimes, telling the truth, most of the time she doesn't know. So that is what my thing is, because I want her to be clean. That's what I'm doing. (JC21-25)

Though both Eveline and Fiona disagreed with each other throughout the conversation, their self-confrontations revealed internal processes not articulated directly with the other.

Eveline reflected that, as she had discussed how she approached helping her mother with specific tasks, she had tried not to become too emotional. She revealed that she couldn't allow herself to get emotional but instead needed to focus on and take care of the tasks at hand so she could be present for her mother:

I have to be as strong as possible, because if I get emotional then everything will go downhill ... I always put a wall in between the emotion and me, because I don't want to be that person. I want to do her caregiving, right? (SC49)

While Eveline focused on holding back her emotion, Fiona reflected that the best thing to do in the moment was not react to her mother's opinions. She had tried to understand her mother's perspective, particularly when they discussed how to approach brushing their grandmother's teeth ("just recognizing that my mom will have her responses" SC38). However, she also felt frustrated as she reflected that her mom was someone who valued speaking up yet wouldn't take the time to communicate with her grandmother ("I know you are this person, you can do this, you can see it" SC47). As she shared her opinion with Eveline, Fiona felt a mixture of hurt and acceptance at how they seemed to be on different pages.

As they continued exploring their different perspectives on how to approach caregiving, Eveline, shared her opinion, that for individuals with AD, maintaining a routine was essential. She elaborated by sharing that change was not good for their grandmother as it could be

disruptive for her (“She knows the routine very well so any little changes, she gets confused. She’s like a small baby” JC40). Fiona only partially agreed and shared her own perception that routines could be stressful and that Eveline also needed a break. As Eveline disagreed and shared her opinion that routines were “the best thing” (JC42), Fiona countered by describing a hypothetical situation: “But if there’s a dinner or something ... one day the routine needs to be broken a little bit” (JC43).

To negotiate the caregiving role that Fiona has

Throughout their conversation, Eveline and Fiona negotiated what Fiona’s caregiving role actually was. On a number of occasions, Eveline engaged in this goal by directly asking Fiona what she believed her caregiving role to be. Though Fiona expressed her desire to help ease the burden for Eveline, Eveline stated her opinion that Fiona only wanted to do specific things (“you just want to brush her teeth” JC16).

Fiona expressed uncertainty throughout the conversation and when she did manage to respond to Eveline’s promptings, she did so with hypothetical statements (“I like to do things, like I don’t know. If you’re tired of feeding her one day, or something” JC6). Eveline disagreed that she got tired and stated what she believed their roles to be (“I don’t think I’m tired of doing things. I know what to do with grandma and then maybe you can help me with the other stuff. That’s kind of helping this situation too” JC7).

Eveline shared that, during the whole conversation, she had thought: “Ok, there are other ways you can help, instead of this ... instead of direct caregiving” (SC6). As she reflected that it took more time to explain to Fiona how to help, she felt increasingly frustrated and angry. Though she did not share her internal process, she revealed that she felt sad that Fiona didn’t understand what needed to be done and what she could actually help with. She elaborated that

she didn't get tired with direct caregiving tasks but instead got bogged down by everything else that needed to get done in the home:

I get tired when I think about what I need to clean or put the things into the washer. I need to fold the towels. I need to cook. I need to get her soup ready. I'm doing everything by myself. (SC18)

On the other hand, when Eveline stated that she didn't get tired with the caregiving role, Fiona had thought that her mother was not being completely honest ("sometimes you kind of need to accept what people say" SC13). As her mom shared the list of tasks that she wanted Fiona to do, during her self-confrontation, Fiona observed herself sighing:

She's about to go into the things I can do. I was just like 'those aren't the things I want to do'. I can understand certain things that I haven't been doing but there are certain things that I would genuinely love to do. (SC17)

Eveline continued to engage in the goal of challenging the caregiving role that Fiona played. She explained that it wasn't direct caregiving that she found stressful but the household work ("even though those are small things, they are big things for me" JC25). Fiona expressed her uncertainty with knowing when Eveline planned to do household work and shared her perception that her mom blocked her from doing things ("you won't let me do it" JC26). As Fiona stated that she wanted to help, Eveline reiterated that she could help with all the household tasks. Fiona vocalized her exasperation: "Why is it also hard if I help with grandma every now and then?" (JC31).

As they struggled to come to consensus with a clear role for Fiona, Eveline shared why she was resistant to compromising. Eveline had reflected on how she believed Fiona couldn't confidently perform direct caregiving tasks on her own. Instead, Eveline thought that Fiona was

comfortable only when she was present to give directions or help as needed:

If I need a break, then I need to get out, away. That means that person needs to take over. That is not happening, so I rather do by myself. I'm fine, I'm happy to do it, but just help me with the other stuff. (SC22)

There was no clear concession throughout their conversation, as Eveline and Fiona held differing views of what Fiona's role should be. On one hand, Fiona wanted to help with her grandmother's direct caregiving tasks, however, Eveline believed there were many other things that would better ease her caregiving burden.

To discuss the impact that experience and knowledge have on caregiving

As Fiona asked her mother why she wouldn't let her do certain caregiving tasks for her grandmother, Eveline answered that she tried to delegate in the past but Fiona couldn't do the tasks the right way ("It's easier for me to do it than you doing it incorrectly and me having to come in" JC32). Fiona shared her perspective that they approached things in different ways because of their differing levels of experience ("you're my mom, you've been taking care of her for like ... I know that you know better techniques" JC33). Using a different example, Eveline invited Fiona to clarify what to do when she was uncertain about the task of applying cream to her grandmother's bruises:

Eveline: So, what can you do, when you see that? Then you can ask me. There's cream, you can put the cream on. That's what the workers are doing.

Fiona: I don't know that if I don't ask you.

Eveline: So then you need to ask.

Fiona: Right. So I know there are things that you see that I can't see. You're you and I'm me.

Eveline: Exactly, so.

Fiona: But we just need to work together. (JC34-36)

This exchange marked a shift in the conversation as Eveline again brought up the significance of maintaining a routine for their grandmother's caregiving. As they talked about why routine was important, Eveline gave different examples of how a change in routine could have consequences for their grandmother. She explained how RestoraLAX®, needed to be given at 5:30PM in order for grandma to be able to use the washroom the next day ("so the whole thing is about timing" JC46). Fiona then acknowledged understanding of her mother's perception of caregiving based on her experience ("see, you could just tell me that, I don't know those things" JC46). Eveline elaborated by sharing that there are many things that are common sense to her that she picked up through experience. Fiona admitted that she herself didn't have that same knowledge:

Fiona: You have to tell me.

Eveline: That's true. Yeah, exactly.

Fiona: Because we're not the same. I'm not, I don't know what happens in your head.

Eveline: But the thing is this is common sense to me. You know? (JC49-52)

This exchange occurred in the last two minutes of Eveline and Fiona's joint conversation. Up until this point, neither Eveline or Fiona were on the same page nor did they acknowledge understanding of the other's experience. Though they both experienced frustration, sadness and anger throughout, neither of them communicated their internal process with the other.

4.4.4 Assertions

Family members engaged in joint actions in an effort to convince the other of their own perspectives of caregiving. While engaging in caregiving conversations, manifest behaviours

were focused on explaining the right way to do caregiving rather than sharing their own internal processes. Further, family members, focused on containing their internal processes (sadness, frustration and anger) in order to not become overwhelmed and in an effort to effectively address their immediate and physical caregiving needs. Family members engaged in joint actions that challenged and evaluated the other's notion of caregiving roles and corresponding tasks.

4.5 Cross-Case Analysis

In keeping with the multicase study, following in-depth analysis of each case using the APM framework, cross-case analysis was conducted across the three dyads. According to Stake (2006), “any case would be incomprehensible if other somewhat similar cases were not already known ... even when there is no attempt to be comparative, the single case is studied with attention to other cases” (p. 4). Though each of the caregiving dyads represented different family configurations, from unique contexts, and were at various life stages, within-case analysis revealed common processes across cases. These commonalities are described here followed by a presentation of the processes that were unique to each case.

Across the cases, participants described roadblocks that hindered the joint caregiving process, such as opposing perspectives and expectations of family members. Though there was a single primary caregiver for each of the cases described, participants discussed their individual roles in relation to the primary caregiver. Lastly, across the cases, participants struggled to vocalize their internal processes, even though their thoughts and feelings influenced their goal directed actions throughout the conversation.

4.5.1 Commonalities

Emerging themes found to be present in each of the three cases were categorized as “common”. Across the three dyads, the following five commonalities were identified: relative

unwillingness to vocalize internal thoughts and feelings as they engaged in joint action, focus on the primary caregiver, different perspectives on caregiving, prioritization of physical needs of the caregiver or care receiver, and grieving the loss of normal. These emerging themes all contributed to addressing the research question: What are the goal-directed actions and projects that family members construct, express and participate in together, relevant to the caregiving process for a family member with dementia?

Relative Unwillingness to Vocalize Internal Thoughts and Feelings as They Engaged in Joint Action. Most striking of all case commonalities was how little family members revealed to their partner of their internal processes. Each family member focused on either sharing perspectives on their specific caregiving project or on addressing a physical need. However, individuals did not openly express the underlying fear, worry, anger or sadness that motivated their actions. Though family members revealed in their self-confrontations their apprehensions about how to engage in their conversation, individuals were often not aware that their partners were similarly overwhelmed.

In one case (Case 2), while a husband and wife negotiated a caregiving boundary, both individuals felt concerned about how the other might be doing though neither explicitly expressed that concern in the conversation. Instead, concern seemed to motivate both individuals to negotiate a caregiving limit, understanding the other's opposing perspective yet still pushing for a compromise. Similarly, while they discussed their individual approaches to confronting their mom, both sisters (Case 1) revealed their apprehension at how the other might take their perspective. Though each worried about the impact their opinion might have on their partner, neither shared that anxiety with the other.

When family members held opposing views (Case 3), individuals focused on justifying

their differing opinions. Though the manifest behaviours were contentious, the self-confrontation revealed that both family members felt misunderstood, overwhelmed and sad during their exchange. Despite this, neither individual was able to express the impact that the other's perception and behaviour had on them.

Primary Caregiver as the Focus. The family caregiving projects that individuals engaged in, centered on the needs of the primary caregiver. Despite the different family configurations and relationships between the participants involved, all family members spoke about the primary caregiver as being key to the caregiving process. Though individuals spoke about their family member with dementia (the care recipient) throughout the conversations, the actions individuals engaged in were largely motivated by the role of the primary caregiver.

This process took the form of negotiating with and supporting the caregiver as they struggled to balance the burden of caregiving. Across the three cases, family members spoke about the overwhelming caregiving load primary caregivers held and the different strategies they used to cope. Participants spoke about the primary caregiver avoiding talking openly about their struggle or of even feeling guilty burdening other family members when in need of support. Where the primary caregiver was present for the conversation, the caregiver spoke about how they struggled to balance all their responsibilities and addressed strategies used in the past.

Particularly for Cases 1 and 2, participants revealed in their self-confrontations a concern for the wellbeing of and a desire to support the primary caregiver. In Case 1, Amy spoke about how her mom, the primary caregiver, felt greatly burdened by her responsibilities. In her self-confrontation, she shared that her mother believed she was a burden to her children and felt bad asking for support ("she feels that it's a burden for us to help out, where it's not ... it's very difficult for her and I think she feels that we feel the same way, and we don't" SC32). In Case 2,

Dan makes it very clear that the focus of the joint conversation is on Christina, the primary caregiver (“I mean, this whole conversation is more about her than him” SC10). The following captures the worry that Dan felt for the burden that Christina carried:

I’m just concerned for her and for all the things that she misses, all the family stuff, all the stuff with our son she can’t go because she doesn’t have enough time. The way that things are structured for care, it doesn’t give her a break. I’m worried about her and all the frustration she has dealing with things all the time. (SC14).

For all family members, the conversation was not focused on the patient but on the burden of the primary caregiver. For Case 3, the secondary caregiver, engaged in manifest behaviours that were largely influenced by her desire to provide direct caregiving and her own frustration with the primary caregiver’s unyielding opinions. However, the primary caregiver struggled to balance all her responsibilities and, through the conversation, engaged in actions to negotiate sharing of tasks in order to alleviate her burden.

Differing Perspectives on Caregiving. Each family member engaged in goal-directed actions that facilitated sharing perspectives on family caregiving that differed from that of their partners. Individuals spoke about their different communication styles, different limits to caregiving, or different approaches to direct caregiving tasks such as assisting with ADLs. Though all participants communicated their differing perspectives related to their family caregiving projects, individuals revealed through their self-confrontations underlying emotions motivating those perceptions.

Family members (Case 1) addressed their different communication styles and approaches to discussing caregiving with other family members. Each participant highlighted their strategies for navigating caregiving specific conversations with their mother. They also evaluated the

other's perceptions and approach, whether through manifest behaviours or their own internal processes. Speaking to Amy, Becky summarized how their differing perspectives balanced each other in their approach with their mother, with one playing "good cop" and the other "bad cop".

Family members also shared differing perspectives on the limits to their caregiving roles (Cases 2 and 3). The husband of the primary caregiver (Case 2), expressed his concerns with his wife's caregiving responsibilities and how overwhelmed she was. He acknowledged that there was a limit to what they could provide as a family but believed his wife resisted setting that boundary ("I feel like that line is always going to keep getting pushed. I think she'll know but she won't do it" SC33). A woman serving as primary caregiver for her mother (Case 3), shared her perception that her caregiving limit did not involve direct caregiving tasks but rather other household responsibilities. Her daughter, on the other hand, disagreed, believing that her mother was not being honest about her caregiving limit.

Family members shared different expectations of what each individual's specific caregiving role entailed and communicated that directly with the other. On numerous occasions, Eveline (Case 3), stated her opinion of what her caregiving role was in relation to her daughter, Fiona. Fiona, motivated by her desire to help her grandmother and her frustrations with her mother, disagreed and expressed her own perception of what her role was, contrary to her mother's opinion ("those aren't the things that I want to do" SC17).

Prioritizing Physical Needs. Without exception, for all family members, each action taken in the conversation was focused on addressing either the physical needs of the primary caregiver or of the care receiver. Where the primary caregiver was involved in the conversation (Cases 2 and 3), family members discussed specific approaches to caregiving including comparing previous supports used in the past, brainstorming additional resources to help with

certain ADLs, or providing detailed descriptions in order to explain how to perform a caregiving task (e.g. how to help with tooth brushing or administering medication). As two secondary family caregivers conversed (Case 1), their manifest behaviour focused on how to approach the primary caregiver regarding the physical needs of the patient. A large focus of their conversation was on navigating how to address the imminent needs of their parents such as finding appropriate living arrangements or following up on health concerns (e.g. flu vaccinations).

Grieving the Loss of Normal. In the joint conversations, family members expressed or acknowledged a loss of what was. For most, this was shared during the self-confrontation as participants internally processed their grief while focusing on addressing physical needs during the conversation. Family members reminisced about the way things used to be and reflected on the changes they themselves, along with their family members, have experienced. One daughter (Case 1) spoke about how family dinners at her parents were no longer the norm (“that’s kind of died off, ‘cause my mom’s got quite a bit on her plate” SC33). She also shared that she felt emotional and worried thinking about her parents aging and eventually passing away. Meanwhile, her sister addressed being in the AD “in between” period, where, despite things being difficult, she is motivated to be proactive and take steps to address imminent caregiving needs for their father.

Others spoke of having to carry on despite the many challenges and losses. One primary caregiver (Case 3) talked about remaining strong and not getting emotional otherwise everything would “go downhill”. Another primary caregiver (Case 2) talked about having no choice but to shoulder all the caregiving burden as other family members couldn’t (“You get your leg amputated, you learn how to walk again, or you don’t and you only got yourself to blame” SC65). Both primary caregivers (Cases 2 and 3) talked about being motivated to provide

caregiving for their loved one but, in order to functionally do their job, they needed to contain their grief (i.e. loss of routine, loss of balance, loss of family roles, loss of their loved one, etc).

4.5.2 Unique Processes

While conducting case study research, Stake (2003) explained that the search for individuality, or particularity, of a single case will be at odds with the researcher's search for commonality. Stake (2003) further explained that a single case will have unique and important defining characteristics, relationships or processes. He elaborated on how competing interests of particularity and generalization can damage the case stating, "when the commitment to generalize or to theorize runs so strong that the researcher's attention is drawn away from features important for understanding the case itself" (Stake, 2003, p. 140). The researcher must adequately present the cases so that readers can understand and draw conclusions while also acknowledging that these conclusions may diverge from those of the researcher's (Stake, 2003). Here we present the processes that were unique to the cases and contribute to the understanding of the particularities of family caregiving for these families.

Being on the Same Page. In Case 1, both sisters who served as secondary caregivers for their father acknowledged their different perspectives while also addressing the need to be on the same page. Despite having opposing communication styles, especially in regards to how they approached caregiving conversations with their mother, both sisters acknowledged that it was essential for them to be a team and communicate the same message in the end. This was also reflected in their self-confrontations as both sisters expressed relief that the other had parallel concerns and thought similarly. At one point in the conversation, one sister expressed frustration as she believed the other was not on the same page concerning the severity of their father's illness ("I think we can be on different wavelengths sometimes about how things are actually

going” SC35).

Obstacles to Accessing Health Care. For participants from Case 2, the family members’ joint project was largely motivated by challenges they faced as they navigated the health care system and the lack of caregiving support they received. The primary caregiver, in particular, redirected the conversation several times to discuss their lack of caregiving support and attempted to brainstorm alternative resources they could access. Overall, both participants were engaged in actions that deliberated the primary caregiver’s ability to provide care in a functional way. However, both participants acknowledged that their ability to provide care was largely restricted by structural systems:

D: I don’t know we talk about all this stuff all the time, just trying to figure out, navigate the system and it’s not just the care system, there’s all kinds of navigating through the government systems ... they don’t make it easy. (SC16)

C: It would be great to have an occupational therapist...but we have no control over that, they would never do that ... the system ... they’re going to send in the lowest paid worker, and that’s not me, it’s business, unfortunately. (SC19-20)

Distribution of Caregiving. Though it was clear across the three cases that there were defined caregiving roles each family member had, only in Case 3 was that distribution of tasks explicitly discussed. Both family members spent considerable effort engaging in joint tasks to establish their individual caregiving role while challenging the other’s. The primary caregiver clearly stated her opinion on what her daughter, a secondary caregiver, should do to help ease her burden of caregiving. However, this contrasted with her daughter’s own opinion of what her caregiving role could be. She expressed her desire to help ease the burden but with direct caregiving tasks as opposed to indirect tasks such as a cleaning, doing laundry, or cooking:

F: She's about to go into the things that I can do and I was just like 'those aren't the things that I want to do' so, I can understand certain things that I haven't been doing, but there are certain things that I would, like, genuinely love to do. (SC17)

The Right Way to be Caregiver. Though all participants expressed differing perspectives on various aspects of caregiving, only two family members (Case 3) engaged in manifest behaviour to discuss what the right way to provide caregiving was. The primary caregiver focused her actions on communicating that because of her experience and caregiving "common sense" she was best suited to provide direct care for her mother. She described how, over the course of five years, she developed the most effective methods for caregiving ("For me, after doing it so many times, I found a way to make it easier ... to find which ways are not stressful" SC40). Though her daughter attempted to share that she could help in a different way, she disagreed, stating that her daughter made things more difficult as she did tasks incorrectly. However, towards the end of the conversation, both individuals acknowledged that the primary caregiver is the one that has caregiving "common sense" and that she would need to share that knowledge in order for the secondary caregiver to functionally provide help:

F: I don't know those things.

E: That's the other thing, there is a lot of common sense coming to my head.

F: But that's your head, I don't have that common sense. You have to tell me.

E: That's true. Yeah, exactly. (JC47-50)

4.5.3 Overall Assertions

In this final piece of the analysis, the resulting key assertions that summarize the within-case and cross-case analyses are presented. These assertions represent the main findings of the study and, through the framework of CAT, address the research question: What are the goal-

directed actions and projects that family members construct, express and participate in together, relevant to the caregiving process for a family member with dementia?

Key Assertion 1. Family members engaged in manifest behaviours that prioritized the physical needs of the primary caregiver or the patient over their own emotional needs. Though individuals expressed feeling overwhelmed, they also acknowledged that they could not let their emotions get to them. For most this meant that emotions were held in abeyance as individuals focused on manageable and tangible direct or indirect caregiving tasks.

Key Assertion 2. Family members frequently expressed their differing and opposing perceptions about caregiving with their partner. The role of the individual, whether primary or secondary caregiver, as well as their relationship to the family member receiving care, impacted the perceptions that they held. With varying success, the secondary caregiver focused on negotiating with the primary caregiver and their opinions about various aspects of caregiving.

Key Assertion 3. Family members took stock of their current caregiving situation by describing various issues including the obstacles to caregiving, recent critical incidents or the availability of resources, in order to determine next action steps. In order to broaden context, individuals also shared experiences and perceptions of other family members and friends.

Key Assertion 4. Family members focused their caregiving conversations around the primary caregiver's role and the limit to caregiving. Family members negotiated their individual roles and discussed distribution of tasks in relation to the primary caregiver. Focus was also on supporting the primary caregiver in various ways, including sharing of tasks or negotiating breaks, so that they could sustainably continue in their role of caring for their family member with dementia.

Key Assertion 5. Though family members had some support from extended family or friends, the main caregiving responsibilities were placed on the primary caregiver with immediate family

taking on secondary caregiving roles. Individuals expressed their frustrations with extended family not being more involved but did not articulate expectations they had of other family members to share in the caregiving load.

Chapter 5: Discussion

This research sought to uncover the actions that family members utilized when engaging together in caregiving conversations for a loved one with dementia. Specifically this research describes the actions associated with familial caregiving as it occurs in the relational context. This discussion relates the findings presented in the previous chapter to the existing literature on the relational context of family caregiving of a loved one with dementia. The chapter begins with a brief review of the research problem then outlines how these research findings address the original research question. The discussion also describes new contributions to the field of family caregiving for an individual with dementia and explores the implications in the field of counselling. The discussion ends by addressing the limitations to this research and highlighting future directions for study related to family caregiving for a loved one with dementia.

5.1 Summary of the Research Problem

This research project developed from a broad spectrum of literature identifying the rapidly growing demographic of adults serving as caregivers for family members with dementia and the negative implications from which these caregivers suffer. As a result of the chronic exposure to multiple stressors common in long-term caregiving, family caregivers can experience an increase in health complications, social isolation, financial difficulty, and decline in mental health, among many other challenges (Barnet, 2015; Bevans & Sternberg, 2012; Leinonen, 2011). Though in most cases, a primary caregiver takes on the brunt of the caregiving load, family caregiving impacts all members of the microsystem, with deeply ingrained patterns influencing how family members navigate caregiving conversations and determine caregiving roles (Blando, 2011).

In families with more collaborative communication and higher levels of mutuality, caregiver well-being increases as family members are better equipped to adjust to caregiving roles (Bailey & Gordon, 2016; Johnston, Bailey, & Wilson, 2014; Lyonette & Yardley, 2003). However, when families experience a divergence in caregiving approaches or an unequal division of caregiving responsibilities, the family can become a source of stress (Kwak et al., 2012). This stress can result in more adverse health outcomes and increased family division (Roberto & Jarrott, 2008). Though extensive research exists highlighting the adverse physiological and psychological health outcomes of family caregivers, previous work is largely based on cross-sectional data or focused on the perspective of individual caregivers. The present research focused on the relational context of caregiving by examining the interactional processes involved in navigating caregiving conversations between family members.

5.2 Summary of the Findings

Existing literature highlights factors such as emotional intimacy that can influence the distribution of caregiving within families (Connidis & Kemp, 2008). However, there is no research that demonstrates exactly how family members engage in negotiation or actual exchanges of support. Based on the families involved, the key family caregiving projects included: (i) trying to be functional amidst the challenges of supporting the primary caregiver while holding in abeyance contrasting emotions, (ii) coming up with alternative care supports while also negotiating the limits to caregiving for a care receiver, and (iii) emphasizing one's individual caregiving role in order to challenge and clarify the other's caregiving role. The current research adds to the literature base by closely examining the specific actions family members engaged in together and describing the process of navigating caregiving conversations

with each other. These findings also add to the literature by explicitly conceptualizing caregiving within families as involving goal-directed actions and projects.

5.3 Contributions to the Literature

Focus on functionality over the emotional process. It is well documented how the caregiving routine can severely impact a caregiver's daily functioning as individual caregivers experience an overall deterioration in quality of life, greater social isolation and an increase in psychological distress including anxiety or depression (Liu & Huang, 2018; Roth et al., 2009; Shooshtari et al., 2017). The current research focused on the interactions between family members as they navigated caregiving conversations together rather than on the individual perspective of just one caregiver. In this research, during caregiving conversations with another family member, caregivers focused their attention on finding practical solutions for immediate caregiving concerns rather than sharing their emotional process. However, all family caregivers felt overwhelmed and, through their video self-reflections, revealed feelings of loss, sadness, and uncertainty with the caregiving process. Family caregivers acknowledged that in order to successfully fulfill the caregiving role they needed to suppress their emotions and prioritize the practical aspects of caregiving. This was most evident for the primary caregivers who were responsible for carrying out the brunt of caregiving tasks.

Throughout their conversations with each other, family members focused on navigating the practicalities of caregiving. They strategized how to address sensitive topics with family members, brainstormed additional resources for meal service or care aids, discussed hypothetical crisis scenarios, or shared opinions on the appropriate ways to help with activities of daily living (ADLs). Though all family members revealed in their video self-reflections that their focus on addressing practical aspects of caregiving was largely motivated by their underlying emotions,

whether it be concern or fear, not one individual openly shared these emotions with the other. Despite the psychological toll caregiving had on them, addressing the practical needs of caregiving took precedence over their emotional ones.

In this research, adult children or grandchildren serving as family primary caregivers perceived caregiving as a task that they alone could accomplish. Primary caregivers talked about being motivated by their love for the care receiver and a desire to successfully carry out the responsibilities and tasks of caregiving. They spoke of a desire to not disappoint the care receiver, while also addressing the tension of balancing other life responsibilities and relationships. Family members accepted the role they had taken up knowing that no one else would or could step into the role as effectively as they could. All this served to motivate caregivers to engage in the functionality of caregiving and hold in abeyance the contrasting emotions that could otherwise overwhelm them. This strategy was necessary for individuals to successfully participate in the last stage of the family life cycle.

Though one family member may have accepted the requirements necessary for the ‘families in later life’ stage (Carter & McGoldrick, 1988), another may remain fixed in old patterns that hinder engagement in the transition to caregiving for an older adult (King & Wynne, 2004). For some, these old patterns included communicating opposing perspectives regarding certain aspects of caregiving and refusing to see the other’s point of view. Though these differing perspectives were directly shared with one another when addressing caregiving concerns, the underlying emotional processes motivating these perspectives were not openly communicated.

For another, these old family patterns were demonstrated through a relationship between parent and adult child that seemed to regress to patterns from an earlier stage of the family life cycle. Both family members shared with each other their opposing views of how to approach

specific tasks, however, both individuals also felt overwhelmed, sad and frustrated. While one was ready and determined to serve as primary caregiver, her adult child resisted the role her mother defined for her and, instead, felt like a trapped child. For this adult child, a secondary caregiver, the underlying anger and frustration with not being heard interfered with her ability to carry out the functional aspects of caregiving. Still in the midst of her own transition to adulthood, the participant's own individual development likely clashed with the families in later life stage. As Ballard (2012) writes, though there are key developmental tasks in the family life cycle, each family member is undergoing their own individual life stage development which will impact how the family functions as a whole.

However, some family members who served as secondary caregivers focused their actions on supporting the primary caregiver. Though not explicitly communicated with each other, family members were more fully on the same page regarding their place in the family life cycle. Secondary caregivers, in particular, recognized that the primary caregiver played a key role in the successful transition to the stage of families in later life and discussed how to best engage together in that transition. Family members did this by sharing different perspectives of specific tasks of caregiving (i.e. setting up doctor's appointments, planning for residential care) and discussing their own responsibilities within the caregiving role. Family members also anticipated how to support the care receiver, discussed with each other hypothetical crisis situations, brainstormed resources and implemented additional supports that might mitigate future stress.

Negotiating limits to caregiving. Bailey and Gordon (2016) described how the ways that individuals engage in caregiving are influenced by both the norms passed along in families and schemas embedded within a social context. For the primary caregivers in this research, the

unspoken but well understood norm was that these individuals were expected to shoulder the brunt of the caregiving load. These caregivers acknowledged that they were better equipped and provided higher quality care for their loved ones than others, including professional health care aides. One individual in particular addressed the large health care gap and insufficient support resources available for families, stating that this deficiency led to an overworked health system and substandard care. Expressing frustration and anger with the system, family members were aware that they could not rely on social structures to support them or help meet their many caregiving needs.

In a Canadian survey of individual resources utilized in order to meet caregiving responsibilities, Shooshtari and colleagues (2017) found that out of ~6300 caregivers surveyed, the most common consequence of caregiving was a reduction in participation of social activities (36%) followed by cancelled holiday plans (24%). In this research, primary caregivers spoke of their determination to follow carefully constructed caregiving routines. These individuals emphasized how a set structure and schedule provided much needed certainty and gave family members a sense of control in the chaos of caregiving. This prevented caregivers from feeling completely overwhelmed by all the tasks they were responsible for and had little support with. However, the rigidity of the structures set in place by primary caregivers also meant cutting back from other social commitments and resisting changes, including taking time for breaks.

While primary caregivers were determined to stick to routine, other family members focused on encouraging flexibility and balance. Family members directly addressed the primary caregiver's resistance to break with routine by inquiring how they could schedule holiday time, discussing when they could offer reprieve support, or suggesting that flexibility was necessary to maintain social connections. Though not addressed openly, all family members reflected on the

struggle primary caregivers faced in balancing responsibility for the care receiver and addressing their own individual needs. Family members spoke of their concern for the primary caregiver and a desire to support them so that they could effectively carry out their role. Though they were willing and able to help share in caregiving responsibilities, these offers of support were mostly met with friction. Family members struggled to know exactly how to communicate their concern for the primary caregiver and persuade them to reevaluate their limits to caregiving.

Defining one's caregiving role in relation to the other. In order to bridge the significant gap in the health care system, when an individual is living with a long-term illness, family members are expected to serve in key caregiving roles for which they have no formal training (Bailey & Gordon, 2016). In caring for a family member with dementia or AD, the tasks that family members need to gain mastery over go beyond ADLs and include navigating larger systems (e.g. government service agencies) and managing resources (e.g. taxes) (National Alliance for Caregiving and AARP, 2015). In most cases, family caregivers are given little guidance or instruction on how exactly to access the help that they need. In this research, family members spoke of their struggle to maneuver through larger social structures and how they needed to become their own experts in caregiving.

Family caregivers discussed with each other the challenges they faced in having to access the resources and caregiving support that they needed. Primary caregivers spoke of developing caregiving “common sense” through years of trial and error being in the caregiving role. As they talked with family members about various challenges they faced in the caregiving process, primary caregivers were clear in communicating their expertise with the other. By establishing their expertise in the caregiving role, primary caregivers gave credibility to their perspectives, especially when they differed from those of other family members. When those in secondary

caregiving roles attempted to express their opinions on how certain tasks should be approached, as caregiving boundaries were largely determined by the capacity of the primary caregiver, others' opinions were often not considered with the same gravity.

Previous literature indicated that a greater proportion of caregivers across cultures, when not the spouse, tended to be female (Leinonen, 2011; Lin et al., 2012). Research also found that with adult children in the role of caregiving, daughters tended to be more involved in addressing direct-care needs while sons took on more indirect caregiving roles (Hequembourg & Brallier, 2005; Matthews, 1995). For all the families involved in this study, all primary caregivers were female and from various familial configurations including daughter, granddaughter, and spouse. In keeping with previous literature, female primary caregivers were in positions of unequal caregiving distributions with these individuals taking on almost all the direct caregiving tasks and care coordination. However, the primary caregivers who participated in this research did not address whether gendered norms had influence in defining their caregiving role within the family. They instead focused their conversation with other family members on the distribution of caregiving tasks and the tasks they could and could not carry out.

Primary caregivers, due to their experience and acquired knowledge, were sources of authority within the family. As family members discussed various caregiving concerns and brainstormed action plans, others would challenge the primary caregiver's role and capacity to perform certain tasks. Family members discussed with each other tasks they could take on in order to develop their own caregiving role and encourage a more equitable distribution. However, they also acknowledged their ability to expand their role would depend on the primary caregiver's willingness to relinquish tasks. In the case where two secondary caregivers discussed with each other how to more equitably participate, both family members acknowledged the

boundaries set by the primary caregiver and expressed concern with stepping over those boundaries. In another case, a secondary caregiver wanting to participate in more direct care tasks faced opposition from the primary caregiver who, as the expert, would not cede her role. Though family members wanted to support the primary caregiver by sharing in caregiving tasks, they were doubtful and uncertain with how the roles could actually shift.

5.4 Improving the Family Caregiving Process

It is well documented in literature that the family caregiving process can be one of the most stressful stages in the family life cycle (Aneshensel et al., 1995; Bailey & Gordon, 2016; Lyonette & Yardley, 2003; Chumblor, Pienta, & Dwyer, 2004). As was demonstrated in this research, often one family member serves as the caregiving expert and is largely responsible for the overwhelming majority of caregiving tasks. This asymmetrical balance in caregiving led to frustration, sadness and a sense of isolation for the primary caregiver while other family members felt uncertain, helpless, and overwhelmed with how best to support the other. Though each family member experienced psychological distress in different ways, individuals were not able to verbalize their internal processes with each other. Instead, managing the functional aspects of caregiving took priority. Consequently, as described in literature (Aneshensel et al., 1995), the underlying and unaddressed emotions resulted in tension within each family system.

In families where the caregiving process is openly discussed, particularly in cases before caregiving even begins, family members are better equipped to adjust to the transition (Bailey & Gordon, 2016). To guarantee a more effective adjustment for all family members involved in caregiving, families should take proactive steps before a crisis actually sets in (Christian, 2004). In this study, family members didn't initially plan for the caregiving role and felt unprepared when the time came. They spoke of an initial orientation to the care supports available through

health agencies; however, what was offered was not enough to prepare them for the caregiver role. Though anticipation of the future and taking proactive steps may ensure a smoother caregiving transition for all individuals within a family system, a more realistic focus might be improving communication within the family as they engage in goal-directed caregiving actions.

For all family members involved, many of the underlying emotional processes motivating their behaviour were not acknowledged to one another. Previous literature looking at the relationship between the caregivers and care recipients found that open communication allowed for more positive and collaborative care relationships (Johnston, Bailey, & Wilson, 2014). Further, individual well-being increased along with attachment between family members where high levels of mutuality between the caregiver and care receiver existed (Lyonette & Yardley, 2003). Though previous research has not extended to understanding how the dynamic plays out between multiple caregivers, family members in this study spoke about their frustrations with mismatched expectations and challenges in communicating with one another.

5.5 Counselling Implications

The current study examined the joint goal-directed actions of family members navigating conversations about caregiving for a loved one with dementia. Though this research was not intervention based, the work did uncover some of the internal processes that motivate the complicated dynamics occurring between family members during a stressful stage of the family life cycle. Using a multicase approach, this research sought to describe the particularities of the cases while also highlighting the more generalizable aspects of the caregiving quintain.

This work identified how family members were engaged in joint goal directed actions that facilitated specific caregiving projects. Though all individuals were motivated by their desire to support the care receiver, family members struggled to balance the overwhelming

responsibilities of care and communicate effectively while holding opposing perspectives. Supporting families by helping foster more transparent and collaborative dialogue may help alleviate the sense of isolation and overwhelming frustration family members feel. Another crucial form of support could also include resourcing individuals so that they can safely access and transform their cognitive and emotional processes. There are many counselling approaches available that could support the individual and the family system through this relationally complex life stage.

As explained by the systems framework, as families go through life transitions, psychological distress increases as each family member either adjusts by adapting new patterns or remains resistant to the changes (Qualls, 1999). Counselling with a systemic therapeutic lens would offer these families the chance to address the changes that have impacted the entire system, challenge current patterns of relating, and find more effective strategies for interacting with each other (Blando, 2011). Counselling support at the individual level could also be beneficial for family members to help access unconsciously suppressed core affects. With therapeutic approaches such as Accelerated Experiential Dynamic Processing (AEDP), counsellors can help family members become more tolerant of emotions typical in the caregiving experience, such as anxiety, fear and sadness (Russell & Fosha, 2008). In AEDP, counsellors use an attachment oriented lens to help clients build their tolerance of anxiety and use of defences so that they can more effectively process underlying core emotions such as grief and fear. As family members become aware of and can more adaptively process their core affects (i.e. grief), their relational defences, such as blame or avoidance, may decrease leading to less tension within the entire family system.

5.6 Family Caregiving as Career

Action theory provides a framework for explaining the processes family members engage in together. It suggests that individuals are continuously co-constructing joint projects, motivated by common goals, over a midterm span of time (Young, Valach, & Domene, 2005). Over a long-term period of time, these co-constructed projects can be organized as a career which holds significant value in an individual's life (2005). For some individuals with a progressive illness, family members can jointly engage in the family caregiving career over a duration of many years.

Previous research has looked at various family related careers as goal-directed processes that are made up of a series of projects that family members engage in together (Domene, Arim, & Young, 2007; Young et al., 2005; Young et al., 2018). In one study, researchers described how parents of young adults with intellectual and/or developmental disabilities (IDD) acted together to support their child through the transition to adulthood (Young et al., 2018). Though the transition was that of child to young adult, Young et al. (2018) found that this was largely a joint process where parents were active agents who attempted to identify and resolve obstacles in their child's transition along with associated challenges they themselves faced. Similar to the caregiving career, family members worked together to facilitate key developmental tasks specific to that stage in the family life cycle. Like parents of young adults with IDD, family caregivers serve as active agents who seek to resolve obstacles to caregiving for their family member while also addressing the concomitant issues in their own lives.

Additional research grounded in the APM has conceptualized the family's focus on health as a career having a goal-directed system of joint and individual actions (Valach, Young, & Lynam, 1996). Families engaged in health careers are engaged in "a series of shorter-term and

more delineated health-promotion projects” (Valach, Young, & Lynam, 1996, p. 51) that could include nutrition, balanced lifestyle, mitigated stress, and physical exercise, among others. These projects are made up of a series of goal directed joint actions which family members engage in with each other towards the betterment of the system. In one example of a family engaged in health promotion projects, researchers used the APM to describe the actions parents and their adolescents engaged in around family sun-protection (Young et al., 2005). Researchers used the method to describe the goals, strategies and outcomes of sun protection as it occurred within the family as well as the project’s embeddedness in other family projects (Young et al., 2005).

Similar to other family careers, caregiving can be understood as a goal-directed process comprised of a series of projects that family members engage in together. Further, these projects could be viewed as health promotion projects focused not only on the health of the care receiver but of all family members involved. Adding to previous APM literature, this research identified the goals and strategies that individuals acted out together to facilitate caregiving for a loved one with dementia. Using the action framework, this research contributes to the literature in a unique way as it describes some aspects of the complex relational processes occurring between family members, something not previously described before.

5.7 Future Research

This study adds to the depth of literature documenting family caregivers’ experiences of caring for a loved one with dementia. However, as is the case with more long-term illnesses, dementia is a dynamic and progressive disease that can span over many years. It would be beneficial for future research to track family members’ caregiving projects longitudinally given the nature of the illness and the changing process of caregiving. This would shed light on the

ways that family members continue to be engaged in their projects or how projects shift in relation to the changing context of the illness.

Often, more than just two individuals are involved in the family caregiving process. Expanding the APM to incorporate the voices of additional family members would be another way to add depth to this area of research and acknowledge the complexity of caregiving. Modifications to the study to account for this could include arranging for multiple family members to participate but in various dyad configurations. This could also account for the different relational patterns individuals might assume with different family members.

An important voice in family caregiving, including the care receiver in future research would also be critical to understanding the entire family caregiving process. Though research is minimal, past literature indicates that the experience and input of care recipients in the caregiving process varies greatly (Bailey & Gordon, 2016; Brosi, Ames, & Carolan, 2009). Particularly in the earlier stages of dementia where the individual still maintains cognitive function, including the care recipient in key decision making around their care would be essential for the maintenance of identity, self-esteem and sense of agency. The APM could serve as a tool to uncover and better understand the joint goal-directed processes by which the caregiver and care recipient navigate caregiving with each other.

5.8 Limitations and Strengths

Though a multicase study approach allows for the in-depth examination of each case separately and then comparatively across cases, this study could have been improved with the addition of more families. Having more cases to add to the cross-case analysis would strengthen the findings related to the quintain and, in particular, the resulting commonalities. Various dyad

configurations exist on the caregiving spectrum and on many occasions go beyond two family members.

Another limitation in this study was the use of a single time point in the caregiving process. Due to time and resource constraints for both families and the primary researcher, only one session was conducted. As described earlier, caregiving for a loved one with dementia can change quickly in response to the progressive nature of the disease. As was the case for some participants in this study, from the time the initial session took place to the time analysis was completed, many changes had already occurred both for the individual with dementia and all other family members involved.

A third limitation in this study was the short duration of the joint conversations. Though the entire session took approximately two hours, the joint conversation itself was quite limited (~15 minutes). The short amount of time for the joint conversation meant that there was only so much data that could get captured in the session and subsequently analyzed. This is largely due to the nature of the APM protocol and the process of the warm up and self-confrontation interviews. In order to complete the entire session in an appropriate time for the participants, this meant putting a limit on the length of the joint conversations.

On the other hand, when considering strengths of this research, the various dyad configurations included in the study added to the diversity and breadth of experience covered. For example, though both the husband-wife and the mother-daughter dyads were involved in caregiving for a family member, the nature and dynamics of their relationships were incredibly unique. Though some similarities emerged in the way all three dyads engaged in the caregiving process, there were many differences inherent in each relationship. This extends to all caregiving

relationships- having a diverse sample better represented the diverse caregiving population that exists.

This study is also novel in its approach of describing the family caregiving process as it examines conversations between family members as they occur. The vast majority of previous research looking into the caregiving process has conducted research from the individual perspective or used survey methods (Leinonen, 2011; Tatangelo et al., 2017; Shooshtari et al., 2017). One study examined family caregiving by conducting semi-structured interviews with two or more family members, including the person diagnosed with AD (Esandi et al., 2018). Unlike previous research, however, this study detailed the actions family members constructed, expressed and participated in together as they engaged in conversations around family caregiving.

5.9 Conclusion

This research attempted to uncover the joint actions between family members as they navigated caregiving conversations for a loved one with dementia. Using the contextual action theory grounded APM as a framework, the study revealed the joint processes that facilitated specific family caregiving projects. Findings from this multicase research revealed that family members engaged in joint goal-directed actions that facilitated the following three projects: (i) trying to be functional amidst the challenges of supporting the primary caregiver while holding in abeyance contrasting emotions, (ii) coming up with alternative care supports while also negotiating the limits to caregiving for a care receiver, and (iii) emphasizing one's individual caregiving role in order to challenge and clarify the other's caregiving role.

The findings of this study add to existing literature on the experiences of family caregiving for a loved one with dementia. Moving beyond previous literature focused on the

individual perspective of caregiving, it describes the ways that family members participated in the caregiving process by uncovering the actions individuals engaged in together. Further, this research expands on previous literature by explicitly conceptualizing caregiving within families as involving joint goal-directed action and projects.

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Appendix A: Recruitment Poster

Are you navigating
caregiving for family with
dementia?



What?
Participate in a
research study for
family caregivers

For whom?
Family members
who provide care
for an individual
with dementia

How long?
Estimated total of
3-4 hours

Participants will be
given \$25/person as
an honorarium

Do you provide care for a family member with dementia? Do you face challenges around family dynamics, balancing responsibilities, or struggle with your overall wellbeing?

We are looking for pairs (e.g. two siblings or a spouse and adult child) to participate in our research study to look at how families navigate providing care for a family member with dementia.

Appendix B: Research Introduction Letter

Dear Prospective Participant,

My name is Vanessa Silva, and I am studying the process of navigating caregiving for a family member with dementia. This research project is a requirement for the completion of my Master's degree in Counselling Psychology at the University of British Columbia. My supervisor and Principal Investigator on this project is Dr. Richard Young. You have been given this letter as you may be interested in hearing about this study and potentially participating.

There is a significant demographic and social shift in Canada as the 'baby boom' generation ages and is in need of care with family members serving as primary caregivers. However, especially in the world of informal caregiving for an family member with dementia, there is little known about the ways that family members interact with each other in navigating the caregiving process.

The goal of this study is to gain a preliminary understanding of the ways that family members engage with each other in the caregiving process for a family member with dementia. We are hoping to learn more about this joint process through the conversations that family members have about their caregiving experience.

Participation is confidential and entirely up to you. I will not be informed that you received this letter unless you choose to contact me directly.

I am looking for two caregiving individuals from the same family, either immediate or extended family members, over the age of 18 who are willing to talk about the shared process of caregiving as it occurs within the family. This study will include an video taped in-person guided conversation which is immediate followed by a playback of the video (approximately 2 hours). Approximately two weeks later there will be a follow-up in person feedback session (approximately 1 hour). The total time to participate is about 3 hours.

If you say "yes" to participating in this study:

Our conversation will focus on your joint process of navigating family caregiving for a family member with dementia. The initial conversation will be guided by myself and I will not be asking you a specific set of questions, but you may be asked to clarify or elaborate on things that you share. For the video playback I will be asking you specifically about your thoughts and feelings during the previous conversation. Approximately two weeks after the initial session I will be meeting with you to discuss a summary of the results. You will be asked to confirm whether they actually represent your individual and joint caregiving process. You will be asked to provide feedback to ensure you are comfortable with how the findings captured your process.

To best focus on what you are saying, I will request your permission to record the interview by video and audio. Some demographic information will be collected as well.

All information will be kept strictly confidential and all questions are optional to answer.

How we keep this information confidential:

The audio recordings will be transcribed, removing all identifying information. Participants will only be referred to by a participant number. All paper documents will be kept in a locked filing cabinet, and computer documents will be password protected. Only myself and my research supervisor, Dr. Richard Young, will have access to the original files.

Contact Information

If you are interested in participating in the study or finding out more information, please contact Vanessa Silva (Primary Researcher). This research is being conducted as a component of the thesis requirement for a Master's degree in Counselling Psychology at UBC. You may also contact Dr. Richard Young (Principal Investigator), Professor, Counselling Psychology Program, UBC.

In summary:

- I am seeking two family members who serve as a caregiver for a family member with dementia and who are willing to talk about their family caregiving process
- Participation is confidential
- Must be 18 or older
- Must be fluent in English

Your participation is completely voluntary. You may refuse to participate in any section of the study, or withdraw at any time without negative consequence and for any reason.

My sincerest thanks in advance. I welcome any questions you may have, and I look forward to hearing from you.

Best regards,

Vanessa Silva
M.A. Candidate, Counselling Psychology
University of British Columbia

Appendix C: Study Consent Form

Title of Study: Navigating Family Caregiving for Dementia- The Joint Actions and Projects of Family Members

Principal Investigator: **Dr. Richard Young**, Professor, UBC Counselling Psychology
Registered Psychologist
Department of Educational & Counselling Psychology,
and Special Education
Faculty of Education
University of British Columbia

Co-Investigators **Vanessa Silva, B.Sc.**
M.A. Candidate, Counselling Psychology
University of British Columbia

Introduction

Thank you for your interest in participating in this research study, which will explore the caregiving process of adult children and/or spouses of a family member with dementia. Vanessa Silva (Co-Investigator) is carrying out this research as part of the requirements for completing the Masters of Arts degree in the Department of Counselling Psychology at the University of British Columbia. Vanessa's supervisor and the Principal Investigator on this project is Dr. Richard Young.

Purpose of this study

The purpose of this study is to learn more about the ways family members engage in the caregiving process for a family member with dementia. We are hoping to learn more through the conversations family members share with us and with each other about what the experience of caregiving has been like for them. We hope that through these conversations with you and your partner, we can identify the current projects and actions that you are working on and that are meaningful to you.

You can help us understand more about how family members engage in the caregiving process and help us find ways that professionals can support others going through similar transitions. You do not have to be involved in this study if you do not want to. You can leave the study at any time. If you and/or your partner decide to withdraw from the study, we will discontinue your participation at that time. Furthermore, we will discuss your wishes as to whether you would like information you have provided to-date included in our analysis.

Who can participate in this study?

This study is open to any family members over the age of 18 years, who are fluent in English and who currently serve in a caregiving context for a family member with dementia. Family

members who identify as caregivers must be providing care at least three hours a week for a family member who live at home (not in residential care). Any family members that meet these criteria are eligible to participate.

What does this study involve?

Consenting to participate in this study involves one video recorded interview and one follow-up interview with the Co-Investigator, Vanessa Silva, and an additional co-researcher. The total time for these procedures could range from 3-4 hours. The location of these interviews will occur in a private space at the University of British Columbia.

We will first conduct a telephone screening interview for you and your partner to determine eligibility for the study. This telephone screen includes questions which will ask you to provide some basic demographic information. Following this there will be an in person interview where we will go over the procedures for this project, including any questions you may have. We will be asking you to talk about and explore your experiences as a caregiver for your family member with dementia. We will help you identify important current projects (short-term life goals) that you and your partner are engaged in pertinent to the caregiving process.

If you agree to be in this study, you and your partner will two face-to-face sessions with our researchers, who are research assistants from our research team. The sessions will occur at the University of British Columbia Point Grey campus. During the first session, you will be asked to talk about whatever caregiving issue is most pertinent to you and your partner. The research assistants will leave the room so that you and your partner can continue to carry on a conversation about the caregiving process. We will video record you during this conversation. Then, you will watch the video recording of the conversation alone with one of the researchers. They will stop the video once every minute. They will ask you what you were thinking or feeling during that part of the conversation.

The second session, about two weeks after the first session, the researchers will go over the main points of what you talked about in the first session, ask you if the main points are correct or not, and explore the main points further. You will be invited here to make any changes including removing or adding information, to ensure that your voice has been accurately represented. This follow-up session will take approximately one hour.

The total time involved for the whole study will be approximately 3-4 hours over about a one month period. The sessions will be video- and audio-recorded. They will take place in a private location at the University of British Columbia.

We will give each participant an honorarium of \$25 for participating in the study and to help cover the costs of transportation and parking.

What happens to the results of the study?

The results of this study will be reported in a graduate thesis and may also be published in journal articles or presented at conferences. Once completed, the thesis will be a public

document that will be available through the UBC library.

What are the possible risks of participating?

We might talk about sensitive or personal things during the session. It is possible that discussing past or current experiences may bring up painful or difficult feelings and experiences. If a question makes you feel uncomfortable, or you don't want to talk about it, you can choose to not answer a question and you can ask to stop the session at any time. We will be providing you with a list of agencies or counselling resources that can help support you should you need the assistance during or after this study.

What are the potential benefits of participating?

Participating, or taking part in this study might help you think about your experiences in being a family caregiver. This study is important to people who are caregivers for family members with dementia, service providers, and policy-makers (the people who help make decisions for the government). By being involved in this study, you will help us understand what parts of family caregiving were difficult, easy, or important. You can help other people and service providers better help other families experiencing the caregiving process for a family member with dementia.

Confidentiality

We will protect your privacy and confidentiality throughout your participation. Your participation in our study and the content of your sessions will be kept confidential. Video recordings will not be shown or used for any other purposes than to show to you as a participant and by the research team for data analysis. Your name or your image will not be on any tapes, reports, or presentations (public talks). All the information from your session will be kept in a locked filing cabinet in Dr. Young's research office at UBC. The only people who will have access to this material are the research team. We will not use your name in any reports of the completed study.

At the end of the study, we want to tell others what we have learned about the caregiving process for family members with dementia. We will share the information with you, and organizations that provide help and education to families with individuals with dementia. We will also share an overview of what we have learned with other researchers and professionals. We will share a brief summary with you at the end of the research study via email and share the information regarding any publications that pertain to the study.

Choosing to stop your participation

Your participation in this study is your choice. You may stop or quit at any time. You may also have a family member or friend whom you trust speak with us and look over this consent form before you agree to take part in our study.

Who do I contact for more information about the study?

If you have any questions or concerns about anything to do with the study you can contact Vanessa Silva. You may contact the lead researcher, Dr. Richard Young.

Who do I contact if I have any questions or concerns about the rights of research participants?

If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in this study, contact the Research Participant Complaint Line in the UBC Office of Research Ethics at 604-822-8598 or if long distance e-mail RSIL@ors.ubc.ca or call toll free 1-877-822-8598.

Consent Form

I understand that my participation in this study is entirely voluntary (I do not have to participate if I do not want to) and, I may refuse to participate or leave the study at any time. By signing this, I am showing that I have received a copy of this consent form for my own records. My signature below indicates that I consent to participate in this study. I do not waive any of my legal rights by signing this form.

Name of Participant (Please Print)

Signature of Participant signing above

Date (mm/dd/yyyy)

Appendix D: Interview Guide

Dear Participants,

Action Project Method research is designed to give you the space to have a conversation around an issue much as you would in the real world. In particular, for this study, the conversation is focused on how you engage in the caregiving process for your family member with dementia. During the first part of this session (approximately fifteen minutes), I will focus on listening to your process of caregiving at the individual and joint level- this is called the warm up conversation. Following this, I will have you continue a conversation with your family member without the researchers present, on the joint-nature of caregiving as it pertains to you both. Immediately following this, we will play back a video of your conversation and ask you “what were you thinking?” and “what were you feeling” at various points in the recording.

To get things started, for the initial warm-up conversation, I may ask you to share more about the following things:

- 1) How long have you been providing care for your family member?
- 2) What kinds of tasks do you help provide care for?
- 3) How have you navigated caregiving along with all your other roles (parent, friend, worker)?
- 4) What changes have you experienced in your life since you have become a caregiver?
- 5) How have you navigated caregiving together?
- 6) What are the challenges that come up as you negotiate with each other?
- 7) In what ways have you managed to support each other in this caregiving process?
- 8) If it has, how has caregiving changed the way you interact with each other?

Appendix E: List of Element Codes for Analysis Procedure

Acknowledges

- Minimal statements such as um-hmmm
- Yes, sure, OK, that acknowledges the statement by the other

Advises

- I think the best idea for you is to get a job in the short term and then think about your educational concerns in the long-term.

Agrees

- Yes, I agree, That's true, You're right, I concur, We see eye to eye.

Ambiguous response

- Response is unclear, not readily interpretable, has more than one possible meaning, hazy or fuzzy meaning

Answers question

Apologizes

- Sorry, I apologize, Oops, My-bad.

Approves

- Positive evaluative or judging statement (affirms)
- It's a great idea that you're _____.
- Validates
- "That's fantastic" "It's good" "It's fine"

Asks for clarification (further explanation or expansion)

- Can you tell me more about that?
- I'm wondering which of your dilemmas seems to have the most importance for you right now. Can you give me more details about that situation?
- Can you expand on that?

Asks for confirmation

- Am I getting this right?
- Is that what you mean?
- So, you'll be here for next week's appointment?

Asks for feeling state

- How do you feel about that?
- What does it feel like when you _____?
- Tell me more about that sadness.

Asks for information (more factual in nature)

- When was it that you moved out of your parents' home?

Asks for justification or reasons

- Why was that?
- What was your rationale for making that choice?

Asks for opinion or belief

- What do you think about that?
- What do you believe to be the most important aspect of becoming an adult?

Asks for speculation or hypothetical scenario (challenges)

- What if . . . ?, Let's say _____ happened?, How do you think you would handle _____?

Clarifies

- Usually in response to asks for clarification. Involves giving more information to clear up an ambiguity or a misinterpretation.

Complains

- My employer gives me every crappy shift. It ruins my weekend plans.

Confirms

- So you are coming for dinner tonight. Response to a request for further information.

Continues other's statement

- After an interruption
- Continues own statement after a pause

Demands

- Tells the other what to do.

Describes future

- My mother will be visiting next week.

Describes other

- It seems to me that you _____. (is usually used with expresses perception)
- It sounds to me that your sister is really trying to work things out with the family.
- In the annotation – describe who the “other” is.

Describes past

- I told my mother that I was grateful for everything she has done for me.

- I went to college 5 years ago.
- When I was a kid, I was bit by a dog and now I can't seem to get over it.
- I used to hate my brother.

Describes possibility or hypothetical situation

- If I can't get into UBC I know I will be disappointed (sometimes used with other codes – i.e. describes self, expresses perception)

Describes self

- I suck at tennis
- I'm a generous person.
- It really wasn't like me to behave that way.

Describes situation or event

Disagrees (denies)

Disapprove

- Negative evaluative or judgment statement
- "I don't like them"
- "She really should have known better than to behave like that."

Dismissive or diminishing statement

- Oh c'mon, Don't be silly, That's nonsense.
- "Whatever"

Elaborates

- Extends a previous statement
- Provides more information, adds depth to a previous statement, gives a deeper explanation.

Encourages

- Give confidence, cheer, hearten

Evaluative or judging statement

- Focused on a phenomenon, or event, or person with approving or disapproving

Expresses anger

- (irritation, exasperation, rage, disgust, envy, torment)
- I was so pissed off with him.
- I was furious.

Expresses belief or disbelief (concrete as opposed to tentative)

- I just know things are going to work out

- I don't believe in God
- I can't believe this is happening to me.

Expresses desire

- I need, I want, I wish....

Expresses disgust

- (usually more of a facial expression, distaste, expression of not liking or loathing)
- It totally grossed me out. It was disgusting to be in that cell with all those crack addicts.

Expresses dissatisfaction

- School isn't what I thought it would be.
- Expression of dissatisfaction.
- Sometimes coded with expresses sadness or some other emotion.

Expresses doubt

- I'm not sure I can handle that.
- I doubt I have the ability to get into university.
- Questioning, has emotional content
- Not about indecisiveness
- I don't know about that, I don't know if that fits for me (POSSIBLE OTHERS – disagrees, dismissive statement)

Expresses fear

- (horror, nervousness)
- Overwhelmed or expressing a lot of concern.

Expresses frustration

- It totally sucks that I didn't get the job I wanted.

Expresses gratitude

- Thank you. I really appreciate what we are doing here. I'm thankful for this opportunity.

Expresses humor

- Tells a joke
- Says something funny (either intentional or unintentional)
- Contextual use of humour, use of wit, lightheartedness, kidding around

Expresses joy

- Happiness, cheerfulness, zest, contentment, pride, optimism, enthrallment, relief

Expresses like

- Liking of idea, object, person; not love

Expresses love

- (affection, lust, longing)

Expresses perception or opinion or hunch

- It seems to me that you may be quite similar to your dad in that way.
- Is usually a tentative statement or interpretation
- Correct me if I'm wrong but I think _____.

Expresses realization

- I realize that these people are very important to me.
- Client expresses an "ah-ha" moment in the present tense.
- Wow, I've never thought about that before. (add surprise to the code)
- "Oh no, really. I hadn't thought about that consequence before" (add disappointment to the code)

Expresses sadness

- Suffering, disappointment, embarrassment, shame, neglect, regret, sympathy
- I was so depressed about it.
- I was really hurt when my stepmother attacked me like that.

Expresses surprise

- More of a facial expression
- I was really surprised that she reacted that way.
- "Oh wow!"

Expresses uncertainty

- Is about decision-making. Not being able to sort something out. Not able to accurately predict.
- I'm not sure.
- I can't decide what option to take.

Expresses understanding

- I get that. I see where you're coming from.
- That makes sense. I see what you mean.

Expresses worry

- I'm worried about my exam.

Incomplete statement

- Can be questions, statements, or sentences.

Interrupts

Invites or elicits a response

- Use of hand gesture to elicit a response from a client.
- “You know what I mean?”
- “Right?”

Laughs

Paraphrasing

- Repeats previous statement
- Repeats a previous statement in your own words

Partial agreement

- “Sort of” – specifying the amount of agreement.
- Half hearted agreement,

Pause

- A break in the sentence or dialogue.
- Silence, a pregnant pause.

Praises

- Compliments, admiring remark, accolade, congratulates
- “Good for you”. “Look at you!” “Congratulations.” “It’s terrific that you have such great insight”

Provides information

- You can get an application on-line if you go to the website.

Reflects affect

- Capturing an image that is beyond what was previously stated beyond paraphrasing
- Advanced empathy, empathy
- You felt disappointment when you didn’t get into UBC this year.

Reflects cognition

- Advanced empathy, empathy
- That was a tough situation for you.
- “You didn’t think that was the right way to go”
- “So you’ve been thinking about a number of career options over the last year”

Requests

- Asks the person to do something. Asks for
- Could you sign this form?

States a plan

- I'm going to go to school next term
- I will be here next week for my appointment

Suggests

- I'd like to suggest that your father didn't mean to hurt your feelings.

Unintelligible response

- Cannot be understood on tape or through transcription

Appendix F: Overall Analysis

.1 Case 1

Context:

Amy and Becky are sisters in their mid 40's who both live in Vancouver. Their father has Alzheimer's and their mother is his primary caregiver. Both sisters serve as secondary caregivers and provide help with caregiving in various ways (e.g. respite care, ADL, finances, etc). They engaged in this study to share about their experience navigating caregiving conversations within their family, particularly with their mom.

Interview:

Topics of the conversation included:

- Discussing their individual approaches and strategies for having conversations about caregiving for their father with their mom.
- Talking about the recent conversations they have had with their mom, other family members, and friends related to caregiving
- Coming up with steps to address with their mother next time they see her
- Discussing the impact of how their mom's decision making process around caregiving impacts them
- Talking about their recent experiences of their father and how he has changed over time

Interactional Pattern:

Amy:

Describes situation (25); expresses perception or opinion or hunch (19); acknowledges (15); describes self (13); elaborates (11); describes other (7); clarifies; agrees (6); describes possibility or hypothetical (5); asks for clarification (4); asks for confirmation (3); expresses doubt; describes past; continues other's statement; evaluative or judging statement (2); answers question; states a plan; expresses desire; expresses worry; expresses like; stating a plan; expresses joy; disagrees; asks for sadness; asks for speculation or hypothetical scenario; provides information (1)

Role:

Amy played a leading role in initiating the conversation by describing her role in situations pertinent to the topic of caregiving (n-25), expressing her opinion (n-19), and describing herself (n-13). She also allowed for balance in the conversation by acknowledging what Becky had to say (n-15), agreeing or clarifying (n-12), and asking for clarification or confirmation (n-7)

Becky:

Acknowledges (24); expresses perception or opinion or hunch (23); describes situation (21); describes other (17); asks for clarification (9); describes self; expresses doubt; elaborates (6); evaluative or judging statement; describes past; continues other statement (4); describes possibility or hypothetical situation; asks for opinion or belief; asks for

confirmation; interrupts (3); agrees (2); disagrees; clarifies; expresses understanding; paraphrasing; confirms; stating a plan; expresses realization; asks for information; incomplete sentence; expresses uncertainty (1)

Role:

Becky initially followed S' lead in the conversation by acknowledging what Amy was sharing (n- 24) and asking for clarification (n- 9). She helped balance the conversation by expressing her perception/opinion (n-23), describing various situations pertinent to caregiving (n-21), evaluating what Amy shared (n-4) and continuing Amy's statements (n-4)

General Description of Interaction (1-2 sentences):

Amy led the conversation initially by sharing what she has been hoping to address with their mom regarding caregiving for their dad. She was dominant at the start of the conversation, describing her recent interactions, expressing her perceptions of those interactions, and describing herself in depth. Becky gave space for Amy to share, acknowledging her experience, but also expressing her own perception of the situation. She then shared her experience of recent interactions and her opinion of priorities regarding caregiving.

Intentions and Purposes:

Amy:

- 1. To engage with Becky around planning next steps to support their parents**
 - Sharing the hypothetical situation of her dad being placed in a temporary residential facility in the case of a crisis situation; acknowledging what R is sharing; clarifying who attended the doctor's appointment with their parents; conveying her understanding of how often her parents go to the specialist; admitting that she hasn't followed up on things with the case manager or care homes
 - Elements: Agrees, describes situation, describes self, clarifies, asks for confirmation, expresses doubt

- 2. To emphasize her own approach to addressing caregiving concerns with her mom**
 - Sharing her perspective that her mom needs to connect with her; sharing her strategy for making room for caregiving conversations with her mom; explaining how she intentionally structures her visits with their parents; describing her strategy of talking to her mom in the car when dad is asleep; acknowledging that time is a factor for these conversations
 - Elements: Describes situation; elaborates; expresses perception or opinion or hunch; describes self; describes other (mom)

- 3. To address how they both should navigate having caregiving conversations with**

their mom

- Acknowledging that they haven't yet made time to have a discussion about how to approach their mom; expressing uncertainty at whether she and Becky should have the conversation with mom together; sharing her opinion that it may be better for her and Becky to have separate conversations with mom; conveying her perspective that it isn't a bad thing that she and R have different approaches in communicating with their mom;
- Elements: Expressing doubt; expresses perception or opinion or hunch; stating a plan; describing situation; expressing joy; elaborates; asks for clarification

4. To share her new insights into how to approach caregiving conversations with her mom

- Sharing that she met with her aunt and talked about caregiving; stating that she is going to be upfront with her mom; describing the consequences of not being up front with her mom; continuing to describe the content of her conversation with their aunt; sharing that she said to her mom that she needs to consider the impact of either parent's death on herself and Becky; explaining that her aunt suggested she reword things to explain to her mom, that a form of love would be her mom addressing her concerns
- Elements: Elaborates; describes situation; describes self; expresses perception or opinion or hunch; describes possibility or hypothetical situation

5. To talk about her recent challenges interacting with her parents

- Expressing how difficult the interactions (particularly around meals and visiting) have been; clarifying how it is difficult to know what to talk with their dad about; conveying her observations that their dad can't concentrate in larger groups; describing how she noticed her dad getting tired and asked to help him with the task
- Elements: Describes other (dad); describes situation; provides information; acknowledges; expresses perception or opinion or hunch; describes past

Becky:

1. To understand Amy's recent experiences with their mom

- Inquiring for more details about Amy's conversation with their aunt; acknowledging that she also avoids caregiving conversations with her mom; agreeing with Amy that there is no time to talk with mom; acknowledging that the conversations take small steps; listening to what Amy is sharing
- Elements: Acknowledges; describes situation; expresses perception or opinion or hunch; expresses understanding; paraphrasing; interrupts; evaluative statement

2. **To share her own experience of her recent interactions with their mom**
 - Conveying her perspective of the difference between herself and Amy; describing how she uses a more sensitive approach to communicate with her mom; sharing that she tries to make sure a caregiver is present on Friday; sharing her perception that their mother wants to be more social with others but not with their dad
 - Elements: Acknowledges; describes situation; describes self; elaborates; evaluative or judging statement; expresses perception or opinion or hunch; describes possibility or hypothetical situation; describes other (mom); describes situation
3. **To share her perspective on what next steps to take to support their parents**
 - Giving her opinion that it is better for her mom to have a caregiver on Friday while she and Amy can cover the weekends; describing an example of how she subtly makes suggestions to her mom; expressing uncertainty over how to approach health care conversations with her mom; asking whether S has attended any of their recent health care visits; acknowledging that their mom wouldn't want help pushed on her; explaining her strategy of being an undercover detective when she calls her parents on the phone
 - Elements: Describes self; describes situation; asks for clarification; expresses realization; expresses doubt; expresses perception or opinion or hunch; expresses desire; asks for confirmation
4. **To support her perspective by sharing about others' experiences**
 - Bringing up the point that their uncle shares the same opinion as their aunt and themselves regarding mom needing to plan for the future; describing the conversation their uncle had with their mom and how blunt he was; describing a recent conversation she had with someone who was dealing with family caregiving; elaborating on how her friend's dad deteriorated in the care home;
 - Elements: Describes situation; describes other (friend, dad); describes possibility or hypothetical situation; evaluative or judging statement; acknowledges; describes situation; expresses doubt

Narrative Feedback:

Response: Participants agreed that the narratives were accurate and did not recommend any changes

Meaning & Concerns: Participants did not ask for any changes, add feedback or voice any concerns

Project

Initial: The project that we see you both working on is finding ways to be a team while also using your individual strengths to support your parents in your own way.

Final: The project that we see you both working on is trying to be functional amidst the

challenges of the context of your father's caregiving, while holding in abeyance the contrasting emotions that you both have.

Conceptualization of participant goals

Joint Goals

Initial

1. To discuss the different roles you play in communicating with your mother
2. To share strategies for interacting with your parents
3. To discuss hypothetical future scenarios and future next steps

Final

1. To discuss how to navigate caregiving conversations with their mother
2. To share and process each other's recent interactions with their mother
3. To discuss strategies and next steps for their parents welfare (e.g. housing, health care, etc.)
4. To process the impact their dad's health care changes have had on them

Differences: Very little change in goals from before and after coding. There is the addition of Goal #4-“to process the impact their dad's health care changes have had on them”

Amy

Initial

1. To share with Becky how you have been reflecting on your past interactions with your mom
2. To understand Becky's recent thoughts on your parents' situation and her own experience of interacting with your mom
3. To discuss your parents' current living situation and how to approach talking about future options with them

Final

1. To engage with Becky around planning next steps to support their parents
2. To emphasize her own approach to addressing caregiving concerns with her mom
3. To address how they both should navigate having caregiving conversations with their mom
4. To share her new insights into how to approach caregiving conversations with her mom
5. To talk about her recent challenges interacting with her parents

Differences: In the initial narrative one goal, “to understand Becky's recent thoughts on

your parents' situation and her own experience of interacting with your mom" is not reflected in the coding. After coding, there are two additional goals that focus on Becky's opinion on how they should be approaching caregiving conversations that is not reflected in the original narrative.

Becky

Initial

1. To highlight the different roles that you play compared to Amy, when it comes to interacting with your parents
2. To validate Amy's perspective that your mother needed more support and to offer your own thoughts
3. To discuss what a good care facility for your dad might look like and what steps you both would have to take to get him there

Final

1. To understand Amy's recent experiences with their mom
2. To share her own experience of her recent interactions with their mom
3. To share her perspective on what next steps to take to support their parents
4. To support her perspective by sharing about others' experiences

Differences: The goals for Becky were similar between initial and after coding. In the initial narrative one goal emphasized the different roles they both played, however, after coding, the emphasis seemed to be more on elaborating Becky's own perspective relative to Amy.

Emerging Constructs:

- I. How to approach and support their mom about how she is caregiving for their father-the focus is on the spouse of the actual patient not really on providing care for the patient at all.
- II. Acknowledging the difference in their own roles and communication strategies but checking in with each other in order to be on the same page
- III. Anxious, overwhelmed, and fearful but feeling motivated to come up with a plan
- IV. Wondering what the other sister is thinking and how they would take their suggestions, but not directly vocalizing their uncertainties

.2 Case 2

Context:

Christina and Dan are husband and wife in their early 50's who live in Surrey. Christina's maternal grandfather, who lives with the family, has Alzheimer's disease. Christina serves as the primary caregiver while Dan serves as a secondary caregiver. Both provide caregiving in various ways including ADL, finances, meal preparation, doctor's appointments, etc. They also utilize care supports, such as health care aids, throughout the day to help provide respite for the family. They engaged in this study to share about their experience navigating caregiving conversations regarding their grandfather.

Interview:

Topics of the conversation included:

- Sharing their frustrations and comparing previous experiences with various health care supports
- Exploring additional supports they need and could utilize to help with caregiving for their grandfather
- Negotiating how and when they each could take a break from caregiving/work
- Sharing their perspectives about what their caregiving line is

Interactional Pattern:

Christina:

Describes situation (23); Acknowledges (17); Expresses perception or opinion or hunch, Confirms (14); Describes possibility or hypothetical situation, Agrees (13); Continues other's statement (10); Describes other (grandfather), Expresses uncertainty (9); Asks for clarification (7); Clarifies (6); Expresses doubt, States a plan (4); Ambiguous response, Answers question, Describes self, Elaborates, Expresses fear, Evaluative or judging statement, Incomplete statement (3); Asks for information, Asks for opinion or belief, Disagrees, Expresses desire (2); Asks for speculation or hypothetical scenario, Expresses dissatisfaction, Expresses like, Expresses frustration, Expresses gratitude, Interrupts (1);

Role:

Christina played more a passive role in the conversation by responding to Dan's statements. She did this by describing situations (23), acknowledging (17), agreeing (13), confirming (14) and clarifying (6). She also brainstormed caregiving solutions by describing hypothetical situations (13) and stating a plan (4). She shared her discomfort with the current caregiving situation by expressing uncertainty (9), doubt (4), and fear (3).

Dan:

Expresses perception or opinion or hunch (28); Describes situation (24); Describes other (20); Describes possibility or hypothetical situation (15); Asks for clarification (13); Confirms (12); Clarifies; Agrees; Asks for speculation or hypothetical scenario (10); Evaluative or judging statement (9); Acknowledges (8); Expresses uncertainty; Incomplete statement; Elaborates; Continues other's statement (7); Invites or elicits a

response; Suggests (6); Asks for opinion or belief; Disagrees; Ambiguous response; Interrupts; Asks for confirmation (5); Describes past (4); Expresses frustration (3) States a plan; expresses dissatisfaction; Expresses disgust; Asks for information (2) Advises; Expresses gratitude; Expresses doubt; Expresses realization; Partial agreement; Answers question (1)

Role:

Dan played more of a leading role in the conversation, initiating various topics by describing situations (24), describing others (20) and expressing his perceptions (28). He also speculated about their future caregiving outlook by describing hypothetical situations (15). He encouraged Christina's opinion by asking for speculation (10), asking for opinion or belief (5) and inviting a response (6). He clarified his understanding of the current caregiving context by asking for clarification (13), expressing uncertainty (7), and asking for information (2).

General Description of Interaction:

Dan led the conversation by suggesting various topics and by inviting Christina to share a response or opinion. He was also very quick to share his perception or beliefs and describe their current situation and his opinion of others (e.g. care aids). Christina responded to Dan by sharing her perception and expressing her uncertainty and doubt about various caregiving decisions. She also focused the conversation on brainstorming alternative caregiving supports by making suggestions and describing possible hypothetical situations.

Intentions and Purposes:

Christina:

1. To process and share what her limits to caregiving for her grandfather are

- Functional steps: Explaining why it's difficult to give a precise answer about the caregiving line; sharing that a hypothetical caregiving line would be when grandpa is no longer mobile and needs a wheelchair; thinking that in past conversations she is usually back-pedaling with her decision about the caregiving line (SC); thinking that she's never really articulated where the line is (SC); sharing her reluctance to take a break and send grandpa away every weekend; expressing uncertainty with why she struggles to send grandpa for respite care; feeling defensive when Dan says she needs a break (SC); feeling very supported by Dan (SC); thinking how much she has had to take on since her mother died (SC); feeling pulled as she wants to do more for her grandpa but also be there for her son and husband (SC); thinking that she wants to make everyone happy (SC); thinking she doesn't want to be a failure (SC); thinking that she's come a long way in letting others help her (SC)
- Elements: Expressing uncertainty; describes situation; describes self; describes others;

2. To assess their current care support and brainstorm alternative care options

- Functional steps: Stating that care aids were supposed to take care of the meals; feeling happy that they are coming up with a solution for what to do with grandpas meals (SC); thinking that she can't keep everything on her plate and needs to delegate (SC); stating that 20 minutes of care support for bed time is sufficient; thinking their suggestions make sense but they are also impossible (SC); thinking the Health Authority is going to send the lowest paid work because it's a business (SC); feeling resigned that they can't do anything to change the health care system (SC); listing of previous care aid supports she has used in the past; stating that arranging meals for grandpa has been a challenge;
- Elements: Clarifies; describes situation; suggests; describes other; acknowledges

3. To agree with Dan's frustration and experiences with available health care supports

- Functional steps: Agreeing with Dan's recommendations regarding finding care support; agreeing with Dan that common sense and experience is important for the work care aids do; thinking that they have had these conversations before (SC); expressing her wish that there were more subsidized care aid options; thinking she's more on board with getting in more private care support than before (SC); thinking she's at a point where she is ready to give up some of the caregiving responsibilities (SC)
- Elements: Agrees; expresses desire; expresses frustration; describes situation; describes others; expresses perception or opinion or hunch

Dan:

1. To invite Christina to share her perspective on her limits with caregiving

- Functional steps: Getting the conversation started; asking what the line for caregiving is; pressing Christina to clarify her answer; stating that 24h caregiving is where his line is; asking Christina if she could take a break every other weekend; thinking that there is always a point where Christina pushes back when talking about taking a break (SC); thinking that Christina likes to be in control of what happens to grandpa (SC); thinking that Christina can't blame herself if something were to happen to him when they were away (SC); feeling frustrated trying to convince Christina to take a break (SC); sharing that nobody has an expectation that anybody should work 24 hours a day except Christina; thinking that Christina is being defensive (SC); thinking that they have conversations that go round and around in a circle (SC); thinking that he can't plan for a vacation until she figures out what to do with grandpa and commits to something (SC); thinking that they have to cut routine things out of their life because they have to rush home to take care of him (SC)
- Elements: Invites or elicits a response, suggests, expresses a perception or opinion or hunch; interrupts; describes possible or hypothetical situation

2. To share his opinion and experiences with available health care supports

- Functional steps: Suggesting that Christina calls Veterans to set up direct billing; stating that it would be convenient for Christina to have meals provided for; describing how big the stress of meal planning for grandpa can be; asking why Christina doesn't have an ongoing list of care aid companies to choose from; highlighting past examples of how care aids have not followed the care plans prepared for them; thinking that they have had this conversation over and over (SC); thinking that its really frustrating for Christina as she is more affected (SC); feeling concerned for E and how she can never get a break (SC); wanting to encourage her to do what she thinks she needs to do (SC);
- Elements: Invites or elicits a response; describes situation; expresses perception; suggests; describes past; describes other

3. To talk about alternative options for additional care support

- Functional steps: Sharing his opinion that care aids revert back to their school training; comparing new care aids with older ones who use more common sense; feeling worried for Christina and everything she misses out on (SC); feeling frustrated by all that she deals with, with the care aids (SC); wondering how they are supposed to navigate the health care system (SC); emphasizing that the care aids need to specialize in one specific thing; thinking that Christina doesn't want to make grandpa feel bad (SC); saying that he understands why care aids are impatient to leave; thinking that they have to keep maneuvering within the system (SC); thinking about Christina's family (uncle) who are always checking in on what they do with grandpa's money (SC); thinking why Christina's family doesn't come around to check that they're not taking advantage of grandpa (SC)
- Elements: Describes situation; expresses frustration; expresses perception; describes others; describes possibility or hypothetical situation

4. To share his perspective on grandpa's current health status

- Functional steps: Sharing how his mom's support needs are different then grandfather's as he is more of a falls risk; sharing his belief that his mom won't fall unless the ground is unsteady; thinking that the caregiving line for Christina will always get pushed (SC); feeling frustrated for Christina and how she can't get the support she needs (SC); thinking that they are comparing two different situations (SC); stating that he doesn't think grandpa has reached the caregiving line yet; thinking that it's a normal thing they do comparing his mom and her grandpa (SC); stating that grandpa's mobility (distance) is already limited; advising Christina to not inconvenience or harm herself trying to move grandpa around; expressing his gratitude for having the wheelchair; thinking how grandpa always used to resist the wheelchair (SC); feeling concerned about Christina's safety and her getting physically hurt (SC)
- Elements: Describes situation; advises; describes other; expresses perception; expresses frustration; clarifies; invites or elicits a response

Narrative Feedback:

Response: Participants agreed that the narratives were accurate and did not recommend any changes

Meaning & Concerns: Participants did not ask for any changes, voice concerns or offer any additional feedback

Project

Initial: The project that we see you both working on is supporting each other and working to come to an agreement on what the limits to caregiving might be within the family context.

Final: The project that we see you both working on is coming up with alternative care supports while also negotiating the limits to caregiving for your grandfather

Conceptualization of participant goals

Joint Goals

Initial

1. To discuss what the line might be when you both decide to take next steps in your grandfather's care
2. To compare care supports you have had in the past and brainstorm additional resources you might tap into
3. To navigate when and how you could take a break from caregiving

Final

1. To express frustration and compare previous experiences with various health care supports
2. To explore additional supports they need and could utilize to help with caregiving
3. To negotiate how and when they each could take a break
4. To talk about what their caregiving line is

Differences: The main difference before and after coding is that before coding the primary goal was discussing what the caregiving line is for both of them. After coding this did not seem to be a major joint goal. A new goal that emerged from coding was to compare and express frustration over health care supports they utilized in the past. Similar to before coding, joint goals that were identified were brainstorming additional supports they could utilize as well as negotiate how to take a break from caregiving.

Christina

Initial

1. To explain why it is easier for you to do the caregiving rather than involve external support
2. To share your struggle with taking a break from caregiving

3. To explore other options for providing food for your grandpa

Final

1. To process and share what her limits to caregiving for her grandfather are
2. To assess their current care support and brainstorm alternative care options
3. To empathize with S's frustration and experiences with available health care supports

Differences: In the initial narrative, Christina's goals were more focused on her explaining or sharing her perspectives or experiences, particularly around her caregiving limits. After coding, her goals shifted to reflect more how she was processing during the conversation itself. After coding one of her goals was revealed to be empathizing with Dan and his frustration with their current health care supports.

Dan

Initial

1. To direct the conversation towards determining what a limit for caregiving might be
2. To help Christina come up with additional resources that might support her caregiving
3. To address Christina's need and plan for a break

Final

1. To invite Christina to share her perspective on her limits with caregiving
2. To share his opinion and experiences with available health care supports
3. To talk about alternative options for additional care support
4. To share his perspective on grandpa's current health status

Differences: Before coding, the goals for Dan were largely focused on he was eliciting Christina's perspective on limits to caregiving for their grandfather. After coding, his goals also seemed to focus on him sharing his own perspective and opinion about their current health supports and to address alternative options.

Emerging Constructs:

- I. Supporting the primary caregiver (Christina) as she tries to balance the demands of caregiving and family
- II. Acknowledging the differences in their own perceptions and limits around caregiving
- III. Negotiating their caregiving boundaries (e.g. when to take a break) despite having different expectations
- IV. Taking stock of their current caregiving support and brainstorming alternative resources they can tap into

.3 Case 3

Context/Warm Up Conversation:

Eveline and Fiona are mother and daughter who both live in Vancouver. Eveline serves as primary caregiver for her mother who has Alzheimer's disease. Eveline's daughter, Fiona, recently moved back into the family home and serves as a secondary caregiving for her grandmother. Eveline agreed to take on sole responsibility of caregiving for her mother and has little support from her other family members. Eveline works full time and has care aids routinely support her mother with ADLs and medical needs during the day. Eveline and Fiona engaged in this study to share about their experience navigating caregiving conversations within their family, particularly around sharing roles.

Interview:

Topics of the conversation included:

- Sharing differing perspectives on how to approach caregiving tasks
- Talking about the impact that experience and knowledge have on caregiving
- Negotiating Fiona's caregiving responsibilities
- Discussing the importance of routine in caregiving

Interactional Pattern:

Eveline:

Describes situation (19); Expresses perception or opinion or belief (17); Describes other ; Acknowledges (13); Describes self (10); Disagrees (8); Asks for clarification (7); Invites or elicits a response (6); Elaborates (5); Evaluative or judging statement; Asks for confirmation (4); Expresses desire; expresses like (3); Describes possibility or hypothetical situation; Continues other's statement; Interrupts; clarifies; provides information; partial agreement; agrees (2); Asks for opinion or belief; Suggests; Describes past; paraphrasing; Expresses need; Expresses uncertainty; approves; paraphrasing; Confirms (1)

Role:

Eveline played more of a dominant role in the conversation by describing her understanding of the situation (19) and expressing her perception (17). She also facilitated Fiona's sharing by asking for clarification (7), inviting a response (6) and asking for confirmation (4). She shared her opposing views by disagreeing (8), giving evaluative statements (4), continuing Fiona's statements (2) and interrupting (2).

Fiona:

Expresses perception or opinion or hunch (14); Describes situation (7); Describes other (6); Elaborates; expresses gratitude; describes self; expresses uncertainty (5); Continues other's statement; expresses like (4); Expresses doubt; clarifies; confirms; incomplete statement; describes possibility or hypothetical situation; suggests; partial agreement (3); disagrees; expresses realization (2); Asks for confirmation; expresses dislike; agrees; expresses desire; invites or elicits a response (1)

Role:

Fiona played a more passive role in the interaction as she expressed her perception, described various situations and described others in response to Fiona's prompts. She was displayed apprehension in the conversation through expressing her uncertainty (5), doubt (3), and through incomplete statements (3) and partial agreements (3).

General Description of Interaction (1-2 sentences):

Eveline and Fiona expressed opposing opinions throughout their conversation with Eveline expressing her opinions and inviting then challenging Fiona's own perceptions. Though they acknowledged what the other was saying both Eveline and Fiona would respond to the other's sharing with conflicting views.

Intentions and Purposes:

Eveline:

1. To share her own perspectives of how caregiving should be approached

- Functional steps: Explaining that she knows how exactly to help grandma; stating that she would have to teach Fiona how to do tasks specific to caregiving for grandma; feeling a desire to get ideas from Fiona as to how she can help (SC); thinking that Fiona doesn't know how to help (SC); feeling sad and frustrated that Fiona isn't able to help (SC); thinking that grandma knows the routine as she's been doing this for years (SC); feeling angry having to explain things to Fiona (SC); stating what she does helps train grandma to get used to routine; giving her opinion that it's not necessary to speak to her grandma when brushing her teeth; thinking that she has to be as strong as possible so she doesn't get emotional (SC); thinking that if she lets her emotions and thoughts get to her head then she will get depressed (SC); thinking that Fiona is criticizing her instead of helping (SC); thinking that sometimes she can't deal with Fiona and the struggle of negotiating caregiving tasks; thinking that it's not just about caregiving for the person with Alzheimer's it involves everything in the house (SC); thinking that she has adapted to her mom having Alzheimer's (SC); stating that no one tells her about caregiving it is something that has become common sense for her
- Elements: expressing perception, opinion or hunch; describes situation; describes other; evaluative or judging statement

2. To understand and challenge Fiona's perception of her role in caregiving

- Functional steps: asking Fiona for her opinion on what helping looks like; stating that they have two different opinions of what helping is; thinking that it's hard to get ideas from Fiona (SC); feeling a desire to get ideas from Fiona as to how she can help (SC); feeling frustrated that Fiona can't think of ways to help (SC); giving her opinion that it would be helpful for Fiona to do other things around the house; sharing that household tasks can be stressful; listing all the household things she needs to do on top of helping grandma; explaining that it's easier to do the direct caregiving tasks herself because Fiona does it incorrectly; suggesting that Fiona ask her directly if she's uncertain about a specific task; agreeing with

Fiona that there are things she knows and Fiona doesn't

- Elements: Expressing perception or opinion or hunch; inviting or eliciting a response; suggests; elaborates; describes other

3. To stress the importance of sticking to a caregiving routine

- Functional steps: Stating that there is a caregiving routine with grandma; explaining that grandma gets distracted when the routine is broken; sharing her perspective that routine (not change) is good for people with Alzheimer's; giving her opinion that grandma knows the routine well and any change will confuse her; comparing her grandma to a small baby; stating that she needs a break from other things (not caregiving tasks); disagreeing with Fiona that routines are stressful; describing an example of how routine is helpful; agreeing with Fiona that she doesn't have that same common sense; agreeing that she needs to share this information with Fiona as she doesn't know;
- Elements: Describes situation; disagrees; expresses perception or opinion or hunch; agrees

Fiona:

1. To express her uncertainty with her caregiving role and compare their caregiving competency

- Functional steps: Expressing her uncertainty with knowing how exactly to help; giving her opinion that Eveline gets mad at her when she tries to help out; feeling oppressed or restricted from doing the things she wants to do (SC); feeling stuck and trapped (SC); expressing her doubt with knowing when Fiona has planned to do household tasks; giving the example of Fiona already cleaning when she tries to help; thinking it would have been more prudent to say "I understand" (SC); feeling defensive and reactive to what Fiona is saying (SC); sharing her perspective that she will help grandma in a different way; giving her opinion that Fiona has better caregiving techniques as she's been helping for much longer; giving the example of not knowing what to do when her grandma's fingers bruise; expressing her perception that they need to work together; suggesting that Fiona could just share the specific caregiving knowledge that she has; sharing her perception that her mom has common sense around caregiving while she doesn't
- Elements: Expresses uncertainty; expresses perception or opinion or hunch; suggests; describes situation

2. To share her perceptions about her mom's caregiving approach

- Functional steps: Sharing her perspective that the way her mom brushes grandma's teeth is a lot of work; feeling like she is ten years old (SC); feeling angry that Fiona is telling her what she already knows (SC); feeling angry that she is not being heard (SC); sharing her perspective that grandma will speak and listen during these tasks; thinking that she has to accept her mom's responses otherwise it will just be hurtful (SC); feeling frustrated that her mom doesn't talk to grandma (SC); thinking it would help if her mom just acknowledged to her

grandma that she was brushing her teeth (SC); feeling hope that things could be better (SC); expressing her opinion that her mom needs a break; sharing her perspective that routines are stressful; providing a hypothetical example of an evening event (dinner) as a time that routine needs to be broken

- Elements: Describes situation; suggests; expresses perception or opinion or hunch; disagrees; evaluative or judging statement

3. To share her desire to help with caregiving tasks

- Functional steps: Reiterating that she likes to do things for her grandma; giving a suggestion of how she could help with grandma (e.g. feeding her one day); thinking that household tasks aren't what she wants to do (SC); thinking there are other things she would genuinely love to do (SC); expressing she would like to do things that help ease the burden for Fiona; sharing that she would like her own responsibilities with grandma (e.g. brush her teeth, put a pillow behind her back); feeling exasperated that Fiona is telling her things that she already knows (SC); thinking that her mom is disintegrating as she lives in the same house (SC); expressing her desire to help; asking why she can't help with grandma every once in awhile
- Elements: Expresses perception or opinion or hunch; expresses desire; invites or elicits a response; suggests; describes self

Narrative Feedback:

Response: Participants agreed that the narratives were accurate. Fiona recommended a small change be made to the background/caregiving context which were then incorporated into the findings.

Meaning & Concerns: Participants did not ask for any changes, voice concerns or offer any additional feedback

Project

First session: The project that we see you both working on is sharing your different caregiving perspectives with and understanding each other in order to facilitate a more effective caregiving strategy for the family

After analysis: The project that we see you both working on is emphasizing your individual caregiving role in order to challenge and clarify the other's caregiving role

Conceptualization of participant goals

Joint Goals:

Initial

1. To share your individual understanding of the division of caregiving tasks
2. To discuss with each other the importance of keeping a routine in caregiving
3. To navigate the roadblocks in communicating about caregiving with each other

Final

1. To explore their differing perspectives on how to approach caregiving tasks
2. To discuss the impact that experience and knowledge have on caregiving
3. To negotiate the caregiving role that Fiona has

Differences: The main goal of sharing individual perceptions on caregiving did not change. Prior to coding, the goal of discussing the importance of keeping a routine shifted to discussing the impact that experience and knowledge has on caregiving. There was also a shift in Goal 3 in the initial narrative as, after coding, emphasis was more on negotiating Fiona's caregiving role as opposed to navigating roadblocks in communication.

Eveline:

Initial

1. To understand what Fiona's perspective is on her caregiving role
2. To stress the importance of routine in caregiving.

Final

1. To share her own perspectives of how caregiving should be approached
2. To understand and reflect on Fiona's perception of her role in caregiving
3. To stress the importance of sticking to a caregiving routine

Differences: The goals before and after were largely unchanged. The main difference was that, after coding, there was the addition of the main goal of sharing her perspective of how caregiving should be approached.

Fiona:

Initial

1. To have your mom understand that you want to help with caregiving
2. To share different approaches to caregiving tasks
3. To emphasize the importance of clear communication.

Final

1. To express her uncertainty with her caregiving role and compare their caregiving competency
2. To share her perceptions about her mom's caregiving approach
3. To share her desire to help with caregiving tasks

Differences: The goals are largely the same before and after coding. The main difference is that before coding one of the goals identified was emphasizing the importance of clear communication. However, after coding, this shifted to Fiona instead expressing her uncertainty and comparing her caregiving competency to that of Eveline.

Emerging Constructs:

- I. Exploring their differing perspectives on how to approach caregiving tasks
- II. Discussing the impact that experience and knowledge have on caregiving
- III. Challenging caregiving roles and who is responsible for what tasks
- IV. Containing their emotions so they are not overwhelmed and can communicate in light of the daily demands of the situation
- V. Negotiating what caregiving tasks encompass- that they go beyond direct caregiving and involve household tasks
- VI. Unwillingness to communicate their internal processes or emotional content (i.e. sadness, anger, not being heard)
- VII. Attempting to convince the other of their own perspectives on caregiving
- VIII. A notion that there is a right way to do caregiving

Appendix G: Counselling Resources

Adler Centre - Counselling Clinic: 604-742-1818
adlercentre.ca/clinic.html

Burnaby Clinical Psychology Centre: 778-782-4720
sfu.ca/psychology/clinical-psychology-centre.html

Family Services of Greater Vancouver, Counselling Program: 604-874-2938
fsgv.ca/find-the-support-you-need/counselling/

Family Services of the North Shore: 604-988-5281
familyservices.bc.ca

Living Systems Counselling: 604-926-5496, ext. "0"
livingsystems.ca/counselling/locations-fees-services#Counselling

Mood Disorders Association of BC: 604-873-0103 x 2
mdabc.net

Moving Forward Family Services: 778-321-3054
movingforwardfamilyservices.com

New Westminister UBC Counselling Centre: 604-525-6651
ecps.educ.ubc.ca/clinical-instructional-resources/new-westminster-ubc-counselling-centre

Oak Counselling - 604-266-5611
oakcounselling.org/

Scarfe Counselling Centre, UBC: 604-827-1523
ecps.educ.ubc.ca/cnps/scarfe-counselling-clinic

Simon Fraser University - Counselling Clinics, Surrey Clinic - 604-587-7320
sfu.ca/education/centres-offices/sfu-surrey-counselling-centre.html

SUCCESS - Individual and Family Counselling Program: 604-408-7266
successbc.ca/eng/services/family-youth/counselling-service/611-individual-and-family-counselling

UBC Psychology Clinic: 604-822-3005
clinic.psych.ubc.ca/

Alzheimer's Disease Specific Resources

Alzheimer Society of BC: 604-681-6530

i. <http://alzheimer.ca/en/bc>

ii. <http://alzheimer.ca/en/bc/We-can-help/Regional-Resource-Centres>

Alzheimer Society of Canada

<http://alzheimer.ca/en/Home>

Family Caregivers of British Columbia: 1-877-520-3267

<https://www.familycaregiversbc.ca/>

First Link ® Dementia Hotline

Province-wide: 1-800-936-6033

Lower Mainland: 604-681-8651

Fraser Health- Caregiver Support: 1-855-412-2121

<https://www.fraserhealth.ca/health-info/home-and-community-care/services/caregiver-support/>

Government of B.C.- Family & Social Supports

i. <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors>

ii. <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/caring-for-seniors/training-and-caregiver-role-management-tools>

North Shore Community Resources: 604-985-7138

<http://www.nscr.bc.ca/information/caregiver.html>

Seniors First BC

<http://seniorsfirstbc.ca/link-categories/caregiver-resources/>

Vancouver Coastal Health- Caregiver Support: 604-263-7377

<http://www.vch.ca/your-care/home-community-care/care-options/caregiver-support>