Abstract

Understanding the needs of families and in particular spouses of people with early-onset dementia (e.g., those who develop a dementia under the age of 65), has become increasingly recognized as an area of importance by the healthcare community because of the negative biopsychosocial consequences to patients and families. However, there is a dearth of research about the experiences of younger spousal caregivers. The goal of this qualitative, grounded theory study was to understand the experiences of spouses of people who have frontotemporal dementia and early-onset Alzheimer's disease, throughout the disease trajectory. I conducted semi-structured interviews with 30 participants; 17 had partners with frontotemporal dementia and 13 had partners with early-onset Alzheimer’s disease. Spouses were recruited with the intention of capturing various stages of the caregiving career. The participants ranged all the way from spouses of people who were newly diagnosed, to individuals who had already been placed in long term care. Three themes emerged from the data analyses initially: (1) issues related to
life-stage, (2) disease invisibility and (3) living with continuous uncertainty. These themes led to a fourth theme of caregivers feeling like they were falling through the cracks of the healthcare and social support systems since there are no appropriate services/policies set up for younger people affected by dementia. Finally, a core theme of surviving chronic crises emerged as spouses described how they coped with the continuous challenges related to their partner’s dementia. Spouses live through series of crises that they need to constantly manage, leading to a feeling that they are barely surviving. The most common coping strategies that spouses employed through the illness trajectory included: advocacy, reframing, self-care and spirituality. Over the caregiving trajectory, spouses adapted to the impact of having a partner with early-onset dementia. The applicability of the findings is that they point to the timing, to the types of clinical interventions and to policy initiatives.
Acknowledgments

The mountains are calling and I must go.
- John Muir

I owe a multitude of thanks to the people who are responsible for getting me to this point. I first want to thank my parents, who taught me from the time I was young, that no mountain was too high to climb (as long as I could have M & Ms at the top). Nothing much has changed since those early days.

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Chapter 1

Introduction

This qualitative study examines the views and experiences of spouses whose partners have early-onset dementia (EOD; people who first have symptoms of dementia under the age of 65), in particular frontotemporal dementia (FTD; for this study, FTD is used as an umbrella term to encompass behavioural variant FTD plus the language presentations) and Alzheimer's disease (AD). This research incorporates the perspectives of 30 spouses who are at different stages of the caregiving trajectory, utilizing a grounded theory approach. A multidimensional theoretical framework that includes the life course perspective, a biopsychosocial model of stress and coping and a temporal model of dementia caregiving, informs this study. The ultimate goal of this dissertation is to explore the needs of EOD spousal caregivers so we can provide appropriate interventions both at the clinical and policy levels of social work practice.

I have worked as a social worker at the Sam and Ida Ross Memory Clinic at Baycrest Health Sciences for 23 years, and over my career I have seen an increase in the number of younger individuals coming to the clinic. What has become evident in my years of practice has been the dearth of empirical knowledge and services for this group of patients and their families. It is this firsthand awareness of the gaps in services for this younger group of people that has led me to conduct this research.

This chapter outlines the background and the context for this study and it specifies the aims and objectives of this research. It also explores the significance and scope of this work. Finally, the organization of this dissertation is delineated through the presentation of the contents of each chapter.
Background and Context for the Study

"Dementia is a syndrome, usually of a chronic or progressive nature, caused by a variety of brain illnesses that affect memory, thinking, behaviour and ability to perform everyday activities" (World Health Organization, 2012). There are different causes of dementia. Alzheimer’s disease (AD) is the leading cause of dementia, representing 63% of all dementias. As of 2012, there were 500,000 Canadians living with Alzheimer’s disease or a related dementia (Alzheimer’s Society of Canada, 2012).

Most of what is known about dementia and dementia caregiving has focused on late-onset dementia (LOD; e.g., dementia that starts after 65 years of age) since it is the most common age group affected by it (Alzheimer's Society of Canada, 2012; LoGiudice & Hassett, 2005). However, EOD is increasingly being recognized as an important medical and psychosocial problem, with devastating consequences for both the people with dementia and their families (Sampson, Warren, & Rossor, 2004; Werner, Stein-Shvachman, & Korczyn, 2009). Out of the 500,000 Canadians with dementia, 71,000 (about 14%) of them are under the age of 65; and of those approximately 50,000 are under the age of 60 (Alzheimer’s Society of Canada, 2012). Prevalence rates vary between 5% and 14% of the dementia population (Chemali et al., 2012; Nunnemann, Kurz, Leucht, & Diehl-Schmid, 2012). FTD and early-onset AD are the most common causes of EOD and their prevalence rates are comparable (Nunneman et al., 2012).

According to Canadian statistics on dementia, the pressure to provide care resides with families (Alzheimer’s Society of Canada, 2010). Family caregivers are motivated to provide support both because of their profound commitment to the patient and because family caregiving is a fundamental tradition in our society (Grunfeld, Glossop, McDowell, & Danbrook, 1997;
Pearlin, Mullan, Semple, & Skaff, 1990). Other reasons why families provide care include: “a sense of love or reciprocity, spiritual fulfillment, a sense of duty, guilt, social pressures, or in rare instances greed” (Brodaty & Donkin, 2009). Family caregiving has been an important topic of research since the early 1970s (Sims-Gould & Martin-Matthews, 2007) and the knowledge about dementia caregivers has grown rapidly since 1995 (LoGiudice & Hassett, 2005; Rosalyn Carter Institute of Caregiving, 2012).

Cantor (1983) observed that while family caregivers of people with dementia experience stress, increased strain exists among caregivers with closer ties to the care recipient (e.g., spouses experienced greater strain than adult children, who in turn experienced greater strain than other relatives). Although spousal caregivers sometimes report positive feelings toward caregiving (Andren & Elmstahl, 2005; Carbonneau, Caron, & Desrosiers, 2010; Connell, Janevic, & Gallant, 2001), looking after a partner with dementia is difficult; it requires time and energy while incurring a sense of loss of personal control. These variables have been associated with depression and physical health problems (Norton et al., 2010). Of all dementia caregivers, spouses are the group of caregivers at highest risk for psychological and physical health problems (Baumgarten et al., 1992; Cantor, 1983; Meshefedjian et al., 1998; Pinquart & Sorensen, 2003; Schneider et al., 1999). More importantly, research shows that spousal caregivers of younger people with dementia have greater perceived difficulties than older spousal caregivers (Arai, Matsumoto, Ikeda, & Arai, 2007; Harris, 2004; van Vliet et al., 2010; Zanetti et al., 1998) and report a greater level of caregiver burden (e.g., the overall physical, emotional, social and financial costs of caregiving; Freyne, Kidd, Coen, & Lawlor, 1999; Nunnemann et al., 2012; Rosness, Mjorud, & Engedal, 2011). Spousal caregivers in the early-onset group are more at risk of experiencing loneliness compared with other EOD caregivers such as parents or
children (Luscombe, Brodaty, & Freeth, 1998). In my social work practice I have observed that spouses of EOD patients face additional challenges compared with those whose spouses develop LOD. For example, spouses of people with EOD describe the difficulties of balancing work and raising children while providing care for their spouse and sometimes their own parents. There are also significant financial worries and, given the young age of patients with EOD, this group often falls through the cracks of existing services and programs which are developed for the over 65 age group. These areas observed through clinical practice are supported by the literature that currently exists (Beattie, Daker-White, Gilliard, & Means, 2002; Grinberg et al., 2007; Harris, 2004; Harris & Keady, 2009; Nunneman et al., 2012; Svanberg, Spector, & Stott, 2011; Williams et al., 2001).

Study's Objectives/Purpose

EOD is an under-researched area of dementia care and there is a particular dearth of knowledge related to EOD families; especially how they cope with the difficult tasks of caregiving for a younger person with dementia (Roach, Keady, Bee, & Hope, 2008). This is not surprising, given that in our society, dementia is socially, culturally and professionally constructed as an older person’s disease (Harris & Keady, 2004; Rose et al., 2010) and therefore, the emphasis has been related to the late-onset types. The significance of EOD caregiving stems from the need to address the scarcity of research about this population. As the numbers of people with an EOD come to the forefront, it becomes imperative that clinicians try to understand the population of their caregivers so that appropriate interventions can be developed to support them in their efforts to care for their spouses.
The goal of this qualitative study is to build on the limited knowledge that is currently available about the experiences of spouses of people with EOD; specifically spouses of people with AD and FTD as these are the two most common causes of EOD. The reason for choosing spouses, as opposed to other types of familial caregivers, is that it is the EOD partners who provide the majority of the care in this age group, yet very little has been published about them. The overarching question of this research is to understand how spouses of persons with EOD view caregiving issues/challenges at different points of the disease progression.

Significance and Scope

Given the limited research in this area, there is no clear understanding about the EOD caregiving experience and on how to best provide services for this group of spouses. Through my extensive involvement in this area of practice, I have found that caregivers, clinicians, and community associations that serve these groups (e.g., Alzheimer’s Society, memory clinics) need resources to develop appropriate services that meet the unique needs of the EOD population. My clinical observations and the early research evidence about the effects of these dementias on spouses, show that the socially disruptive behaviours and the relative youth of people with EOD present unique challenges to spouses (Nunnemann et al., 2012). The impact of difficult behaviours coupled with the early-onset of these dementias cannot be dealt with by using the current LOD caregiving intervention models, which are the ones currently employed, since they do not take into account the ‘off-timing’ of the life stage when the dementias occurs.

This research, based on the voices of the caregivers themselves, will aid in advocating for the development of services so that their unique needs can be met in the most effective ways. Although social workers possess a number of transferable skills in this area, they need to be alert
to an emerging knowledge base concerning this population. EOD cases require a lot of tenacity and advocacy on the part of the social worker, since these clients otherwise fall through the social safety nets of services (e.g., community provided welfare services at local, provincial and/or federal level geared towards reducing poverty in the community), which are tailored to an older patient population (e.g., adult day programs and drug coverage that are geared to the over 65 group). FTD and early-onset AD cut across different generations and thus, the demands for social workers often include working with adolescents in the home (generally not an area of competency in geriatric social workers), working with schools and children’s aid agencies. At the same time, social workers need to know about supports for EOD patients and the EOD patients’ and spouses’ parents, who are ageing as well and need support from their children.

A goal of this study is to develop a preventive model of care rather than waiting until families are in crisis to obtain social support and professional services. This study will inform health and social welfare policy development with the idea to create effective and innovative interventions and programs to support spouses looking after their EOD partners (Bakker et al., 2010; Beattie et al., 2002).

Thesis Outline

The contents of each of the chapters are outlined below, and they follow the sequential elements of the research process as they evolved through this study.

Chapter 2 (literature review and theoretical frameworks) is divided into two sections. The first one is a scoping review of the literature as it relates to dementia caregiving. First, it explores the research on LOD and compares its findings to the emergent EOD caregiving literature. The second part explores the theoretical frameworks that underpin this study, which include the life
course perspective, stress and coping theory and the stages of dementia caregiving model and their relevance to this study’s population.

Chapter 3 (research design and methodology) describes the choice of research methodology and study design. It explains the rationale for using a qualitative methodology and more specifically the grounded theory approach to data collection and analysis. Strategies are discussed to foster trustworthiness of the data. The chapter concludes with the ethical considerations which are the foundations of a trustworthy study.

Chapter 4 (findings - the experience) explores how participants experience living with a partner with EOD. This chapter is divided into three sections. The first section includes descriptive statistics, which are presented to contextualize this group of young spousal caregivers, followed by an exploration of behavioural disturbances in FTD and AD. Behavioural disturbances are analyzed as a way to understand how these behaviours affect the study’s participants. Third, this chapter concentrates on qualitative findings and focuses on the main categories and themes that emerged from the in-depth interviews.

Chapter 5 (findings - survival and coping) explores the most commonly utilized coping strategies by spousal caregivers as it continues to develop the core themes discussed in the previous chapter.

Chapter 6 (the analytic story) is the essence of the study, whereby the stories of 30 participants are presented through a comprehensive narrative developed from the emerging data analysis.

Chapter 7 (the EOD model of spousal caregiving) moves the reader forward, taking the knowledge developed in Chapters 4, 5 and 6 to develop a substantive theory about the experience
of spousal caregivers. This substantive model is presented diagrammatically. The framework is then applied as a basis to propose interventional clinical and policy initiatives.

Chapter 8 (conclusion) synthesizes the analysis of the study by providing an overview of the study, the findings, contributions and implications to social work practice. The next steps for research and policy development are explored. Finally, the study's limitations are considered.
Chapter 2

Literature Review and Theoretical Models

This chapter presents the literature review and the theoretical background for this thesis. This chapter is divided into two sections. The literature review includes relevant dementia caregiving research and it states its relevance to this study. This section will first report on findings from late-onset dementia (LOD), since this is where most of the knowledge on dementia caregiving has been developed. It then compares findings between LOD and EOD caregiving and it explores areas where there are similarities between the two populations. Then the focus changes to EOD caregiving research, including its methodological limitations. Finally, nine specific studies carried out on EOD spousal caregivers are analyzed and their significance is applied to this study.

The second section of this chapter focuses on three distinct theoretical models, which help to establish the groundwork for understanding EOD spousal caregivers. The first model reviewed is the stress and coping model since most of the dementia caregiving literature is framed from this perspective. Then, the chapter concentrates on the life course perspective and its relevance to understanding spousal caregivers. The life course perspective provides an overarching framework to the study since it helps contextualize the trajectory of spouses over the course of the entire disease. Third, the application of a stages, or temporal approach, to dementia care is provided since this study is interested in the experience of caregiving over time. Finally, the relevance of each of the theories is presented in an integrated manner.
Literature Review

Dementia Caregiving

The vast majority of the literature dealing with the impact of dementia on families has focused on caregiver outcomes and has focused on LOD (Arai et al., 2007; Baumgarten et al., 1992; Freyne et al., 1999; Schulz et al., 1995; Vitaliano et al., 2004). Even though this study deals with the experience of EOD caregivers, given the very limited research on EOD caregiving, it is important to review the body of knowledge on LOD caregiving as it is the logical comparable body of knowledge and have been the basis of models of care that have been utilized with the EOD population. Therefore, this paper first explores the LOD caregiving literature to assess if findings from LOD can elucidate areas that are relevant to the EOD caregiving group.

There are other conditions in the under 65 age group, such as acquired brain injury (ABI; damage to the brain, which occurs after birth and is not related to a congenital or a degenerative disease, Ontario Shores, 2014), that share similar psychosocial consequences to spouses of affected individuals (Braine, 2011). However, I chose not to include them as part of the literature review since the major difference between ABI and EOD is that ABI is a chronic condition and EOD is a terminal disease. (World Health Organization, 2006). ABI is more stable than the progressiveness of EOD, which would result in differences in sequelae for families (World Health Organization, 2004) and therefore, this body of knowledge will not be explored.

For the purpose of this study, the review of the literature was a scoping review (e.g., a process of synthesizing a range of evidence in order to convey the breadth and depth in an area
This literature review section is divided into three sub-sections. The first part focuses on an overview of the LOD caregiving literature and where available, comparable EOD findings. The second section explains the clinical features of EOD and the two most common types of EOD (early-onset AD and FTD). The third section includes an analysis of the EOD caregiving literature.

**Comparisons Between LOD and EOD Caregiving Outcomes**

It is well established that caring for a relative with dementia has negative physical and emotional impact on the care provider (Brodaty & Donkin, 2009; Norton et al., 2010; Pinquart & Sorensen, 2003; Vitaliano et al., 2002; Vitaliano, Zhang, & Scanlan, 2003). Most of what is known about dementia caregiving comes from studies conducted with older adults with dementia since dementia is mainly a disorder of late-life (Alzheimer’s Society of Canada, 2010). The focus of LOD caregiving research has been to identify patient and caregivers characteristics that predict caregiving stress (Covinsky et al., 2003; Vitaliano, Scanlan & Zhang, 2003). Overall, LOD caregivers report more health problems, less life satisfaction, more overload, increased familial conflict, more anger and more use of psychotropic medication than caregivers of older people with physical impairments (Livingston, Manela, & Kantona, 1996; Morris, Morris, & Britton, 1988; Schofield et al., 1998; Schultz et al., 1995; Vitaliano, Young, & Zhang, 2004). The chronic stressors of dementia caregiving raise the risk of health problems, are linked with the onset of new diseases, and speed up pre-existing caregivers’ illnesses (Mittleman, Roth, Clay, & Haley, 2007; Pinquart & Sorensen, 2003; Vitaliano, Zhang, & Scanlan, 2003).
Although limited, the findings in the EOD literature are analogous to the outcomes for caregivers of older people with dementia (Kaiser & Panegyres, 2006; Nurock, 2000; Riediejk et al., 2006; Svanberg, Spector & Stott, 2011; Takano & Arai, 2005). However, there are differences: there are additional issues due to the ‘non-normative’ timing of the EOD such as employment and dependent children (Svanberg, Spector, & Stott, 2011). The issues pertinent to the EOD group will be explored in depth in this chapter’s EOD caregiving research section.

**Patient characteristics.**

Numerous studies of LOD caregivers suggest that it is the patient’s behavioural disturbance (e.g., agitation, aggression, eating disturbances, obsessive-compulsive behaviours, psychotic symptoms), not the cognitive decline (e.g., poor memory or mental disorganization), that is the most significant predictor of social and emotional distress for the caregiver (Bedard, Pedlar, Martin, Malott, & Stones, 2000; Davis & Tremont, 2007; Rankin, 2008; Robinson, Adkinsson, & Weinrich, 2001). Schulz, O’Brien, Bookwala, and Fleissner (1995) conducted a literature review of 41 articles on dementia caregiving and found that the only patient characteristic that is a consistent source of stress for spouses is problem behaviour (e.g., aggressiveness, wandering and disinhibited behaviour). Pinquart and Sorensen (2003) reviewed 228 studies and came to the same conclusions. Surprisingly, Schulz and colleagues (1995) found that cognitive (e.g., memory, executive functioning) and functional (e.g., managing finances, dressing, toileting) impairments did not have an effect on caregiver outcomes. Yet when Pinquart and Sorensen (2003) did their review and analyzed the results separately for spouses versus adult children, they found that functional/physical impairments did have a negative effect on spousal caregiver outcomes. This negative effect on LOD spouses may be attributed to spouses being older and thus unable to physically care for their elderly partners. The findings of patients'
behavioural problems as a predictor of caregiver stress are consistent with findings in the EOD literature (Arai et al., 2007; de Vugt et al., 2006; Kumamoto et al., 2004; Mourik et al., 2004). These results will be reviewed more specifically in the EOD caregiving review section.

**Spousal caregiver characteristics.**

The research on the effects of caregiver characteristics on stress, physical and psychological morbidity is inconsistent. However, certain characteristics have been found to be more common. Overall, spouses with lower incomes, who use emotion-focused coping skills and who have fewer social supports experience more caregiver burden (Brodaty & Donkin, 2009). Other caregiver variables such as education and quality of past and present relationship between patient and spouse have not been found to have a reliable effect on spouses’ level of caregiver burden (Brodaty & Donkin, 2009). There appears to be a consistent finding that there are gender differences (Yee & Schulz, 2000). In a comprehensive review of 31 articles, Yee and Schulz (2000) found that wives who were caregivers reported more psychiatric morbidity than caregiving husbands when compared to noncaregivers. This gender difference is consistent with the EOD caregiving literature (Takano & Arai, 2005). In the LOD group, even though wives report higher caregiver burden, husbands have a higher rate of heart disease and metabolic syndrome, which has been found to be influenced by the chronic stress of caregiving (Vitaliano, 2002). Men may report fewer difficulties, yet their physical health suffers. In the EOD literature, there were no comparable studies exploring cardiovascular risk factors in EOD spouses.
Psychological and physical factors.

Psychological factors: caregiver burden.

Most of the studies on psychological effects related to LOD caregivers have measured caregiver burden (Pinquart & Sorensen, 2003). The term “caregiver burden” refers to the physical, psychological, social and financial problems that can be experienced by caregivers of people with dementia (George & Gwyther, 1986). Zarit and colleagues (1980) initially used the concept of caregiver burden in the dementia caregiving literature. Since their pioneer work on stress and burden associated with caregiving, the concept of burden has been widely applied to dementia care. Understanding why some caregivers report more burden while others remain the same or adapt over time is one of the most important goals of caregiver research (Vitaliano, Russo, Young, Teri & Maiuro, 1991). In terms of caregiver burden, caregivers of both LOD and EOD reported physical and emotional burdens (Arai et al., 2007; Freyne et al., 1999). However, spousal caregivers of younger people with dementia (45-65 years of age) had greater perceived difficulties than older spousal caregivers and greater level of caregiver burden (Arai et al., 2007; Freyne et al., 1999). A study conducted across Europe found similar results indicating that spousal caregivers of EOD patients are in an especially stressful situation (Nunnemann et al., 2012; Schneider, Murray, Benerjee, & Mann, 1999). The high levels of stress may stem from the long duration of caregiving in the EOD group and the lack of formal and informal supports (Arai et al., 2007; Freyne et al., 1999; Tindall & Manthrope, 1977; Williams, Dearden, & Cameron, 2001). EOD caregivers may have a longer duration of caring, lasting on average an extra 3.4 years longer than caregivers of people with LOD (Freyne et al., 1999; Tindall & Manthrope, 1997). The fatigue related to length of caregiving may account for higher burden in EOD caregivers (Svanberg, Spector, & Stott, 2011). The extended duration and the fatigue that ensues
were seen as risks for future caregiver mental health outcomes if not properly addressed (Arai et al., 2007). Williams and colleagues (2001) found that two thirds of EOD caregivers reported that their emotional well-being was poor or very poor and that the longer the length of caring, the worse their mental health status. This is consistent with findings on LOD caregiving (Norton et al., 2010; Vitaliano, 2010).

In terms of psychiatric morbidity, just as in LOD caregivers, anxiety and depression disorders were found to be present in caregivers of the EOD group (Rosness et al., 2011). Harvey (1998) found as many as 60% of EOD caregivers reported feeling anxious with higher rates observed among female caregivers. Kaiser and Panegyres (2007) and Harvey (1998) found depression to be prevalent among caregivers of persons with EOD, especially among spouses.

**Physical and health factors: caregiver burden.**

In the last ten years, the focus of research related to caregiving outcomes has started looking at the physical/health morbidities that accompany caregiving. Vitaliano, Scanlan and Zhang (2003) conducted a meta-analysis; the authors looked at the results of 23 studies that compared the physical health of LOD caregivers with matched LOD noncaregivers. Vitaliano and his group (2003) examined issues such as chronic stressors, psychological distress and risky health habits and then they reviewed the relationships known to exist among chronic stress, distress, health habits, health indicators and potential physiological mechanisms. They also looked at the differences between dementia spousal and adult children caregivers. Overall, they found that caregivers had a 23% higher level of stress hormones and a 15% lower level of antibody responses than did noncaregivers. Whereas this information does not mean that caregiving is hazardous to spousal caregivers’ health, it does mean that caregiving may be associated with vulnerability to illness. Vitaliano and his colleagues (2002) conducted specific
research on spouses of people with Alzheimer’s disease to find out if chronic stress, psychophysiology and heart disease were different between older adult men and women. They found that chronic stress in husbands of people with dementia led to heart disease. In wives, they found that over a longer period than men, distress led to metabolic syndrome and heart disease. In contrast to the ongoing research on LOD physical and health consequences to dementia caregiving, there has only been one study on physical morbidity in spouses of people with EOD by Bristow and his colleagues (2008), but the results are not congruent with the findings on the LOD population. The reason for these outcome differences will be further explored in the more in-depth EOD caregiving section.

**Newer trends in LOD spousal caregiving research.**

There have been two newer areas of exploration in dementia caregiving research. The first one is on positive aspects of caregiving and the most recent area of interest has been the cognitive impact of living with a partner with dementia. These two areas are being studied in the LOD caregiving population but have not been developed in the EOD group and the reason that they are included is that they are potential future research areas to consider for the EOD group.

**Positive aspects of caregiving.**

Research in LOD has begun to focus on positive outcomes (e.g., gains, satisfaction) associated with looking after a relative with dementia (Andren & Elmstahl, 2005; Bacon, Milne, Sheikh, & Freeston, 2009; Carbonneau, Careon, & Desrosiers, 2010). The constructs of ‘gain’ and ‘satisfaction’ refer to the extent to which the role of caregiver is appraised to enhance and enrich an individual’s life (Kramer, 1997). The evidence shows that there are rewards to be gained by looking after a relative with dementia. Some of the factors that contribute to positive
outcomes include a desire to promote a positive (or avoid a negative) outcome for the person being cared for; satisfaction in the reciprocity in the caregiving relationship; finding satisfaction in the caregiving situation; and using it as a way of coping with the loss associated with the dementing process (Andern & Elmstahl, 2005). The advantage of looking at positive outcomes in caregiving is that it views caregiving from a strength perspective, which recognizes the capacity for continued growth in each person. However, the research in the LOD caregiving experience has been mostly based on family caregivers as a whole, and the positive effects on spouses have not been well established. In the EOD caregiving literature there has only been one study, conducted by Nurock (2000) that found some evidence of positive effects of caregiving. Nurock reported positive outcomes with 11 out of 12 ex-caregivers reporting higher self-esteem and increased assertiveness. One difficulty in interpreting her findings is that she asked the questions retrospectively to ex-caregivers given that there is a tendency for people to reconstruct the past in the light of present situations as well as ex-caregivers having selective recall (e.g. certain characteristics are remembered and perceived as significant while others will be overlooked or re-interpreted; de Vaus, 2006).

**Caregiving outcomes: cognitive impairment.**

The latest area of research in LOD caregiving focuses on the negative cognitive sequelae of spousal dementia caregiving. It was not until 2003 that investigators reported on the cognition of caregivers and noncaregivers (Vitaliano, 2010). In 2009, Vitaliano and his colleagues published one of the first studies on the negative cognitive consequences to spouses of people with Alzheimer’s disease. They showed that spousal dementia caregivers have lower scores on a measure of cognitive function (Digit Symbol Test, DST) and higher scores on the Hamilton Depression Inventory scores, meaning more cognitive decline and more depression. According
to the authors, the implication of this research is that depressed mood in caregivers may influence the risk of cognitive impairment, which was not found to be present in the non caregiving group of spouses. Norton and his colleagues (2010) expanded on this finding: not only did they find cognitive decline in spousal caregivers, but also they found a higher incidence of dementia. Their results were astounding in that they found that spouses who had a demented partner had a six times greater risk for developing dementia themselves as opposed to spouses whose partners did not develop dementia. Vitaliano (2010) stated that that there may be other variables contributing to these findings. He stated that for one, spouse caregivers of people with dementia tend to have greater depressed mood than non caregivers and they also report poorer sleep quality; depressed mood and poor sleep are risk factors for dementia. As well, spousal caregivers tend to be more socially isolated and less social engagement results in less stimulating cognitive opportunities, which may increase the risk for dementia. Spousal caregivers also report eating more calories and having a higher fat intake with less physical activity, which increases the risk for dementia. Vitaliano (2010) pointed out that what was most important about Norton’s research was the finding that the risk for spouses of developing dementia increased from 48% to 600% when the authors incorporated into their analysis the amount of time that spouses were exposed to their spouses’ dementia. Thus, it may be the length of exposure living with a dementing partner that may have such a deleterious outcome. If this is the case, are EOD caregivers, who have a longer duration of caregiving than LOD caregivers (Freyne et al., 1999; Svanberg, Spector, & Stott, 2011) at higher risk of developing dementia? Would we see these findings in the younger population even though younger people have a lesser risk of developing dementia?
LOD dementia caregiving literature: methodological concerns.

One of the difficulties in reviewing the LOD literature is that discrepancies in findings among studies are common due to methodological concerns (Pinquart and Sorensen, 2003). The first one is that there are different subgroups of patients (e.g., all dementia diagnoses are lumped together for analysis: Alzheimer’s disease, vascular dementia, and Lewy body dementia), yet different diagnoses bear different caregiver outcomes. Second, all types of caregivers (e.g., spouses, adult children and friends) are pooled together yet degree of closeness makes a difference (Cantor, 1983; Covinsky et al., 2003; Hooker et al., 2000; Sink et al., 2006; Vetter et al., 1999).

There are also measurement issues related to the miss utilization of tools. For example, using a depression scale validated for the geriatric population such as the Geriatric Depression Scale with adult children who are younger is invalid. Another concern regarding validated tools are differences between reporting a finding of depression that was made by a clinician versus the use of self-report measures, which are less reliable (Bedard et al., 1999; Bedard et al., 2000; Pinquart & Sorensen, 2003; Schulz et al., 1995). Other limitations include the type of research design (e.g., using cross-sectional studies when prospective or longitudinal studies would have been better) and statistical techniques (e.g., using univariate/bivariate statistical methods instead of using multivariate statistical analysis, to account for the multitude of co-variates that contribute to the outcome; Malonebeach & Zarit, 1995; Montgomery, 1996; Zarit, 1989). In addition to the above methodological issues, discrepancies in findings may relate to study design stemming from a lack of use of theoretical perspectives. A lack of theoretical frameworks creates difficulties in interpreting findings. Without the underpinning of theoretical frameworks, different constructs and diverse definitions of variables among researchers can vary widely.
Overall, one of the greatest methodological challenges in LOD research is the lack of consistency in the definition and the understanding of constructs (e.g., burden, stress, depression, caregiver) among studies. Another concern is that studies are based primarily on real-world natural observations and not through experimental design. Ideally, more prospective and longitudinal naturalistic studies of different cohorts of older adults could be carried out to help tease out the variables related to LOD caregiving research. Not surprisingly, these methodological concerns in LOD are present in the EOD literature. These concerns are more pronounced in the EOD literature as there is a relatively small number of cases, making recruitment more difficult. The methodological difficulties with the EOD caregiving research will be further explored in the next section.

**EOD Caregiving**

The first published papers in EOD caregiving started in the early 1990s; however, this body of knowledge remains under-studied (Beattie et al., 2002). Most studies have come from the UK, other European countries, Australia and Japan and there is not as much work being done in North America. This sub-section examines the specific literature related to EOD. This chapter first focuses on the clinical/medical presentation of EOD, early-onset Alzheimer’s disease and FTD. It is important to explain the clinical features of these diseases to grasp what spouses of people with EOD must cope with. The second part centres on a detailed analysis of EOD
caregiving, with particular attention given to nine studies on spousal caregiving. Lastly, a review of methodological concerns is included.

**EOD: epidemiological and clinical perspectives.**

Before proceeding with an analysis of the literature on EOD caregiving, a review of EOD from a clinical/medical perspective is provided. There are numerous conditions that can lead to EOD; ranging from Alzheimer’s disease to FTD to vascular dementia and many other neurodegenerative processes (Liesbon, Rauch, Graff, & Folstein, 2005). In the international literature, there is an estimated EOD prevalence rate of 5% - 9% of all dementia patients (Van Vliet et al., 2010; World Health Organization, 2012). The percentages are significantly lower than Canadian figures of 14% presented in the *Rising Tide Report* commissioned by the Alzheimer Society of Canada and published in 2010. This difference in prevalence rates may be due to the inclusion criteria of EOD. While some epidemiologists include HIV related dementias and alcohol induced dementias, others only include neurodegenerative diseases (Liesbon et al., 2005). These rates are *estimates* only as no actual incidence studies have been carried out (Alzheimer’s Society of Canada, 2010; Roach, Keady, Bee, & Williams, 2014; Alzheimer’s Association USA, 2006). Finally, a lack of international awareness of these conditions, which are only now beginning to be studied, has generated insufficient prevalence and incidence data (Beattie, Daker-White, Gilliard, & Means, 2002; Chemali et al., 2012; Roach, Keady, Bee, & Hope, 2008; van Vliet et al., 2010).

The age of onset of these dementias varies widely, and while most forms of EOD are very rare before the age of 45 (Harvey, 2001), onset is possible at even younger ages (Filley et al., 2007). EOD is more likely to have a genetic etiology than LOD cases (National Institute of Aging, 2012; Sampson, Warren, & Rossor, 2004). People with EOD differ in characteristics such
as duration of the illness and prominence of psychiatric and behavioural symptoms (Kaiser & Panegyres, 2007; Panegyres & Frenchman, 2007). There does not seem to be a sex difference in the development of EOD (Mercy, Hodges, Dawson, Barker, & Brayne, 2008). The two most common types of EOD are early-onset Alzheimer’s disease and FTD. In people under the age of 65, the incidence and prevalence rates are similar in both early-onset AD and FTD (Mercy et al., 2008; Ratnavalli et al., 2002).

**Early-onset Alzheimer’s disease (AD) and frontotemporal dementia (FTD).**

To understand the issues that EOD caregivers must contend with, early-onset AD and FTD are described below.

**Early-onset AD.**

Early-onset AD is largely characterized as a cognitive disorder. The areas of the brain affected by AD produce symptoms of short-term memory loss, word-finding difficulties and visual-spatial problems (Merrilees & Miller, 2005). Early-onset AD affects men and women equally (Fratiglioni, 1993) and the median survival in these patients is 11.7 years (Robertson et al., 2005). Social skills and the ability to interact appropriately with others are often retained late into the disease (Merrilees & Miller, 2005). Although people with early-onset AD may develop behavioural symptoms such as apathy, motor disruption, aggression, irritability, appetite changes and sleep disturbances, these do not develop on average until 4 years into the disease (Merrilees & Miller, 2005).

**Frontotemporal dementia (FTD).**

FTD is an umbrella term for a diverse group of rare disorders that primarily affect the frontal and temporal areas of the brain (areas generally associated with personality and
behaviour; Hodges, 2007). Generally, FTD affects men and women equally (Merrilees & Miller, 2005) but a study on prevalence by Ratnavalli and colleagues (2002) reports that men may be more frequently affected. The course of FTD has a mean duration of 8 years (Merrilees & Miller, 2005). The disease duration in FTD is shorter than in AD (Chow, Hynan, & Lipton, 2006). The clinical variants of FTD are either the behavioural variant FTD (bv-FTD), in which changes in personality and social conduct predominate, or the language presentation, causing aphasia (aphasia is a language disorder that results from damage to the brain; Chow, Hynan, & Lipton, 2006). The initial presentations of both clinical variants tend to converge over the course of the illness (Chow, Hynan, & Lipton, 2006). Patients who have the language subtypes of FTD start by having language and communication difficulties (e.g., aphasia; Chow, Hynan, & Lipton, 2006) whereas the prevailing presenting feature in bv-FTD is an alteration in the patient’s social conduct and personality (Merrilees & Miller, 2005). In bv-FTD, a cluster of symptoms forms the diagnostic criteria: apathy, disinhibition, a distinct lack of empathy, hyperorality and perseverative/compulsive behaviour (Rascovsky, 2011). The lack of inhibition results in impulsive or inappropriate behaviours (University of California in San Francisco [UCSF], Memory and Aging Centre, 2009). As well, the bv-FTD group has impaired insight; this is in marked contrast to patients with the language variant of FTD, who commonly recognize their deficits. As well, neglect of self-care and basic activities of daily living (ADL; e.g., hygiene, dressing) are disproportionately affected in bv-FTD compared with the language variants. Behavioural variant FTD patients have problems with initiation, planning and execution of their instrumental activities of daily living (IADL; e.g., dealing with finances, performing chores; Mioshi et al., 2007).
Why choose to focus on these two groups?

Not only are these two causes of dementia the most prevalent EOD, but both dementias have commonalities and differences that are worth exploring. Both diseases are degenerative in nature and there are no cures for them. These dementias affect people at the same life stage as their average age of onset is 45-65, and therefore the age related stressors (e.g., finances, employment, dependent children) associated with this stage are similar. Examining these two groups may reveal some important findings regarding the needs of these two populations, which would inform service provision.

EOD caregiving overview.

EOD caregiving research is still in its early stages (Ducharme et al., 2013; Roach, Keady, Bee, & Hope, 2008; Werner, Stein-Shvachman, & Korczyn, 2009, van Vliet et al., 2010) and much of the information is based on the clinical experience of health care professionals rather than on scientific evidence (Beattie et al., 2002). The lack of research in this area is not surprising since there has been a lack of awareness about EOD disorders in general (Bettie et al., 2002; Chemali et al., 2012 Harvey, 1998). Nonetheless, these EOD disorders represent an important social and medical problem because of the burdens that EOD places on patients, caregivers and demand for services (Beattie et al., 2002; Harvey, 1998, Luscombe et al., 1998; Nunnemann et al., 2012; Svanberg, Spector & Stott, 2011). As limited as the current literature is, research in this area is growing as more interest is being placed on this group of dementia patients and caregivers (Roach, Keady, Bee, & Hope, 2008; Werner, Stein-Shvachman, & Korczyn, 2009). This knowledge is necessary for the development of appropriate health care
services which are currently inadequate not only in Canada but in most countries (Bakker et al., 2013; Van Vliet et al., 2010).

The focus of early-onset dementia caregiving research has been to identify the caregivers’ characteristics, which are predictors of caregiving stress and psychological and physical morbidity (Svanberg, Spector, & Stott, 2011). Overall, the limited findings show that the issues facing this group of spousal caregivers are related to life stage issues, diagnostic difficulties, dealing with difficult symptoms and changes in relationships (Svanberg et al., 2011). The unique strains associated with EOD caregiving include financial insecurity, high stigmatization and negative effects on the marital relationship (Luscombe, Brodaty, & Freeth, 1998). EOD generally affects people who are still employed and productive and who may be the main providers for their families. There is a double financial strain in this group: not only are people not able to work due to the dementia, but in many circumstances they are not eligible for financial assistance as people under 65 do not qualify for the same financial benefits as those available to older people (Hasse, 2005). Furthermore, people with EOD might still be parents of relatively young children or may have parents who depend on them.

The relative youth of people with EOD means that individuals are mostly married or in committed relationships (Hasse, 2005) and the disease will have detrimental effects on the quality of their relationship (Harvey, 1998; Roach & Keady, 2008). The point in time when the EOD develops can affect the marital relationship in different ways (Zastrow & Kirst-Ashman, 2007). It can come about at a time when the couple is at the prime of their careers and are still raising younger children and/or adolescents. Those who develop EOD in the later period of the EOD time frame may have just retired and be looking forward to more leisure time as a couple; or the illness of a spouse at this time may be complicated by other losses such as retirement. A
common finding is that EOD spousal caregivers may feel socially isolated, especially given the lack of appropriate services and the lack of understanding of these dementias for this young onset group (Freyne et al., 1999; Harris & Keady, 2009; Kaiser & Panegyres, 2007). As well, spousal caregivers for people with EOD are more likely to be care providers for longer periods (Freyne et al., 1999; Schneider et al., 1999). Overall, caregivers of younger people with dementia have very different needs in the types of support that they require (e.g., financial support), have greater difficulty accessing placement and respite services, and have the additional challenge of fulfilling competing roles such as work and caring for children in comparison to caregivers of older people (Bettie et al., 2002; Roach et al., 2008; Williams et al., 2001).

Another challenge for EOD spousal caregivers is the frequency of misdiagnoses in this younger group (Bentham & Fontaine, 2005; Kelley, Boeve, & Josephs, 2009; Mendez, 2006; Svanberg et al., 2011; Tindall & Manthorpe, 1997; van Vliet, 2013). When dementia affects people in midlife, both family and physicians generally assume that a psychiatric disorder is responsible (Liebson, Rauch, Graff, & Folstein, 2005). The most common misdiagnoses in the EOD group are depression, stress, burnout and menopausal changes (Harris & Keady, 2004). The problem of improper diagnosis occurs because the younger-onset dementias are more diverse than the late-onset dementias; in addition, the younger-onset dementias frequently appear simultaneously with neuropsychiatric characteristics (e.g., depression, apathy, irritability, agitation/aggression) that are out of proportion with the cognitive deficits (Harris, 2004; Mendez, 2006; Reed, Cantley, Clarke, & Stanley, 2002; Roach et al., 2008). One of the reasons that there is a higher incidence of neuropsychiatric symptoms in persons with EOD is the high prevalence rate of FTD, which presents with problem behaviours as the presenting sign of the dementia (Van Vliet et al., 2010). Moreover, not only are there a high rate of misdiagnoses, but there are
delays in obtaining a diagnosis earlier in the disease process (Chemali et al., 2012; LoGiudice & Hassett, 2005; Van Vliet et al., 2010). This is due to the inability of younger persons and their families to consider the possibility of dementia at a young age, which results in a delay of seeking help. This is further compounded by family doctors being less informed about diagnoses of dementia in young patients (Werner et al., 2009).

Although these factors make it difficult to diagnose EOD in a timely fashion, a proper diagnosis is essential for several reasons. People with EOD and their families need to appreciate what is happening to the person. Physicians need to know the cause of the dementia as cause-specific treatments may exist to slow progression and reduce symptoms (USA Alzheimer’s Association, 2006). Health care and social service professionals need to know the cause of the dementia to give accurate information and appropriate treatment and services, even if very few are currently available (Weintraub & Morhardt, 2005). One potential consequence of delaying diagnosis is that even the few services that are offered at a time of crisis are reactive, rather than proactive, for when diagnosis does not happen in a timely manner, there is a delay in response and intervention (Keady & Nolan, 1994).

Overall, the literature on EOD has not distinguished between the different types of dementias or the types of caregivers. Of note, differences in the subjects’ diagnoses may account for higher burden in caregivers due to the type of behavioural disturbance (e.g., agitation/aggression, depression, anxiety, disinhibition) rather than the amount (e.g., frequency and severity; Svanberg, Spector, & Stott, 2011). Moreover, the literature clusters all caregivers under one category and rarely differentiates between spousal caregivers and other types of care providers (Svanberg, Spector, & Stott, 2011, Werner, Stein-Shvachman, & Korczyn, 2009). Research on spousal caregivers of people with FTD and/or early-onset AD is scarce. As well,
most information is from a few studies assessing small numbers of people and there are very few intervention studies (LoGiudice & Hassett, 2005; Nunnemann et al., 2012). Bakker and his group (2013) conducted a study in the Netherlands, which looked at the needs of patients and caregivers of people with EOD. This was the first prospective cohort study on the needs and course of EOD based on 215 patient-caregiver dyads. They found that in EOD, families provide most of the care, especially spousal caregivers and in particular in the later stages of the dementia. They found that there were age related differences, with younger spouses who work and have childcare responsibilities feeling more burden. They also found that there was a delay on utilizing formal supports, even though they were needed, which could be due to the lack of specialized dementia services for younger people, such as appropriate respite care supports (e.g., day programs) geared to younger people.

**EOD dementia caregiving literature: methodological concerns.**

As in the LOD caregiving literature, a main concern in the EOD literature is the lack of theoretical frameworks guiding research. Of all the studies discussed so far, there were no explicit theoretical frameworks used to direct questions or explain findings. Another methodological concern includes small sample sizes, which reflect low prevalence of EOD. The rest of the difficulties with the EOD research are not unlike the methodological concerns within the LOD caregiving research. First, kinship between patient and caregiver has an impact on outcomes. In some of the above studies, different types of relationships were analyzed together and the definitions of ‘caregiver’ were not consistent. For example, some definitions of caregivers included someone who is the ‘legal representative of a patient’; another study looked at anyone ‘who sees a patient on a regular basis’ and this was aggregated with data from adult
children and spouses. Second, in all studies but one, gender was not controlled and from the LOD literature, gender may play a role in outcomes. A third concern is the disparity in the stage of progression of the disease that people were experiencing (e.g., some of the studies included people who were newly diagnosed along with people who were already institutionalized and did not take into account the differences in caregiving stages when looking at mental health caregiver outcomes). This would affect the results as there is a temporal quality to caregiving which would have been missed given that length of caregiving is known to affect caregiver burden (Nolan, Lundh, Grant, & Keady, 2003).

Lastly, the lack of proper conceptualization of measures is a concern. An example of this includes Bristow and his group's (2008) work on stress and caregiving. They looked at stress as an acute event but they did not define stress as a chronic experience. Perhaps, their findings that FTD spousal caregivers had better immune responses (measured by IgA secretion at only one point in time) arose from measuring an indicator of ‘acute’ stress instead of ‘chronic’ stress (e.g., Vitaliano and his group’s (2002) work looking at cardiovascular disease as a measure of chronic stress). Caregiving for someone with a dementia is a chronic stressor and measuring a biomarker of acute distress may be inaccurate.

**EOD caregiving: EOD spousal caregiving specific research.**

In an attempt to find the most pertinent literature for this study, the next section focuses on studies conducted with only EOD spousal caregivers. Through a scoping review of the literature, I found nine studies where EOD spousal caregivers were the focus of the research. However, I am including in this section studies where different types of caregivers participated, but the spousal data was analyzed separately as well. In addition, given the dearth of research in
this area, studies that include mixed types of caregivers, and where spouses made up a minimum of 80% of the participants, are included as well.

Inclusion criteria consisted of the following: studies had to be published in peer-reviewed journals; articles had to be about early-onset AD and/or FTD and/or EOD caregiving and they had to be studies based on psychosocial issues related to caring for a partner with an EOD, which started before the patient was 65 years of age. Studies that dealt exclusively with evaluation of intervention and/or support, causes of early-onset dementia, medical considerations or prevalence/incidence or literature reviews were excluded.

I will first present studies I read prior to conducting this research (from 2004-2012) and were useful in the study design. The second section will present research published in 2013, during the data analysis and dissertation writing phases, and they are reviewed since they inform the discussion chapters. Studies presented include: five studies that examined FTD spousal caregiving issues (Bristow et al., 2008; Cosseddu, et al., 2013; Mourik, 2004; Riedijk et al., 2008 & 2009), one study that looked at the effect of early-onset AD on spouses (Takano & Arai, 2004), and three studies that looked at EOD spousal caregiving in general (Bakker et al., 2013; Ducharme et al., 2013; Harris & Keady, 2004; Kaiser & Panegyres, 2007).

Studies on spousal caregiving and FTD: studies up until 2012.

Bristow and his colleagues (2008) looked at the psychological and physiological impact of caring for an FTD partner. The authors studied 24 caregivers of people with FTD from a support group and compared them to 36 non-caregivers. The authors found that caring for a partner with FTD increases distress and half of the caregivers met criteria for a diagnosis of psychiatric disorder at the time of the study. One surprising finding from their study, which is
inconsistent with the general dementia caregiving literature, is that in contrast to previous research, caregiving did not lead to suppression of mucosal immunity (a marker of poor psychological well-being) and FTD caregivers actually had enhanced immunity. However, this inconsistency may be attributed to the small sample size and to the way stress was measured (e.g., stress was measured as an acute event instead of using a measure of chronic stress). Additionally, participants were recruited from an existing support group, which could affect the results as they were already receiving support.

Mourik and colleagues (2004) studied 63 patients and their caregivers longitudinally (97% of them were spouses) from nationwide neurologic and psychiatric outpatient clinics and nursing homes in the Netherlands. The authors utilized the NPI to measure caregiver distress and they found that after controlling for confounding factors, caregiver distress was most strongly related to agitation/psychosis, followed by mood. They found that disinhibition and aberrant motor behaviour were mildly related to caregiver distress, and euphoria and apathy were not significantly related to distress. Congruent with the literature on LOD, Mourik and colleagues also found that caregivers of patients living at home were more distressed than caregivers of patients living in a nursing home.

Riedjik and colleagues, in their 2008 study, looked at 63 FTD caregiver-care recipient dyads (83% were spouses) longitudinally over a two year period. They found (contrary to their expectations) that over the two year period, caregiver burden, psychological well-being, health related quality of life and relationship quality remained stable. The authors attributed this to an indication of caregiver adaptation. Riedjik and colleagues found that coping style and social support changed for the worse and these findings are consistent with the general dementia caregiving literature. In their 2009 article, which was based on their 2008 longitudinal study, the
authors also looked at caregivers’ sense of self-efficacy and found that it was unrelated to
dementia severity and patient behavioural problems. They concluded that people that look after
FTD patients and who sacrifice their personal life to caregiving had an increase in psychological
complaints and a worse physical and mental quality of life score. The strength of both this and
Mourik’s (2004) research is that they looked at caregiving longitudinally and looked at stress in
the period prior to institutionalization. In the general dementia caregiving literature, burden
peaks during the process of institutionalization (Gaugler, Kane, Kane & Newcomer, 2005; Yaffe
et al., 2002). However, in this study, caregivers reported a reduced burden during the placement
process (Riedjik et al., 2008/9). This may be because FTD caregivers feel an impending sense of
relief at the time of placement after enduring such difficult behaviours and personality changes in
the years leading up to placement.

**Study on spousal caregiving and early-onset AD: studies up until 2012.**

Only one study looked at early-onset Alzheimer’s disease and its effect on spousal
caregivers (Takano & Arai, 2005). The authors looked at gender differences and caregivers’
burden in 24 patients with early-onset AD (13 male and 11 females) and their caregivers, who
although not stated explicitly, seemed to be spouses. All patients were recruited from an
outpatient unit for early-onset AD patients in Tokyo. The authors concluded that female
caregivers are more likely to experience burden (e.g., personal strain and role strain) than males.
Of importance was the finding that the younger the patient, the higher the personal and role
strain for female caregivers. The associations between burden and gender and burden and age
were not found among male caregivers. This study reinforces the previous findings that female
caregivers are more likely to experience caregiver burden. However, in terms of the scores on the
Zarit burden interview (a 22-item self-reporting measure of perceived burden widely used in care burden research), there was no significant difference between female and males caregivers. There was no difference between men or women in terms of depression as measured by the Beck Depression Inventory (a measure of depression widely used in mental health outcome studies). As with other studies in dementia caregiving, the authors found no correlation between caregiver burden and patient's cognitive decline. The one interesting and unexpected finding in this study was that caregiver burden was not affected by behavioural problems. One possible reason for this outcome is that there were more patients with mild dementia, which is associated with fewer behavioural problems, and 79% of patients had three or fewer behavioural symptoms. This number is lower than what the general literature reports in terms of the average number of behavioural and psychiatric symptoms of dementia (BPSD; Takano & Arai, 2005). This finding could also be related to the small number of participants in the study. Another possibility is that burden of EOD spousal caregivers is less affected because they are in better ‘baseline’ health compared with spousal caregivers of LOD.

**Study on spousal caregiving and EOD: studies up until 2012.**

Kaiser and Panegyres (2007) looked at psychosocial burden of spouses of patients with EOD. They analyzed a 100 mailed in questionnaires from spouses of people with EOD (mixed diagnoses). There were 54% wives and 46% husbands. They found that husbands caring for wives had less emotional distress than wives did. They also found higher levels of depression in spouses of people with FTD. They did not find a correlation between the age of spouses and level of depression. Many respondents highlighted concerns about finances. A concern of this
study though is that the results were based on self-ratings, which underestimate level of depression. Perhaps women report depression more often than men report.

**Studies on spousal caregiving and EOD: studies published since January, 2013.**

I found three studies looking at EOD spousal caregivers published since the last search through peer-reviewed journals. Ducharme and her group's (2013) work from Montreal looked at EOD spousal caregiving, as well as Bakker and his group's (2013) study conducted in the Netherlands. The third one was from Cosseddu and her group's (2013) study from Italy, and it focused on FTD spousal caregivers.

The most relevant study for this dissertation was not published until the data analyses were completed (September, 2013). Ducharme and her group (2013) reported on the experience of Canadian EOD spouses using a qualitative methodology to interview 12 spouses whose partners were patients of a memory clinic in a Montreal teaching hospital. On average, EOD patients had dementia for 4 years prior to participation in the study. This would presume that there would not have been many people in the later stages of dementia; however, no information was provided other than an average number of years since diagnosis. Nine out of the 12 participants had a spouse with early-onset AD and only three patients had a diagnosis of either FTD or vascular dementia. There were eight women and four men interviewed. Main findings included the delay in accurate diagnosis, disclosure of diagnosis to others and denial, managing behavioural symptoms, grief, difficulty managing roles and responsibilities and problems with planning for the future. Ducharme and her colleagues also found that spouses had a common concern around managing behavioural symptoms, even though the comportment and disinhibited
behaviours would not have been much of a concern in her sample since only one or at the most two participants had FTD.

Bakker and his group (2013) looked at the use of informal care prior to institutionalization and its association with patient and caregiver characteristics. Ninety percent of caregivers were spouses, so this study was chosen for inclusion. They found that family members provide most of the care (as opposed to formal services). They also concluded that younger spouses of EOD patients who still work have the double burden of work and care responsibilities. This group has a different set of stressors and there may be important age-related differences between spouses who are still in the workforce as compared to older spouses of EOD patients.

Lastly, Cosseddu and her group (2013) conducted a study of FTD caregivers, and they looked at quality of life, burden, depression and anxiety to identify which caregivers would need more support. They looked at 56 patients with FTD and 73% of the caregivers were spouses. This study is included since the data between children and spouses were analyzed separately. The authors found that the severity of behavioural disturbances was associated with worse caregiver mental health and higher anxiety and was independently related to caregiver burden. They also found that spousal caregivers have more risk of developing depressive symptoms as opposed to children who were caregivers. They did not find a significant effect of disease duration on caregiver burden or on quality of life or mood, suggesting that there may be adaptation over time. The authors report that their findings are in contrast with Riedijk and colleagues' (2006) previous findings where they found that the longer the time caregiving, the higher the caregiver burden.
Summary of EOD literature review.

The studies reviewed in the EOD section dealt with the impact on caregivers in general, and then explored the effects EOD spousal caregivers. It is difficult to compare findings since a variety of measures were used, making comparisons between studies hard. In addition, the above studies differ in how they define caregivers and differ in their recruitment methods. Therefore, the findings are not directly comparable. Overall, the results suggest that FTD caregivers have higher burden and distress than the early-onset AD caregivers. Women report higher burden than men, and the younger the patient the more difficult it is, specifically for female caregivers. On the whole, FTD and early-onset AD caregivers report burden, depression, poor emotional well-being, anxiety and stress. While all of these investigations indicate that FTD and early-onset AD caregivers are affected by particular symptoms, these studies suggest that other factors such as life stage issues, relationship difficulties and availability of support may play a role. Finally, spousal caregivers of people with EOD have different outcomes than other caregivers with other relationships to the patient.

In order to address the difficulties with interpreting the research findings in the area of EOD caregiving, the focus needs to shift to conducting research based on theoretical models that could explain the multiple factors that predict different caregiver experiences, challenges and outcomes. With this in mind, the following section focuses on a review of three theoretical perspectives that aid in the development of a theoretical framework to help identify the factors that affect how spouses of people with an early-onset dementia cope.
Theoretical Models

How caregivers manage their stress is a hallmark of dementia caregiving research and it is basic to understanding this study's population. In this study, I am not just interested in how EOD spousal caregivers manage their stress at one point in time, but how the challenges of caregiving change over time throughout the progression of the disease. Three frameworks are presented, which will provide the theoretical background that supports this study: (1) the life course perspective (2) the stress and coping model, and the (3) stages of dementia caregiving framework. Utilizing multiple perspectives can provide differing but complementary views related to family research allowing for a fuller understanding of a process (Rank & LeCroy, 1983). In applying these theories to inform the study, my aim is to understand the factors that may influence EOD dementia caregiving. This will help frame the types of questions and other information I ask of participants, and will sensitize (e.g., sensitizing concepts suggest ways of understanding experience; Charmaz, 2003) me to other areas that need attention as well.

(1) - Life Course Perspective

The life course perspective looks at the significance of time, context, process, and meaning on human development and family life (Bengtson & Allen, 1993). Directly related to the life course perspective in the sociology literature is the life span perspective from psychology (Baltes & Graf, 1996). However, this perspective is not as helpful to understanding EOD caregiving as it does not include the significance of such issues as social timing (e.g., “the incidence, duration, and sequence of roles, and … relevant expectations and beliefs based on age”, Elder, 1994, p. 6), which is critical in interpreting the impact of caregiving in younger people.
The life course perspective is three-layered with micro, meso and macro perspectives, which can be linked. In the life course perspective, the family is perceived as a micro social group within a macro social context — a "collection of individuals with shared history who interact within ever-changing social contexts across ever increasing time and space" (Bengston & Allen, 1993, p. 470). This perspective proposes that individual development is *multidimensional* (occurs along biological, psychological, and social dimensions). In addition, it is *multispheral* (occurs in family, work, education, leisure and other spheres). It not only looks at multiple dimensions and spheres, but it also links dimensions together and spheres together (Settersten, 2003). Furthermore, individual development is *multidirectional* (different levels and rates of change across dimensions of functioning) and development involves the simultaneous occurrence of both gains (growth) and losses (declines; Settersten, 2003). Uttal and Perlmutter (1989) suggest that gains and losses may be permanent (irreversible) or impermanent (reversible) and they may be more or less advantageous or damaging depending on when they are experienced. This is relevant in FTD and AD caregiving since these dementias are *irreversible* and they represent a loss. They are detrimental to the caregiver and this damage is further exacerbated by the ill-timing of when these diseases present themselves. These diseases affect the caregiver from a biological (e.g., physical sequelae to caregiving), psychological (e.g., poor mental health outcomes) and social (e.g., loss of employment, role changes) perspective. As well, they affect the multiple spheres of family life, work, finances and leisure time. In turn, each of these areas interacts with one another, and in EOD caregiving, this interface generally produces further stress. According to the life course perspective, the timing of health transitions (e.g., the age at which dementia develops) may have important consequences for the illness course (George, 2003).
The life course perspective has already been applied to psychosocial stress research (Wheaton & Gotlieb, 1997) and emerged as a central organizing framework for the study of health, illness, and mortality (Wethington & Johnson-Askew, 2009). The notion of process serves as a natural link between the life course perspective and the study of stress and illness, as the notion of process is an inherent part of the life course perspective (e.g., the stress process, illness course and outcome; George, 2003). The life course perspective provides a foundation from which to understand the stress process, in terms of the ill-timing of the disease and how the macro and micro factors exacerbate (or diminish) caregivers’ burden. The life course perspective emphasizes the timing by which individuals and families make their transitions into and out of different roles in relation to the time schedules prescribed by society (Hareven, 1996). Timing refers to the idea that there are appropriate ages for going through various life course transitions and that these are embedded norms in our society that are pervasive and hard to change (Cohler, 1991; Quadagno, 2005). When one is ‘off-time’ in coming in and out of these roles, it creates stress. A related concept in the life course perspective, which relates to stress and coping, concerns the notion of a "time table for events" (Roth, 1963). Assumptions of particular social roles (e.g., being the caregiver to a partner with dementia) is understood in a temporal manner and thus, this caregiving role in the early-onset group emerges too early. In life, it is those unpredicted, premature and off-time events that are experienced as adverse (Cohler, 1991). This is typically what occurs with younger people with dementia, as the societal belief is that only “old people” contend with Alzheimer’s disease. Thus, the intersections between the stress process, how caregiving is experienced over time and within people’s social context, is where the EOD caregiving experience can begin to be understood. The life course perspective provides
insight into how adverse circumstances (stressors) vary with changes both in social contexts and over time.

I have chosen to focus on the life course perspective as it can be utilized as an overarching conceptual approach within which two other theoretical frameworks can be embedded. This perspective can be incorporated and used in conjunction with other biopsychosocial paradigms, such as Vitaliano's (2003) stress and coping model, which will be presented in the next section. The life course perspective provides “a set of conceptual and methodologic tools for enriching our understanding of the many domains in which human lives unfold” (George, 2003, pp. 183-4). Moreover, it is a holistic perspective as the person’s entire life is emphasized and taken into account. Thus, caregivers are not studied in the vacuum of their present predicament, but can be seen within the totality of their lives. As previously reviewed, there is a temporal dimension to caregiving, and throughout the various stages of the dementia progression there are different issues for caregivers to contend with. The life course perspective is congruent with this temporal aspect of caregiving. If one were being guided by this perspective to do research, longitudinal research would be the optimal way to reveal the temporal nature of caregiving. As presented in this paper, the life course perspective provides a strong scaffold from which to build knowledge about EOD caregiving. Its ability to support other paradigms makes it valuable in developing a comprehensive model for understanding the caregiving experience of spouses of people that develop dementia under 65.

Where are EOD families within the life course?

To stage where EOD spouses for this study are within the life course, the family life-cycle, by Carter and McGoldrick (1980) is presented. The authors describe six stages and the
corresponding developmental tasks associated with each of them. The first stage occurs when a young adult leaves the home and establishes him/herself as an individual apart from his family of origin. The second stage involves forming a relationship and becoming a couple. The third stage begins with the birth of a child, as the couple becomes parents and the extended family become grandparents. The fourth stage occurs when the child becomes an adolescent and the couple must adapt to increased independence of the child and dedicate more time to the marital relationship, career and looking after the older generation. The fifth stage begins when the children move away from home and the couple becomes a dyad again. As well, the couple takes on the grandparenting role and deals with the deaths of the older generation. Finally, the family in later life works to maintain functioning and interests, and deals with a decline in health and losses of spouses and friends and the middle generation takes on a more involved role within the family. As part of the life course, this model looks at external (e.g. illness) and developmental (e.g. life cycle transitions) stressors and disruption to the family life cycle process at a time when it is not expected (such as the arrival of an early-onset dementia). Although all normative change is to some degree stressful, when dementia arrives at an unlikely time, the stress increases (Carter & McGoldrick, 1980). Given the age of the population being studied for this research, EOD spouses fall within the third to fifth stage of the family life cycle.

**Life course perspective: critique.**

This perspective has multiple strengths; however, it is not without limitations. As the life course has changed historically, so has the “rhythm of the life course” (Settersten, 2003, p.36). One of the changes that has occurred over time is the trend towards destandardization and an increasing individualization of the life course. This has led to more individual diversity in the
timing and kind of transitions (Heinz & Kruger, 2001). Traditional assumptions that tended to be made about the life course, such as the nature and timing of employment, marriage, children, parenting and grandparenting may not hold to the same degree anymore. These life domains may be less predictable than in the past and may not follow the conventional sequence. Even with these societal changes, this perspective continues to be relevant as these transformations are reflective of the changes in the social environment; making the life course perspective a flexible perspective that can adapt over time.

(2) - Stress and Coping Models

This section explores models of caregiver burden and focuses on how the constructs presented can be incorporated into a framework to study caregiving in the EOD population. For the purpose of this study, the terms stress and distress are used interchangeably; they are meant to express experiences that are negative, painful, and something to be avoided (Rice, 1999). According to Rice (1999), stress has at least three meanings. First, it may refer to any external stimulus that causes a person to feel tense. When discussing stress as an external stimulus, it is more appropriate to call it a stressor. Second, stress may refer to a subjective response and in this sense, stress is the internal mental state of tension or arousal. This subjective response to stress may produce mental strain. Finally, stress may be understood as the body’s physical reaction to a demand. This demand promotes a natural arousal of the body to a higher level of activity, which over time could bring about exhaustion, disease and death (Rice, 1999). The way one deals with stress is through coping. Coping means engaging in behavioural and cognitive efforts to manage the environmental and internal demands and the conflicts between the two (Coyne & Holroyd, 1982).
The models of stress are offered in a historical manner starting with the work of Lazarus and Folkman (1984). Subsequent models of stress, which were developed from Lazarus and Folkman’s seminal work, are presented in sequence. The stress and coping theoretical models have been developed on LOD caregiving populations and their goal has been to try to understand why some caregivers report more burden while others adapt over time to the stresses associated with caregiving (Vitaliano et al., 1991). These models of stress propose that burden is related to patient and caregiver variables and that burden is likely a multivariate phenomenon.

**Lazarus and Folkman’s (1984) Transactional Model of Stress.**

The most prevalent paradigm used in the LOD dementia caregiving literature has been the transactional model of stress developed by Lazarus and Folkman (1984; Kramer & Vitaliano, 1994). This framework is intended to be applied to all types of stressors. The transactional model of stress theory suggests that appraisal and coping are mediators between stress and outcomes (Lazarus & Folkman, 1984). This is a cognitive model of stress as in essence, this theory suggests that external stimuli are not inherently stressful or not stressful; it is each person’s cognitive appraisal that makes this determination (Rice, 1999). This model suggests that the individual characteristics, such as beliefs about personal control, the coping resources that they have available to them (including material resources and social support) and the type of stressor impacting on people (e.g., duration of the stressor) all interact with one another through a process called cognitive appraisal (Folkman, Lazarus, Gruen, & DeLongis, 1986). Both person and situation factors affect the appraisal of the stressor. Person factors are characteristics such as relationship capacity, personality traits and self-efficacy beliefs (Marziali, McCleary, & Streiner, 2010). Situation factors have been described in terms of their type (e.g., problems of health,
work, family, finances, etc.) and their attributes (e.g., novelty, salience, ambiguity, changeability, etc; Lazarus & Folkman, 1984). For instance, events that affect one’s health or the health of a relative (e.g., Alzheimer’s disease) are appraised as less changeable than events that involve work (Lazarus & Folkman, 1984). This model is transactional “in that the person and the environment are viewed as being in a dynamic, mutually reciprocal, bidirectional relationship” (Folkman, Lazarus, Gruen, & DeLongis, 1986, p.572).

Stress is experienced when the perceived threat is greater than the available coping resources. Individuals who face a stressful situation commonly use a combination of problem-focused coping (take action to change a threatening relationship between themselves and their environment) and emotion-focused coping (regulate the emotional distress produced by the person-environment relationship; Lazarus & Folkman, 1984). The literature suggests that emotion-focused strategies (e.g., wishful thinking, avoidance, regression) are associated with negative outcomes such as depression and anxiety, whereas problem-focused strategies (e.g., taking action) are associated with positive outcomes of life satisfaction, well-being and lower depression (Kramer & Vitaliano, 1994). Seeking social support has been viewed as an emotion-focused coping response (Folkman & Lazarus, 1980) and as a coping response with both emotion-focused and problem-focused elements (Folkman & Lazarus, 1985). It is important to note that coping changes with different circumstances and/or people and it is not consistent across situations. Thus, looking at how people coped in the past and in different situations may not be helpful in understanding how people cope in general (Kramer & Vitaliano, 1994).

Lazarus and Folkman (1984) differentiate between primary appraisal (the point where a situation is experienced as either stressful or not) and secondary appraisal (the point when an individual determines if anything can be done to respond to the situation). In this model,
cognitive appraisal determines if a situation or event is experienced as a threat, a challenge, or harmful and is directly related to how a person will actually cope with a stressful event.


This model’s strength lies in the recognition that both environmental and personal factors interact to generate stress. This model has also been widely used in stress research and it has a large body of supporting evidence (Rice, 1999). However, this model has weaknesses. The first one is it that some constructs are not well defined. For example, this model does not identify environmental stressors with which people may be dealing. As a result, researchers have defined these stressors by narrowly focusing on those factors directly associated with caregiving and omitting familial and societal factors that influence stress. Consequently, the LOD studies guided by this model have focused on discrete caregiving stressors (e.g., managing difficult behaviours) without looking at coexisting stressors such as the interplay between caregiving and work. It is in the sphere of balancing caregiving, work and other tasks where stress occurs. In the EOD group, these coexisting stressors are potentially greater, since parenting roles, finances and sometimes even looking after one's own parents are added to the stress equation. Another critique of this model is that the consequences of stress on caregivers’ physical health outcomes have not been fully developed in this model.

Zarit, Orr and Zarit’s (1985) Caregiver Stress Model.

After the transactional model of stress proposed by Lazarus and Folkman (1984), the first researchers to talk about ‘caregiver burden’ in dementia were Zarit and colleagues (1985), who proposed that to determine the stresses that the patient places on a family caregiver, it is
important to understand the patient’s memory and behavioural problems as well as the caregiver’s reaction to those problems. They suggest that it is also important to consider the social supports available and the amount of burden on the caregiver all of which are influenced by the quality of the prior relationship between caregiver and patient.

**Zarit, Orr and Zarit’s (1985) caregiver stress model: critique.**

Although Zarit and his group were the first ones to talk about ‘caregiver burden’ (and thus, its inclusion in this review), this model seems too simplistic and too linear. For example, this model does not look at how the caregiver influences the patient’s behavioural difficulties – it only looks at how the patient’s behaviour affects the caregiver -- and it does not include other determinants of burden that are known to affect it (e.g., socioeconomic status [SES], and caregiver's physical health, personality and coping resources, etc.).

**Pearlin and colleagues’ (1990) Stress Model.**

Pearlin and his colleagues (1990) developed a model of caregiver stress based on spouses and adult children who care for relatives with Alzheimer’s disease. This model is more appropriate for dementia caregiving since they acknowledge that caregiving is stressful not only through its direct demand for readjustment to the role of caregiver, but also through its indirect exacerbation of other life strains. Pearlin and colleagues argue that dementia caregiving may create new life strains or intensify pre-existing life strains, and it is these new or intensified strains that in turn result in stress (Pearlin, 1983).

Pearlin’s model views caregiver stress as a consequence of a process consisting of a number of interrelated conditions, including the SES characteristics and resources of caregivers
and the primary stressors (hardships and problems anchored directly in caregiving) and secondary stressors. Secondary stressors fall into two categories: strains outside of caregiving (non-caregiving roles that may be compromised by the activity of caregiving such as strains related to family conflict, pressures between job and caregiving, economic problems and family life), and intrapsychic strains (e.g., self-concept) that arise. Coping and social support can potentially intervene with stress and coping at multiple points along the stress process. Secondary role strain consists of those non-caregiving roles that may be compromised by the activity of caregiving such as the strains related to family conflict, job-caregiving conflict, economic problems, and constriction of social life. The secondary intrapsychic strains can either be global (self-esteem, sense of mastery) or situational (loss of self, role captivity, competence, gain). Both the caregiver’s self-concept and personality states can be influenced by caregiving. A premise of this stress process model is that “one set of stressors can lead to another” (Pearlin et al., 1990, p.588). Therefore, it is important to appreciate the notion that primary stressors (those related to caregiving) may in turn have an impact on role strains and intrapsychic strains, which may or may not be directly related to caregiving. The third domain is the caregiver outcomes, which looks at depression, anxiety, cognitive disturbance, and physical health. Physical health is included because elements of emotional distress are likely to surface first and if they persist they may eventually affect health and well-being. The last domain in this model are the mediators, which look at coping and social supports.

Other points that need to be considered in this model include the notion of networks, which is different from social supports. Social supports refer to the assistance that a caregiver may derive from someone from the network. One cannot have social support without network, but may have network without social support. As well, Pearlin emphasizes that although it is
useful to know that global burden contributes to depression, we need to know which specific burdens are most likely to result in depression. In stress research, people exposed to seemingly similar stressors are affected in dissimilar ways. It is the mediators (coping and social supports) that are usually called upon to provide the explanation for the outcome variability. Stress research may typically underestimate the power of the mediators. In this model, both coping and support are mediators of stress. Pearlin includes social support as an independent stress mediator, whereas Lazarus and Folkman view social support as a resource capable of influencing appraisal and coping.

**Pearlin and colleagues’ (1990) stress model: critique.**

One strength of this model is its acknowledgement of the impact of structural barriers (e.g., race, gender, family composition, service availability, educational, occupational and economic attainments) to the stress and coping process. Another strength is that this model includes multiple measures of distress. In response to a critique in the literature that distress is often limited to one mental health outcome such as depression or anxiety (Schultz et al., 1995), this model attempts to account for other indicators of distress. Taking into consideration multiple measures of distress may reveal how individuals from different social and economic locations, or at different life stages, are more vulnerable to particular sources of distress (Pearlin, 1989). This is of particular relevance to the EOD population since finances and a sense of ‘ill-timing’ at onset of the disease are a great source of stress.

Of the models discussed so far, this is the most comprehensive one. Areas where this model could be expanded upon include some of the relationships amongst constructs, which have been presented in this model as unidirectional, but in fact may be reciprocal. For example, this
model proposes that primary stressors (e.g., patient’s behavioural difficulties) lead to secondary role strains (e.g., caregiver having to give up work to look after spouse) which in turn lead to secondary intrapsychic strains (e.g., low self-esteem from staying at home) which lead to negative caregiver outcomes such as depression, anxiety and poor physical health. It may be that negative outcomes for caregivers do not follow this linear pathway and there is a more complex interrelationship between these constructs. Thus, good or bad health is not necessarily an outcome of caregiving, but it is a main reason why care providers can or cannot manage the stressors. Another point is that the idea of calling some stressors ‘primary’ and some ‘secondary’ implies that there is a hierarchy of stressors. The connotation is that for a caregiver, dealing with the patient’s difficult behaviour is more ‘stressful’ than struggling with the work-family conflict. This does not reflect the lived experience of caregivers who are swamped with a multitude of stressors, which together contribute to their distress.

**Vitaliano and colleagues’ (1991, 2003) Model of Stress and Health/Illness.**

Vitaliano postulated that caregiver burden (appraised distress in response to caregiver experiences), is the product of the caregiver’s exposure to stressors (e.g., patient’s level of functional impairment) coupled with the caregiver’s vulnerabilities (e.g., caregiver’s age, gender, personality variables, physical health), which are mitigated by the caregiver’s psychological and social resources (e.g., social supports, satisfaction with and outlook on life and coping). This model is depicted in Figure 2.1
\[
\frac{\text{Distress}}{(\text{burden})} = \frac{[\text{exposure to stress + vulnerability}]}{[\text{psychological and social resources}]}
\]

*Figure 2.1. Theoretical Model of Distress (Burden), Vitaliano et al., 1991.*

This model, like the previous models, suggests that burden is related to many patient and caregiver variables and is a multivariate phenomenon. Research suggests that caregiver gender, age, personality and health problems may be variables that increase one’s risk for burden in response to dementia caregiving. On the other hand, social supports, coping processes and belief systems (e.g., outlook on life) may decrease the dementia caregiving burden. This model predicts that caregivers with high vulnerability (e.g., being female, being younger age) and low resources (e.g. few social supports, financial difficulties) would have higher burden scores than caregivers with more favourable combinations of these variables. The strength of this model is that it simultaneously examines the contributions of stressors, vulnerability and resources and it considers all of these variables together rather than in isolation.

Vitaliano continued to develop his model of dementia caregiving and, in conjunction with Scanlan and Zhang (2003), developed a model that built upon his previous work to incorporate physical health (adding a biological perspective to his previous model) as an outcome of dementia caregiving. Just like his earlier model, this updated model shows that coping and other resource variables interact with vulnerability variables (e.g., anger, health) to predict burden over time. This more comprehensive model is illustrated in Figure 2.2

This model represents an improvement over the other models in that it incorporates features from biological, environmental and psychological perspectives of stress and coping. Additionally, it was developed from work on spousal dementia caregivers. Furthermore, it is a fuller developed framework since it looks at the interactions between stress and vulnerability in addition to the interactions between psychological health and physical health.

In this model, there is room to further develop some relationships among variables since they seem to be unidirectional (e.g., exposure to stress and vulnerability leading to poor health habits). However, ‘health habits’ may have a reciprocal impact on caregiver’s vulnerabilities and stressors. For example, people who had good health habits prior to becoming caregivers may perceive and react to stress differently than people with prior poor health habits (Rice, 1999). Moreover, this model does not look at caregiving over time and how it changes as the caregiving trajectory continues. From the depiction of this model, it seems that once negative outcomes begin to unfold for the caregivers, it leads to illness and mortality, without mentioning that perhaps this is not a linear path and that other variables may come into effect to improve caregivers' outcomes.
What all these models have in common.

Overall, these models look at the caregiving process, which includes background and contextual variables, stressors, resources, appraisals and outcomes. The models frame coping as a complex multidimensional construct that includes both cognitive and behavioural strategies. All these frameworks suggest that there are additional variables that influence the caregivers’ ability to adapt to stressful experiences. For example, resources are considered important in understanding what is available to individuals in developing their coping repertoires and are viewed as mediating the effects of stressful life events on personal functioning. Other than in Zarit and colleagues’ (1985) model, these variables include social resources, financial resources and psychological resources. In Vitaliano’s (2003) model, the biological resources are better articulated, so this framework provides an improvement over the other ones. Pearlin (1990) alludes to the physical sequela of caregiving, but does not emphasize it to the same extent as Vitaliano and his group (2003). What is clear in these models is that one person’s stress is another’s one challenge and that stress is based on one's perception.

These models assess ‘appraisal of stress’ differently. Vitaliano and colleagues (1991, 2003) found that caregivers who appraised their stressors as changeable were more depressed than those who appraised it as not changeable. Would this mean that for the EOD spousal caregivers in this study, having a partner with an EOD, something that is unchangeable, would result in less depression than if their partner had cancer, with the potential for a cure? Lazarus and Folkman (1984) and Pearlin and colleagues (1990) separately assessed primary and secondary appraisal of a stressor. In dementia caregiving studies, ‘appraisal of stressors’ is not generally an outcome measure and it should for this construct to be properly understood.
Therefore, measuring the caregiver’s *perception* of the stressor as opposed to just measuring the stressor (e.g., difficult behaviour), should always be included in dementia research. This study will include spousal perceptions only, given that the data for this study only comes from their narratives and their interpretations of their lives.

**Overview: stress and coping model for understanding EOD caregiving.**

Based on the inclusion of physical health outcomes for caregiver burden (as opposed to only mental health outcomes), the stress model most relevant in the conceptual EOD caregiving framework is Vitaliano and colleagues’ (2003) model. It emphasizes the interactions between stress and vulnerability of both the patient and the caregiver as well as the interconnection between psychological health and physical health. This multidimensional and non-linear construct of stress will be utilized as sensitizing concepts for the development of the interview guide.

In essence, the analyses of various stress models were provided as no single theory of stress provides a complete picture. Although it is crucial to recognize the stress that EOD spousal caregivers go through, other constructs need to be included into this model if a more complete description of their experience is to be understood. To accomplish this, there are other perspectives that need to be added to this conceptual framework. The next section will delve into two other models that are useful for creating a model for understanding this group of caregivers. Each theoretical framework is presented as contributing a unique perspective to the understanding of this unique group of dementia caregivers.

As presented in the above section, a biopsychosocial model of stress and coping is a fundamental way to conceptualize the EOD caregivers’ experience. How caregivers manage their
stress determines how well they fare through the caregiving journey. However, the various causes for differences among caregivers’ responses to stress are not well understood (Marziali, McCleary, & Streiner, 2010). There is evidence that it is the interaction between the stressors experienced by caregivers and caregiver-specific factors that contributes to the physical, psychological and social problems for the caregiver (Schulz et al., 1995; Vitaliano et al., 2003). Caregiver-specific factors are those that Vitaliano and colleagues (1991) call ‘vulnerabilities’, such as personality traits and self-efficacy beliefs. As well, stress is not necessarily related to the objective circumstances of care but is exacerbated by difficulties within the patient-caregiver relationship (Keady & Nolan, 1994; Montgomery & Williams, 2001).

The perception of stress and how people cope varies as circumstances change. Thus, it is significant to understand how stress and coping changes over time. To continue building on a conceptual framework that aids in the understanding of EOD caregiving, a third framework is offered: (3) the stages of dementia caregiving framework. This model aims to fill in the gaps that are necessary to answer the question: How do spousal caregivers of people with EOD experience and cope with stress, and do these experiences and coping change over time?

(3) - Stages of Dementia Caregiving Framework

This perspective presents Keady and Nolan's (2003) six-stage model of dementia caregiving based on the patients' progression of the disease and the caregivers' experience of providing care. This model is grounded on Lazarus and Folkman’s (1984) stress and coping theory model. Keady and Nolan's temporal model of caregiving was originally proposed by Skodal-Wilson (1989) and Keady and Nolan later expanded it. Skodal-Wilson developed a longitudinal framework, which she used to describe families’ experiences of dementia
caregiving. This model emphasizes that caregivers experience different issues at particular stages of the caregiving ‘career’ and she emphasized that this needs to be taken into consideration when doing research in this population.

Keady and Nolan (2003) describe a six-stage model to understand the stages of caregiving. This model was not developed for spouses, but it was meant to be inclusive of all caregiving relationships. These stages include:

1. *building on the past* - this is not a stage per se, but it recognizes the importance of the caregiving dyad's premorbid relationship and its effect on how caregiving unfolds.

2. *recognizing the need* – this is the stage when the caregiver becomes aware that their relationship with the person with dementia is changing. This stage may go on for a long time as the changes may be subtle.

3. *taking it on* – this is the stage when the caregiver realizes that there is a fundamental change in the relationship due to the cognitive changes. At this stage, caregivers realize that they have become in fact, caregivers.

4. *working through it* – this stage is intended to represent the proactive way in which caregivers respond to their role and the coping strategies they employ to feel in control. At this time, caregivers gain expertise in looking after the person with dementia.

5. *reaching the end* – this is the stage where other caring arrangements are made, for example pursuing long term care placement.

6. *a new beginning* – this stage is when caregivers move on with their lives, either after the death of the person with dementia or after placement.
Why choose this model?

The reason for choosing this model is that it adds a longitudinal (temporal) approach to Lazarus and Folkman’s (1984) stress and coping model and is congruent with the life course perspective. The stages of caregiving model adds a temporal dimension to the stress and coping models since these coping models do not capture the dynamic nature of family caregiving, which changes with context and changes as demands and the disease progress over time. Keady and Nolan (1994, 2003) have suggested that this model could be applied to people with EOD, and that this framework is subject to empirical testing and refinement with both LOD and EOD populations.

Temporal model of dementia caregiving: critique.

This model provides a framework for conceptualizing caregiving as a trajectory, with various stages that change over time as experienced by dementia caregivers. The importance of this framework is that it recognizes dementia caregiving as a process that changes over time, and caregivers’ needs are not static. However, this model’s main limitation is that it conceptualizes caregiving as a linear progression of stages. The authors propose a continuum of phases starting from stages two to six; however, these stages may not be necessarily experienced sequentially. They do not necessarily have a ‘beginning’ and an ‘end’ since these stages may not be discrete. Nevertheless, this model presents a good attempt to understand the stages caregivers go through in looking after a person with an EOD.

Finally, although this model is related to the progression of the dementia, it is important to understand that the *stage of the illness* that patients are in is not the same as the *stage of*
caregiving of the well-spouse. For example, a spousal caregiver may not recognize the need (stage 2 of this model) well into the progression of the dementia.

**An Integration of the Three Theoretical Frameworks**

This concluding section presents an integration of three frameworks to contextualize the experiences of spousal caregivers of persons with EOD. These frameworks, although coming from different paradigms, build upon each other to create an inclusive model of EOD spousal caregiving. These apparently different frameworks converge to articulate a preliminary framework that explains the multiple variables that come into play in the EOD caregiving experience. As previously reviewed in this chapter, there is a dearth of EOD caregiving research guided by theory. This has led to an inability to interpret even the modest data that are currently available in the EOD caregiving field. The importance of articulating this comprehensive model of EOD caregiving stems from the need to guide research in this area.

A model of integration of these three frameworks is offered. This model proposes the addition of a temporal dimension to a biopsychosocial conceptualization of stress and coping in conjunction with the micro, mezzo and macro perspective that the life course provides. This framework needs to be understood as interactive and dynamic, where each of the three frameworks has something to offer in understanding the variables that affect spouses’ experience of living with a partner with EOD. A graphic representation of this model is depicted below (Figure 2.3)
Figure 2.3. Conceptual integration of theoretical frameworks to understand the experience of spousal caregivers.

In this model, the two rectangles, which represent one of two different paradigms: the stress and coping model and the stages of caregiving model, provide a theoretical model for framing how EOD spouses experience caregiving. Although both rectangles have the same size, this does not mean that each perspective necessarily contributes the same proportion to the understanding of the dementia caregiving experience. All perspectives contribute toward this model, but different variables may become more or less important at various stages of the dementia journey. The life course perspective is depicted as an arrow as it provides a foundation traversing across paradigms providing a temporal dimension to the conceptual framework. In this model it is important to note that how a caregiver perceives his or her situation is not assumed to be one of ‘burden’ or ‘stress’, but it is viewed as the ‘caregiver experience’. The reason for this
use of language is to acknowledge that although most of the experience is stressful, there may be other experiences that spouses go through (e.g., positive effects). In summary, I propose to combine Vitaliano and his group's (2003) biopsychosocial stress model of dementia care with Keady and Nolan (2003) temporal framework, embedded in the life course perspective. All these perspectives are imbued within a systems overview. This systems perspective is not just to be understood at the micro (family) level but also within the context of society (macro) and how government policy affects the kinds of supports to this population. The areas of intersection between these perspectives seek to explain the factors and conditions encountered by these spousal caregivers to explain how they experience the journey of their partner’s dementia. The relevance of this model is to provide structure to begin to frame the kinds of questions that need answers in this population.

Chapter Summary

The first section of this chapter looked at the LOD literature on dementia caregiving and then, more specifically, at the EOD caregiving research. Specific studies on EOD spousal caregivers were reviewed and methodological concerns with the literature were explored. This scoping literature review provides support for this study since it exposes the scarcity of the existent body of knowledge about EOD caregivers. The second section offered three theoretical models, which were synthesized into a conceptual model. The importance of providing an articulated theoretical model is that it guides the design and development of how this study is carried out and it points to the type of methodology that best supports this inquiry. This study's methodology is explored in Chapter 3.
Chapter 3

Research Design and Methodology

Introduction - Methodological Rationale

This chapter explains the choice of research methodology and study design. The choice of a particular methodology depends on its suitability in answering the research question. The overarching question of this research is to understand how spouses of persons with EOD view caregiving issues/challenges at different points of the disease progression.

This chapter explores the rationale for using a qualitative methodology and more specifically the grounded theory approach to data collection and analysis. This chapter describes the origin of grounded theory methodology, its relevance to the study of EOD spousal caregivers and how this approach is applied to the design and analysis in this particular study.

Why choose a qualitative methodology?

Qualitative research is an approach to the study of human behaviour that employs the analysis of narrative data to construct an interpretation of the meaning of these behaviours from the perspective of the participants themselves (Kuckelman Cobb & Forbes, 2002). Qualitative methodologies assume that there are various realities and perspectives to be discovered, that the participants and researcher simultaneously influence one another, that causal relationships are impossible to determine and that all research is value-laden (Denzin & Lincoln, 1994; Kuckelman Cobb & Forbes, 2002). In contrast, quantitative research presumes that there is an objective, measurable reality or “truth” to be uncovered, that the findings must be generalizable to other populations, that causal relationships can be identified and that scientific investigations are bias-free (Denzin & Lincoln, 1994; Kuckelman Cobb & Forbes, 2002). Qualitative research
is not about the objective world itself but rather how it is interpreted and understood by individuals. Thus, the goal of qualitative research is exploring how people perceive their world, their beliefs, and experiences and conceptualizing these in meaningful ways (Williams, n.d.). Qualitative research can offer a rich and rigorous descriptive base of people’s experiences, viewpoints and attitudes which can be the basis for further explanatory research.

Another reason for utilizing a qualitative approach is that in the stress and coping literature, which is a main theoretical framework utilized in this study, there are major criticisms related to measurement concerns (Folkman & Moskowitz, 2004). These authors suggest that using narrative approaches to the understanding of coping provide a good alternative to quantitative approaches. Folkman and Moskowitz (2004) state that "a great deal can be learned by asking people to provide narratives about stressful events, including what happened, the emotions they experienced, and what they thought and did as the situation unfolded" (p.750). A third reason why a qualitative methodology is appropriate for this study is that the topic under investigation is insufficiently understood and therefore is best researched through in-depth and rich narratives of the participants (Kuckelman Cobb & Forbes, 2002). Within health care, understanding people's beliefs and attitudes is important since the way individuals experience their health and how care is delivered should be at the heart of health care service models, especially in dementia care (Morse & Field, 1995; Prorok, Horgan, & Seitz, 2013). Finally, the lack of empirical and theoretical foundations for understanding the experience of EOD spousal caregivers, as mentioned earlier, makes the logico-deductive requirements of quantitative research difficult. The analytic inductive process of qualitative research, which is characterized by openness and flexibility, serves the nature of this study well.
Why choose a grounded theory approach?

There are different styles and approaches for doing qualitative research. The three most common qualitative methodologies are grounded theory ethnography and phenomenology (Kuckelman Cobb & Forbes, 2002). Although these approaches share many elements and there is an overlap of epistemology, ethics and procedures, there are distinctions in relationship to their histories, strategies, epistemology and ontology (Holloway & Todres, 2003).

This study is informed by a grounded theory approach. This approach was originally developed by Glaser and Strauss (1967) and has been reinterpreted and revised by subsequent qualitative researchers. Grounded theory methods have guidelines that are systematic, yet flexible for collecting and analyzing qualitative data with the ultimate goal of construction of theories, which are ‘grounded’ in the data themselves (Charmaz, 2006). This process of data collection is inductive (e.g., categories and themes of analysis emerge out of the data rather than being imposed on them prior to data collection and analysis), and it seeks to build theory about issues of relevance in participants’ lives (Bowen, 2006; Mills, Bonner, & Francis, 2006). Not only is grounded theory inductive, but is also deductive in that "the concepts and the linking statements are interpretative; that is, constructed by the analyst from data" (Corbin & Strauss, 2008, p326). Grounded theory builds toward a substantive theory from an ongoing process of continually evaluating the data, refining questions, and re-reviewing these changes (Jacelon & O'Dell, 2005).

There are four main reasons for choosing this approach. In grounded theory, the way a person experiences events and the meanings that they give to those experiences are important; however, this approach also looks at experience within the larger context in which the experience is embedded. It also examines the process of actions, interactions and emotions that are taken in
response to events (Corbin & Strauss, 2008). Locating the EOD caregiving experience within a larger contextual frame (e.g., societal, health care system, financial, etc.) is important since understanding the circumstances of EOD caregivers and how these circumstances affect how caregivers cope is the aim of this study. Second, grounded theory mandates that all theories generated from the study must be ‘grounded’ in data (Charmaz, 2006). The depth, scope and richness of the data are important since they contribute to the quality of the work. For this study, based on extensive EOD spouses' narratives, the empirical nature of grounded theory offers solid ground for theorizing about the effects of EOD on spouses. Third, grounded theory has been extensively used in health and illness research (Bowen, 2006; Charmaz, 2006; Riessman, 1994). In fact, the foundation of grounded theory is based on a study of peoples’ ‘awareness of dying' by the co-founders of grounded theory Glaser and Strauss (1965, 1967). Finally, grounded theory is congruent with social work values since both grounded theory and social work focus on the interaction between individuals and society. Grounded theory research can generate theories about how people navigate their environments that can be tested in social work practice and, ultimately, be used to guide social workers in the field (Oktay, 2012).

**Historical context of grounded theory.**

Glaser and Strauss (1967), the co-authors of grounded theory, proposed that systematic qualitative analysis has its own logic and is able to generate theory. Their interest was to construct abstract theoretical explanations of social processes (Charmaz, 2006). Glaser and Strauss (1967) provided strong arguments that properly carried out qualitative research is a credible methodological approach in its own right, rather than just a precursor to carrying out quantitative research.
Glaser and Strauss came from two different epistemological perspectives. Glaser came from the Columbia University positivism perspective, where his systematic approach of grounded theory reflects rigorous quantitative training; more akin to quantitative methodology. He permeated grounded theory with rigorous coding methods, gave prominence to emergent discoveries and utilized language that resembled quantitative research (Charmaz, 2006). On the other hand, Strauss came from the Chicago school pragmatism and field research background. Glaser viewed individuals as active agents in their world rather than as passive recipients of larger social forces. He emphasized process, not structure, as fundamental to the human experience and the notion of subjective meaning in research (Charmaz, 2006). The union of these two different epistemologies gives grounded theory a hybrid approach between the quantitative tradition of Glaser combined with Strauss’s tradition of symbolic interactionism (e.g., individuals construct the external world by their perceptions and interpretations of what they conceive that world to be; Benzies & Allen, 2001). Thus, grounded theory has both positivist and interpretivist components.

Since Glaser and Strauss’ early work in 1967, these co-authors have taken grounded theory in divergent directions (Charmaz, 2000). Glaser (1999) has attempted to downplay the qualitative nature of grounded theory. Strauss, on the other hand, in conjunction with Corbin (1990), emphasize the qualitative nature of grounded theory. This epistemological discrepancy between the co-founders of grounded theory has led to much confusion about the nature of this methodology. Though there are many adaptations of grounded theory, some procedures have remained consistent through the various versions. These are "the constant comparative method of analysis, the use of concepts and their development, theoretical sampling and saturation. And for
those researchers who want to build theory, there should be the construction of a well-delineated theory” (Corbin & Strauss, 2008, p.303).

**Core concepts of grounded theory approach.**

Of the various approaches to grounded theory, this study is informed by the Corbin and Strauss (2008) approach, in conjunction with Charmaz’s (2006) more constructivist approach. Although these three researchers have a subjectivist orientation in their approach to grounded theory, Charmaz (2006) views Corbin and Strauss as being closer to the positivism spectrum of the continuum than she is. Strauss and Corbin (2008) and Charmaz (2006) all agree that grounded theory guidelines describe the steps of the research process and provide a path to code and collect data, memo-writing and ways of sampling for theory development in a way that is co-constructed between the researcher and participants. However, Charmaz (2006) gives a stronger emphasis to the idea that researchers are not neutral in their approach to scientific inquiry and *how* researchers utilize ground theory guidelines is not unbiased. Unlike Glaser (1999), Charmaz views grounded theory as “a set of principles and practices, not as prescriptions or packages” (2006, p.9).

The reason I have chosen a more constructivist approach for this study is that it is most congruent with this inquiry. Before proceeding with this interprevist perspective I must disclose why it would be incorrect to use a more positivistic methodology. I have worked with spouses of people with EOD since 1991. I know this population well and I am familiar with most of their issues. To pretend that when I interviewed the participants I had a totally “blank” mind about their narratives would be naïve. When I did the in-depth interviews, the direction in which I may have taken the interview in and the way I interpreted responses is rooted in my experience with
this group of caregivers. It is difficult for me to separate my “clinical” self, from my “researcher” persona when I interview participants. Thus, it would be untruthful to say that this research is “objective”. This intimate familiarity I have with this study’s topic provides a vantage point; it has guided me to look at certain areas; nevertheless, it has been crucial that I remained as open as possible to whatever came up when I conducted and interpreted the interviews. The knowledge I have about this population provides me with a starting point for building analysis (sensitizing concept; Charmaz, 2006) and having an initial foundation to formulate interview questions and to interpret data analytically. Nonetheless, knowing this population well has only provided me with a place to start, not end. Thus, close familiarity with this group of caregivers is a strength that I have brought to the research; one that forms the foundation of grounded theory inquiry (Charmaz, 2004).

**Research Method and Process**

**Participant description and inclusion/exclusion criteria.**

Participants for this study were spousal caregivers of persons diagnosed with either FTD or early-onset AD whose first symptoms began before the age of 65. It is important to note that the patients’ diagnoses were as per spouses’ report since for this study’s I did not have access to patients’ medical information; however, all patients had been diagnosed by a specialist (e.g., neurologist, psychiatrist or geriatrician).

To be eligible, participants had to have a good command of English and they had to be either Canadian citizens or landed immigrants. Patients with EOD could be at any stage of the disease process and the well-spouses were recruited with the intention of capturing them at various stages of their partner’s illness. The range of participants included those spouses of
people who were newly diagnosed to individuals that had already been placed in long term care. One person, whose husband had died two years prior to the interview was included as well, covering the span of the caregiving trajectory.

Staging of the disease process was evaluated by the patient’s functional and cognitive abilities as described by the participant. For the purpose of staging patients, I classified patients, as being in either the early, middle or late stages of EOD. These categories were based on the dementia stages described in the Alzheimer Society of Canada’s (2013) website. The website describes an early (mild), middle (moderate), late (severe or advanced), and an end of life stage. It is important to note that the stage of the disease progression was established from both their caregivers’ portrayal of their ill-spouse (Appendix C), and from my interpretation of what caregivers described, based on my clinical experience since I did not have access to the patients’ medical charts.

According to the Alzheimer Society of Canada (2013), the early or mild group is categorized as needing “little help”. For the purpose of this study, those patients who needed minimal help and who were still independent with most activities of daily living (ADL) were staged as being in the *early stage* of EOD. For example, patients who were still driving would fall under this category. The *middle stage* was categorized as patients needing “help with many daily tasks” and this included help with both ADL and instrumental activities of daily living (IADL; Appendix C). An example would be a patient who could not stay alone for an entire day and the family considered day programs. The middle stage was the point where families needed to increasingly provide care and for the purpose of this study it lasted up until people needed care with all ADLs and IADLs, at which point they entered the *late stage*. The late stage was characterized by patients who were unable to communicate verbally and who were physically
more frail and needed 24-hour care. In this study, this was the group of patients in LTC and/or who were home with constant care. The Alzheimer Society of Canada describes a fourth stage, the end of life stage, where patients not only need total care, but they are actively dying. This stage was not included since I was not able to recruit caregivers of patients that were actively dying. However, most of the patients in the late stage where at the end of life, but were not necessarily actively dying. The Alzheimer Society of Canada does not have clear criteria in their definition of stages and thus, these stages were utilized as a gage of the disease progression. These stages occur in a continuum and staging served the purpose of capturing caregivers whose partners were in different stages of the illness as best as possible.

Participants were married to someone with either FTD or AD. There were 17 spouses whose partners had FTD and 13 who had AD. Within each diagnosis, participants had a spouse in either the early, middle or late stage of the disease. Therefore, there were three stages of the disease progression per diagnostic category. One participant, whose husband had died two years before the interview was included. Table 3.1 presents the demographic characteristics of the 30 participants and their spouses (patients), based on age, gender, diagnosis and stage of the disease progression.

Table 3.1. Frequency Distribution of Demographics/Characteristics by Participants (N=30) and Patients (N = 30)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Participant</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Frequency</td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50 and under</td>
<td>3 (10)</td>
<td>1 (3)</td>
</tr>
<tr>
<td>51-55</td>
<td>8 (27)</td>
<td>5 (17)</td>
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<tr>
<td>56-60</td>
<td>6 (20)</td>
<td>6 (21)</td>
</tr>
<tr>
<td>61-65</td>
<td>6 (20)</td>
<td>8 (28)</td>
</tr>
<tr>
<td>Over 65</td>
<td>7 (23)</td>
<td>9 (31)</td>
</tr>
<tr>
<td>Totals</td>
<td>30</td>
<td>29†</td>
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</table>
### Gender

<table>
<thead>
<tr>
<th></th>
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<th>Female</th>
<th>Totals</th>
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</thead>
<tbody>
<tr>
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<td>21 (70)</td>
<td>30</td>
</tr>
<tr>
<td>Female</td>
<td>21 (70)</td>
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</table>

### Diagnosis

<table>
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<tr>
<th></th>
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<th>AD</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
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<td>17 (57)</td>
<td>30</td>
</tr>
<tr>
<td>AD</td>
<td>13 (43)</td>
<td>13 (43)</td>
<td>30</td>
</tr>
</tbody>
</table>

### Stage of disease for FTD & AD

<table>
<thead>
<tr>
<th></th>
<th>Early</th>
<th>Middle</th>
<th>Late</th>
<th>Deceased</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>9 (30)</td>
<td>10 (33)</td>
<td>10 (33)</td>
<td>1 (3)</td>
<td>30</td>
</tr>
<tr>
<td>Middle</td>
<td></td>
<td>7 (41)</td>
<td>7 (41)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late</td>
<td></td>
<td>4 (24)</td>
<td>4 (24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deceased</td>
<td></td>
<td></td>
<td></td>
<td>1 (3)</td>
<td></td>
</tr>
<tr>
<td>Totals</td>
<td></td>
<td>9 (30)</td>
<td>10 (33)</td>
<td>1 (3)</td>
<td>30</td>
</tr>
</tbody>
</table>

### Stage of disease by diagnosis (FTD)

<table>
<thead>
<tr>
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<th>Early</th>
<th>Middle</th>
<th>Late</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>6 (35)</td>
<td>7 (41)</td>
<td>4 (24)</td>
<td>17</td>
</tr>
<tr>
<td>Middle</td>
<td></td>
<td></td>
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<tr>
<td>Late</td>
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<tr>
<td>Totals</td>
<td></td>
<td>6 (35)</td>
<td>7 (41)</td>
<td>17</td>
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</table>

### Stage of disease by diagnosis (AD)

<table>
<thead>
<tr>
<th></th>
<th>Early</th>
<th>Middle</th>
<th>Late</th>
<th>Deceased</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>3 (23)</td>
<td>3 (23)</td>
<td>6 (46)</td>
<td>1 (8)</td>
<td>13</td>
</tr>
<tr>
<td>Middle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late</td>
<td></td>
<td></td>
<td>6 (46)</td>
<td>1 (8)</td>
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<tr>
<td>Deceased</td>
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</tr>
<tr>
<td>Totals</td>
<td></td>
<td>3 (23)</td>
<td>3 (23)</td>
<td>6 (46)</td>
<td>13</td>
</tr>
</tbody>
</table>

*a One patient is deceased.

In sum, 17 participants had spouses who had FTD and 13 had spouses with early-onset AD. The three stages of the disease progression (early, middle and late) for the FTD and AD group were equally represented. Of the participants with early-onset AD, three had an atypical
early-onset AD with frontal features. Of those participants whose partners had initially been diagnosed with FTD, one was later diagnosed with corticobasal syndrome (CBS), one with primary progressive aphasia (PPA), one with stroke, and one with atypical AD. The diagnoses changes occurred prior to the study and were reported by participants during the interview in spite of my best efforts to obtain an accurate diagnosis from the spouses before our interview. For the study's purpose, the three participants whose spouses had CBS, PPA and stroke, where included in the FTD data analyses group. The person who had atypical AD was included in the AD data analyses. There was one participant who at the time of the interview had a diagnosis of FTD, whose wife called me six months later to tell me that the diagnosis had been changed to a stroke in the frontal lobes. This participant was analyzed with the FTD group. One participant, at the time of the interview was not sure of the diagnosis, either atypical AD or possible FTD. I contacted him after they completed all the medical tests (post interview), and diagnosis was confirmed as FTD. Thus, this participant was included in the FTD sample.

There were 21 wives and 9 husbands; all in heterosexual relationships. Men were more difficult to recruit since they did not reply to the invitation to participate in the study as readily as women. All stages of the disease progression were represented for both FTD and early-onset AD including one participant whose spouse had died two years prior to the interview. The number of participants per diagnostic stages were divided equally; with 30% in the early stage and 33% each for the moderate and late stages.

**Recruitment strategy.**

I recruited participants from three venues. Five participants were recruited through the Sam and Ida Ross Memory Clinic at Baycrest, an outpatient clinic at Baycrest Hospital, in
Toronto, that specializes in the diagnosis and management of memory disorders. Potential participants were identified by the interdisciplinary Memory Clinic Team at the Sam and Ida Ross Memory Clinic (a team composed of two behavioural neurologists, three geriatric psychiatrists, one geriatrician, one psychologist, two nurses, one speech-language pathologist, and myself).

The second, and most successful form of recruitment (25 participants recruited in this manner), occurred from a self-help group of spouses of people with FTD who meet monthly in peoples’ homes for mutual support. This group started to meet many years ago as an off-shoot from an email group of FTD caregivers brought together by Dr. Tiffany Chow. This group continued to grow as people that had participated in an FTD on-line support group at Baycrest joined the self-help group. This FTD spousal caregivers' self-help group has more recently included people with early-onset AD as the group members believe that they deal with very similar issues. This came about after the spouse of one of the co-leaders was switched from an initial diagnosis of FTD to AD. This co-leader, along with the other group members, realized that life-stage was more relevant for belonging to this group than diagnosis. It is important to note that not all spouses who participated in the study are active group members, but they were in the email distribution list of this group. Participants who were in the distribution list but were not active where those that initially contacted the a co-leader to be added to the group but either never came or only came a few times and have not participated in the last year prior to this study.

I initially contacted one of the group organizers and described the study to her. This group co-leader was supportive of this study and she sent an email to the group members with an REB approved flyer stating the purpose of this study (Appendix A). Of those people that received the email, only those that volunteered to participate and directly initiated contact with
me were screened for participation. Once potential participants contacted me, I provided them with a brief overview of the study. This occurred over the phone. Informed consent was explained to them and a copy of the informed consent form (Appendix B) was sent to them either electronically or by mail for participants to review. Only participants that returned the informed consent and/or contacted me after reading it were eligible to participate, allowing for autonomous decision-making since they contacted me instead of me contacting them. If someone did not return the informed consent or did not call/email me back I did not pursue them as I considered them not be interested in participation. This only happened in two instances. Both of these cases were from the self-help group distribution list.

The third way that recruitment occurred was through word of mouth among the EOD spousal community. Although this method was not planned, I received two calls from spouses who had heard about the study and wanted to participate and were included in the study.

Finally, it is important to mention that through my 22 years in the field of dementia care, and in particular EOD, I have come to meet many of the participants through either Baycrest, or through presentations in the community and by word-of-mouth. Some participants stated that the reason they agreed to participate was that I had served one of their friends as a social worker. Whether this prior knowledge gave me an advantage in acquiring participants, or whether it enabled the interview process and the kind of information participants shared with me is an unknown factor. However, this is viewed as a positive in grounded theory since it allows for a more in depth perspective of participants and their issues, and it recognizes that this prior knowledge may even enhance the process (Charmaz, 2006).
Data collection.

Once potential participants were identified, I provided them with a brief overview of the study and I explained their right to participate in and withdraw from the study as they saw fit. Prior to participants' interviews, I obtained signed informed consent (Appendix B). I conducted all the study interviews personally. Interviews were done in one session and lasted between one and a half hours to two hours. A total of 30 participants were interviewed. Twenty-eight interviews were done face-to-face, at a time and location that were convenient for the participants (12 interviews were done at Baycrest, 14 were done in their own home and two in participants' work place). As two participants lived out of town, interviews were done over the phone. All interviews were digitally recorded and then transcribed, verbatim. The interviews took place from July 23, 2012 until April 30, 2013.

For each interview, three strategies were combined to obtain rich data (Patton, 2002). First, a structured socioeconomic interview guide was administered to ensure a systematic way to gather data which included participants’ characteristics and contextual background data (Appendix C).

Second, a Life Events Time Line Calendar was utilized to record major personal, family and caregiving significant events in chronological sequence (Appendix D). This method of data gathering is utilized in life course research to highlight important events about the life course via the verbal reports that are elicited from the participants (Belli, Stafford, & Alwin, 2009). This type of tool provides a framework for reporting events within a temporal context since it cues participants to report about events that occurred over time. This is important, since finding out about the experience of EOD spousal caregivers over time is a goal of this study.
Third, an in-depth interview schedule with open-ended questions was used (Appendix E) to understand participants’ lives and experiences. In-depth interviews call for a flexible approach and allowed probing certain topics in more depth or to look into new areas of inquiry which were not anticipated (Patton, 2002). This aspect of the interview incorporated an exploration of the subjects’ perceptions of their psychological and physical well-being, their perception of their role, types and strengths of informal and formal supports, financial repercussions as a result of the dementia, amount of knowledge that they hold about the illness, types of coping strategies that they currently use the presence of other potential stressors and the impact of behavioural disturbances. These are areas of exploration identified in the EOD caregiving literature as sensitizing concepts (Bowen, 2006). Within the context of a grounded theory approach, “sensitizing concepts offer ways of seeing, organizing, and understanding experience…they provide starting points for building analysis” (Charmaz, 2003, p. 259). These sensitizing concepts can be helpful in providing a framework for analyzing empirical data and ultimately for developing a thorough understanding of the EOD spousal caregiving experience.

**Compensation.**

Participants were compensated for their time at a rate of $10 per hour, which is the rate set by the Baycrest Ethics Review Board. Participants did not incur any expenses as a result of participating in this study as any costs associated with the interview were covered. These costs included transportation, parking and long distance phone calls. Funding came from my SSHRC Doctoral Award.
Sample size.

Although there are not many guidelines in terms of how many participants are needed in grounded theory, Charmaz (2006) suggests that “25 interviews may suffice for certain small projects” (p. 114). Charmaz (2006) suggests that the aims of the study are the ultimate driver of the sample size. In theoretical sampling there should not be any predetermined sample size. The benchmark for judging how many participants need to be interviewed occurs when the researcher determines when the point of category saturation has been reached (Corbin & Strauss, 2008). Saturation is the point when no new data is emerging and the point in the research when all the concepts are well explained and defined (Corbin & Strauss, 2008). For this study 30 EOD spousal caregivers were interviewed; this was the point where theoretical saturation was reached. Having 30 participants gave me the opportunity to interview spouses of people with either FTD or AD, in all three stages of the disease progression. By the time I finished the 30th interview, I detected repetition in the categories and themes that were emerging and no new novel data were brought forth.

Sampling and interviewing process.

Grounded theory is a methodology driven by the analysis process which determines the method of sampling and data collection. This study used convenience sampling (e.g., selecting participants who are readily available and who meet the study criteria; Padgett, 1998), whereby spouses who were interested in participating in the study contacted me.

There are two types of sampling strategies in grounded theory: initial sampling and theoretical sampling (Charmaz, 2006; Corbin & Strauss, 2008) and both strategies were utilized in this study. Initial sampling was comprised of the first set of interviews, which once analyzed
provided a point of early departure. This initial sampling allowed for an early emergence of patterns. Interviews were then conducted by sampling from the EOD spousal caregiver population through theoretical sampling. Theoretical sampling is a method of data collection based on concepts that emerge from the data. The analysis of the early set of data leads to generating concepts which formulate questions which lead to more data collection. This circular process carries on until the data reach a point of saturation (e.g., the stage in research when all the categories/concepts are well defined and explained; Charmaz, 2006). The benchmark for judging saturation is that “no additional data are being found whereby the [researcher] can develop properties of the categories” (Strauss & Corbin, 1998, p.61). In grounded theory, unlike conventional methods of sampling, the researcher does not collect the entire data set before beginning the data analysis (Corbin & Strauss, 2008). Therefore, the participants chosen for the interviews after the initial data were analyzed were based on the concepts that were generated by the previous interviews. Theoretical sampling means sampling for the purpose of developing a theoretical category, not sampling for population representation (Charmaz, 2012).

In this study, theoretical saturation was followed when deciding on the number of participants in each of the six disease by stage sub-groups (e.g., FTD at three different stages of the disease progression: early, moderate and late, and early-onset AD, early, moderate and late stages). Participants within each sub-group, were chosen based on looking for a rich variety of experiences (e.g., people who had younger children in the home, participants that had experienced immigration and were visible minorities; participants who had no financial concerns, participants who lost their money to the disease, participants who chose to look after their spouse at home at the very last stage of the disease, participants who placed their spouses in
LTC earlier on in the disease process, and someone whose husband had early-onset AD and had died two years prior to the interview).

The interview process was conducted in a manner to achieve theoretical saturation and thus, the interview schedule (Appendix E) was utilized only as a reference. The questions were mostly open-ended and I only referred to it at the end of each interview to ensure that all the necessary questions were answered. Due to the nature of grounded theory, the interview structure and questions varied according to the stage of theory development during data collection (Wimpenny & Gass, 2000). In the early stages of interviews (initial sampling), the interview was less structured to allow participants to respond in a free manner. For participants interviewed at later stages of the research process, the structure and types of questions were tightened to focus on concepts and categories that needed further development. For example, as categories related to the concept of survival became an important area of participants’ narratives, I started to focus more on this area as the project continued. However, before the interview was finished, areas of importance to participants were always explored and everyone was asked if there was anything that was not covered that they would like a chance to discuss. This left the door open for participants to bring up issues that had not come up to that point. Although this approach is not traditionally utilized in grounded theory, I felt that it was an important aspect of the study since not much is known about this population and it provided an opportunity for EOD spouses to voice issues that had not yet been explored.

The interview guides (Appendix C, D and E), were piloted with the first two participants and they were found to be very useful. The only question that was dropped from the Patient Demographic Information Form (Appendix C) after piloting was "household income". After two interviews, it became evident that this did not indicate the whole financial picture since spouses
were not forthcoming with the answers related to their sources of income. Instead, the question became: Are finances a concern and is your current household income adequate to manage your family's needs? By reframing this question, a more accurate picture of the financial situation was obtained.

It was important to spend time with participants following the interview to debrief and explore feelings that came up from the interview (Charmaz, 2006). After each interview, I debriefed with all participants about the interview process and to follow up on possible referrals to community agencies. Out of all participants, there were three whom I felt would benefit from further support and they I referred them to appropriate services for follow-up (e.g., Alzheimer's Society counselling service, FTD on-line support group and the FTD and early-onset AD self-help group). Participants who were served at the Sam and Ida Ross Memory Clinic were given the option to book an appointment with me after the interview for clinical follow-up. Two participants chose to book another appointment with me after the interview was over. This option was only offered once the research interview was completed.

Data Analysis

This section discusses the different analytic strategies that were utilized to examine the data based on a grounded theory approach to data analysis.

Field notes and memo writing.

The first step in data analysis occurred right after the participants’ interview. This first round of analyses included my observations such as participants’ non-verbal communications, home or interview environments and field notes (e.g., the preliminary data conceptualizations
and analytic remarks that I wrote during the interviews). Although each interview was digitally recorded, I took copious notes throughout the interview. I created memos (e.g., preliminary ideas about codes and comparisons between codes and any other concepts about the data that came up (Charmaz, 2006). Memos are the written records of the data analysis processes and represent the researcher’s rudimentary early thinking about the data. Charmaz (2006) maintained that writing memos is a way for the researcher to be self-reflexive within the context of the data collection and analysis process. In this study, memos were written after reviewing my notes and after re-listening to the recorded interviews. This occurred within 24 hours of the interview. Memos included in-depth thoughts about an interview, which I wrote each time after I left the field. These were more analytical in nature than the field notes that I took during the interview. In the memos, I included my impressions, major issues that were discussed, categories and themes that emerged together with the participant's and my own views about that participant's situation. Memo-writing was utilized for theoretical sampling throughout the interviewing process.

**Data transcription and coding.**

After all 30 interviews were completed they were all transcribed verbatim to maximize reliability of data analysis (Silverman, 2005). There were 875 single-spaced pages of transcriptions in total. The subsequent analyses of transcripts involved several tasks: (1) discovering categories/concepts and subcategories through coding, (2) narrowing the categories to the ones that answer the study's main question, (3) building hierarchies of categories through linking the categories by comparing data with data, data with codes, codes with codes, codes with categories and their finished analyses with relevant theoretical and research literatures. (Charmaz, 2012; Ryan & Bernard, 2003).
Coding.

Once all the data is transcribed, coding is an analytic tool that allows for the preliminary examination of the data. Codes are short labels created as we interact with the data (Corbin & Strauss, 2008). The initial stage of coding is a line-by-line examination of the data with the goal of developing provisional concepts. Line-by-line, versus coding for topics or themes, allows for a richer and deeper interpretation of the data and it works best with interview and narrative data (Charmaz, 2012). This line-by-line coding included in-vivo codes (e.g., using the actual words of participants rather than codes labeled by the researcher) in conjunction with my own interpretation of the codes. It is important to note that coding is more than paraphrasing. This type of early, line-by-line coding leads to a process of constant comparison of codes, and these concepts that emerge from the codes are collapsed into categories. Through the examination of these categories, core themes emerge which are integrated to develop a theoretical framework (Draucker, Martsolf, Ross, & Rusk, 2007).

In this study, I conducted line-by-line coding of all 875 pages of transcripts. Once all the initial codes were reviewed I focused on the ones that answered the question of this study. The filter for coding the data and formulating each category was related to understanding the experiences of EOD spousal caregivers throughout the caregiving career. Table 3.2, below, is an example of the process of the emergence of codes and a category from a transcript where a husband explains his feelings about his current relationship with his wife:
Table 3.2: **Coding Process from Narrative to Category**

<table>
<thead>
<tr>
<th>Transcript</th>
<th>Line-by-line coding</th>
<th>Code</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;...I'm lonely, because she is not really my wife anymore....If you need to go on a date, go on a date....but there is still compassion and love, but the sharing process and the time spent is different. She is not my partner....she is the person I am caring for.&quot;</td>
<td>Feeling lonely \n Needing to find companionship \n Redefining new relationship with spouse</td>
<td>Married but no longer my partner \n Ambiguity about relationship</td>
<td>Ambiguity</td>
</tr>
</tbody>
</table>

Table 3.3 further illustrates the process of how various codes and categories from multiple narratives from participants eventually lead to the emergence of the theme of uncertainty.

Table 3.3: **Examples of Codes, Categories and Theme Development**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Uncertainty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category: Codes</td>
<td>Unpredictability \n Having to be always on guard \n Things changing all the time \n Our lives changed within minutes \n My husband is a loose cannon \n Some days are better than others \n Not sure about the future</td>
</tr>
</tbody>
</table>
I named each category according to the meaning behind the ideas/feelings of participants. At times, participants' statements or language inspired the naming of the categories. Other times, I labeled them based on my interpretation of the data. After all categories were identified, I classified them into five different themes. Creating themes allowed for comparisons and groupings to emerge from the data in a way that could tell the story of these caregivers. I was very conscious not to label themes using jargon or difficult to understand language in order to make it most congruent with participants’ language (Charmaz, 2006). The five emergent themes will be developed in Chapters 4 and 5, where the findings are discussed.

Summing up, data analysis was achieved through a bottom-up emerging process. This process started from coding raw data (the actual narratives of participants), developing categories and a constant comparing and redefining of these categories. Through this process, the transcripts were analyzed and organized into the core themes which were utilized to describe the EOD spousal experiences.

Quality Criteria

In social science research, validity is one of the criteria that serve as a benchmark for inquiry and its definition varies depending on one's epistemic criterion. For the purpose of this study, validity is defined as how accurately the study's findings represent the participants' realities of the social phenomena and whether these findings resonate with them (Schwandt, 1997). It is important to note that the standards for validity in qualitative research (e.g., trustworthiness), differs from the positivistic criteria of internal and external validity, reliability and objectivity (Denzin & Lincoln, 1994). Trustworthiness is another way to look at this
construct. A trustworthy study is one that is carried out ethically and its findings represent as closely as possible the experiences of the respondents (Padgett, 1998).

Discussing validity in qualitative research is challenging on many levels. Many standards of validity, such as rigour and trustworthiness, have been proposed that are common to qualitative approaches in general (Chiovitti & Piran, 2003; Corbin & Strauss, 2008). These include member checking, triangulation, thick description and peer reviews; however, there is little guidance in the literature about knowing which validity procedure might be selected for use over other procedures (Creswell & Miller, 2000). Given the different epistemologies within the various methodologies in qualitative research, and even within grounded theory approaches, validity and ways to "measure" it take on different meanings based on the approach that the researcher utilizes. In spite of the multiple approaches to validity in qualitative research, there is consensus that researchers need to demonstrate that their studies are credible (Creswell & Miller, 2000).

As previously stated, this study has been informed by the grounded theory approach initially proposed by Corbin and Strauss (2008) and further developed by Charmaz (2006). One difficulty with their approach is that as explained by Cooney (2011), Corbin and Strauss do not specify how to demonstrate quality. Another difficulty I find with Charmaz's (2006) approach is that to achieve what she considers "quality" in a study, her approach require self-evaluation during and after the analysis process. Experienced researchers are very capable of self-evaluation; however, assessing the quality of one's work is complicated. It requires experience to accurately evaluate one's own work and it is very difficult not to be blind to one's own biases. Self-evaluation and reflection is crucial in qualitative research, but it should occur in conjunction with other strategies. For this reason, I have chosen to incorporate other validity measures which
have been extensively used by other qualitative researchers. Creswell and Miller (2000) proposed a framework for choosing which strategies to use in qualitative research based on the researcher's and the study evaluators' epistemologies. The six trustworthiness techniques that I have incorporated based on Creswell and Miller's model include: member checking, multiple coding, audit trail, reflexivity, prolonged engagement and negative case analysis. These strategies were chosen so that the process of data analysis would be both transparent and verifiable (Creswell & Miller, 2000; Padgett, 1998).

**Member checking.**

Member checking involves sharing the preliminary findings with participants and considering their reactions to the accuracy of the way in which the data has been analyzed and how the content has been interpreted (Padgett, 1998; Sorin-Peters, 2004). The first way I achieved this was by seeking clarity and additional perspectives from the participants during the interviews. A second way of attaining this was by having four participants look at the themes that were emerging during the process of data analysis and see if they resonated with them. These preliminary themes were verbally explained to them. Three of the participants found that all of the emerging categories resonated with them. In one case, the participant did not find it reflective of his experience; however, in retrospect this participant should not have been asked as his wife was in the early stages of the disease process and there were a lot of issues that he still had not experienced.

**Multiple coding**

Multiple coding is a response to the charge of subjectivity sometimes encountered in qualitative data analysis. Multiple coding does not demand complete replication of results, but it involves the cross checking of coding strategies and interpretation of the data by independent
researchers (Barbour, 2001). In this study, a second year MSW student in health care, who was well trained in qualitative methodology and was a research assistant for several investigators, coded six of the transcripts and the data was compared to see if there was substantial agreement. The transcripts chosen were one from each category (e.g., FTD and AD early, middle and late stages). Overall there was congruence with the categories and themes that emerged. The most helpful element about this process was in the discussion of the findings that emerged from the coding with someone who was very well versed in the area.

*Audit trail.*

Audit trails include detailed field notes and memos which were maintained to enhance reproducibility and dependability (Padgett, 1998). I created an audit trail with all the originally transcribed data and all the handwritten notes taken in the field. Each transcribed interview has its own file folder with all the field notes and memos related to that particular encounter. In addition, memos comparing emerging themes were kept in different file folders which were organized by diagnosis and stage of the disease. In some instances, participants emailed me and provided me with some of their journal entries and narratives about their experiences as well as media interviews that they had participated in. These were included in their file folders and I read them. Although these materials were not included for data analysis, the themes of the materials that participants chose to share with me reinforced the categories and themes that emerged in the data. This is a form of data triangulation, which although was not consistently used, added to the quality of the study by complementing and providing support for the emerging themes.
**Reflexivity.**

The process of self-reflection is not only about the researcher’s experiences and reactions while interviewing participants, but also about the way the researcher feels and the emotions that may be provoked (Arber, 2006). Through this process the researcher tries to identify his/her personal values, judgments, background and assumptions and attempts to make these factors transparent to minimize their impact on the phenomenon under study (Gearing, 2004). This is particularly relevant to this study as I have been involved in this area of work for over 23 years and I have my own preconceived ideas and feelings about this population. Furthermore, since I am a middle-aged clinician and researcher in the same stage of life as the participants I am studying, it is particularly important to be aware of identification issues.

One way I engaged in reflective work was by writing memos throughout the research process to document the activities undertaken and the emotional responses triggered in me by the interviews. Additionally, I consulted with two social work colleagues at Baycrest, who have extensive experience working with EOD caregivers to see if the themes that were emerging resonated with them. I provided them with a copy of Chapter 6, where the findings were discussed in a narrative format, for their review. Both social workers agreed with the findings and stated that they found them to be true to their experience with this population and had never seen it written up in such a clear manner. As well, I provided the same two chapters to one of the nurses in the Sam and Ida Ross Memory Clinic at Baycrest who works with this population. She found the narrative very informative and felt that given her experience, the information resonated with her.
**Prolonged engagement.**

The duration the researcher has spent in the field and his/her level of experience builds the researcher’s credibility in the topic being studied (Charmaz, 2012; Padgett, 1998). I have spent over 23 years of working in an outpatient memory clinic with all types of dementia caregivers, and my particular interest has been in working with the EOD population. My intimate knowledge of the issues the participants in this study deal with has guided my research. Prolonged engagement adds credibility to the study; however this is a double-edged sword. As I immersed myself in the data, I have needed to be honest and vigilant about my own perspective, my preexisting thoughts and beliefs when developing hypotheses and theory about the data.

**Negative case analysis.**

The ‘outliers’ or the unique aspects of the lived experience of the participants are highlighted (Padgett, 1998) to ensure that all the voices are represented. This is done deliberately to determine whether or not the preliminary ideas about this population still hold. It also provides for a fuller exploration of the dimensions of a concept as it is developed (Corbin & Strauss, 2008). In this study I chose to include as many perspectives as I could find since multiple points of view add richness to explanations and shows that there are many dimensions to people's experiences. For example, I chose to include a spouse whose partner had died two years prior to the interview to see if her perspective added a different dimension to the data. As well, I recruited a husband caregiver who quit his job when he was 49 to look after his wife full-time, which is not the norm. Another form of looking for negative cases is through the emerging data. For example, most people referred to the impact of the disease as having disastrous consequences. However, one person felt that it was a "blessing" to be going through this process and her perspective was very different than the rest of the participants.
Ethical Issues

In this study, all the ethical principles including the ethics of treatment of participants, the ethics of data collection and analysis and the ethics of responsibility to society were followed (Singleton & Straits, 2010). In terms of the ethics of participants' treatment, this study strived to achieve the principles of protection against harm and deception, and maintenance of privacy and confidentially. In regards to data collection and analysis I have strived to be as transparent, forthright and careful in my reporting of the research activities and this is demonstrated throughout this dissertation. Finally, regarding societal responsibility, it is my task to use the findings of this study to educate, advocate and to promote better supports and interventions for EOD spousal caregivers. Although all these three areas of ethical research merit further discussion, only the section on ethical treatment of participants is discussed in more detail as it is a requirement of the Review Ethics Board (REB). The REB helps ensure that research meets the highest ethical standards, and that the greatest protection is provided to participants who serve as research participants. It is guided by the principles of the Tri-Council Policy Statement (TCPS), Ethical Conduct for Research Involving Humans, which sets the standard for research ethics boards in Canada.

Ethical treatment of participants.

In this study, several measures were taken to ensure the rights of participants were upheld. First, the study's ethic protocol was presented to and approved by both the Baycrest Health Sciences (Appendix F) and the University of Toronto Review Boards (Appendix G). Second, potential participants were asked to contact me as a way to minimize coercion to participate in this study. Once they contacted me, I introduced the study, provided verbal and
written details of the proposed research and obtained informed consent to participate in this investigation. Third, participants signed informed consent (Appendix B), which describes the study and its objectives, the potential risks and benefits to participants and the safeguards to maintain confidentiality of their information. This consent form also let participants know that they could withdraw from the study at any time. Most importantly for this population, assurance was provided that their choice to participate in this study would not impact their clinical care. The reason this is important is that as clinical resources in EOD care are limited, there are ample potential opportunities for my clinical involvement with participants over time. Participants were assured that, regardless of their decision to participate, their follow-up as well as future social work or any other kind of care at Baycrest would not be affected.

**Potential risks and benefits.**

Risks associated with participation in this study were considered minimal as I have found that most caregivers want to have an opportunity to tell their stories. Nevertheless, some caregivers may have found it distressing to discuss or relive their issues. My expertise as a clinician in this area, allowed me to recognize and respond to participant distress. If I felt that a participant was upset, I allowed participants to express their feelings in a supportive manner during the interview. Participants were asked if they wanted to terminate the interview then. Nobody chose to terminate the interview since they found the process of recounting their stories therapeutic.

Benefits of the study were explained to participants. The most important benefit to them, as stated by some participants, was their feeling of contribution to the development of knowledge of EOD caregiving issues. Once this thesis is completed, I will utilize this information to
advocate for appropriate interventions and services; something that this group of spouses has been requesting for a long time.

**Confidentiality.**

Every effort was made to keep data and other personal information confidential. Confidentiality was maintained by assigning a code number to each participant and if participants' spouses were patients of the Sam and Ida Ross Memory Clinic, the information would not be included in the clinical chart. Written information has been kept in a secure and locked cabinet in my office which is always locked if I am not there. Digital recordings and the transcriptions are stored in my locked office and in my computer which is password protected. All digital information will be deleted after one year from this study's completion. The hard copies of the transcriptions will be kept until I publish from this study. These hardcopies are in my office at Baycrest, in a locked cabinet. After I finish all publications the transcripts will be shredded through the Baycrest shredder system.

**Chapter Summary**

This qualitative study was informed by a grounded theory approach. The goal behind qualitative research is not generalization but to gain understanding about a phenomenon. In qualitative research there are not hypotheses to be tested but, rather, questions and ideas to be explored, in this case the experience of EOD spousal caregivers over their caregiving career. The reason for utilizing a grounded theory approach has been its previous extensive use in health care and social work research. This methodology provides a strong foundation in the provision of analytic tools, which can effectively be applied in answering the main question in this study.
This methodology follows the goal of theory generation through an inductive and deductive emerging process by utilizing a theoretical sampling method, a constant comparison model and a theoretical coding system. Through the use of this approach, emerging themes appear which contribute to theory development with regards to understanding the issues/needs of EOD caregivers. Although some qualitative researchers claim that they are able to "bracket" their own beliefs when analysing data, this is next to impossible (Corbin & Strauss, 2008). In an interpretivist grounded theory approach, it is more helpful to acknowledge ones viewpoints and deliberately use experience to enhance the analytic process. Even though there is controversy about how to measure "validity" in grounded theory, some strategies were discussed to foster trustworthiness of the data. Finally, the chapter concludes with the ethical considerations which are the foundations of a trustworthy study.
Chapter 4

Findings – The EOD Experience

Initially, the main inquiry of this research was to understand how spouses of persons with EOD view caregiving issues/challenges at different points of the disease progression. Through the data analyses, it became evident that this question had two parts. The first component was about spouses’ experiences and the second element was about how spouses coped with these experiences as a consequence of EOD. Thus, as the study evolved, the aim became not just about understanding these spouses’ experiences, but also learning about how they coped with the impact of their partner's EOD within the temporal context of the disease progression. The next three chapters will discuss the findings of this two-part question sequentially. Chapter 4 will explore how participants experience living with a partner with EOD and Chapter 5, will center on how participants cope with the impact of EOD over time. Chapter 6 will integrate these findings into a narrative that tells the story of how spouses experience and cope with their partners’ EOD.

Chapter 4 is divided into three sections. The first section includes descriptive statistics, which are presented to contextualize this group of young spousal caregivers based on a structured sociodemographic interview guide meant to gather data which included participants’ characteristics and contextual background information (Appendix C). The section that follows explores behavioural disturbances in FTD and AD collected from the both the structured interview (Appendix C) and the in-depth interview schedule (Appendix E), as a way to understand how these behaviours affect the study’s participants. Finally, the section of this
chapter concentrates on qualitative findings from the in-depth interviews (Appendix E) and focuses on the main categories and themes that emerged from the in-depth interviews.

**Quantitative Findings: Descriptive Statistics**

This section presents descriptive statistics from the structured interview guide (Appendix C) to give context to the rest of the study. This includes the participants' socioeconomic background, living arrangements and data related to caregiving and length of time to diagnosis. Since this is a qualitative study, this sample is not representative of all EOD spousal caregivers. Therefore only descriptive information is provided.

**Sociodemographic Characteristics**

The caregivers’ demographics were presented in the previous chapter (Table 3.1). Out of the 30 participants, 21 were women and nine were men; 17 had a spouse with FTD and 13 had AD. The mean age of participants was 59 years, with a range between 44 and 72. All three stages of the disease progression were included, and every stage category (e.g., early, middle and late) was each comprised of a third of the total number of participants. One spouse, whose husband had died two years prior to the interview, was included as she was very involved in the EOD spousal community and had a lot of experience with advocacy and educational issues in the EOD field. Table 4.1 presents this group's sociodemographic characteristics and is analyzed below.
Table 4.1: *Frequency Distribution of Characteristics by Participants*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Participant Frequency n (%)&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Working status</strong></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>9 (30)</td>
</tr>
<tr>
<td>Part-time</td>
<td>7 (23)</td>
</tr>
<tr>
<td>On medical leave</td>
<td>2 (7)</td>
</tr>
<tr>
<td>Unemployed (looking for work)</td>
<td>2 (7)</td>
</tr>
<tr>
<td>Early retirement to caregive</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Retired by choice/age</td>
<td>3 (10)</td>
</tr>
<tr>
<td>Never worked/not working now</td>
<td>2 (7)</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>30</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
</tr>
<tr>
<td>Grade school</td>
<td>1 (3)</td>
</tr>
<tr>
<td>High school</td>
<td>6 (20)</td>
</tr>
<tr>
<td>Trade/community college</td>
<td>9 (30)</td>
</tr>
<tr>
<td>University</td>
<td>14 (47)</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>30</td>
</tr>
<tr>
<td><strong>Are finances a concern?</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>18 (60)</td>
</tr>
<tr>
<td>Yes, and downsized already</td>
<td>5 (17)</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>7 (23)</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td>30</td>
</tr>
<tr>
<td><strong>Dependent children</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>14 (47)</td>
</tr>
<tr>
<td>Dependent and living at home</td>
<td>9 (32)</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td>16 (53)</td>
</tr>
<tr>
<td>Non-dependent living at home</td>
<td>3 (11)</td>
</tr>
<tr>
<td><strong>Age range</strong></td>
<td>(years)</td>
</tr>
<tr>
<td></td>
<td>(8-27)</td>
</tr>
</tbody>
</table>
### Totals
30

<table>
<thead>
<tr>
<th>Immigration status</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Immigrant</td>
<td>11 (37)</td>
</tr>
<tr>
<td>Canadian born</td>
<td>19 (63)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Immigrants: Years in Canada</th>
<th>Range (years)</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 – 15 years</td>
<td>3 (27)</td>
</tr>
<tr>
<td>15 – 25 years</td>
<td>0</td>
</tr>
<tr>
<td>26 years and over</td>
<td>8 (73)</td>
</tr>
<tr>
<td>Totals</td>
<td>11</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Participants' partners in LTC</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>7 (24)</td>
</tr>
<tr>
<td>No</td>
<td>22 (76)</td>
</tr>
<tr>
<td>Totals</td>
<td>29a</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Length of time caregiving (years)</th>
<th>Mean (range)</th>
</tr>
</thead>
<tbody>
<tr>
<td>FTD (n=17)</td>
<td>7.6 (2-17)</td>
</tr>
<tr>
<td>AD (n=13)</td>
<td>9.5 (1-18)</td>
</tr>
<tr>
<td>Totals (n=30)</td>
<td>8.6 (1-18)</td>
</tr>
</tbody>
</table>

*a One patient was deceased at time of interview
b Only 28 participants had children out of total of 30

### Work.

More than half of the participants (53%) were working outside the home while caregiving and of those, 70% were working full-time while the rest were part-time. Two participants were on medical leave at the time of the interview due to depression. Another two spouses were actively looking for work due to financial need since they had lost their jobs, which they attributed to the impact of their spouses' EOD on their work performance. Five spouses took early retirement to care for their partners and this had financial repercussions for the family.

Although these participants retired early to caregive this was never done by choice: it was out of
necessity. Having to stop working and becoming a care provider prematurely is consistent with findings in other studies of caregivers having to quit work due to lack of adequate services (e.g., day programs, respite services, in home support) in the community (Passant et. al., 2005).

**Finances.**

Although the interviews all included a question about participants' total family income, these data did not prove to be meaningful. Some people, who had high incomes still had major financial obligations since they had children to support and mortgages, while others with smaller incomes had fewer financial commitments and were thereby relatively more stable financially. The question about their perception of financial concerns was also included since this proved to be a better indicator of financial distress. Furthermore, finances are related to education and this was an overall highly educated group, with 77% having post-secondary education and of those, 47% with university level training.

Seventy-seven percent of participants reported financial stress and out of this group, 17% had already downsized (e.g., sold their home, moved to a smaller dwelling, rented) due to financial concerns by the time of the interview. Financial stress was related to having dependent children. Ninety-three percent of all study participants had children and of those, 50% were still dependents (e.g., lived at home and/or attended university and were financially supported by the participants). The other 50% had financially independent adult children.

Of the 23% of spouses who did not have financial distress, they all had financial independent adult children. Moreover, 71% of the ill-spouses were receiving a full disability pension and 29% had their own business and were still receiving revenues from it. Thus, all patients were still getting their own source of income.
Immigration.

Thirty-seven percent of participants were immigrants, but all of them had been in Toronto for a minimum of 10 years. Overall, this was a highly assimilated group of immigrants as the average length of time since moving to Canada was 32 years, with a range between 10 and 52 years. The majority of participants were Caucasian, with the exception of five participants who were visible minorities and of those, four were immigrants.

Living arrangements.

The majority of patients were living in their homes (76%) with their spouses, while the rest were in LTC, with one patient being in an inpatient unit waiting transfer to LTC. Thirty-two percent of participants had dependent children in the home and another 11% had children living in the home, but in fact, they provided support to their parents.

Length of time caregiving.

On average, spouses have been looking after their partners for 8.6 years with a range between 1 and 18 years (Table 4.1). For the FTD group, this number was slightly lower, at 7.6 years and for AD it was 9.5 years (Table 4.1). This makes sense since proportionally there were more AD patients in later stages of the disease (46%) than for FTD (24%; Table 3.1). This is relevant information as length of time caregiving is correlated with caregiver levels of burden in young-onset dementia (Svanberg, Spector, & Stott, 2011; Williams et al., 2001).

Delay of time to diagnosis.

Length of time to diagnosis is an area in the EOD literature considered to be of crucial importance since delayed diagnosis greatly contributes to caregiver stress (Chemali, 2012; Wald, Fahy, Walker, & Livingstone, 2003). The reasons for this stress are related to tensions with family members living in the same household (children and spouses) and a high chance of job
loss and divorce (van Vliet et al., 2011). Table 4.2 reports on length of time to diagnosis for FTD and AD combined and for FTD and AD separately, calculated by subtracting the patients' age at time of initial symptoms from their age at diagnosis.

Table 4.2: Years from First Symptoms to Diagnosis for FTD and AD Combined and by Each Diagnosis

<table>
<thead>
<tr>
<th>Time (years)</th>
<th>FTD and AD Patients</th>
<th>FTD Patients</th>
<th>AD Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency (%) (^a)</td>
<td>Frequency (%) (^a)</td>
<td>Frequency (%) (^a)</td>
</tr>
<tr>
<td>Under 1</td>
<td>1 (3)</td>
<td>1 (6)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>1-2</td>
<td>10 (33)</td>
<td>5 (29)</td>
<td>5 (38)</td>
</tr>
<tr>
<td>3-4</td>
<td>3 (10)</td>
<td>1 (6)</td>
<td>2 (15)</td>
</tr>
<tr>
<td>5-6</td>
<td>9 (30)</td>
<td>5 (29)</td>
<td>4 (31)</td>
</tr>
<tr>
<td>7-8</td>
<td>2 (7)</td>
<td>1 (6)</td>
<td>1 (8)</td>
</tr>
<tr>
<td>9-10</td>
<td>3 (10)</td>
<td>3 (18)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Over 10</td>
<td>2 (7)</td>
<td>1 (6)</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Totals</td>
<td>30</td>
<td>17</td>
<td>13</td>
</tr>
</tbody>
</table>

\(^a\) All percentage values are presented as percentages of the total group.

The average (mean) length of time was 4.8 years for FTD and 4.5 for AD; however, this does not give a true picture, as there is a bimodal distribution of length of time for both FTD and AD combined, and within each diagnosis separately. The table indicates that a third of patients were diagnosed within a one to two year period and another third were diagnosed after 5 to 6 years of initial symptoms.

Below (Table 4.3) is the breakdown of the length of time to diagnosis for the two subgroups (1-2 years and 5-6 years) by stage of disease.
Table 4.3: Length of time to diagnosis for patients who were diagnosed within 1-2 and 5-6 year range

<table>
<thead>
<tr>
<th>Time (years)</th>
<th>Stage of disease</th>
<th>Early Frequency (%)&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Middle Frequency (%)&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Late Frequency (%)&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-2 (N = 9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FTD</td>
<td></td>
<td>4 (44)</td>
<td>1 (11)</td>
<td>0</td>
</tr>
<tr>
<td>AD</td>
<td></td>
<td>1 (11)</td>
<td>1 (11)</td>
<td>2 (22)</td>
</tr>
<tr>
<td>5-6 (N = 9)</td>
<td></td>
<td>0</td>
<td>3 (33)</td>
<td>2 (22)</td>
</tr>
<tr>
<td>FTD</td>
<td></td>
<td>1 (11)</td>
<td>0</td>
<td>3 (33)</td>
</tr>
</tbody>
</table>

<sup>a</sup> All percentage values are presented as percentages of the total group for each category.

This table shows that in the sub-group that took one to two years to diagnosis, 55% of patients were in the early stages. This differs from the five to six years' group, where the majority of patients (89%) were in the middle and late stages of the disease and of those, 63% were in the last stages of the illness. On average, this group of people that took 5-6 years to diagnosis and were in the last stage of the dementia, were diagnosed seven years ago, with a range between four and ten years. The group of patients who was diagnosed faster (1-2 years) was mostly in the early stages of dementia and thus, the diagnoses have been more recent. On average, this early group was diagnosed within the last year prior to study participation. This faster time to diagnosis in this sub-group of people in the early stages of dementia, could be a reflection of improved awareness in the medical community in regards to EOD, leading to faster diagnostic times.
Spousal Perception of Behavioural Disturbances in FTD and AD

This section includes the behavioural disturbances in FTD and AD perceived as most stress-inducing by the well-spouse participants. This information was collected through the in-depth interview (Appendix E). The limited findings in the EOD literature shows that caring for a relative with dementia is detrimental to both mental and physical health (Kaiser & Panegyres, 2007; Nurock, 2000; Riediejk et al., 2006; Svanberg, Spector & Stott, 2011; Takano & Arai, 2004). Although the risk factors for caregiver burden are multifactorial, LOD research findings show that the most important risk factor for adverse outcomes for caregivers is the patient's problem behaviours (van Vliet et al., 2010). Arai and colleagues (2007) found that perceived behavioural disturbances were positively correlated with caregiver burden in both EOD and LOD. Boutoleau-Bretonnier and colleagues (2008), who compared ADL and caregiver burden in early-onset AD and FTD, found that caregiver burden was higher in FTD even though functional disability was similar in FTD and AD patients. They concluded that activities of daily living (ADL) were not the main reason for caregiver burden in these two groups, but they postulated that burden was correlated with the patient's level of behavioural disturbance as experienced by the caregiver. Since behavioural disturbances are common in EOD, especially in FTD (Armari, Jarmolowicz, & Panegyres, 2012; Passant et al., 2005; van Vliet et al., 2010; van Vliet et al., 2013), it follows that this is an important area of exploration when studying the experiences of EOD spousal caregivers. Below is an exploration of what spouses considered to be difficult behavioural issues.
What do Spouses Perceive to be Difficult Behaviours in FTD and AD?

Table 4.4 and 4.5 present the findings by diagnosis and stage of illness based on previous and current behavioural difficulties as per participants' responses to the question: What kinds of behaviours do you find the most stressful currently and in the past? The data were divided by diagnosis since FTD presents with more behavioural disturbances than AD. Behaviours were categorized using the language that participants utilized and included the behaviours that were the most problematic to them. Table 4.4 includes the findings for participants with FTD and Table 4.5 for AD.

**FTD findings.**

Table 4.4: *Current and Past Behavioural Issues for Patients with FTD by Stage of Illness and Participants' Gender*

<table>
<thead>
<tr>
<th>Patients with FTD by stage</th>
<th>Participant's gender</th>
<th>Current behavioural issues</th>
<th>Past behavioural issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>11(^a). FTD, early</td>
<td>Female</td>
<td>Very rigid</td>
<td>Aggressive</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Started drinking</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Obsessive-compulsive</td>
<td></td>
</tr>
<tr>
<td>13. FTD, early</td>
<td>Female</td>
<td>Pushes</td>
<td>Aggression</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Throws objects</td>
<td></td>
</tr>
<tr>
<td>27. FTD, early</td>
<td>Female</td>
<td>Sexual disinhibition</td>
<td>N/A(^b)</td>
</tr>
<tr>
<td>21. FTD, early</td>
<td>Female</td>
<td>Apathetic</td>
<td>Apathetic</td>
</tr>
<tr>
<td>23. FTD, early</td>
<td>Female</td>
<td>N/A</td>
<td>Stubborn</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Resistive Agitation</td>
</tr>
<tr>
<td>30. FTD, early</td>
<td>Male</td>
<td>Sleeping</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Rude</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disinhibited</td>
<td></td>
</tr>
<tr>
<td></td>
<td>FTD, moderate</td>
<td>Gender</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>---</td>
<td>--------------</td>
<td>--------</td>
<td>-----------</td>
</tr>
<tr>
<td>2.</td>
<td>Female</td>
<td>Sexual disinhibition</td>
<td>Aggressive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>Female</td>
<td>Obsessive-Compulsive</td>
<td>Sexual disinhibition</td>
</tr>
<tr>
<td>7.</td>
<td>Female</td>
<td>Obsessive-compulsive</td>
<td>Urinating in inappropriate places</td>
</tr>
<tr>
<td>8.</td>
<td>Female</td>
<td>Childish</td>
<td>Lack of empathy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Started drinking</td>
</tr>
<tr>
<td>10.</td>
<td>Female</td>
<td>Sexual disinhibition</td>
<td>Resistive</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Male</td>
<td>Obsessive-compulsive</td>
<td>Lack of communication</td>
</tr>
<tr>
<td>29.</td>
<td>Male</td>
<td>Resistive</td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>Female</td>
<td>Inpatient Unit</td>
<td>Shoplifted</td>
</tr>
<tr>
<td>4.</td>
<td>Female</td>
<td>Obsessive-compulsive</td>
<td>Shoplifted</td>
</tr>
</tbody>
</table>
The most common types of distressing behaviours for spouses of people with FTD, in order of frequency were as follows: disinhibition, followed by aggression, obsessive-compulsive behaviour and resistive to care behaviour. Disinhibited behaviours included sexual disinhibition, shoplifting, stealing and rude behaviours and were reported as the most stressful by 59% of spouses. An example of disinhibited behaviour was a man with FTD whose wife stated: "I don’t really trust him around the girls. You know it’s very…you know he walks around naked". Another example was reflected by a wife's concern about her husband's driving: "I noticed he was driving like a teenager. He could drive through a crosswalk because no one was there, even though the lights were flashing". Another example was a man who was impulsive: "He jumped out the window to look for me, so they put him on an antidepressants and he was okay. Then in March he started almost stalking and touching her [a neighbour], so they sent him to the hospital". Spousal distress related to disinhibited behaviour is consistent with de Vugt and colleagues' (2006) study, which found high scores of distress for disinhibition in FTD spouses. It is also congruent with Massimo and colleagues' (2009) study, which found disinhibition to be the biggest stressor in FTD caregivers.

The second most common type of stressful behaviour was aggression, which was defined as any type of physical violence; 41% of spouses had to manage some form of aggression/violence at some point of the disease trajectory. Most of the people who reported
aggression as problematic were women (6 out of 7 respondents). An example of this was a man in the early stages of FTD, before the diagnosis was made: "He was aggressive, rude, violent, and he moved out. We were gonna separate I had had enough". As well, another man with FTD was starting to become aggressive toward his wife in the earlier stages: "He was vaguely aggressive at one point...I called the police, it was more a preventive because he was starting to push". These examples do not mean that female patients with FTD did not have aggression, but husbands may not have reported this to be problematic as they were physically stronger and could handle their wives' violent behaviours. For example, the husband of a woman with FTD, in the late stages, reported that "one time she punched me in the nose". The difference with this husband was that although his wife punched him, he was not scared by her, and the tone in his voice was more comical than fearful.

Obsessive-compulsive behavior and resistive behaviour were reported as problematic with the same frequency (six out of 17 patients). Thirty-five percent of spouses had difficulty with their partners' stereotypic and ritualistic behaviours, which they labeled obsessive-compulsive behaviours. For example, one spouse, whose husband compulsively alternated days into "good and bad days", could not do or plan anything on a "bad" day. She found this intolerable as she felt that this was within his control and he was just "being difficult". She could not understand how someone with executive dysfunction (not her words), could plan for good and bad days so well. Other compulsive behaviours led to financial problems such as: "she used to like to go to casino. She was obsessed big time". Other ritualistic behaviours were embarrassing; for example, one husband who compulsively had to rake leaves from all the neighbors on the street. When there were no leaves to rake he would shake trees to make leaves fall to the ground; or a husband who went around barking at dogs every time he saw one.
Finally, resistive to care behaviour was experienced by 35% of participants. Spouses reported that it was stressful in that it impaired a spouse's ability to provide care. For example, a wife recounts her trying to have her husband join her for dinner: "he doesn’t want to get out of his chair to go to eat he just wants to stay there and eat later. Sounds minor but you know everything is like that". Resistive behaviour was probably the reason for some of the aggressive behaviour, given that sometimes aggression was a result of asking the patient to do something he/she did not want to do (e.g., shower). Here is an example of a husband trying to shower his wife: "it is getting to a point that she doesn’t want to take a shower and it becomes tough, because I have to drag her to the shower and last night I gave up, I’m not going to go through this, I’m going to slip, she is going to slip; the dogs were freaking out, the dogs actually ran into the shower and she became belligerent". However, in spite of all the difficulties, because this husband could physically restrain his wife, the situation did not become worse.

Disinhibition, aggression, obsessive-compulsive behaviour and resistive behaviours were the most stressful behaviours and they were present in all three stages of the disease progression. However, disinhibition, which was found to be the most frequent source of caregiver distress, was no longer an issue in the later stages. This is congruent with Chow and colleagues' (2012) findings of a crescendo-decrescendo trajectory of behavioural symptoms in FTD.

**AD findings.**

Below are the results for behavioural disturbances, which were perceived to be most stressful for spouses of people with AD. The data are divided by stage of disease progression to explore differences in behaviours that were problematic based on stage of disease.
<table>
<thead>
<tr>
<th>Patients with AD by stage</th>
<th>Participant's Gender</th>
<th>Current behavioural Issues</th>
<th>Past behavioural Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>14(^a) atypical AD, early</td>
<td>Male</td>
<td>Rude Sexual disinhibition Over spending Obsessive-compulsive</td>
<td>N/A(^b)</td>
</tr>
<tr>
<td>26. AD, early</td>
<td>Male</td>
<td>No concerns</td>
<td>No concerns</td>
</tr>
<tr>
<td>3. AD, early</td>
<td>Male</td>
<td>Forgetful</td>
<td>N/A</td>
</tr>
<tr>
<td>9. AD, moderate</td>
<td>Female</td>
<td>Apathetic</td>
<td>Apathetic</td>
</tr>
<tr>
<td>22. AD, moderate</td>
<td>Female</td>
<td>Resistive</td>
<td>N/A</td>
</tr>
<tr>
<td>25. AD, moderate</td>
<td>Female</td>
<td>Paranoid Delusional</td>
<td>N/A</td>
</tr>
<tr>
<td>5. AD, late</td>
<td>Female</td>
<td>Resistive</td>
<td>Aggressive Loud vocalizations Swearing Pushing</td>
</tr>
<tr>
<td>16. AD, late</td>
<td>Female</td>
<td>(In LTC) N/A</td>
<td>Aggressive Incontinent</td>
</tr>
<tr>
<td>18. AD, late</td>
<td>Male</td>
<td>(In LTC) Hallucinations</td>
<td>Screaming Hallucinations Paranoid</td>
</tr>
<tr>
<td>19. AD, late</td>
<td>Female</td>
<td>(In LTC) Resistive</td>
<td>Wandering Aggressive</td>
</tr>
<tr>
<td>20. AD, late</td>
<td>Male</td>
<td>Needs total care</td>
<td>Aggressive Wandering</td>
</tr>
<tr>
<td>24. atypical AD, late</td>
<td>Female</td>
<td>(In LTC) Wandering</td>
<td>Aggressive (pushed/shoved) Sexual disinhibition Verbally abusive</td>
</tr>
<tr>
<td>15. AD, deceased</td>
<td>Female</td>
<td>Resistive Aggressive</td>
<td>N/A</td>
</tr>
</tbody>
</table>

\(^a\) Numbers refer to the assigned number to each participant. \(^b\) None reported
The two most common behavioural disturbances for AD spouses were aggression, followed by resistive behaviour. Aggression, referring to any form of physical violence, was the most common reported problem; out of 13 participants with AD, 6 (46%) reported aggression to be a challenging behaviour. As in the FTD group, it was women that found this to be stressful and 75% of the women whose husbands had AD experienced aggression. Again, like in the FTD group, male caregivers did not find aggression to be difficult to handle. This is consistent with Takano & Arai’s (2004) study on gender differences in burden for spouses of people with early-onset AD.

Resistive behaviour, especially in relation to care, was found to be problematic for 31% of AD spouses. However, just as with aggressive behaviour, it could be a gender issue. All four spouses that reported resistive behaviour to be stressful were women, who are not strong enough to look after husbands who are physically much bigger and heavier than they are.

Lastly, neuropsychiatric symptoms such as delusions, hallucinations and paranoid behaviours were of concern even though they were not as frequent as aggression and resistive behaviour. These findings are consistent with Takano & Arai’s (2005) study who found these behaviours to be correlated to caregiver burden in EOD. What was particularly difficult for the well-spouses was when their partners thought that they were having affairs or when they did not recognize them and kept asking repeatedly to see their spouses. As well, patients who thought others were stealing from them made it difficult to hire help.

**FTD and AD findings.**

Overall, the results for FTD and AD are very similar in relationship to aggressive and resistive behaviours and this is consistent with the literature’s findings that both FTD and AD
have behavioural and psychological symptoms of dementia (BPSD; Takano & Arai, 2005). The main difference between FTD and AD results from the disinhibited behaviour in FTD and its impact on spouses. Disinhibition was more problematic in the early and middle stages of the disease and in the middle-late stages, both groups of spouses seem to have to deal with similar stressors. Proportionally, there were more AD patients in LTC (31%) than for FTD, where only 18% were institutionalized. Although spouses of patients who were already institutionalized did not have to manage resistive and aggressive behaviours directly, they still felt that these behaviours were stressful, as they needed to advocate with staff for appropriate care (e.g., keeping spouses clean, fed and not being treated with force). Spouses did not want their partners to be oversedated to deal with these behaviours.

Finally, spouses noted that behaviours perceived as stressful shifted with the advance of the disease. Thus, the stress of having an "embarrassing spouse", in retrospect, was less stressful than currently having to deal with aggressive behaviour. The perception of what is stressful at various points in the disease trajectory will be explored in depth in the remainder of the chapter.

**Qualitative Findings**

**Themes – The Experience of Spousal Caregivers**

In this section, qualitative data is presented through illustrations of analytic statements with supporting descriptions of the main categories and themes, and examples of how these themes evolve through the study's narrative. These main themes will lay the foundation for the subsequent chapters where the findings are applied to create a framework for understanding the experience and coping of EOD spousal caregivers. As suggested by Corbin and Strauss (2008),
sufficient conceptual details and descriptive quotations will be provided so that a comprehensive understanding can be offered. Quotes chosen for inclusion were selected since they illustrated a particular theme clearly. References to the literature are interwoven in the findings and discussion sections to demonstrate points of divergence as well as convergence from previous research (Charmaz, 2006). This iterative process of returning to the literature throughout the course of the data analysis process is in keeping with the philosophical underpinnings of the grounded theory approach (Charmaz, 2006).

Although there were unique ways each spouse was impacted by EOD, most participants shared similar experiences. These commonalities make up the themes and describe the essence of this study while providing the framework for this chapter.

Data analyses showed that the spouses' experience across the EOD trajectory essentially revolves around five themes. Figure 4.1 illustrates these five themes. It is important to note that although these themes are presented as discrete groupings, this is done for the sake of clarity. In reality, there is a great deal of overlap among the themes. How and where these themes intercept will be explored in the following sections.
In this study, the overall emergent theme is what I have labeled: *surviving chronic crises*.

The following series of quotes describe what participants meant by the word *crisis*. They described it as a feeling of “everything exploding at the same time”; “being close to the edge” and “being on the verge of insanity”. Spouses described having to survive crises as being central to the experience through the progression of the disease. By *surviving* they meant “living with the disease but trying not to drown with it”; “life is like pebbles in a glass, you put too many and it tips over; so my goal is the constant avoidance of the last few pebbles” and the continual feeling of having to “dig myself out of this one [situation] but really feeling like I am sinking”.

Participants recounted the ways they coped with the continuous crises, which were precipitated by the constant state of change that comes with EOD, and their struggles to maintaining a sense of normalcy and equilibrium. Surviving essentially occurred through a process of constantly re-adapting to new situations brought on by the multiple impacts of the
disease. This core theme of surviving chronic crises will be discussed in detail in the next chapter. The reason for giving it its own chapter is that it builds upon the findings from this chapter and more importantly because it is central to the discussion on coping.

The central theme of surviving chronic crises is built from four other themes. These four themes are explored in this chapter and they include: (1) the life-stage (e.g., early-onset of the disease) and its effect on participants, (2) the disease invisibility and its impact on spouses and families, (3) the continued uncertainty spouses experienced as a consequence of the disease process and (4) a feeling of falling through the cracks. Participants felt that the combination of themes (1), (2) and (3) led to being ignored and forgotten by the system and society, which contributed to the development of theme (4). In summary, first I examine the four themes in this chapter and the overarching theme will be explored in Chapter 5.

(1) Life-Stage

The onset of a dementia during middle adulthood is significantly out of sequence in terms of a person's life course (LoGiudice & Hassett, 2005, Svanberg, Spector, & Stott, 2011). Participants described how the off-timing of the disease impacted their lives. Categories subsumed under life-stage theme include: (a) multiple roles, (b) employment, (c) finances and (d) intimacy, and are depicted in Figure 4.2. These categories included as part of the life-stage theme although are depicted as separate, they are in fact interrelated.
Figure 4.2. Categories associated with life-stage.

(a) Multiple roles.

One of the salient characteristics about this group of middle-aged caregivers is the multiplicity of roles and responsibilities they have (Svanverg et al., 2011; van Vliet et al., 2010) and the results from this study demonstrate this. Not only do spouses of people with EOD care for their partners, but also they need to balance this with caregiving responsibilities for both young and/or adult children as well as aging parental family members. The challenges related to multi-generational caregiving have an impact on the overall lifestyle of middle-aged adults including personal time, career development, financial stability as well as increased risk of mental health disorders (Riley & Bowen, 2005).

In this study, some of the participants not only looked after and lived with their parents, children and siblings but also had the additional difficult task of looking after an ill spouse while working. The following excerpt illustrates this from the perspective of a wife with a husband in the earlier stages of Alzheimer’s disease:

[Husband] was already struggling in his 40s and you throw a major change in our living arrangements to accommodate his mother who was a senior and having difficulty living on her own, and my own parents, my dad at the time had serious heart disease ...and my sister-in-law who is a paraplegic...we combined the three
households into one...I also work full-time and have two kids to look after
(participant #9 — 51 year old female, caring for spouse with AD).

Some families also contended with looking after children, ill spouses and were the
primary caregivers to grandchildren. This added another level of strain to the already stressful
situation of having a spouse with FTD.

We have three of our grandchildren [living with us]... Our daughter, she is a lost
soul... I did everything humanly possible to help my daughter, but she is beyond
my helping... The Children's Aid is involved, they are in my temporary care right
now...I am not allowed to leave the kids alone with him [husband] because of his
diagnosis... My husband is a loose cannon... I'm realizing that he is starting to have
trouble... My son is an angry young man... he moved out recently... The children's
[paternal] grandmother called, he [husband] put out an invitation for her to stay
with us... I can only save so many people ...(participant #23 — 55 year old
female, looking after a spouse with early-moderate FTD).

The above illustration is characteristic of other spousal caregivers in this study who not
only looked after a partner, but also had multiple dependents, competing roles, and young
children. Their stress was further exacerbated by the financial impact of this disease. Participant
# 23 also worked full-time and she has had to take an extra part-time job.

I need the extra money, but I don't have the time... I get some medical coverage
through this part-time job... I need it to pay for medications, I am a cancer
survivor... they [the company] is looking for ways to downsize ... so any moment,
I'm waiting for the phone call where they say that I don't qualify for these benefits
anymore (participant #23).

This participant had the stress of having to manage two jobs while raising her three
grandchildren and trying to support her daughter and son, both of whom have mental illness. At
the same time, she was struggling with having the Children’s Aid “on my back”, a husband with
FTD in addition to having to support her family on her salary. Her risk of losing her medical
benefits added extra anxiety and insecurity about her future and her family’s well-being. This example, although appearing extreme, is a typical illustration of spouses who have multi-generational family responsibilities while having to support the family financially.

Of all the participants, four families had young children in the home (in elementary school) and three of them had Children’s Aid Society (CAS) involvement. CAS became involved through police and school referrals. In one case, the police referred to CAS due to the FTD parent's violent behaviour. In another case, the school had concerns about an 8 year old child’s sudden incontinence problems and difficult behaviours at school and reported it to CAS. The last case was through becoming a foster parent to grandchildren because of her daughter's mental illness. Although the CAS was there to provide support, understandably, they were a source of stress. Out of the four families in this study with school-aged children, one was in the moderate - late stages of AD, two were in the early stages of FTD and one in the moderate stages of FTD. Participants, who had CAS involvement, experienced this as the main crisis and they identified the dementia as a stressor but not their main one. However, even though participants did not feel that the dementia was their chief source of stress, in two out of the three cases, it was actually the EOD that resulted in CAS involvement. To make matters worse, the ill partners could not help with household tasks, could not provide emotional or financial support and could not care for the children. The following is an example of a wife with three children ranging in ages from eight to eleven that illustrates another example of the multiple stressors of having to work to support the family, having young children and CAS involvement:

I worked while the kids were at school and I would work every other Saturday and I'd get a babysitter for part of the time. Then eventually, my youngest was having trouble with his toilet training and Children's Aid became involved and said that they were being hit....they then realized that [my husband] had Alzheimer's disease and he was also incontinent [which explained my son becoming incontinent as well]... they provided some support... but I could have
done without the stress [of CAS involvement] (participant #16 - 44 year old female, looking after husband with moderate-late stages of AD who was subsequently institutionalized as a result of the CAS intervention).

Having multiple roles and responsibilities also meant that spouses knew they needed to take care of themselves, however, participants did not have the time to pursue their own medical care since they were busy taking care of others. This was especially true for younger spouses who had children in the home and were working. The following example illustrates this.

Try and find another family doctor, right? I have menopausal symptoms to deal with. So this is just a peachy time. So I’m sitting there and thinking am I getting really hot and fevers because of this cold or because I’m premenopausal. I have no idea, and I’m not being followed with a doctor, so I just go on the net (participant # 9 — 51 year old wife looking after her husband with AD, while working full-time and having extended family that needs help as well as two children in her home).

As seen through these excerpts, having young children/grandchildren added another layer of strain to participants. Having to constantly balance the needs of children and an ill spouse was one of the biggest stressors for these families. This finding is congruent with the literature, which states that looking after children, spouses and the other multiplicity of commitments is a major source of stress in EOD caregiving (Kaiser & Panegyres, 2007).

This study's findings also show differences in perceived stress based on spouses' age. The younger sub-set of spouses (under 55), who had more responsibilities and a poorer financial picture experienced more stress. This supports Rosness and colleagues' (2011) study that found that the younger spouses of individuals with EOD had the poorest Quality of Life Scores and Fitting and her group's (1986) results that younger spouses were lonelier and more resentful of their role than older spouses. This study is also congruent with Bakker and his group (2013), which also found more burden experienced by the younger sub-group of spouses.
(b) Employment.

EOD affects people active in the labour force and whose employment earnings constitute all or part of the family's income. This group has a double financial strain since the people affected with EOD cannot work, and their spouses may need to cut back or stop working to provide care for their spouses (Harris & Keady, 2004; Luscombe, Brodaty, & Freeth, 1998; Nunnemann et al., 2012; Sperlinger & Furst, 1994).

The findings in this study were consistent with previous research in regards to negative outcomes related to loss of employment for both patients and their spouses (Van Vliet et al., 2010). However, what has not been thoroughly noted in the literature, and it was a main finding in this study, are the repercussions to those that lose their jobs due to poor performance and subsequently do not qualify for long-term disability pension. These patients either quit their jobs prematurely, since they feel they cannot perform, or they are fired or 'downsized' with disastrous financial consequences. Of note is the fact that in this study, only people with FTD were fired or downsized from their jobs, which makes sense given the lack of judgment, impulsive, disinhibited, and inappropriate behaviour that is common in FTD (Passant et al., 2005).

He was working in his company [but he could no longer perform as well]. His short term [disability] was declined... [Since husband lost his driver's license] I drove him every day and came back and then I'd pick him up...He eventually was 'downsized'... it was devastating...He then got some contracts, but they were cut short...I think there were problems...there was an abrupt ending with the last contract (participant #27 — 59 year old female caring for husband in the early-moderate stages of FTD. Husband was downsized when he was 54).

This case, which is representative of other participants' experiences, was further compounded when his wife was denied short-term disability. Due to her depression, she found it impossible to work while caring for her husband. Her physician, who needed to complete the short-term
disability form, had unknowingly filled it out incorrectly. It stated that her diagnosis was 'caregiver stress', even though she had major depression. The consequence to not writing the correct diagnosis was that she did not qualify for a pension that she would have been entitled to receive. Sometimes, when health care providers are not aware of the system, incorrectly completed forms can have dire consequences to families.

Below is an example of a patient with FTD, who unknowingly jeopardized the family's financial situation by quitting her job, instead of going on disability. By prematurely renouncing her job, she gave up her entitlement of going on long-term disability.

She was so stressed at work and decided to take a package and leave… I'm using my retirement fund [to support us]. The thing is, I'm going to run out of money and when that happens I'll have to sell the house... we have no income coming in... we're going into bankruptcy (participant # 28 — 53 year old male, looking after his wife who has late stages of FTD. Wife stopped working when she was 43).

The most tragic examples of financial losses were those individuals who were self-employed and went into debt, stopped paying bills, made poor financial decisions and nobody noticed as they worked on their own. By the time someone became aware of these changes, it was too late.

[Husband] told him [doctor] that he was fine in his business... During this period I found out that he'd been locked out of his business ... by the time he was diagnosed in 2006, there was no way he could carry on working... there was all kinds of stuff going on... He'd been taken to court, had all these gentlemen against him, none of which I knew anything about... There were bills coming out your ying yang, he hadn't paid the mortgage in three months, and Revenue Canada was after us (participant # 2 — 58 year old female caring for her husband in the moderate stages of FTD. He lost his business when he was 55).
Another example was someone who sold his business without consulting his wife and consequently the couple lost their retirement fund 15 years before he was supposed to retire.

He sold our business, he sold our retirement just like that...So, he just did it. And I said don't do it, come home. [He said] "The lawyer is so happy, you should see him"...I told him come home. And he wouldn't and he just did it and I remember telling my mother he is selling the [business] and there is nothing I can do, nothing I can do (participant # 1 — 56 year old female looking after her husband with FTD in the moderate-late stages).

This illustrates not only the financial consequences, but also the all too common sense of impotence that spouses feel about their situation. This sense of powerlessness comes about from their spouses still appearing competent enough to make decisions while not having the judgment to make the correct ones.

The following quote is another example of the double-financial strain experienced by families with EOD:

I was working and I decided to retire [early]. So you see why I decided to retire. I took two [medical] leaves of absence over the years. I was off about six months at a time...Then I went back to work and I was visiting [husband in LTC] every night after work and coming home and having to do prep for work for the next day...I was going crazy (participant #19, 61 year old female caregiving for husband in LTC with late stages of AD. Wife retired when she was 60).

Spouses have limited choices when making decisions about their work and their ability to manage caregiving tasks at the same time. This participant also had the added responsibility of looking after her own mother, who had moved in with her and was on a waiting list for LTC.

Below are two further examples of women having to give up their jobs to become caregivers. The financial uncertainty that ensues was a typical experience:

I cannot work, I have to be a full-time caregiver....I would not have made enough money to pay for quality care, and I would still have to come home and do the
shopping and cooking and cleaning...with [husband] not working for four years and me not working for two, we have kids at school....we have to count every penny...I've got no pension, I will not have worked. Right now we're on [husband] dental care package and all the benefits - that will stop [when he dies]. When his long-term disability stops, I will be poor. (participant # 25 —52 year old female looking after a husband with early-moderate AD).

I’m going to give up my job to take care of him ... Then I thought I’ll be at home for five years caring for him, then I’ll be early 50s and can’t get a job so I’ll be a Walmart greeter because I can’t pay the bills (participant #11 —47 year old female looking after a husband with early stages of FTD and who has three school aged children in the home).

In contrast to the above examples, some people did not make the "choice" to stop working, but spouses lost their jobs since their caregiving duties were impacting their work performance.

You gotta look after him and you feel the pressure from work. I feel it was direct result of the sickness [depression] that I lost the job. I said I was ready to come back, and I was functioning. But the damage had been done (participant #12 —58 year old female caring for a husband in LTC, in the late stages of FTD who was let go of work at 57).

(c) Finances.

There is great overlap between the previous section on employment and this section on finances; however, this section merits its own discussion since monetary distress permeated every other theme in this study. Most of the literature in EOD discusses financial distress as a psychosocial outcome of EOD, but does not single it out as the most important one (Arai et al., 2007; Hasse, 2005; Sampson, Warren, & Rossor, 2004). In this study, financial distress was the most frequently raised issue in regards to negative caregiver outcomes of EOD. The only other study that found finances to be the top stressor was by Diehl and colleagues (2004), who emphasized that financial problems due to loss of work represent one of the cardinal problems for families with an FTD patient.
Participants in this research clearly expressed how finances became a major stressor and how monetary difficulties overshadowed other psychosocial problems. It was repeatedly expressed by caregivers that "money is everything". Every single participant brought up the issue of how finances affected him or her, even when they had sufficient resources to cope. Although money meant something different to each participant, there was the common understanding that either money could afford care for the person with EOD, the spouse or the family and it would alleviate some of the current and future stress.

The future worries me the most...I will be worn when this is over. I've got no pension, I will not have worked. I will be poor...I just wish we were rich. If I had money I would be way happier. If I could hire somebody to clean the house, cut the grass, and do little things life with FTD would be easier (participant # 25 —52 year old female looking after a husband with early-moderate AD).

I tried to get a reduction in my mortgage, but they won't because [husband's] income on paper is high...but I have to pay for his nursing home and have three kids at home... I've gotten into debt because it is just not enough (participant # 16 —44 year old female, whose husband with moderate-late stages of AD was in long term care [LTC]).

Countering these experiences was the awareness of one spouse, who did not have financial difficulties but was cognizant about the difference that money makes in this disease.

I'm very fortunate in that I don't have financial worries. For others in the [on-line] group is so sad. I can afford to hire help to keep him here...it's not fair for those that are not in that position... That's why I am saying I'll be ok (participant # 6—66 year old female, looking after husband in moderate-late stages of FTD).

Participants had to adjust their living situations when finances became a concern. For example, two women moved in with their adult children to save money. A man had his son move in with him and the son was paying rent to help both financially and with his mother's care. Among all participants, 40% had already downsized at the time of the interview and 23%
planned to sell their home to afford care. This is out of time with the social timing of individuals through the life course, where generally downsizing occurs at a later point (e.g., post retirement). Proportionally, men were a lot less impacted financially and were not thinking of downsizing; 67% of husbands interviewed did not feel that they needed to downsize and although they talked about the financial impact of hiring help and the cost of LTC, they did not feel they had to move to afford help. This was probably due to women having lesser wages and thus, the impact of them not working was not as great. I'm in such debt, I keep going further into debt...I'm eating up my house in order to keep [husband] at home (participant #1 — 56 year old female looking after her husband with FTD in the moderate-late stages).

Those that were most affected by finances were spouses of people with EOD who had mismanaged their finances due to the dementia and/or had dependent children. As well, women overwhelmingly were negatively affected when their husbands could no longer work.

I was trying to downsize, and from a four bedroom house I moved to a three bedroom house. And it's still the same story, I'm struggling so much...I'm still working as a substitute teacher and it's not on an everyday basis...I run around and whatever I can get to do, I do. Sometimes I even work in a banquet hall, whatever comes my way. It's very difficult to struggle on your own...In the past he [husband] had a tendency of giving money, loan to his own friends. And I am there just to put all the threads together, because he doesn't remember who he has given the money to. (participant # 21 — 47 year old female, caring for her husband with FTD, moderate stages. There were four dependent children in the home).

Those families that went from feeling financially secure to being in a situation of being financially insecure, described being in a constant state of anxiety. As in the example below, there were three wives whose partners' misspending created financial distress and these wives expressed the most anger. The case that follows was the most challenging among all participants.
I couldn't touch anything because the government had a lean on the house...he had accrued thousands of dollars on VISA fees...by November, he'd overspent by $25,000... He cleaned me out. I had nothing, and I didn't even know...the government refused to negotiate over his back taxes. He accrued interest over a debt of $1,000 to over $80,000 ... that little shit. I couldn't even leave, I had nowhere to go, we had no money... I never knew what was coming in and going out, I couldn't understand how I'd worked so hard all of my life, and we don't have anything...I thought of going to a shelter. That is the hardest thing. You have to fight so hard for everything...he couldn't even get a pension when it first happened. (participant #2 — 58 year old female caring for her husband in the moderate stages of FTD. He lost his business when he was 55 and wife lost her job at the same time).

Finally, the consequences of financial losses can also affect one's sense of self-esteem (Alzheimer's Association, 2006). A spouse described her feelings in these terms:

Got stopped by a policeman and asked me why I did not have the sticker [car registration renewal]. He said, is it the 407 bills? I said yes, I couldn't afford to pay them. So you know I am a good Catholic girl. I would never do anything illegal, and I went oh. He said I should know better. They towed the car as I could not pay the ticket. So I had to call a lovely lady I work with and I said I had a problem with my car. I thought my nose was going to grow. I am so ashamed. (participant # 27 — 59 year old female caring for husband in the early-moderate stages of FTD).

(d) Intimacy.

Finally, the last category from the data in the theme of life-stage was spouses' intimacy needs. This included both physical and emotional intimacy. Although intimacy for spouses of individuals with dementia is an important issue at any age (Baikie, 2002; Lockeridge & Simpson, 2012), it is of major concern to younger people and one that has been under-researched (Bettie et al., 2002; Harris & Keady, 2004; van Vliet et al., 2010). Indirectly, Kaiser and Panegyres, in their 2007 study of the psychosocial impact of EOD in spouses, found that the highest reported response on the Beck Depression Inventory (BDI) was reduced 'interest in sex' in the well-spouse. 'Interest in sex' was examined within the context of depression symptomatology and not
in terms of intimacy issues. Unfortunately, Kaiser and Panegyres’s did not report the differences in responses of BDI items between genders, so it is difficult to ascertain if there were differences between men and women.

In this dissertation, there was a marked difference how men talked about their needs for intimacy versus women. Husbands brought up intimacy more openly, more frequently and within the context of a sexual relationship. Out of the nine husbands interviewed, eight spoke about their need for sexual intimacy candidly; however, only three out of the 21 wives brought up their wishes for an intimate relationship without me asking about it. Below are two examples of husbands' narratives.

When I felt lonely, I used to go to bars …actually you meet new people. [Wife] is not really my wife. If you need to go on a date, go on a date, it's fine. You're an adult, do it, as long as you feel okay with it (participant #28 — 53 year old male, looking after wife at home in late stages FTD. He has been a full-time caregiver to his wife since he was 48).

I stopped trying [making love] because she says don't touch me. So I have to wait until she, from time to time, she feels the need to. That's not a way to live...I don't have a wife, I don't have anybody to talk to, I 'm really lonely. I'd like to just hug her, caress her...and then, if I find someone in the same situation as me, am I allowed to do it, I'm not allowed to do it, what? (participant # 26 — 67 year old man caring for wife in early stages AD. Husband was 65 when she was diagnosed).

Women, on the other hand, were a lot less likely to discuss intimacy and framed it in the context of loneliness and their ambivalence about even considering relationships with other men.

I think my problem is, and it's unique to us, we're young, and we're like widowers but we're not...I've never been so alone. What are you going to do, find someone else? That will cause internal stress, it's not the answer. ..I don't know if I could do that again, trust again (participant #12 — 58 year old female caring for a husband who is in LTC, with late stages of FTD).
As stated earlier, only three women directly addressed their wish for male companionship. However, the participant whose quote is shared below stated that in her support group, women openly discussed their needs for intimacy and companionship with men. It is possible that women I interviewed did not feel comfortable talking about their sexual and intimacy issues with me.

I mean, I feel very alone...He sleeps beside me, but he's not the man I married...We don't have the intimacy that we had. I can't share my feelings with him. And I'm so busy doing for everybody, that I don't get intimacy anywhere else...like if I wanted to have an affair, there is no time for it...this is one thing that comes up in our group when we meet on Thursdays (participant #23 —55 year old female, looking after a spouse with early-moderate FTD).

Another woman that spoke about wanting a relationship with a man was in the last stages of caregiving and her husband was in a LTC facility. As it will be further explored in the next chapter, participants in the last stages seem to move on in their lives and start to think about a future beyond being a caregiver.

I would still like to have an emotional relationship with somebody else...Emotionally, I think you have to feel ready...I'm married but technically I don't have a husband…I just need a relationship now (participant # 19—61 year old female caregiving for husband in LTC with late stages of AD).

The third woman that openly talked about wanting a relationship with another man described the ambivalence she experienced between wanting a relationship and her commitment to her husband.

When I wanted to be with another guy, I get angry at [husband]. It turns out the other guys aren't interested so it's obviously not meant to be...but lately I just want to take care of him...he is my sweetheart (participant # 10 —61 year old female looking after husband with FTD).
In spite of the differences between how men and women perceive their needs for intimacy, a constant theme for both groups was the longing for companionship. When men and women talked about intimacy, many participants positioned it as needing emotional and recreational connections in general, not just someone of the opposite sex. The following passage clearly demonstrates companionship needs.

It's kind of lonely...it would be nice to go with someone to the theatre...you know, just go to the movies, have a dinner out, have a conversation, I have not been able to do it (participant #18 — 64 year old male, caring for a wife in long-term care in late stages of AD. His wife was diagnosed when he was 58).

The participants’ feelings of loneliness were not just related to lack of intimacy and opportunity to go out with others, but they were also linked to the theme of disease invisibility, which will be discussed below.

(2) Disease Invisibility

Another main theme was participants' feeling that their situations were ‘invisible’ to the rest of the world because others could not easily see the signs of dementia in younger people. In addition, the well-spouse's depression that ensues is invisible to others as well. Spousal depression as a consequence of EOD has been documented in the literature (Freyne et al., 1999; Kaiser & Panegyres, 2007). Both the ill participants and the well-spouses were affected by this lack of visibility as both dementia and depression do not necessarily have physical, observable symptoms. Participants felt that this 'invisibility' led to delay in diagnoses, people being fired from work, people feeling misunderstood, and the paucity of both formal and informal supports. To outsiders, including health care professionals and the public alike, people with EOD appear healthy and consequently, spouses feel judged and unsupported. The categories subsumed under
this theme include: (a) lack of understanding, (b) delayed diagnosis, and (c) lack of support from extended family.

![Disease Invisibility Diagram]

*Figure 4.3. Categories related to disease invisibility.*

(a) **Lack of understanding.**

Related to not being recognized, there was a common thread of feeling misunderstood by health care professionals, family, friends and society. Feeling misunderstood led to feelings of isolation and loneliness, which were major issues in the participants' lives. Feelings of isolation have been documented in a Swedish study by Passant and her group (2005) and in an Australian study conducted by Kaiser and Penegyres (2007). Below are two quotes from wives, which could have represented the experience of any of the other participants.

It's the aloneness, not feeling understood, the grief, not being understood by most people. People don't know what to do with you, friends, family doctors (participant # 12 — 58 year old female whose husband is in LTC and has late stages of FTD).

The thing that bothers me is that nobody has a clue. And if I hear one more person say oh, you're just going to have to accept it because that's life, or oh, it's not that
bad. It's like how about you come and live my life (participant # 11 — 47 year old female looking after husband in the early stages of FTD. She was 46 at time of her husband's diagnosis).

Every single participant discussed feeling misunderstood by at least someone from their inner circle of friends/family. In one instance, friends thought the wife had problems, not the patient.

He [husband] has been so mean to most of our friends, he even told them that it was me [with the problem]...even some friends still think that I am the one with a problem...and other friends saw the personality change, but, still blamed me (participant # 2—58 year old female caring for her husband in the moderate stages of FTD).

Even close family members seem unaware of the well-spouses' pain and sense of alienation.

I've got two brothers and two sisters and they say, oh [husband] looks okay, they just don't get it... they talk about golf and their holidays...I just let it go...my sister has been hurtful...nobody really knows (participant # 27 —59 year old female caring for husband in the early-moderate stages of FTD).

Feeling misunderstood and judged, even by strangers, is a source of shame and discomfort for caregivers. This finding is congruent with Passant and her colleagues' (2005) study who also found that behaviours associated with dementia lead to feelings of embarrassment for family members. One husband reports going clothes shopping with his wife:

[Wife] changing sizes and she needs new clothes. So you try to deal with sales people, and they don't really want to talk to me...and then of course, you have to go try things on, the two of you have to go in the change room and you both have to go in for so long. So then I wonder what they're thinking (participant # 18 —64 year old male, caring for a wife in long-term care in late stages of AD. His wife was diagnosed when he was 58 and she was 53).

One participant, whose husband was recently diagnosed with motor neuron variant of FTD, stated that ever since he developed physical problems, and his difficulties are now 'visible',
life has been easier. This is due to increased supports from both health care professionals and other people. Society appears to understand the illness now that the symptoms are visible and he "looks sick".

I started to get so much help the minute, the day, he practically got the motor loss diagnosed. There was no help before...if you went for a walk with him, there was no physical disability. And especially earlier in that it was so embarrassing, so you just didn't want to go, it was so awkward....now, immediately they can see there is a problem, and they are understanding, almost everybody (participant #6 — 66 year old female, looking after husband in moderate-late stages of FTD).

Others felt misunderstood by family physicians, specialists and health care professionals.

I need to know what is wrong with him [husband]. Nobody's listening to me. You know, you go to the family doctor and like ok, they do their best, but you know what it is like, they see him for 10, 5 [minutes]. You [doctor] don't get it, come home with me (participant # 8 — 53 year old woman caring for a husband with moderate FTD).

As illustrated through the excerpts up to this point, the misunderstanding and lack of visibility for this group of patients and their spouses led to disastrous psychosocial consequences (e.g., financial and emotional).

(b) Delayed diagnosis.

Delay of diagnosis has been reviewed in the literature as another cardinal problem in EOD. Lack of knowledge on the part of the lay public and family physicians about the diagnosis can greatly contribute to caregiver stress (e.g., consequences related to finances, impact of behaviours on family, can wreak havoc in couples' relationships; Chemali, 2012; Wald, Fahy, Werner, Stein-Shvachman and Korczyn (2009) have reported that misdiagnosis has been reported in 30% to 50% of patients with EOD. Chemali and colleagues (2010) strongly criticize the high rate of misdiagnoses in younger individuals with dementia and
advocate for more awareness and education about the prevalence and symptoms of EOD within primary care physicians. Chemali and her group feel that if patients were diagnosed sooner, EOD patients and their families would be able to obtain the support and education they need at an earlier point, which would diminish the psychosocial impact of EOD.

According to the literature, during the first few years of their disease, patients may see many different physicians and specialists and undergo extensive investigations resulting in significant delays in diagnosis. The literature reports that on average, it takes 4.4 years from the time between symptom onset to diagnosis of EOD and delays of up to five years have been reported (van Vliet et al., 2013). In van Vliet and colleagues’ (2013) study, it took 4.2 years to diagnose AD and 6.4 years to diagnose FTD from time of initial symptoms. Interestingly, these numbers were much smaller for the LOD population, where it took 3 years to diagnosis of AD and 3.3 years to diagnose FTD. These data are consistent with findings of delayed diagnosis in the EOD population.

In this study, although there was some difference between FTD and AD, both dementias took an average of 4.6 years to diagnose. Diagnoses took an average of 4.8 years for FTD and 4.5 years for AD.

There are psychosocial implications that result from a delay in diagnosis such as adequate treatment, planning and coping with the impact of the diagnosis (Vernooij-Dassen et al., 2005). As already explored in this study, delay in diagnosis had tragic financial consequences for some participants. As well, the pre-diagnosis period, when others (e.g., family, friends, and health care professionals) could not see problems, was devastating for spouses. The literature reports how common it is for couples to seek (or be told to go) for family counseling as the symptoms of the ill spouse begin to unfold (Mordhardt, 2011; Weintraub & Mordhardt, 2005). When
psychotherapy does not "fix" the problems, a common feeling for spouses (mainly for wives) was a sense of being 'blamed' for their partner's behaviour. This was particularly disturbing as it mostly came from physicians.

He [husband] threw me against the wall. I kept going to the family doctor...and the doctor said to me "What are you doing to start these fights?" (participant #1—56 year old female looking after her husband with FTD in the moderate-late stages).

After a six week admission to a psychiatric unit, they treated him for depression. The psychiatrist wouldn't listen; this was a complete waste of time. I'm back to where we started and they wouldn't listen and then they told me that, this is what really bugs me, that I was the stressor, you are causing the problems. [Your husband] needs to get back to work and probably if you separated he would be back at work, because you are the stressor (participant # 11 — 47 year old female looking after husband in the early stages of FTD. She was 46 at time of her husband's diagnosis).

Interestingly, not one of the nine husbands in this study reported being blamed for their wives’ behaviours.

With the exception of three husbands whose wives had familial AD/FTD and were prepared for a potential diagnosis, the illness seemed to come as a shock, even when behaviours were clearly problematic.

I take care of her and all the time she kind of insults me all the time. She is very rude. There are some signs with memory, but it happens to me also, age is age. You are sure my wife has dementia? (participant # 14 —67 year old male, caring for a 64 year wife with early-moderate AD).

I don't know what goes on at work, but at home, quite honestly, I didn't really notice anything. ..My mother-in-law knew that there was something wrong with my wife...when there is an issue I call it "instant confusion". Outside of that, she is fine (participant # 30 — 53 year old husband whose wife was in the earlier stages of FTD).

By far, the most distinctive examples of husbands being surprised about the diagnosis were participants #17 and #18.
One day she got sick and I was shocked...I was in shock for almost one year. Even just when there were symptoms, I was shocked (participant #17 — 72 year old husband caring for his wife who was in the last stages of FTD).

The way participant #17 described “shock” made it sound like an acute process, when in fact it was very gradual and he had been dealing with symptoms for four years before wife's diagnosis.

The second husband noted that:

They sent her home on a sort of stress leave...my wife told me that she was on a stress leave from work. I didn't really know what was going on at all....the first time they suggested Alzheimer's disease I was like what are you talking about? (participant #18 — 64 year old male, caring for a wife in long-term care in late stages of AD).

By the time she was diagnosed and the husband understood that his wife had a problem, she was unable to work or drive. In the LOD literature, there is evidence that husbands were slower to recognize the symptoms of dementia (Hayes, Zimmerman, & Boylstein, 2010), but this has not been reported in EOD research.

Another reason for delay of diagnosis was the well-spouses inability to attribute symptoms to a medical condition: “In retrospect, at the time, you don’t think, but once you get the diagnosis then you start sort of rewinding the tape” (participant #3). Consequently, it appears that it is not only the physicians’ lack of proper and timely assessment that delay diagnoses, but spouses that seem to be in denial of their partners’ problems delay the diagnostic process as well.

The literature in LOD reports that spouses deny cognitive changes and delay help seeking, often until some crisis forces them into action (Adams, 2006) and this may be true of EOD as well. Although, maybe it is not denial, but given the lack of awareness of dementias in younger people, spouses are truthfully not prepared to consider dementia as a plausible explanation for their partners' changes.
Finally, patients whose employers noticed problems and were advised to go for testing were diagnosed sooner than those that relied on spouses’ realization that their partner had difficulties. This was also found by Kumamoto (2004), although it was a case report based on only two participants. In the case of the following participant, it took only eight months from the time the employer noticed problems to diagnosis.

Her boss said that she had missed deadlines, and she'd prepare for a meeting but it'd be the wrong meeting. So that's why HR said to go on short term disability and then we went for testing (participant # 30 — 53 year old husband caring for a wife with earlier stages of FTD).

(c) Lack of support from extended family/friends.

Another way in which disease invisibility affected spouses was the lack of emotional support they experienced from family and friends. There were different reasons why participants felt that they lacked support. In some instances, it was the participants’ difficulty in sharing the diagnosis with others, kept others from taking on supportive roles.

You’re trying to protect her dignity, right? Cause maybe we should have come out of the closet and said ‘everybody: look here it is’, but people treat you differently, I don’t mean so much me, but her, right?... There’s this elephant in the room, it’s her condition. Her side of the family, I just don’t find they are there…I’m going to reach out to them to see if they can be a little more helpful (participant # 3 — 53 year old male caring for a wife with early stages of AD).

Not wanting to share the diagnosis usually led to isolation; this finding is congruent with Ducharme, and her group's (2013) study of EOD spouses. However, even when the diagnosis was shared, participants did not feel supported. For those well-spouses that actually shared the diagnosis and sought support from their families and friends, they found their family responses were overwhelmingly negative (e.g., became less involved, did not offer either emotional or practical help, or acknowledged what the well-spouse was experiencing). This lack of acknowledgment and support was very hurtful to spouses and was common to most participants.
Although the literature reports changes in support from people’s spouses and children (Luscombe et al., 1998; Svanberg, Spector & Stott, 2011; van Vliet, 2010), I was not able to find any references associated with decreased family support for EOD, stemming from families of origin and extended family members. Below is a representative experience of how participants felt.

I have friends, but no one is involved. Not even the family is here to support. They do their own thing...It's disappointing. They don't come here [to visit], they just talk to me [on the phone] (participant # 17 —72 year old male caring for wife at home with full-time help in late stages of FTD).

One participant calls the way friends/family treated her “the partial dump”:

The partial dump, because you are dumped, but only partially because they’d still call occasionally and see how you were. And then my cousin said, said to me, ‘it’s not a partial dump, it’s just a different relationship.’ And I sort of bought into that for a long time, but I’m back to the partial dump (participant # 1 —56 year old female looking after her husband with FTD in the moderate-late stages).

There is also the full-dump: "You know what the difficult part is? It’s people being unsupportive. You know what, they, they, some of them treat you like you have leprosy" (participant # 8—53 year old woman caring for a husband with moderate FTD).

The lack of emotional support from family and friends leads to isolation as these losses are compounded to other relational losses. These include the loss of a relationship to one’s spouse and the loss of colleagues and support networks from work.

Loneliness was a very common feeling and it permeated the experience of the well-spouses. As the disease progresses, this sense of alienation from close family and friends became a common feeling for the majority of spouses. Loneliness was one of the most common feelings among participants. This is of great concern, as feelings of isolation and loneliness have been associated with poor outcomes in terms of health and well-being (Cacioppo et al., 2002; Cohen, 2004).
As the following excerpts illustrate, loneliness took on many forms.

I'm really trying not to isolate myself...My friends don't always want to be around somebody with dementia, I get it...The contacts that I have now are at the nursing home, with 500 dementia patients (participant # 5 — 62 year old female whose husband is in LTC and has late stages of AD).

I am all alone in the house, even with [wife] being here. If I have a heart attack, [wife] can't relate to it, and the dogs are going to go on my chest and lick my face. I have a fear of dying alone...even with [wife], I'm still alone (participant # 29—57 year old man whose wife has moderate FTD. He has already had one heart attack).

On the other hand, some spouses started to feel less lonely and better supported in the latter stages of the disease as they started to move on with their lives. This will be explored in Chapter 5, when participants' experiences are discussed in the context of the disease progression.

(3) Continued Uncertainty

The theme of continued uncertainty became a more complex topic than I initially expected. Again, this was one of the themes brought up by every single participant. In the literature, illness uncertainty has been described as a stressor that leads to a sense of loss of control and a constant feeling of doubt (Wright, Afari, & Zautra, 2009). Illness uncertainty was first proposed by Mishel (1988, 1990), who proposed that if the uncertainty is continual and cannot be eliminated, as is the case in the EOD caregiving experience, the chronicity of the uncertainty is likely to promote a high level of instability (Mishel, 1990). Mishel's work is consistent with the findings of Lazarus and Folkman's (1984) stress and coping theory that suggested uncertainty is always present at times of stress.

The literature describes illness uncertainty as a subjective experience that the actual person with the illness experiences because of his or her own disease (Mishel, 1990). However,
in the context of this study, spouses and not the ill person experience the uncertainty, given that patients do not have insight into their conditions. In the narrative of this study, two main categories generated the theme of continued uncertainty: feelings of (a) unpredictability and (b) ambiguity. These categories are interrelated as depicted in figure 4.4

![Figure 4.4](image.png)

*Figure 4.4. Categories related to continued uncertainty.*

(a) **Unpredictability.**

Unpredictability in EOD relates to not being able to know what to expect in the future (e.g., caregiver retirement, finances, time of patient demise). The literature suggests that people prefer predictability regardless of its outcome (McCormick, 2002). However, EOD is anything but predictable. Unpredictability has a temporal component: how long (duration) will the disease last, how fast (pace) is the decline or deterioration, how often will crises occur and what effects will it have on the spouse over time? There are multiplicities of unpredictable situations in this population. For example, most participants had questions about how the course of the disease would progress and affect them. They were also concerned about how they would handle...
difficult behaviours as they occur over time. In addition, they were afraid that they would not
know when to place a spouse or what the future would bring in relationship to finances and they
wondered whether they would ever find a new partner. It was the feeling of not being able to
predict or have control about what could happen next that created such anxiety for participants.

    Things change all the time....the disease is unpredictable...used to have to deal
with aggression, the yelling I mean he was always yelling...now he has no real
behaviours but the resisting...When is it going to end? How is it going to end?
(participant #5, 62 year old female caring for husband in LTC in the last stages of
AD).

    During the early and middle stages of the illness, it was the unpredictability over the
spouses' behaviours that created stress.

    You never know what's going to happen next...once he went to a coffee shop and
was shouting and screaming in front of all these people...I'm quite small and he'd
shove me out of the way...I always have to be on guard (participant # 13, 59 year
old female caring for a husband with early stages FTD).

    As the example above illustrates, unpredictability was a concern from a physical safety
perspective. It was a common worry of female caregivers since they had to care for sometimes
aggressive and out of control husbands, who were bigger and physically stronger than they were.
A wife described her husband as "a caged animal", which was a typical depiction of how wives
viewed their husbands with behavioural issues, particularly those with FTD. An illustration of
both physical safety and personal health (e.g., sleep deprivation) concerns follows: "I locked the
door because I was scared, 'cause I could see the man was gone. He kicked down the door...you
could see the rage, he terrified me" (participant #1). An additional example was a wife, whose
husband was 6 feet, 5 inches and weighted 300 lbs.:

    You don’t know, like even at nights you don’t know if he will stay in bed
all night. You’re sort of half sleeping. And like [the] doctor asked me if
I’m scared... He can bulldoze anybody, he’s a big man (participant #7—70 year
old wife looking after husband in moderate stages of FTD).
What was not only scary but painful about their husbands' aggression was that "this was the person that you loved and trusted".

Finally, the following metaphors, as told by five different participants, describe the overall feelings of unpredictability eloquently: "My day is like a box of cracker jacks, you don't know what you're getting every day when you open the box"; "Every day is a wild card"; “It's been a roller coaster”; " Life is like a pinball machine, but the pinball is just going all over the place. You have no control where this ball is going" and lastly, “He is a loose cannon”.

(b) Ambiguity.

Ambiguity is another component of uncertainty; for a feeling to be ambiguous, it has to be able to be interpreted in more than one way (Ambiguity, 2013). Ambiguous feelings toward one's spouse, toward the disease and its impact on their lives make uncertainty harder to tolerate. By far the most common theme related to ambiguity was the notion that people were married, but their spouses were not their partners. This is referred to in the literature as ambiguous loss. Boss (2010) defines ambiguous loss as a type of loss that occurs when someone is physically present, but psychologically absent. In EOD, the person is here, but not here, so grief is constant and life is put on hold: “Even though you're married, you don't have anybody. And your life dreams that you had before no longer exist” (participant # 18 — 64 year old male with wife in LTC in late stages of AD).

Participants also talked about how ambivalent they felt about becoming a caregiver to their spouse and seeing them as a responsibility. This ambivalence generated feelings of guilt as people talked about wishing their spouses were dead, yet wanting the best care for them and wanting them to be healthy and stable.
He's diabetic; I have to hide all the candies. I think he is stable because I cook from fresh. It must make a difference because there’s no preservatives and very low salt. … How long does this thing last? It would be nice if he died (participant # 7 — 70 year old wife looking after husband in moderate stages of FTD).

At times, there were also signs of an ill-spouse who temporarily appeared "normal" and when this happened, the diagnosis was questioned by the participant. The inconsistency in behaviour created ambivalence in spouses; especially those that had a difficult time accepting the diagnosis: “Sometimes, he comes back alive, for a little while anyway. But then it fades away...He is impaired, but he is not impaired” (participant # 9 — 51 year old female looking after a husband with moderate AD).

(4) Falling Through the Cracks

Falling through the cracks is the next main theme that emerged from the data as stemming from the subthemes previously explored. This theme integrates all the themes and categories described in this chapter up to this point since falling through the cracks occurs as a result of the life-stage this population is in, because of the diseases' invisibility and the continued uncertainty that envelops the caregivers' lives.

Being a younger person with dementia creates major difficulties, as our systems are not set up to meet their needs. This lack of appropriate supports for this age group of people with dementia is widely documented in the literature (Diehl et al., 2004; Harris & Keady, 2004; Nunnemann et al. 2012). One of the main complaints from spouses was the lack of appropriate services ranging from: home care from the Community Care Access Centre (CCAC), appropriate day programs or support groups, being eligible for LTC, bad experiences in acute care hospitals and poor interactions with health care professionals. The lack of understanding from the health
care community, family, friends and society, in combination with their young age, affects the lack of social/formal supports. This lack of available or appropriate services generated a common theme, which participants described as "falling through the cracks". This idiom is defined in the dictionary as someone who has been overlooked, especially within a system. It also stands for not fitting either of two alternatives (Falling through the cracks, 2013). Well-spouses talked about falling through the cracks of systems they encountered; most importantly (a) health care and (b) government programs/disability plans. Figure 4.5 illustrates these two categories where people fall through the cracks.

![Figure 4.5. Categories related to falling through the cracks.](image)

(a) **Health care system.**

Participants felt that the health care system was not responsive to their needs. Health care system discontent included dissatisfaction with: family physicians, specialists, emergency departments, acute care and LTC. It also involved home support services such as CCAC, day programs and support groups. Caregivers felt unheard by the family physician and the years it took for diagnosis demonstrates how this population falls through the cracks. Two spouses of
people with FTD described how the family physician performed a Mini Mental State
Examination (MMSE) and since the scores did not show evidence of memory deficits, they were
told that there were no neurological issues. As explored earlier, this is congruent with the
literature in relationship to misdiagnoses (Chemali et al., 2012).

Being in the emergency department was a traumatic experience for people with EOD and
their spouses. Five people raised their struggle in the emergency department as one of the most
infuriating experiences. They all agreed that it was the fact that they looked young and healthy
that made it so difficult to receive appropriate care.

When he has to see a doctor and he doesn't cooperate, they walk away and don't
come back for hours, because they don't have time for that. So I'm sitting there
[ER]...from midnight to ten, with no food for him. I couldn't get up because I
heard the doctor might come and then nobody could speak for him (participant #
22 —67 year old female looking after a husband with moderate stages of AD).

He started falling so I called 911. The ambulance came and got him and they sat
him up and they restrained him, they put him in cuffs and gave him some
antipsychotic medication...they just kept yelling at him... then,[in ER] just
restrained him the whole time. Unless he breaks something, he's not going to the
hospital again (participant # 5 — 62 year old female whose husband is in LTC
and has late stages of AD).

I told the nurses, he doesn't understand due to dementia. When I came back the
next day, he was in unbelievable pain. They didn't give him any pain meds all
night, when I asked them why, they said "we came in and asked him and he said
I'm ok" (participant # 13—59 year old female looking after husband with early
stages of FTD who was subsequently diagnosed with primary progressive
aphasia).

At the point that someone was admitted to acute care, their experience continued to be negative.

They put him through hell in the hospital... The health care system would have
saved a lot of money just by having someone who listened to us when we said:
you have to approach him slowly... they then had to bring six security guards to
hold him down. He bellowed really like a caged animal. It was awful and it was
non-stop. He nearly died that time (participant # 15 —64 year old female whose
husband died two years ago of AD. He had been diagnosed when he was 55).
After transfer to LTC, the feeling of falling through the cracks did not improve. A common concern among participants was the admission criteria to long-term care through the CCAC. In spite of people needing care, some individuals did not have an appropriate score for eligibility for LTC (e.g., interRAI CHA). In particular, those who did not need assistance with activities of daily living and had behavioural problems were prevented from applying to LTC. Participants voiced that this systemic barrier to LTC was discriminatory and continued to make them feel marginalized instead of supported.

These difficulties continued throughout the health care system. Situations were not much better in the community, where people felt that the services did not address their needs. A typical concern was not being eligible for a personal support worker (PSW) through the CCAC as the spouse was assessed to be too physically well to qualify for care. All spouses who had any contact with CCAC shared the feeling stated by participant #1: "CCAC is the biggest letdown". Another common feeling from spouses is feeling unhelped by them: "the CCAC, they have a lot of suggestions but nothing concrete" (participant # 26—husband of someone with early stages of AD).

Younger people with dementia do not qualify for services in the same manner as younger patients with other chronic conditions. Participant # 16 stated, “I used to say that I never knew a disease could make cancer look good”. When participant # 23 talked about her own cancer experience, she stated that the level of services and supports (e.g., Wellspring) she received had no comparison to what she is now receiving for her husband.

The other source of disappointment was day programs. There were two concerns that every spouse who dealt with day programs brought up; one was in relationship to the ages of the other day program members, and the second was being discharged from the program due to
behaviours that the program was not equipped to look after. The findings in this study support a study done of eight Alzheimer's day programs in Massachusetts by Silverstein, Wong and Brueck (2010), which also found that day programs did not meet the needs of people with EOD: “The Alzheimer's Society, all they say is well, we've got this group, and [wife] goes and its' a bunch of 80 year olds drooling. I don't want her to be there” (participant # 3 — 53 year old husband of wife in early-moderate stages of AD). The excerpt below exemplifies both the age and limits of care issues:

I toured the day program twice. My husband does not belong there. My husband plays table tennis, tennis, bikes, hikes. He is not a 90-year old man waiting for LTC. He does not belong there. However, there was nothing else and he started to go. But they have qualifications and when he could no longer go to the bathroom on his own, so he could not attend. I bawled and screamed and cried and I behaved like a lunatic because what would I do now? (participant # 25 — 52 year old female looking after her husband with early-moderate stages of AD).

In some instances, it is the youth and strength of younger people that create a problem for other day program members.

She used to go to a couple day programs. But the problem with the day program is that they’re all designed for older people...it got to the point that they [day program members] were like bowling pins to her because she was so strong and so physically able. So we had to discontinue those, we didn’t want to risk other people attending the programs (participant # 20 — 51 year old husband looking after wife with AD in late stages of dementia with the support of live in private companion).

In contrast to the examples, two participants found suitable day programs for their husbands. The two excerpts are explored below.

He goes five days a week... he usually gets picked up around, is supposed to be eight o’clock in the morning, and return time is four o’clock in the evening. So the York Region transit takes him. And that usually gives me enough time to
get to work and back. I now lost my job, so they give me a subsidy (participant # 2 —58 year old female caring for her husband in the moderate stages of FTD).

Although this wife did not comment about the quality of the program or if her husband enjoyed it, the respite she received from it was invaluable. Interestingly, this man had difficult behaviours, yet the day program was able to manage them. The example below is another example of someone who was satisfied with the program. After only one visit to the program: “He was there for the first day last week, and he loved it he wanted to go back, so he’s going Monday, Wednesday and Friday. And they said he could go more”. (participant # 7 —70 year old wife of husband in the moderate stages of FTD). In the example above, it is possible that her husband, who is older (69 years) and had no behavioural issues, was more like other day program members and thus, was better suited.

(b) Government agencies, programs and insurance plans.
This area relates to involvement with programs such as pensions, drug plans, Revenue Canada, and social safety nets for those that have been affected by EOD; especially those that have had dire financial difficulties due to the EOD.

An example of people falling through the safety net occurred when someone lost their job and consequently lost their medical benefits. People that are middle class and have minimal assets do not qualify for the Trillium Foundation drug reimbursement program. They are not ‘poor enough’ to be on the Ontario Disability Support Program (ODSP) but have ‘too much money’ to qualify for medication reimbursement. For example, participant # 21 whose husband had moderate stages of FTD and had four dependent children, did not qualify for medications because when she sold her house to downsize, and was in the process of finding alternate living arrangements, she was deemed to have too much money to receive reimbursement.
Another worry was not qualifying for government programs due to bureaucrats not being well informed:

I am still angry...it's like when I filled out the government forms for his disability they wrote back: REFUSED. They said FTD is not a terminal disease. So here you are at your weakest, you wonder did you just reject it to see if I'm going to go back? (participant # 12 — 58 year old female whose husband has late stages of FTD and is in LTC).

Finally, one participant was most frustrated by Revenue Canada since her husband had not paid taxes for many years and she was not aware since he always handled the finances. When the wife tried to negotiate the money owing with Revenue Canada and tried to explain their circumstances, she felt that Revenue Canada had no awareness of the impact of EOD on people's ability to file taxes and had no formal way to address this issue with them.

Well, I think what affects me more than anything else is Revenue Canada. They are such evil, evil people that they won’t take anything [will not negotiate]. And I even went and asked the doctor about the FTD, and it’s like, you know you get this, the doctors are guarding themselves now and are not backdating the medical forms (participant # 2 — 58 year old female caring for her husband in the moderate stages of FTD. He lost his business when he was 55).

One of the most difficult issues for spouses to endure was the catastrophic financial complications due to EOD with no government safety net to mitigate the impact. There were three wives that were middle class; while their husbands were healthy they were double income earners and owned a house. These three wives ended up in poverty yet were not considered "poor enough" to qualify for social assistance. These wives were receiving some financial support from their families.

My stepmother has paid for his [husband] dental treatment when he needed it, because I haven't had the money. I mean I haven't been able to go to the dentist myself, at least if you can get ODSP, they give you some...I can get nothing. I couldn't even get into stuff [government financial help]...I couldn't get him glasses, when he turned 60, I thought he could get Old Age Pension, but even the
seniors’ programs won’t help, because you are not 65 (participant # 2 —58 year old female caring for her husband in the moderate stages of FTD).

He lost his business when he was 55 and wife was a teacher until she lost her job. The example below is a woman with four dependent children: “So far it’s okay. This is the month I’m so worried about. I generally take financial help from my brother but I can't ask him all the time like that (participant # 21—47 year old female, caring for her husband with FTD, moderate stages.).

As these participants illustrate, families, who may not be supportive from an emotional perspective as explored earlier, when needed, helped financially. Without their monetary support, these families would have been in worse financial situations than they currently are.

Summing up, falling through the cracks is a common experience and one that every single participant discussed. People had a sense of an unfair system that was not there when they needed it. Whether it was from a financial or medical perspective, at some point or another, every participant felt that the system failed him or her. Even the last comment from participant # 12, where her husband was denied disability because they did not think that FTD was a terminal disease, felt that the government rejected the application just to make her life even more difficult.

**Chapter Summary**

The goal of this study was to understand how people are affected by EOD throughout the disease process. The first section of this chapter provided descriptive statistics related to socioeconomic status, immigration status, living arrangements, length of time caregiving, delay of time to diagnosis, to contextualize this group of caregivers. This was followed by behavioural disturbances in FTD and AD. Subsequently, this chapter focused on understanding how people are affected by EOD through the exploration of the main themes that emerged from the narratives. Themes raised by participants were examined and excerpts were presented to add
depth and richness to the findings. Themes included the impact of the life-stage and its effect on participants, the problem of disease invisibility and its consequences related to delayed diagnosis and lack of support from formal and informal networks as well as the continued uncertainty that the well-spouses endure. The issues raised by spouses in this study have psychosocial implications and affect participants at all levels: financial, emotional and social.

Through the exploration of the four themes presented in this chapter, a central theme, which I refer to as surviving chronic crises, emerges. This core theme relates to how spouses experience and cope with a partner with EOD. How spouses cope over time is the second area of inquiry in this dissertation and is explored in the next two chapters.
Chapter 5

Findings - Survival and Coping

The goal of this study is to understand how spouses of persons with EOD view caregiving issues/challenges at different points of the disease progression. Through data analysis it became apparent that this inquiry had two components and consequently the study became about understanding both how spouses experience and how they cope with a partner with EOD over time. It is important to understand what the experience is, before delving into how people cope, and this was explored in Chapter 4. This chapter focuses on spousal coping through the multiple crises brought on by EOD.

Surviving Chronic Crises

As a result of the dementia, participants’ lives were tremendously disrupted, and to cope spouses dug deep into personal and social resources in a process that they called “surviving”. Spouses talked extensively about the recurrent crises they experienced over the years. The coping process (e.g., the ongoing responses that participants utilized to deal with crises) is what I refer to as: surviving chronic crises. This is the core theme that emerged through the data and builds from the subthemes explored in the previous chapter. Before delving into the theme of survival and coping, I will present how participants view their crises and why I chose to call this theme chronic crises.

Crisis is defined as "a perception or experiencing of an event or situation as an intolerable difficulty that exceeds the person's current resources and coping mechanisms" (James & Gilliland, 2005, p. 3). A crisis has a subjective component; even though participants in this study experienced the stressors that precipitated the crises differently, there were many commonalities.
Crisis theory generally focuses on one particular crisis (e.g., diagnosis of new illness; Dass-Brailsford, 2007), but spouses of people with EOD have to cope with multiple major crises including: loss of spouse, unemployment, financial difficulties, downsizing/moving, Children's Aid/police involvement. Although some of these challenges are true of other illnesses (e.g., cancer, heart disease), in EOD there is the emotional loss of a partner due to the changes in personality and comportment; the ill-spouse has no insight into the extent of their problems, creating a major shift in the marital relationship. This theme represents the chronicity of problems that people need to manage on a constant basis. I juxtaposed the word chronic (e.g., persisting for a long time or constantly recurring; Chronic, 2013) and crisis (e.g., a turning point, a stressful/traumatic event or change in a person's life; Crisis, 2013) intentionally. The purpose was to highlight how two diametrically opposed constructs, crisis implies acute or short term and chronic stands for long term, co-exist through many years of caregiving.

Participants described different precipitating events, which led to crises. Most commonly, crises occurred at transition points that demarcated entrance into a new state of circumstances (e.g., EOD diagnosis, losing driver's license, loss of employment for either or both spouses, downsizing, placement to LTC). Another condition which precipitated a crisis occurred when there was a sharp change, either medically or behaviourally, which necessitated immediate intervention (e.g., wandering behaviour, aggression, agitation, infection, falls, disinhibited behaviour such as inappropriate sexual overtures to others, or a time when a particular behaviour from the ill-spouse created chaos for the family such as stealing or violent behaviour that required involvement with the police). What all these precipitating elements had in common was that there was a change in the status quo resulting in a feeling of being unable to deal with the current stressor.
The trademark of a crisis is its unpredictability (Dass-Brailsford, 2007) and in this group of caregivers these continuous crises is what created this sense of not being able to forecast what was coming up next. A crisis was always perceived as such because spouses needed to deal with the new situation immediately and because it caused significant disruption in their lives or the lives of their families. For example, the loss of driver's license was a crisis for a wife who financially depended on her husband's driving to generate the family income. For others, the loss of driving privileges was a crisis of a different nature. For instance, if an ill-spouse lost their driving privileges, now the well-spouse needs to provide transportation. Having to drive a spouse and be the sole mode of transportation was disastrous: not just to the marital relationship but to both partner’s diminished autonomy. Sometimes the crisis took different meanings based on other factors (e.g., whether they lived in a rural versus urban area, availability of alternative modes of transportation, importance of the meaning of driving in someone's life). What these examples had in common was that the loss of being able to drive was a drastic change and it was perceived as a crisis for everyone. Although this loss had a different impact in each particular situation, the commonality was that every single person had to problem solve around how they were going to manage this new problem.

What wore people down was the emergence of new sets of circumstances brought about by each crisis, which compounded the distress. For example, not only did people have to adjust to their partner not driving anymore, but also the lack of transportation now created a new set of problems: "I am his day program all day, every day". When participant # 25 tried to problem solve and address the issue of having to provide stimulation for her husband every day she encountered the next set of barriers: "[we found] a great day program, but they changed criteria
and said that he was no longer eligible". This example was representative of the majority of the participants.

The constant sense of not knowing what is coming up is exhausting. It is the continuous need to adjust to new, unpredictable situations and the recurrent changes in demands, which make caregiving for this group of EOD spouses so draining. This relentless dance between new situations being resolved while new ones emerge best describes the experience of these spouses. Although traditionally crisis theory has been applied to acute care situations (Shaw & Halliday, 1992), this study supports the notion of a chronic sense of crises starting in the pre-diagnostic phase and lasting throughout to the entire illness trajectory. The effects of this chronic stress are described in the section that follows.

**Sequelae of Chronic Crises: Negative Health Outcomes**

The continuous stressors of EOD take their toll on spouses and have consequences to the mental and physical health of caregivers. When analyzing the health sequelae of the stress of caregiving on the well-spouses, Vitaliano and his colleagues' (1991, 2003) inclusion of both mental and physical health outcomes in their stress and coping model, makes their theoretical framework relevant for EOD spousal caregivers.

**Mood issues.**

Through the above narrative, there emerges a common thread of persevering and finding a way to struggle and survive the difficulties. From my interpretation of the data, the difference between surviving and coping is associated with participants' level of depression. When people
are depressed, no amounts of resources are helpful since people are unable to avail themselves of help.

Depression is a cardinal feature of being a spouse of someone with an EOD (Cosseddu, Albericic, & Pelizzola, 2013; Kaiser & Panegyres, 2007; Mioshi et al., 2009; Rosness, Mjorud, & Engedal, 2011; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Zanetti et al., 1998). These findings were corroborated in this study since all participants had experienced depression at some point through their caregiving trajectory. In addition, the EOD literature reports that female caregivers experienced higher rates of depression than men (Kaiser & Panegyres, 2007; Mioshi et al., 2009). It should be noted, in this study all the men interviewed reported having gone through depression at some time during their caregiving trajectory. There could be at least two reasons for this discrepancy. Perhaps, men that agreed to participate in a study that involves an open-ended interview are different from men that respond to mailed, self-reported measurements as the two studies conducted by Kaiser and Panegyres, and Mioshi and colleagues. Second, this study asked about experiences retrospectively to garner if spouses had ever experienced depression at any point during the disease trajectory while the other two studies asked about depression at the time of the investigation.

Depression plays a key role in how spouses cope. Those that were depressed and who were not treated for their mood disorder barely managed and felt they were "running on empty". Spouses that were depressed had a very difficult time dealing with their spouses' illness: "on my days off I just veg...In January I slept for three weeks, and I wasn't hungry" (participant # 27 --59 year old female caring for husband in the early-moderate stages of FTD). Initially, this participant did not want to get help because she felt that: “It’s not the stigma of mental health, it isn't. It's that I feel like I'm losing control. I've lost control". Her depression was not treated by
her physician, instead she stated: "my doctor prescribed me something to help me sleep. So I thought I’m not going to take that, it’s not going to make everything go away". It was not until this participant received treatment for her depression, through anti-depressant medication and social work intervention, that her ability to cope dramatically improved. She was also able to gain perspective on what constituted a crisis and started to manage the challenges directly on. Again, the way one perceives a crisis is a subjective experience and if someone is depressed, even small events would be perceived as disastrous.

Addressing depression in caregivers is one of the most important interventions to help spouses cope with the impact of EOD. Social workers may not be able to obtain more financial support for these families that are going through a financial downturn since patients with EOD nor caregivers qualify for services that currently exist. Nevertheless, clinicians can help in the early detection and treatment of the underlying caregiver depression, which will aid in people's ability to cope. Given the high prevalence of depression in this population, this is an area where health care professionals need to intervene early on. When spousal depression is addressed, the difficult events that precipitate a new crisis do not change, but spouses' responses and ability to manage the new circumstances are ameliorated.

**Negative physical consequences.**

Not only were the well-spouses affected emotionally; their physical health was affected as well. One spouse talked about her own health as being "a mess...I have had a sinus condition since the start of this [husband’s diagnosis]", (participant # 9--51 year old female whose husband was diagnosed two years ago). Another wife talked about her health "falling apart; I have arthritis and I don't know if it would have happened this early if everything had been ok, but ten
years of wrestling with [husband], the stress and all” (participant # 5--62 year old woman looking after husband with late stages of AD). These examples were just two out of multiple instances, of how spouses felt that the impact of EOD directly affected their health.

This study found that spouses' physical health was negatively affected as a result of caregiving, which is congruent with the literature for LOD caregiving (Pinquart & Sorensen, 2003; Schulz et al., 1995; Vitaliano et al., 2002; Vitaliano, Young & Scanlan, 2003; Vitaliano, Young & Zhag, 2004). However, it is difficult to compare the findings of this study with the EOD literature since there is a dearth of research related to the physical health impact of caregiving on spouses. I only found two studies related to physical health and EOD caregiving. One study by Nurock (2000) reported poor physical health in EOD caregivers, which tended to be longer lasting than mental health problems, since mental health issues improved after the death of the relative but the physical problems did not. In contrast to Nurock’s findings, Bristow and colleagues (2008) did not find an association between FTD caregiving and suppression of mucosal immunity, which they used as an indicator of vulnerability to minor infections. However, these results should be interpreted with caution in view of the small sample (25 participants). Although this qualitative study of the experience of EOD spousal caregivers is not representative of the population of EOD spouses, there is an indication that physical health outcomes needs further investigation.

**Sequelae of chronic crisis over time: unique findings.**

The chronic stressors negatively impacted spouses from a mental and physical health perspective. However, an interesting finding was that from a mental health perspective, spouses seemed to adjust and cope better in the later stages of the disease progression. This is
contradictory to the EOD literature, which states that there is a positive linear correlation between the length of time caregiving and caregiver stress (Freyne et al., 1999; Williams, Dearden, & Cameron, 2001). The findings from these authors would predict that over time, spouses' distress should increase and this was not the case in this study. There were methodological weaknesses with these studies, which call into question their outcomes. Freyne and her group found that EOD caregivers had more caregiver burden than LOD caregivers did. The researchers attributed this to the length of caregiving. However, it could be that caregiver burden was higher due to other factors such as more behavioural issues in the younger dementia population. Williams and his group divided the length of time caregiving into three categories: less than three years, between three and five and five years and over. For this dissertation, the mean average length of caregiving for partners in the late stages of dementia was 11 years each for both FTD and AD (range 6 – 18 years). It may be that spouses had a longer duration of caregiving and they may have adapted to the stresses over time. Perhaps it could be that Freyne and Williams' and their colleagues studied all caregivers (e.g., spouses, children and others) together and therefore, the results cannot be compared. More likely, I think that although length of time of caregiving and stages of disease progression are associated, they do not measure the same thing. There may be a different effect from having gone through all the stages of the disease progression, irrespective of length of time that helps people adapt to their new circumstances.

**Quality of pre-morbid relationship and coping**

Despite the existent difficulties, spouses continued to persevere and always wanted the best services, support and care for their ill-partner. There was a deep sense of love and
commitment amidst the chaos and anger. Deep down, I feel that this was the ultimate reason that kept spouses fighting for the well-being of their partner and enduring the difficulties for themselves and their families.

Every spouse was asked about their previous relationship with their partner, prior to the illness onset. All spouses had positive things to say about their marriages and below is a list:

- some rough spots but worked on marriage
- did everything together, but had some spotty times
- he was my caregiver and looked after me emotionally and physically
- good solid marriage
- was very emotionally dependent on wife
- good, very good relationship prior to dementia, very close
- feeling sustained now, knowing that we had a great relationship
- I was under his umbrella, the umbrella of marriage
- had a close, fun relationship, it was just the two of us would rate it at a 70%, now I appreciate things about him I did not appreciate then
- good marriage, based on intellectual compatibility, second marriage
- had a good relationship
- feeling grateful for our past together
- it was perfect, we grew up together, childhood sweethearts
- now feel lost without his guidance
- I got him and he got me
- we had lots of fun together
- relationship was pretty good, but not fantastic, second marriage, was going to separate prior to diagnosis, but in retrospect problems were related to diagnosis
- great relationship, enjoyed the outdoors together
- great relationship, we were both musicians and teachers

What all these comments had in common was a sense of love, commitment and longing for a type of relationship that existed before the onset of illness. It is possible that these responses are reflective of spouses that were in long-term relationships since they would not have met criteria for research otherwise. Those couples, who split before or during the disease process, would have not qualified for this study and the findings would likely be different. The quality of the premorbid marital relationship in terms of closeness and affection has been shown to be
related to reduced caregiver stress and the quality of the relationship has also been demonstrated to be a motivating factor needed to care for in the LOD literature (Baike, 2002; Carpenter & Mak, 2007; Steadman, Tremont, & Davis, 2007). This study's findings are compatible with the LOD findings.

Surviving and Coping

The clearest definition of coping states "coping are the things that people do to avoid being harmed by life-strains" (Pearlin & Schooler, 1978, p.2). Categories related to themes of survival and coping are explored below and special attention is given to the coping processes (e.g., series of actions, interactions and/or emotions, occurring in response to events or problems that lead to a particular outcome; Corbin & Strauss, 2008). This next section represents the analysis of the survival and coping processes that spouses employed to deal with the impact of a partner with EOD. Survival is tied to coping; it means dealing with the demands of this disease as best as one can. It means having to continually manage situations/circumstances in a way that the difficulties are either resolved, or at least minimized.

In this study, participants used the term surviving interchangeably with coping but the meaning and the choice of wording had different nuances. Coping implied a higher (or more adaptive) level of managing problems while surviving meant, "just struggling to manage". The theme of “survival” appeared in some form in every interview. Every story was essentially a survival story: the survival of the impact of the disease at multiple levels (e.g., people's physical, emotional and social dimensions of life). Surviving, as a theme, includes categories related to being able to function and to persevere despite the difficulties brought on by the illness. Comments like the following one were typical: "I’m wondering how I am going to survive this". Although this quote has an element of doubt about how this spouse will manage, this wife never
says, "I wonder if I am going to survive this". The implication is that it is possible to persevere and survive somehow.

**Stress and Coping Models**

To provide a framework for the way in which participants coped, I will review the stress and coping theory briefly. Historically, there have been two approaches to understanding coping. One perspective involves understanding the individual's personality/psychological characteristics such as self-efficacy, learned helplessness and locus of control beliefs (Skinner, 1995). The second one is a contextual approach, initially proposed by Lazarus (1966) and later refined in conjunction with Folkman (1984). Their work introduced cognitive and behavioural responses to coping by extending the boundaries of understanding coping to include the context of a situation. In this model, people are guided by assessing each stressor within its own unique set of circumstances. Although these early stress and coping models have been widely used, they do not explain the whole picture as coping is a complex, multifaceted process that includes both understanding the personality traits that influence how one perceives the stressor and the environment and resources that are available to the person. Over time, Lazarus (2000) has acknowledged that unconscious processes and personality traits may play a role in the way people cope and that coping cannot be understood by looking at cognition and context alone.

Pearlin and Schooler (1978) integrate both personality and situational constructs and make a distinction between *social resources, psychological resources, and specific coping responses*. Resources refer to what is available to people in developing their coping repertoires, not what people do with them. Social resources constitute the interpersonal networks that people are part of (e.g., family, friends). Psychological resources are the personality characteristics or traits (e.g., self-esteem, mastery) that people draw upon to help them survive threats posed by
events in their environment. Thus, psychological resources represent some of the things people are. In contrast to the social and personal resources, there are also specific coping responses: "the behaviors, cognitions and perceptions in which people engage when actually contending with their life-problems" (Pearlin & Schooler, 1978, p. 5). Coping responses or coping strategies stand for some of the things that people do; the concrete efforts to deal with a stressor. Therefore, both social and psychological resources influence how people cope or what they do to deal with the current crisis. Pearlin also based his research on dementia caregivers, making the model even more relevant to this population.

Vitaliano and his colleagues (1991, 2003), built upon Pearlin's model by adding a biological component to his model. Vitaliano did not just study the psychosocial resources that people possess, but also looked at how biology influences coping. His model is the most inclusive way of looking at coping since it combines the psychosocial factors from previous models with the addition of biology to form a biopsychosocial model of stress and coping.

Coping is a multicomponential process that unfolds over time, and therefore, coping is framed as a dynamic process. This study does not attempt to categorize coping as either stemming from personality traits, or contextual factors such as social, psychological or biological. Instead, an integrated perspective of coping is presented.

**Coping strategies.**

The caregiving literature describes coping strategies as either problem-solving or emotion/cognitive-focused (Folkman & Moskowitz, 2004; Garnefski et al., 2001). Other caregiving researches, such as Nolan and his group (2002a), have included a third category: stress-reduction strategy. In problem-focused coping one acts on the environment or oneself to
change it; in emotion-coping, or cognitive approach, one alters the perception of the problem which mitigates the stress, even though the actual stressor has not changed (Lazarus, 1993). In stress-reduction strategies the caregiver utilizes tactics that help minimize any potential stress (Nolan et al., 2002). Thus, an illustration of a problem-focused approach included, "I deal with the most immediate problems first", "I'm organized and I always have a plan B". Examples of emotion-focused or cognitive tactics included: counting one's blessings, “I’m grateful that I live in Canada and not Jamaica with this disease"; reframing "bowel movements are just digested food" in order to be able to cope with incontinence, or drawing on spirituality: "it's meant to be". A stress reduction strategy included: "going to my car to have a good cry", "I belong to a meditation group", or "I spend a lot of time on my stationary bike".

Although problem-solving approaches are promoted as being the most beneficial (Garnefski et al., 2001; Lundh & Nolan, 2003; Nolan et al., 2002), Lazarus (1993) points out that it is essential to have a broad range of coping strategies and he acknowledges that all strategies are potentially helpful; what matters is applying the right strategy for each particular situation. In fact, a more recent meta-analysis conducted by Li and his group (2012) found that solution-focused coping was not associated with caregivers' better mental health outcomes as had been the typical assumption. A problem-focused approach is only useful when a situation is amenable to change: if a spouse needs a break from having their partner at home with them all the time, looking for a day program can be categorized as a problem-focused strategy, which would be the most adaptive to the situation. Some authors suggest that emotion or cognitive focused approaches are more commonly used when people feel nothing can be done about the stressful situation (Carver, Scheier, & Weintraub, 1989). However, thinking and acting are not independent processes employed at different times; it seems that one has to think about a
problem before acting on it. In the example above, spouses first experience frustration with having their partner at home all the time. Then they have to think where to get help to deal with the situation. Then they need to look at the various options they have available in terms of day programs and deal with the difficulty of finding the right program for their partner.

Consequently, looking for a day program can be construed as an emotion or cognitive-focused strategy (e.g., I am frustrated and need to figure out what to do), a behavioural-focused approach (e.g., look for a day program), or a stress reducing tactic (e.g., time to themselves when their partner is at the day program). These approaches may work in tandem. First, one needs to use emotion-focused strategies to deal with the frustration, which will allow the individual to focus on the problem-solving strategies of looking for an appropriate day program, which will finally provide a reduction of stress by having time away from the ill-spouse. More realistically, these processes are highly interactive and likely do not occur in a linear fashion.

Although these ways of classifying coping may appear to provide a clear framework for categorizing these strategies, looking at coping as being either problem-focused, emotion-focused or stress reducing does not fully explain the full range of coping mechanisms that people use. Coping is far too multidimensional a construct to relegate it to being explained as a choice between alternatives. In order to avoid oversimplifying this topic, coping in this study will be explored within the context of participants’ coping experiences as a narrative instead of pigeonholing them into neat categories. Ultimately, this narrative will be the basis of a coping model in EOD caregiving.
Emotion regulation and coping.

Living in a constant state of uncertainty and with continual problems that need resolutions creates a state of anxiety. In this study, participants employed the term "anxiety" as a way to express feelings of apprehension, such as fear and worry: "I worry about having a roof over my head", "I'm worried; too many people depend on me financially", or "I fear being alone". Anxiety is an emotion characterized by feelings of tension, worried thoughts and physical changes such as increased blood pressure (American Psychological Association, 2014). Given the level of uncertainty this group of caregivers deal with on a daily basis, it is no surprise that anxiety is a common emotion.

Regardless of what type of coping approaches are used, in the end, all spouses try to achieve the same goal in coping: to reduce the anxiety brought on as consequence of their partner's EOD. Coping is related to how well spouses are able to manage their emotions, through emotion regulation. Emotion regulation refers to "the processes by which individuals influence which emotions they have, when they have them and how they experience and express these emotions" (Gross, 1998, p.275). As an illustration of how emotions impact behaviour, a spouse unable to complete an application to LTC could be viewed as someone who does not know how to complete them or is lazy, or it could be framed as a person who is experiencing overwhelming feelings of anxiety and guilt over placing their ill-partner, which impede completing the form. Thus, coping is not just the process of completing a task (e.g., completing LTC applications), but the process of coping means that first spouses need to acknowledge their feelings so that they can continue with the placement applications. Those that managed their anxiety were able to function better as they were able to follow through with tasks such as the completion of forms. There are many more examples of tasks that spouses needed to achieve, that they experienced as
emotionally difficult and as a result they were not being completed. Examples included calling the CCAC, calling family members to share the diagnosis or any other activity that required acknowledgment that there was a problem. Again, it is not that spouses could not make the call, but in order to call the CCAC one had to recognize that there was a problem. People that are "doers" may cope better because they are able to identify what emotions stop them from performing something and are able to move on. The step that is required between 'doing' and 'not doing' is awareness of emotions and managing them so that crises can be dealt with. In this manner, emotions do not get in the way of solving problems and there is a possibility for life to become less overwhelming.

Perhaps a way in which emotion regulation works is related to Folkman's (1997, 2008) findings on the importance of positive emotions when dealing with stressful situations. The author revised the original stress and coping model she initially co-developed with Lazarus in 1984, to include the significance of positive emotions. She stated that positive emotions influence the stress process by restoring coping resources and providing motivation to continue problem-focused coping over the long term. Folkman (1997, 2008) states that making meaning out of a stressful situation generates positive emotions. Possibly, in this study, making meaning out of the illness helped participants cope better.

**The coping narrative.**

In this study what people do to manage their feelings, or more specifically their anxiety, is the lens through which coping is explored. Coping strategies are not considered inherently adaptive or maladaptive. What matters is how beneficial a coping strategy is for each particular individual in each specific situation. Minimizing problems as a coping strategy can be seen as
positive or negative: "I don’t worry about anything anymore, everything is ok, I have no fears."
In this situation, this husband takes a laissez-faire attitude, which helps him cope with his wife's last stages of a rapid progressive AD. How else could someone care for their spouse at home for six years and continue to do it well until the end? Maybe, what he is saying is that he does not worry anymore, because by this stage of the disease progression he has come to realize that worrying does not help. Could it be though, that his newly diagnosed diabetes is a sign that the stress of caregiving has taken its toll? As Vitaliano and his colleagues (2002, 2004) have shown, metabolic disease is the common response in men to caregiving. It does not matter for this husband if minimizing issues is problematic or is an adaptive way to cope. Perhaps the attitude of "everything is fine, everything is under control", "concentrate on all the positives 24/7", works well for some spouses at particular stages.

To deal with the anxiety that EOD generated, spouses tried to cope by attempting to gain some sense of control in their lives. Uncertainty and feelings of losing control go hand in hand. Lazarus and Folkman's (1984) research on stress and coping, suggested that uncertainty is always present at times of stress and they categorized uncertainty into temporal uncertainty (e.g., when will something happen?), event uncertainty (e.g., what will happen?) and efficacy uncertainty (e.g., what can be done?).

A common attempt to cope with uncertainty was to plan, even when planning was not possible: "planning ahead and anticipating problems makes me feel better, even when I know I can't plan". There were also those spouses who did not plan and were still constantly "worried about planning for the future". When I asked them the reasons for not planning, a common answer was "I can't". Since this was a highly educated group the reason for not planning was not lack of ability or education. Perhaps anxiety was what made it difficult to plan since planning
required acknowledging reality; or maybe it was impossible to plan given the unpredictability participants were facing.

For participants that were planners and liked to be in control of situations, living with EOD was extremely difficult. These spouses did not feel in control. Spouses who wanted to predict what would happen and were not able to know the future were at a loss. This group of spouses wanted to have plans in place for different eventual circumstances but could not, as they did not know what the future would look like. Two common worries were, "When will my husband need to go into a nursing home? How will I know when the time comes?" Not knowing when this transition would take place and what it would look like was very difficult for people. The unpredictability about what this stage would look like, coupled with the CCAC's system of unexpected bed calling, made planning for something like placement extremely difficult. Well-spouses who perceived they had control over their situation fared better. This was irrespective of whether they actually had control of a situation or not. Perceived control is a strong predictor of people's behaviour, emotion, motivation, performance, successes and failure in many aspects of life, including caregiving (Skinner, 1995).

With the unpredictability of EOD, well-spouses who tried to plan, versus those who waited for a crisis before acting did not appear to have different outcomes. Both groups experienced anxiety throughout the course of the disease since both groups knew that they could not plan for and predict the future in spite of whatever arrangements they made. For example, one participant stated that she had applied to LTC and had one facility in mind, but when her husband was run over by a car and needed to be in hospital for over six months, everything she thought she had prepared for was no longer valid. There is strong evidence in the stress literature that loss of control is one of the few constructs that is universally aversive (Skinner, 1995).
Participants learned that since planning was not always helpful, a better way to cope was adopting a 'one day at a time' attitude. Some examples include comments like, “just focus on the present”, "getting through the day", "deal with issues as they come up", and "cross the bridge when I get there". To be able to cope with the present crisis, a spouse needed to be flexible in the way that they adapted to changes. Some examples of spouses that coped well included attitudes such as: "I keep adapting as the disease progresses...had to makes changes in the house", "keep learning about the disease...I'm learning to listen better, slowing down and prioritizing", "I keep adapting to the changes as they happen". Although these spouses experienced crises like everyone else, they were able to rebound with more ease. Interestingly, when I analyzed the data, more positive attitudes like "every problem has a solution", “life is unpredictable, so don’t worry" or "the older I get, the more relaxed I get about life" were more frequent in caregivers that were in the later stages of the disease progression.

Maybe spouses in the later stages of the disease progression became the most adaptable since by that stage they had experienced it all: "We’ve gone through all the stages – angry stage, no sleeping stage, giggling stage, the you know touching her hair 10 times, doing her zipper up and down. We’ve done it all" (participant #10, husband of wife in last stages of AD). This same husband had also learned to adapt as the disease progressed:

We used to sleep downstairs on the waterbed, and then one day she rolled out, and then she got her head stuck between the night table and the waterbed, so now we sleep upstairs on a mattress on the floor. So when she falls out of bed it’s not a big deal.

Flexibility to adjust to what each stage of the disease changed over time was an important coping strategy. As a wife whose husband was in the moderate stages of FTD eloquently stated, "at some point you need to adjust ". This is consistent with Folkman and Moskowitz's (2004) understanding of coping as a process that changes over the life span. Perhaps those spouses that
were not flexible and did not adjust, were no longer together at the end of the disease trajectory and would not have been captured in this study.

**Commonly Used Coping Strategies**

Strategies such as planning for the long term were not very effective, but short term planning, such as having a day by day attitude in coping with immediate issues worked better for this group of caregivers. In addition, being able to adapt to circumstances that frequently changed was an important coping element. Along with short term planning and being flexible, other coping strategies were utilized. They included advocacy, reframing, self-care and having a spiritual connection. These coping tactics are in alphabetical order to indicate that no single one was more important than another. Finally, the importance of having social supports as a way to cope will be explored in a later section.

**Advocacy/Assertiveness.**

Being a good advocate was crucial to survive EOD given the dearth of appropriate resources for this group of caregivers. Examples of advocacy ranged from writing to the Minister of Health to get support and becoming part of the advisory committee for Ontario's Local Health Integration Networks (LHIN); to advocating for your spouse's care in LTC and in the emergency room; to returning multiple times to the family physician for a diagnosis. People fell through the cracks at every stage and what seemed to help spouses cope was knowing where these cracks where, doing what was necessary to patch them up (which generally consisted of asking for help) and moving along until the next crack appeared. For example, if someone did not qualify for a PSW, knowing who to call (e.g., health care professional, their MPP) to advocate for hours of care made all the difference. Advocacy included both knowing where to advocate as well as who to advocate to.
Being assertive was an important component of advocacy and spouses quickly learned "how to pick your battles" in a bureaucratic system. Spouses knew that they "need to find allies" to help them with their partners' care. Assertiveness sometimes bordered on the verge of aggressiveness. One had to fight at every stage of the disease, from diagnosis to the last stages. This was particularly true for ill-spouses who were in LTC. Metaphors related to "war" were most commonly used to describe coping with LTC: "It's a new battle every day", "it's a constant fight", "putting my army boots on when I go visit", "that's where [LTC] the battle starts". Examples of metaphors related to fighting for services included: "had to fight, scratch and claw to get extra CCAC hours", and "I don’t have enough to take care of and now I gotta fight for him".

Participants also spoke about developing assertiveness in standing up for their spouses and explaining their behaviours, both with services (such as day programs and LTC) and in public situations. They talked about learning to face others to protect the dignity of their spouses. This was not just about getting appropriate services, but about respect and love: "I want to protect him from all the nurses...I want everybody to know, this is a really good guy. Stop looking at him as being fat, because they do".

Having to fight the system to get what was needed and having to be an advocate to get support was experienced by all participants. What varied was the way people 'fought' the system. Some learned early on that you needed to make the nurses and health care practitioners your allies. Being assertive, whether it was through advocating quietly or being confrontational, was a coping tactic that most participants utilized in dealing with various systems.
Reframing.

The emotional toll that dementia had on caregiving spouses was devastating. Participants managed to cope with the effects of this illness even though they felt "at the edge of the precipice", "feeling bottom deep", "being on the verge of insanity", "being completely dried up", "being between a rock and a hard place" and "going down a tunnel". All these metaphors have a tone of despair and feeling out of control. Participants tried to implement strategies to help themselves feel better and feel like they could survive the situation confronting them. Reframing was the most common way people employed to see their situation in a more positive light. As an illustration, a husband, whose wife was in the later stages of FTD, would find meaning out of her illness when he was feeling low and despondent.

You have to think, did I get a flat tire for a reason, maybe it’s preventing me from something bad that would have happened. Or maybe you’ll meet someone who is going to help you. So there’s a reason for certain things [like wife's illness], you have to say okay I’m caring for [wife] and I’m having a hard time but there is a purpose (participant # 28).

Another husband dealt with his wife's resistive behaviours by reframing it as "she is resistive out of fear, she wants to be helpful but she can’t". A wife who had a difficult time placing her husband said, "I didn't place him, the disease did". Another example was a husband whose wife sang constantly; he understood her vocalizations to mean, "she must be happy, she sings all the time". This way of reframing a difficult behaviour, which most people find hard to tolerate, allowed him to find something positive. These findings are congruent with The Cochrane Collaboration review of cognitive reframing for caregivers of people with LOD, and found a beneficial effect, specifically on anxiety (Vernooij-Dassen et al., 2011).

An additional type of reframing strategy was employed to compare one's situations to others (downward comparisons) to help alleviate the feelings of despair: "I look at the children
dying all over the world and the wars and my friend's niece, 13 years old, just died." As seen in this quote, reframing one's problems by comparing oneself to others is a common example of what spouses do to protect themselves from the pain and anxiety of life with EOD caregiving. This coping strategy made participants feel that their situations were easier than other people's circumstances. This was a common reason why people found support groups so helpful: "It puts things in perspective. I see what others are going through”.

Refocusing was another strategy employed by participants to deal with the uncertainties and anxiety brought on by EOD. The following excerpt is a representative illustration of a participant's experience of angst and the ways she finds to decrease her anguish by refocusing.

"It’s overwhelming, holy shit! I still get overwhelming days! Don’t think I don’t. It’s pretty tough and I’m thinkin’, like how do I, like how do other people do this because, because, I can barely do it, and I think I’m a strong person, and it’s like, ok, whatever, and you know, you have to refocus. It’s just constantly refocusing on the positives (participant # 8 -- 53 year old woman caring for a husband with moderate FTD).

In this excerpt, the participant acknowledges how overwhelming life is now. Refocusing on the positives does not necessarily help her solve the problem (e.g., living with a partner with EOD) but it helps her focus on something more constructive than her negative feelings. Pressman and Cohen (2005) have found that positive emotions may have a protective function in respect to physical and mental health. In the above example, through what the participant labels "refocusing on the positives", she is able to regulate her emotions and move on. Emotion regulation is an important way that spouses manage the impact of EOD. This is consistent with the literature in that emotion regulation is considered to be an important element in determining well-being and/or successful functioning (Cicchetti, Ackerman, & Izard, 1995; Folkman, 2008; Garnefski, Kraaij & Spinhoven, 2001).
Self-care.

Self-care has been found to foster healthier outcomes for LOD caregivers (Furlong & Wuest, 2008) but there are no comparable studies in EOD. Although many spouses were successful in learning to care for self while meeting the needs of their partners and others, self-care took on different forms as the disease trajectory brought changes.

Overall, spouses in the early and early-moderate stages did not engage in self-care activities as frequently as those in later stages. There were many reasons for this such as lack of time, lack of energy and depression. At some point, spouses realized that if they did not look after themselves, both physically and emotionally, nobody would: "my struggle is keeping myself healthy and together so that I can do this every day". In addition, spouses in the earlier stages were overall younger and thus, they had more responsibilities related to dependent children and work and consequently less time and energy for self-care.

Over time, spouses were able to incorporate activities that gave them pleasure, or at least made them feel like they were doing something good for themselves such as exercising. Some examples of self-care activities in this group include: "I take a day off from visiting him and lounge", "I paint", "get manicures", "try to exercise", "I swim", "do yoga", "meditate", " I go to my car and clean it; it's my toy", "I have a lazy day", and "I eat right when I can". One wife talked about having a book with a list of self-care activities that she has divided by the amount of time she has at a particular instance for self-care:

I have a duo tang with some ideas.... When you have 2 minutes, 5 minutes, half an hour, little things about what you can do. Because everybody says take care of yourself but that doesn’t mean anything, it means nothing. Actually maybe I’m taking care of myself a lot better than I think I’m taking care of myself. When I stop and look at that flock of geese going over the beautiful sea and actually see it... the ‘me moments’. And they don’t need to take a long time. Your partner can be right there with you and you can enjoy the 'me' moment together (participant #
25--52 year old wife looking after her husband in the early-moderate stages of AD).

This wife stated that if she had to give advice to other spouses in relationship to self-care, this would be the most important one. She stated that one of the difficulties with being a spouse is that when you finally have a few moments to yourself, you do not have the energy to start figuring out what to do with this time. Having a booklet with different options makes it easier to find something that may give you joy.

Participants, especially those in the early stages, talked about self-care as something they "should" do, versus something they wanted to do. A common complaint was "everyone tells me to take care of myself, but what does it mean?" There were mainly two types of self-care strategies. One type included things that provided a break from their spouse such as "going out for coffee", "going to my wood-burning class", "walking the dogs on my own" and "time away when he is in his program". The other types of activities were directed toward looking after their own health such as exercising, watching their diets or going to medical appointments. These activities were less common. These self-care activities were probably more infrequent as their benefits were more long term. Taking a break and reading a book provided immediate gratification; eating an apple instead of chips did not. In a group that is generally so stressed, it is understandable that spouses go for self-care tactics that bring immediate rewards.

Although self-care went a long way in helping people cope with the daily stresses, those that were truly stressed, like participant # 21 who had four dependent children and had to take any temporary, on-call job that became available said that she does not do anything to take care of herself since she is too overwhelmed. Between her depression and the stressors related to finances, she could not see even a possibility for self-care.
Spouses were aware of the importance of exercising to maintain their health and decrease stress. They viewed exercise as a way to cope with the impact of EOD. The majority talked about needing to exercise more. However, they felt that there was not enough time or energy to exercise. "I try to go to yoga one night a week. I need to increase my physical activity, I'm finding that very difficult". The next example also talks about the difficulty in finding the time to look after oneself: "So I find like with stress in the evening I don’t eat as well as I should and don’t exercise as much as I should. So I guess that’s how the stressors affect me physically".

In contrast to the above example, there was one man who coped by exercising almost too much: "I spend four to five hours a day with exercise, so maybe I'm a bit of an addict, but for me it's very good because I feel really healthy and it helps me feel better" (participant # 14). Although his example was unique, I included it to add another dimension to the physical repercussions of EOD caregiving. This husband talked about being able to manage the disease by feeling healthy, but he also acknowledge that exercise was 'me' time and a way to escape his troubles. This participant labeled himself an "addict" and in many ways was no different from three other spouses who started to drink more alcohol as a way to cope. Some spouses were able to escape their pain, albeit temporarily, by either exercising or drinking more.

In this study, self-care was a useful way for people to cope with their daily struggles; but overall, it was not until the later stages of the disease progression, when people either had more time or were not as depressed and already knew the importance of self-care, that this occurred.

**Spirituality.**

There is a growing body of research in the area of spirituality and health care (Astrow, Puchlaski & Sulmasy, 2001; Burgener, 1999; Dalmida, 2006; Pargament, 2013; Sulmasy, 2002)
and in particular on its effect on coping (Folkman & Moskowitz, 2004). In spite of having knowledge about the importance of spirituality in health care, I found the extensiveness of people's beliefs in spirituality to be an unexpected finding. I did not include questions related to religion or spirituality, yet it came up in most of the interviews as a common way to cope. The question that generally moved the conversation to spirituality was: "What sustains you?".

There are differing views between what spiritual and religious ways of coping are. In this study, both religious and spiritual coping are seen as "efforts to find meaning and purpose, or efforts to connect with a higher order or divine being that may or may not be religious" (Folkman & Moskowitz, 2004, p. 760). The most inclusive definition was proposed by a palliative care consensus conference dealing with improving the quality of spiritual care in health care:

Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred (Puchalski et al., 2009, p.887).

With this definition in mind, people's view of spirituality and coping is explored.

Not everyone saw themselves as belonging to a particular religion, but many felt that there was a spiritual component to their lives which gave them meaning and support. Participants described spirituality in very different terms and from broad perspectives. Two participants used their spiritual lives to try to understand EOD and thought of this illness as an opportunity to evolve as people: "He [husband] has given himself, he has given of his life to help others...it allows other people to come to the plate to give...He is a role model...I am here to learn [from him]". A second spouse stated that, "we’re on this earth for a reason, and we’re never given anything we can’t handle. I mean there are reasons why some of us have been given this disease to deal with and maybe why other people haven’t". Meaning making was experienced within the context of spirituality.
Five wives participated in meditation and/or spirituality groups. One spouse believed so strongly about the benefits of spirituality that she wanted another wife from the FTD online group to join her spirituality group. When the other spouse refused, she said: "she obviously didn’t deal with it, she wasn’t spiritual, I tried to get her into it". Another wife found practicing spirituality with her ill husband a bonding experience: "we call it our spiritual exercises. So we do this together and we listen to our teacher’s ... CDs". This time together was important as couples affected by FTD rarely have opportunity to do meaningful bonding activities together. Several spouses talked about "karma" and "meant to be" concepts. At least ten people shared the idea that there were no coincidences in this world and that a higher power had control over what was happening. Examples included, "there’s no such thing as coincidence", "coincidence is when God intervenes", "Nature has its ways for everybody". At times of stress, well-spouses relied on God for support: "I realize I’m riding on empty a lot, and I don’t like that. Believe me, and I say it, I pray to God, just, well, you know what, God? You gotta give me relief here".

Having a sense that there was something greater than oneself seemed to give meaning and hope to people's lives. There were people who talked about religion as a new experience since becoming a caregiver: "The Church gives me support for me to keep on going... It’s funny that I’m talking about this, because before [wife's illness] I never did". For some, Church was always part of their lives and through this illness, it has continued to be a source of support: "I go to mass and I’m sitting there and thinking how am I going to continue and a lot of time I’m in tears. And it seems sometimes that the homilies were directed to me personally".

For some people, Church was a place where they experienced community:

My church, I’m not really involved, but I go to the concerts, and every Sunday that it’s possible. The people in the church, I take the bus to go, but I always get a ride home. Somebody will always give me a ride home. So these things are what
keep me going (crying) (participant # 22-- wife of a husband with AD in the moderate stages).

Some spouses saw spirituality as a way of expressing gratitude: "the good Lord gave me a pretty good life", "I thank God I have a beautiful home, the kids are safe, they have something to eat". Some used spirituality as self-assurance that they were doing a good job as a caregiver: "I believe in the spirit, I believe in reincarnation, and I hope when he [husband] gets there, he thinks that I was okay to him". A few participants found meaning in the teachings of their religion: "even the Bible talks about change, constant change".

Although this was not as common an experience, some people seemed to be angry at God: "my Church used to sustain me, but now I question faith". Another example included: "You’re mad. You’re not mad at your spouse; you’re mad at Life. It’s like why, why? Well, we know that there’s no answer to why". Maybe, being angry with God or Life was easier than viewing life as random, where anything can happen to anyone. This feeling of not having control was a crucial theme and the belief that 'someone' was responsible for such terrible illnesses may be the reason why people turned to the spiritual realm. People did not just want support, but they needed answers.

Pargament and his colleagues (2000) developed a tool (RCOPE) to measure religious coping. What is helpful about this tool is the way it divides the functions of five religious coping strategies. These include: (a) finding meaning in the face of suffering, (b) providing a way to achieve a sense of mastery and control, (c) finding comfort and reducing fear by connecting with a force that is bigger than the individual, (d) promoting social solidarity and identity and (e) helping people find new sources of significance while enabling them to give up old objects. All the illustrations above can be fitted into at least one of these categories.
Through spirituality, spouses were able to better cope with the anxieties brought on by EOD by way of finding meaning in this disease, by feeling that if they were not in control at least someone was and finally, by experiencing support through a force that went beyond them.

**Social supports.**

This last section on what helped people cope describes spouses' social supports. Pearlin (1990) makes a distinction between ‘networks’ and ‘social supports’. Social supports refer to the assistance that a caregiver may derive from someone from their network. People's engagement with others can be described as part of a continuum, with social isolation at one end of the spectrum and social participation at the other (Gierveld, van Tilburg, & Dykstra, 2006). What all spouses experienced, other than participants in the diagnostic/early stages, was their perception that they were trapped at the isolation end of the spectrum during most points of the disease trajectory.

Different strategies to engage with others were used at different stages of the disease process. Early on, well-spouses tried to obtain support from their own friends and family and although they initially appeared to be available, over time this source of support disappeared. By families, I mean families of origin and extended families since adult children were always involved. Paradoxically, friends and families were both a source of support and strain. Siblings appeared to be the biggest source of disappointment, even when participants initially thought that they would be allies. Some spouses had some falling-out with siblings, in particular in the early stages of the disease progression, "I lost my husband and family at the same time, as my family initially disappeared when his problems started".
Coping is related to social supports (Berkman & Glass, 2000; Brodaty & Donkin, 2009; Cohen, 2004) and participants talked extensively about their informal and formal support systems. They discussed the types, quantity and quality of their interactions and what became clear was that in as much as supports had protective outcomes, they were also a source of extra stress. The literature reports that the way in which support protects against caregiver stress and burden is not only by the concrete supports that are present, but also by increasing the perception that resources are available to handle stressful events (Cohen, 2004).

The finding that social networks were as much a source of stress as they were a source of support was surprising. Social support is a multifactorial construct and it is influenced by actual and perceived support, instrumental and emotional support and it varies by gender, race, individual differences, personality traits such as neuroticism, and culture (Brodaty & Donkin, 2009; Owens, 2003; Shurgot & Knight, 2005). However, given the complexities of relationships, the paradoxical relationship between receiving support and the stress created from these same networks should not be have been unexpected.

In spite of the difficulties that participants experienced with families, for those people that felt connected and supported, these familial bonds were extremely helpful. "My sister’s coming this weekend...and I can have some fun with my sister, I can get a break". Others provided instrumental resources: "I generally take financial help from my brother but I can't ask him all the time". Other ones provided emotional support: "on my online support group, a couple of them have a very hard time asking for help; and I know partly it’s because they don’t seem to have a network of friends like I have". Participants who had close connections to families of origin found these bonds sustaining.
Non-dependent children were also a source of support and to the extent that they were able, they all tried to help with their ill-parent. Other sources of support included friends that spouses made during the illness' progression; people who understood them, such as other spouses of people with EOD, who became their closest sources of support. In the majority of cases, relationships with family and friends did not improve until later stages of the disease. Spouses that were able to reconnect with families were not the norm, but when this occurred, they became a very strong source of support. The experience of immigrants was different; spouses who were immigrants and did not have family in Canada longed for these relationships. They all felt that if their families had lived closer, they would have been supportive and involved.

Spouses obtained their support from various sources and these ranged from going to bars to attending Church to connect with others. A few of the participants that went to Church stated that they did not just go for the spiritual component, but the community itself provided a much needed sense of connection: "their philosophy is that they walk beside you through your troubles" (participant #28). In this sample, support groups were also a means of becoming socially engaged; 20 out of the 30 participants had been part of a support group at some point of the caregiving trajectory. The most attended support group was the FTD online group, which was led by a social worker at Baycrest Health Sciences. Out of the 30 participants, 12 belonged at some point to the FTD online support group. Participants described this group as "a lifeline", "my community", "a place of support I could not get anywhere else", "we bare our souls to each other", "puts things in perspective" and "it's my 'me' time". The reason this group was so successful was that it finally gave spouses a place to belong to, somewhere they could be understood, not just by a health care practitioner, but by their peers. To this day, these spouses continue to meet via Skype and some have continued their weekly meetings on their own for
over three years. This online support group has filled the vacuum that occurred from the
loneliness of the alienation from family and friends as well as the loneliness of not having a
partner.

In the later stages, some of the participants seemed to reconnect with family and friends.
As well, by this stage, spouses had made new friends such as other spouses of people with EOD,
who they met online, or through word-of-mouth and through support groups. This is reflective of
this study's population given that the sample was mostly obtained through support groups and the
EOD community. Seeking social support was a strategy that all participants utilized at various
points in the disease trajectory.

Coping – Key Findings

What all the coping strategies have in common is that they allow participants to perceive
that they have some measure of control over what is happening in their lives. People have a sense
of impotence with this disease. Not only do spouses feel that they do not know how to predict
what will happen next in terms of the disease; they also feel that the system does not support
them. This sense of powerlessness occurs at every stage of the disease. It occurs in the initial
phases, when participants could not even get the family doctor to believe them that there was a
problem. It continues through the long diagnostic process to the lack of appropriate services and
scarcity of structural supports that help people manage with the impact of dementia at this young
age. Therefore, it seems to make sense that strategies that allow people to feel a sense of control
over their fractured lives would be helpful.

Approaches like long term planning, where there were too many unknowns, were not
helpful strategies as they generally did not materialize (e.g., LTC choice). Shorter-term strategies
that helped with the problem at hand seemed to work better. Advocacy and being assertive over immediate concerns, such as asking nurses to clean your soiled spouse, helped people feel in control since they resulted in the resolution of the current problem. However, for those who were planners and needed to feel prepared for the longer term, planning may have been beneficial since proactive people have a sense of perceived control that translates into a 'take charge' attitude (Greenglass & Fiksenbaum, 2009). If people do not have control of the progression and impact of the dementias, at least they can feel that by planning they are taking control of a situation.

The most common strategies used to change the perception of problems were reframing, downward comparisons and refocusing on something positive. Reframing was actually the main strategy since comparing oneself to others and focusing on something positive are just ways of reframing a situation. If a crisis could not be changed, at least how one made sense of it could change one's emotions about it.

Self-care as a coping strategy also empowered spouses, as it was something that they could do which was within their control to help themselves feel better. Self-care and positive emotions co-occur; one can only take care of oneself when feeling worthy. Furlong and Wuest (2008) developed the "self-care worthiness" concept, which they explain as "the degree to which caregivers believe that they deserve physical, social, emotional and/or spiritual sustenance" (p. 1665). It would seem that self-care worthiness is partly related to depression in that the degree to which someone could self-care was related to the extent that they felt deserving of it. Thus, in the earlier stages of the illness, when most spouses were not treated for depression, it would have been more difficult to self-care. It was not until the later stages of the illnesses, when most spouses' depression had been treated, that they could better look after themselves.
Spiritually not only allowed participants to reframe their experiences and give them meaning, but also gave people a sense of security that "someone is watching over me". This sense of security may have assuaged their anxiety by feeling that at the very least, someone was in control.

It is important to point out that although these were the most common strategies utilized by participants, they were not the only coping tactics used. People seemed to go through a process of “trial and error” until they found what worked. I would like to conclude this section by stating that through this study, I did not see adaptive or maladaptive coping strategies as the literature refers to (Garnefski, Kraaij, & Spinhoven, 2001; Lundh & Nolan, 2003). Having a partner with EOD is tragic, and as health care providers, we should not be judgmental of spouses’ coping mechanisms. Over the disease trajectory, there were changes in how spouses coped and with the progression of time participants seemed to cope better. Perhaps, learning to cope with the impact of these dementias takes time and is part of the adjustment process.

Finally, coping was influenced by the quality of participants' social networks and it was important to people’s perception of stress. Notwithstanding those who were depressed and had difficulty reaching out to others in the initial stage, all sought the comfort of friends and family.

Chapter Summary

This chapter was an examination of how EOD spousal caregivers' cope with the multiple changes and disruptions in their daily lives throughout the illness trajectory. The most commonly utilized coping strategies had in common that they gave participants some measure of feeling of control over a disease that was unpredictable, and created much anxiety for caregivers and their families. The findings from this chapter and from Chapters 4 will be integrated in Chapter 6,
where the development of the participants' narrative about how they *experienced* and *coped* with EOD through the disease trajectory is recounted in the form of an analytic story.
Chapter 6

The Analytic Story

This chapter presents the data as an analytic story, integrating the previous explored main themes into a discourse about people's experience through the entire process of caregiving. This chapter brings process into the analysis by looking at patterns of coping, interaction and emotions in order to discover how spouses manage to overcome the difficulties and/or threats to survival they continuously encountered.

The Narrative - Life with a Spouse with EOD

This chapter tells the story of living with a partner with EOD from the well-spouses' perspective. The findings are presented in a narrative format to illustrate what life is like for these spouses over the dementia caregiving years. This section of the analytic story does not draw upon the literature to back up statements since it is exclusively based on how people tell their stories and how I recount and interpret their experience. This storyline is presented in relation to the following chronological headings:

1. The pre-diagnostic and diagnostic period - early stage
2. Middle stage of disease progression
3. Late stage of disease progression

Although the analysis will be presented from three distinct phases of the disease progression, it is important to understand that these stages are part of a continuum. Presenting them in a linear logic is done for the sake of clarity, although people’s experiences are neither necessarily straight-forward, nor always conveniently delineated with clear boundaries.
This portrayal of people's stories is based on data from participants at various stages of the caregiving journey. For example, interviews from spouses of people in the early stages of AD and FTD were included to tell the story at this early diagnostic stage. However, participants who were interviewed in the moderate and later stages of the disease also discussed their earlier experiences with the benefit of hindsight. These retrospective interpretations are also included since they enrich the story by adding the perspective of time.

(1) Early Stage - What is Going on?

"The only thing that is sure is that there ain’t going to be a for sure" (participant #8).

The process of diagnosis is a long and difficult journey; it is not easy having to wait for doctors, specialists and tests to find a reason for changes in one’s spouse. People have a hard time accepting that even doctors do not always have the initial answers to their problems. Sometimes they have to take a "wait and see" approach for symptoms to develop in order to get a diagnosis. Spouses often experience frustration because personality, behavioural or memory problems are not understood as the manifestation of a neurological disease. During this phase, some people's symptoms are wrongly diagnosed and some examples of misdiagnoses include menopause, stress, mid-life crisis and depression. Couples are referred for marital counseling and psychiatric interventions. When these therapies do not seem to work, people are finally referred to neurologists. Once patients are worked up and a diagnosis is obtained, the physician's opinion may be subject to change as new symptoms develop over time. This uncertainty about what is wrong lasts for an average of four years and people become exhausted from trying to figure out what is going on.
The three common feelings that participants experienced in the pre-diagnostic and diagnostic stages were feelings of denial, shock and relief. Some participants only experienced one of these three feelings, while some expressed that they had felt all of them at different points. Denial, shock and relief were not experienced in a linear fashion nor were these feelings exclusive from one another. Even over the course of one-to-two hour long interviews, participants wavered in their perceptions of their partner's illness. For example, some would start the interview stating that they were relieved that there was a diagnosis and later on in the interview, they would ask me if I really thought that their spouse had dementia. This back and forth from feelings of disbelief to relief that there was actually something wrong frequently lasted from the early phase up until the middle stage of the disease. However, there were some people who seemed to experience these feelings of ambiguity and uncertainty up until the end: “I still think it’s [the dementia is] a misdiagnosis and it’s something else, because I see Alzheimer’s patients in the nursing home and [husband] doesn’t fit in that group.” This excerpt is from a wife whose husband was in LTC and has had AD for 15 years. One wonders if some spouses ever really come to terms with the illness.

There was a small group of individuals in the early stages, who did not understand the implications of what was ahead; this group did not seem very distressed. In this study, this apparent lack of worry about the implication of having an EOD was more common in men. The following quote is an example of a husband whose wife had FTD, trying to explain his wife's inappropriate behaviours by saying "I tell people now that she's just happy go lucky." It could be that this was a form of denial, or it could be an attempt to normalize the looming problems. Furthermore, in this early stage, it was more frequent to find husbands who did not realize something was wrong. Could it be that as long as wives were cooking and maintaining household
tasks things were perceived as being fine? On the other hand, wives appeared to recognize that there were problems earlier and they seemed to worry more about the future. Wives pushed for a diagnosis more often than their husbands, who seemed to be more passive about obtaining a diagnosis. Given that on average couples had been married almost 28 years at the point of initial symptoms, one wonders how the well-spouses do not realize their partner’s early signs of dementia.

For wives, there was initially a sense of relief that there was a diagnosis as it explained the years of wondering what was wrong, not only with their spouses but with themselves. One wife felt that she was actually the one “going crazy” since others did not believe her. Once there was a diagnosis, there was finally an explanation for the bizarre behaviours and multiple problems they were living through. Although some spouses felt relieved that there was a medical problem, for those who had not fully realized the extent of their spouses’ troubles there was a deep sense of shock, even when it seemed clear that there had been issues for years.

Some spouses were in denial and tried to make excuses for each symptom, including symptoms that were undeniably problematic. For example, one husband felt that there was nothing unusual about his wife's sudden urge to start buying numerous baby strollers for their dog or buying $400 worth of candy all at once as long as she bought these items out of her own money. One woman started becoming belligerent in restaurants and her husband excused this behaviour as his wife becoming assertive in her 50s. Additionally, there were those spouses that realized there were problems, but coped by wishing the illness away: "I almost want [wife] to just be part of whatever and pretend nothing's wrong." Although denial may be seen as a poor way of coping, in these situations it may provide a way of dealing with a difficult emergent
reality. Denial is not a black and white state, but it is a process that moves along a continuum until not 'facing the facts' no longer works.

(2) Middle Stage - Adjustment/Readjustment

"There is a continuous dance between acceptance and denial, but the reality of the disease hits us rapidly and [one] can't stay in denial for too long" (participant #15).

**Awareness of impact of disease.**

As the disease progresses, the EOD symptoms and subsequent problems become irrefutable and illness awareness marks the beginning of a new phase. However, even when people have an understanding of their partner's dementia, well-spouses fluctuate between realizing this is a neurodegenerative illness (e.g., "understanding the illness makes me feel calmer because I know that it is not her fault"), while hoping for the illness to disappear (e.g., "Let the nightmare be over and let me wake up"). This tenuous awareness leads to a constant state of ambiguity.

Having a new awareness is generally followed by wanting answers about "Why us?" and "Why now?" Questions like "He was so smart, how could this happen to him?" or "How could someone who was so healthy and even ate salad without dressing, develop this?" It is as if healthy, strong and smart people cannot develop dementia, especially at this juncture in life. Dementia may be fine when you are old and frail, but not now. There is a pervasive belief that "life is not fair"; that the timing is off given the normative chronology for the life course that most people embrace.

As the EOD advances, the symptoms and subsequent difficulties become overwhelming and anger, fear, anxiety and grief seem to become the predominant emotions. Their partners are
not getting better and it is difficult to deny that there are problems. Some people talk about entering into a depressed phase in the earlier stages of their partner’s disease; however, the majority of well-spouses begin to experience depression when the reality of the disease is undeniable. Depression is the term that most spouses employ to talk about their feelings of sadness, grief and loneliness. However, there were many spouses who had been depressed since the pre-diagnostic stages given that at that time there were no explanations for the ill-spouses’ changes. The intense emotions and depression appear to be related to how soon participants start to appreciate their partner’s illness. For some participants, the stage of intense emotions is present throughout the progression of the disease trajectory. Well-spouses, who were interviewed and were in the last phase of the disease, had stronger feelings of grief, less anger, and less depression. The anger had subsided by then and the depression had been generally treated. There was an existential component to this sadness and it seemed to be experienced once the initial anger subsided. Well-spouses appeared to be in a chronic state of sorrow.

All participants experienced anger, fear, anxiety, grief and depression; the difference among participants was the intensity of these feelings, at what point in the disease trajectory these feelings emerged and how long these feelings lasted for. Although a few spouses were depressed through all of the phases of the disease, for the majority these feelings were experienced with more intensity at particular points, which I call ‘transition points’. Transition points had a temporal component and they included: the time of diagnosis; disclosing diagnosis to others; the loss of employment for ill-spouse; the loss of employment for the well-spouse; ill-partner's loss of driver's license; the point where major financial difficulties impacted people’s lifestyle and ability to provide for their families; problems with children and/or parents; allowing formal services in the home; starting a day program; identifying oneself as a caregiver and not a
spouse; dealing with government/health care systems; medical crisis and placement to LTC. These transition points, with few exceptions, were all experienced as crises. These points of crises demanded immediate responses from spouses and had the potential to cause considerable disruption and distress.

Individuals that had multiple roles and responsibilities, mainly caring for dependent children, seemed to experience more anger, anxiety, grief and depression. This makes sense based on having many stressors and not having a partner to share them with. All spouses I interviewed had depression at some point in the caregiving journey. The only ones that did not feel depressed were participants whose partners were in the early stages of the dementia and who did not truly believe that their spouse had an issue.

For those spouses who felt that they were losing it all to the disease (e.g., ill-partners that spent their family's money prior to diagnosis, having to downsize multiple times, loss of employment and disastrous financial downturns), anger, anxiety and depression seemed to be ongoing features. It is difficult to cope with behavioural and personality changes in a spouse when a participant worries about paying rent and having food.

**Continued adjustment/re-adjustment to the disease.**

Continuous adjustment to the impact of EOD was necessary because EOD symptoms and new evolving situations were unpredictable and difficult to manage. If in the past stubborn behaviour was a problem, now apathy was an additional one, perhaps followed by an acute medical problem requiring hospitalization, which produced a completely new set of issues. What is normal one day changes and thus, the day to day way of coping alters regularly. Needing to accept what ‘the day brings’ on an ongoing basis is exhausting since it requires a constant readaptation. As soon as a spouse becomes used to the staff and routines in an in-patient
behavioural support unit, a LTC bed comes up and with it the need to adapt to new staff and new set of rules. As sleepless nights are dealt with through multiple medication adjustments, patient's falls become a concern. There never seems to be enough time and energy to adjust to the realities of the situations: "it’s a constantly changing process and once you get set and things are really good, it changes.” Caregiving spouses burn out from the continual need to adapt to changes. There is a feeling of being extended to the limit.

**Interim adaptation.**

Through the middle phases spouses cycle from feeling that they are coping with a particular issue, to feeling that they are falling through the cracks and not able to manage the current struggle, then reverting to feeling back in control. The coping strategies that sometimes work for some stages of the disease progression cannot be utilized throughout all stages. Not being in control makes spouses feel like they are "free-falling”, which is a major experience in this group of caregivers. Attaining control of a situation seems to be a major theme. As per participants’ choice of word, "crazy" becomes the new normal for a lot of people. This participant felt that her life was “crazy” since she was feeling "… happy that my husband is in love with another woman in the day program as he now wants to attend the program”.

An important goal for well-spouses seems to be keeping life as normal as possible; however, this disease threatens any sense of normalcy that caregivers may have. Being ‘normal’ becomes a major goal. Since the dementias and the well-spouses' depression are invisible to the "outside world", others tend to be judgmental about the way the well-spouse is managing his or her life. Feeling misunderstood by others is another important sentiment of caregivers.

Trying to come to terms with the embarrassment and the indignities that these dementias bring on becomes a way of life. Temporary acceptance is one of the stages that some spouses
achieve some of the time, until a new symptom/issue surfaces. Even though some people state that they have accepted the disease, I did not detect that any participant fully accepted the disease; rather, participants learned to manage it and kept trying to adjust to their situations as they arose. Perhaps, a better term for what well-spouses call acceptance is 'disease awareness'.

As stated earlier, this phase of interim adaptation is neither static nor linear. Adaptation seems to occur along a continuum and as people move along the disease trajectory, they may sometimes backslide as problems become too difficult. To adapt to a current challenge does not necessarily mean coming to terms with or accepting the impact of EOD in their lives. As a participant stated, "I can accept reality, but not like it. I can be angry and grieve while at the same time realize that I need to deal with what is in front of me".

(3) Late Stage: Moving on

"It has been a long, long journey and we are in the autumn of the journey now" (participant # 5).

This phase of the trajectory is characterized by having one's spouse placed or having more care in the home; generally private care. Placement in LTC is a time of crisis for people. It signals the separation of the dyad as a couple and although there is relief of not having to look after one's spouse full-time, there is guilt. When the ill-spouse enters a LTC institution, well-spouses lose control of their partner's care. Spouses experience stress associated with institutionalization but their depression seems to have been lifted.

In the later stages of the disease, caregivers start contemplating their own future. Some participants seem to have a sense of excitement, while others seem scared of the next stage without their spouse. Some feel that they have been caregivers for so long, that they don’t remember life before EOD. Although some people say they are looking forward to moving on
from being a caregiver, there is always trepidation. Spouses want to move on, but are afraid of what life will look like. As the ill-spouse progressed into the later stages, participants started to reconnect with friends and started to become more socially engaged. This was partly due to not having to be the sole caregiver for their spouse and having more time. Those in LTC were cared for, and people that were still at home had some form of private care and/or support from the CCAC.

There were differences in the way that men and women viewed their future. Only three spouses, all of them husbands, cared for their partners at home into the later stages. As women caregivers pointed out, men are at an advantage as they are physically stronger than their wives and thus, they can care for them; if they become aggressive they can contain them and when they need two people transfers, they can lift them. Men concurred with this point. The husbands in this study presented as very devoted to their wives and prided themselves in providing great care. They did not talk about guilt in how they are looking after their wives, felt that they had fulfilled their duty as caring partners and thus, felt entitled to a new life. All three of them talked about future relationships, dating and “having fun” at some point in the not so distant future. They all talked about rejoining the workforce and focusing on work as part of the moving on process. For some this is a necessity as the disease drained their savings. As one husband put it: "My life now is like a car wash - there is light at the end of the tunnel and I am only trapped for a short time" (participant # 25).

Wives seemed to be more ambivalent about what life would look like as they entered the later stages of the disease. Some talked about their wish to have new relationships, while others seemed more concerned about finances and the prospect of being “poor”. The wives that were concerned about money talked more about rejoining the workforce and were worried that they
would become "Walmart greeters" given that they had been out of the labour force for so long. Only those wives that did not have many financial difficulties expressed their wishes to form new relationships.

**Synthesis of the narrative.**

The experience of these spouses is one of survival; from surviving the early signs of the disease and the diagnostic process to the impact of the disease progression. The effects of EOD include surviving changes to all types of relationships (with spouses, family, friends) and living with the fear of the unknown. EOD had consequences that ranged from an emotional, physical, social and financial perspective.

Spouses' narratives are best described by the feelings that people experienced through the dementia journey: from denial and shock to relief; from anger to fear and grief to eventually a chronic sense of sorrow that seemed to insidiously develop. Caregivers in later stages of the trajectory did not have the same level of anger that those in the early and moderate stages verbalized. Spouses concurred that after the anger subsided a stage of acceptance, or perhaps resignation, set in. They had many years of dealing with the disease and felt that in some way they had dealt with this anger by trying to find meaning in their experience. At some point spouses were able to move to a new place of hope and seeing a future for themselves, notwithstanding, with some feelings of trepidation over what their future may look like. This analytic story has a common thread through the entire disease trajectory: the survival of couples affected by EOD, with all the trials and tribulations that these dementias bring. Surviving these continuous crises, over a period of many years, becomes these spouses’ narrative.
What makes these stories so powerful is the determination of the well-spouses to persevere in spite of such terrible circumstances. No matter what the difficulties were, participants constantly strived to maintain a sense of couplehood. Even when well-spouses were angry, there was a sense of protectiveness and love that permeated their stories. This did not mean that they were in love with their partners necessarily, but there was some form of love, even while some spouses hated the person their spouse became. Every participant was able to talk about previous happy times as a couple and found this sustaining. There is something that makes these spouses so devoted in the face of having a partner who was not their partner anymore and I think it is a combination of love and commitment.

Developed from the narrative in this chapter and the findings presented in Chapters 4 and 5, an EOD model of spousal caregiving is presented in the next chapter. The purpose of developing this substantive theory is to understand how people cope through the chronic state of crises over the course of the disease. This knowledge is the crux of learning about this group of caregivers. It is through this understanding that future interventions can be developed, which ultimately is this study’s goal and will be explored in Chapter 7.
Chapter 7

The EOD Model of Spousal Caregiving

This chapter introduces a model of EOD spouses’ experiences over the course of the disease and offers a diagrammatic illustration (Figure 6.1) of this study's findings by synthesizing all of the data together. Following the model presentation, the implications to social work practice are introduced. The core theme of surviving chronic crises and the way spouses manage their caregiving trajectory was the basis from which this substantive theory (the EOD model of spousal caregiving) evolved. Figure 6.1 illustrates the theoretical interpretation of the data and serves as a framework to understand the EOD spousal coping experience through the disease trajectory.

Figure 6.1. Continuum of EOD spousal coping experience through the disease process.
This model tells the story of the well-spouses in a chronological manner; starting at the pre-diagnosis stages all the way until death of the EOD patient. The framework starts with the early phase including the before, during and after diagnosis phases. At some point during this early phase, there is a new awareness of the illness that is responsible for all of the current difficulties. Individuals have to confront reality and deal with problems as they come up. As each crisis develops, spouses have to continuously readjust until they find a new equilibrium in their lives. Once stability is attained, spouses carry on until they have to confront the next crisis; this constant process of negotiating new problems drains people's resources and is manifested by a sense of being extended to the limit. The chronic manner in which these crises occur creates anxiety. Spouses cope by utilizing approaches that help them feel some measure of control over their circumstances. Elements that have an effect on coping are participant's ages, gender, whether they are dealing with FTD or AD and where they are in the caregiving trajectory. Coping is also affected by the quality of their social networks and their personal resources. At some point during the trajectory people start rebuilding their lives and seeing a future, while still caring for their spouses. Although these stages are all part of a continuum, the middle stages, which go on for years and last the longest, are the most distressing.

Even though this model appears to depict the continual readjustment process only as occurring in the middle stages, this is not the case. The difficulties that spouses confront occur throughout the trajectory and can occur at any point. Difficulties also occur in the very early and in the later phases, but generally, at those junctures spouses cope better that in the middle stages. In the early stages, spouses manage stressors with more ease perhaps because they do not yet know what they are dealing with and they do not have the cumulative years of exhaustion that
follows years of caring for a partner. In the later stages, it could be that spouses cope better because they have lived through most of the disease trajectory, have survived and have emerged with a different perspective.

**Theoretical frameworks' integration and the EOD spousal coping model.**

This study arrived at a conceptual model to understand the EOD spousal caregivers underpinned by three different but interrelated frameworks, which were presented in detail in Chapter 2 and included the life course perspective, the stress and coping model by Vitaliano and colleagues (2003), and the temporal model of dementia caregiving. Theoretical models help researchers to focus the questions and provide a framework within which results can be interpreted. These models share a temporal perspective that is so crucial in understanding this population. This temporal component is also part of the grounded theory approach since grounded theorists believe in looking at processes over time (Charmaz, 1990). These theoretical frameworks, in the context of a grounded theory methodology, supported the findings from this study and helped to narrow the complexity of the findings through the development of a substantive theory. How these perspectives contributed to the EOD spousal model are explored below.

The life course perspective positions the findings from this study into a temporal perspective and is depicted in Figure 6.1 as an arrow symbolizing the passage of time. The life course frames the spouses' trajectory and the relevance of transition points as junctures where crises occur. EOD is disruptive to multiple areas of life and it limits age-appropriate activities at all levels (e.g., career, marriage, parenting, driving). The stage in life that these dementias occur in is at the core of understanding the difficulties that EOD spouses go through. The life course
contextualizes EOD as a "nonnormative, biologically based life event that is a developmental challenge with a distinct set of trajectories that are characterized primarily by loss and decrements in adaptive capacity across multiple domains of an individual's life" (Kinney, Kart & Reddecliff, 2011).

The biopsychosocial stress and coping models (Vitaliano et al., 1991, 2003) recognize the dynamic nature of caregiving and the fluidity of coping responses, and are useful in explaining how spouses cope with their experiences over time and its effect on mental and physical health outcomes. Although the EOD model is depicted as linear, the only element that is sequential is the passage of time, from pre-diagnosis until death. The stress and coping model is included in Figure 6.1 and is represented from the initial state of denial, shock and relief, to the cycle of chronic crises and continued adjustments processes and ultimately to the moving on phase. Each phase is characterized by a set of crises that needs to be resolved. Spouses cope with these crises sequentially as they move through the years of caring for their partner. Sometimes, the crises are not sequential since there are multiple crises co-occurring, such as dealing with the loss of employment while at the same time needing to care for an ailing parent who had an acute medical episode and having to deal with a child acting out in school.

The third perspective that informed this study's design was a caregiving model based on stages, which views caregiving as a process changing over time. Interviewing spouses at various phases of the caregiving trajectory was built into the study’s methodology as a result of recognizing that caregiving is an evolving, dynamic process with distinctive burdens at different points. Keady and Nolan's (2003) framework developed for LOD caregiving, was a sensitizing model applied to situate the spousal experience within a temporal, longitudinal model of understanding the changing nature of spousal caregiving. In Figure 6.1, this perspective is
depicted by labeling each stage from pre-diagnostic phase through death. However, these stages are not discrete, but represent a continuum of phases that patients together with their spouses navigate from beginning to end.

Finally, what emerged from the data was the importance of including a fourth theoretical perspective. Crisis theory became part of the model given its relevance. Crisis theory is a temporal construct since by its definition it is time limited (Dass-Brailsford, 2007). The relevance of crisis theory for this study is that even though a crisis is meant to be short-lived, the continued short-lived crises over years of caregiving have a cumulative negative impact.

These four perspectives share the temporal aspects of EOD caregiving and integrate different dimensions such as the transactional nature of stress and coping, the chronic experience of dealing with crises, and their effects on the mental and physical health of spouses over time. The relevance of including these frameworks to the EOD caregiving model is that each theoretical framework offers models of interventions based on their theoretical underpinnings. This knowledge will be adapted to the proposed intervention strategies for EOD spousal caregivers in the next section.

**Relevance of EOD Model**

This model is the culmination of the dissertation’s findings and is presented as a substantive theory, which provides a theoretical interpretation of the experience of EOD spouses over the caregiving journey. This model is intended to serve as a framework, representing and synthesizing a range of experiences and ways of coping. It highlights potential points and types of intervention during transition times. As current setbacks are resolved and new ones appear, different types of support may be required.
This EOD coping model's explanatory power is limited as it only fits the situation being researched in this study. It is restricted to EOD spousal caregivers living in the Greater Toronto Area (GTA) and within up to two hours' driving distance. All of the participants have been followed by a specialist or a memory clinic and have received a diagnosis. The majority of participants were well-educated, with more access to services and supports than those who never come to the attention of the medical system. However, it is reassuring that the findings from this study are overall congruent with the limited research in this area.

In spite of its limitations, the model serves to identify the different facets of EOD spouses' daily life experience, which is necessary before offering services and interventions tailored to their needs. Understanding when to offer what types of support at particular points in time is examined in the next section.

**Implications for Social Work Practice**

This section examines the implications of this study to social work practice. Social work is an applied profession; therefore, it is important to highlight the significance of the study’s findings and translate them into practice. The current state of knowledge on EOD spousal caregiving is mostly based on social workers' clinical experience and not on research. Although studies of EOD caregiving are coming to the forefront, little is known about young dementia spouses who provide most of the care.

This section explores how the findings from this study and the subsequent theoretical model generated from the study's 30 participants, can be applied to intervening with this population. This model offers an integrative depiction of the experiences of EOD spouses through the EOD journey that clinicians can use as a guide to interventions. The model will be
the platform used to articulate various intervention approaches that can be helpful for EOD spouses through the caregiving trajectory. This framework serves as road map for professionals, not only to theorize about areas of intervention, but also to identify which modes of interventions are most appropriate at different transition points.

**Areas of Intervention**

Almost all intervention programs for dementia spousal caregivers that are evidence-based have been aimed at the family care providers of older adults and have employed an individual intervention approach (Lockeridge & Simpson, 2012; Parker, Arskesey, & Harden, 2010). Unlike in LOD caregiving, there is a dearth of research in understanding the needs of the EOD spousal caregiving population, and consequently there is an even greater shortage of adequate services and interventions. The lack of services becomes evident when families and social workers seek appropriate care and supports. Social workers are quickly confronted with system issues (e.g., lack of financial support, few appropriate day programs, non-existent in-home respite programs), which provide no viable solutions to families in distress. It is difficult for social workers to deal with the problems that spouses bring, knowing there is little we can do to find suitable resources.

Knowing how to intervene is as important as knowing when to intervene (Bakker et al., 2013, Diehl-Schmid et al., 2012). How to provide the appropriate kinds of supports at the right time is critical knowledge for social work practice. The next section will focus on intervention strategies (how) based on the findings from this study and by applying the EOD spousal coping model as a framework to identify which points in time (when) are most helpful for interventions. For the sake of clarity, this section is divided into two proposed areas of intervention: macro or
systemic, and micro or clinical level of analyses; these two levels of intervention are not mutually exclusive since changes to one will affect the other. The proposed areas of intervention delineated below are based on three perspectives: what participants suggested would be helpful, my clinical experience and research findings.

**Macro level of intervention.**

The health and well-being of families is strongly related to the public policies that are implemented within a society, known as the social determinants of health (e.g., income and income distribution, employment, food security, housing, and the availability of health and social services; Raphael, 2012). The literature reports that the quality and distribution of the social determinants of health in the United States and Canada lag well behind those seen in other wealthy developed countries such as United Kingdom, Australia, Finland, Norway, and Sweden (Organization for Economic Cooperation and Development (OECD), 2014; Raphael, 2012). This study found that EOD spousal caregivers fall through the cracks of our social safety net, creating crises that could be preventable if better supports had been in place. EOD spouses and their partners need age and stage in life appropriate services, increased care in the home and suitable respite programs that are flexible to the needs of younger families. In addition, they require a responsive medical health system and governmental financial security measures. These systemic interventions first require an increase in public and professional awareness of EOD and its impact on families.
Age appropriate services.

Having adequate age appropriate services was a concern for most spouses, who felt that day programs and LTC facilities did not meet the needs of their physically strong and active spouses. This is a complex area to address, since it is difficult to provide age appropriate care for a relatively small number of people living in geographically diverse areas. However, there are ways to integrate younger people into existent day programs and LTC facilities. For example, The Samuel Lunenfeld Mountainview Club at Baycrest Health Sciences, in Toronto, Ontario, provides the extra staffing and collaboration with the medical system to offer day programming for people with FTD. This service is integrated into their adult day program (Grinberg & Phillips, 2009). For LTC, a similar model could be applied, where a few LTC facilities within each catchment area could have smaller units for people with EOD, where staff would be additionally trained and where there would be a higher ratio of staff to care for the younger, more mobile patients.

Home supports and LTC.

Another concern is the eligibility criteria and hours of respite care in the home. Currently in Ontario, the CCAC only provides hours of care if a patient needs personal care. Many people with EOD do not need assistance with bathing, but they need staff to keep them engaged while providing meaningful activities. Respite in the home, with someone trained to deal with the behavioural and management issues of younger people with dementia, is needed to allow spouses relief. Additionally, as some participants suggested, dinnertime is the most stressful time for families where the well-spouses work and where there are children in the home. Having support in the form of someone that can help with dinner and keep the person with dementia occupied while the well-spouse transitions into arriving home from work would be beneficial. This would
allow the well-parent to interact with the children and address their needs without compromising their well-being and feeling like they have to choose between their children or their partner's welfare.

Flexibility and short turnaround time to request hours of respite care is another important issue. Sometimes, spouses have unscheduled activities or need off-hours care and they have no option but to leave their ill-spouse alone, even when this is not a safe situation. A realistic way to address this concern would be for a well-spouse to have the option to request a professional support worker (PSW) online for a particular day up to 24 hours in advance. To contain costs, the CCAC could allocate a specific amount of hours/week and spouses could utilize the hours as necessary. This would allow for flexibility for these younger families, where the current predetermined schedule for receiving a PSW would not work.

Finally, CCAC could institute a different way to assess the need for in home support and for LTC admission. Their present criteria is based on functional ability and memory, areas that may not be impaired for some EOD patients, yet their judgment and lack of insight puts them at risk. Currently through the CCAC, there is an Acquired Brain Injury (ABI) program, where patients receive many more hours of support and more professional services are included than for the average dementia client. EOD patients could become part of the ABI program and qualify for at least the same level of services.

**Health Care System.**

A major roadblock in the health care system is the lack of information amongst professionals at all levels of practice. Education is crucial and this is particularly important for acute care hospitals, where spouses have reported extremely upsetting situations, particularly in the emergency departments and medical acute care units. In Ontario, some hospitals have
geriatric teams that become involved from the initial point of entry in the emergency department to provide support. Since EOD patients are under 65, EOD patients are not given any form of specialized services, even when spouses clearly tell the triage nurses that their partner has dementia. A simple solution would be to accept patients under 65 with dementia to these specialized teams, which would advocate and alert staff of the patient's needs.

Another area of improvement would be to treat the patient-caregiver dyad as one unit of assessment and treatment, rather than just assessing the patient. When an EOD patient comes for the first time to a specialized memory clinic, a social worker should assess families, to determine if there is need for intervention. In this manner, caregivers could be screened for depression/caregiver stress early on, in a more proactive manner. This would also give the social worker an opportunity to have a baseline assessment of family functioning, which would help to contextualize post-diagnostic adjustment. Other areas that need to be addressed at this initial meeting include financial planning, Power of Attorneys, and assistance related to children and/or parents. Caregivers who are having difficulties could be offered interventions from the beginning to mitigate further problems.

**Government/Insurance programs.**

Young families who are impacted by EOD are at a financial disadvantage. Especially, those who lose their jobs, do not have long-term disability, and/or whose spouses cannot work. In the cancer care community, there are funding bodies that provide emergency subsidies and financial support for families dealing with cancer; however, there is nothing comparable for families dealing with neurological conditions.
In addition, places of employment and private insurance policies/plans could have a clause that if people were fired and a major illness were found to be the cause, these patients would have the right to appeal their termination and qualify for long-term disability. If companies and private insurance cannot do this, the government could provide bridge financial coverage until people turn 65.

Partners of individuals with acquired brain injuries, Huntington's disease, strokes, brain-cancer, multiple sclerosis and HIV have to cope with similar issues as EOD spouses. Perhaps a system of services and supports for neurological-based conditions for people under 65 years of age would be beneficial. There should be a safety net such as financial support other than the Ontario Disability Support Program (ODSP), since many people do not qualify for it. Other forms of financial support could be by providing more hours of home help for those spouses that need to work outside of the home, not charging for day programs and respite services, or at least offering subsidies. In Ontario, there are some free day programs and day hospitals for people with psychiatric conditions and for developmentally delayed individuals, but there are no comparable programs for the neurodegenerative diseases. The funding for these programs can be re-distributed to serve the needs of more individuals by combining people who are in the same life-stage with different neurological conditions. In suggesting this, I am not stating that it is best practice to integrate all these groups of patients, but given the lack of current resources, it may be a good place to start.

Another point to consider is that many countries in Europe already have in place a salary for caregivers as recognition of what they are doing. If this were instituted here, this would have the double benefit of allowing patients to be cared at home for longer, while saving the government money and ensuring a modicum of financial support for families.
Finally, for these areas of intervention to be successful, the first step is to develop knowledge transfer strategies both for professionals and the public about EOD and how it impacts individuals, families and society. It is necessary to create educational interventions for professionals at all levels, including health care, social service agencies and government. This would include curricula development both at the post-secondary level of education and training of professionals at places of employment. In addition, university affiliates and organizations whose purpose is to translate research into practice, such as the National Initiative for the Care of the Elderly, could be enlisted to disseminate information. This has already started to occur through the dissemination of pocket tools. Additionally, knowledge transfer needs to occur at the public level. This could be organized through the Alzheimer Society of Canada since they are best positioned to educate the public about dementia.

**Micro level of intervention.**

Systemic and structural changes occur slowly; however, clinical interventions can be implemented from the initial time a social worker sees an EOD caregiver and can be beneficial without causing a financial burden to the system. More importantly, clinical interventions are important approaches to increase caregivers’ quality of life regardless of current systemic deficiencies. This section of the chapter will explore clinical areas of intervention from a social work practice perspective.

Prior to exploring how to intervene, it is important to ascertain when those points of intervention can be most effective. Based on the EOD spousal coping model, caregiving has a trajectory and through the various phases, it is possible to anticipate when crises are more likely to occur. The transition times, when spouses encounter changes which lead to crises (e.g., time of
diagnosis, when someone loses their driver's license, placement), are critical points of intervention. Crisis theory stipulates that during a crisis, the individual tends to be less defensive and more open to suggestions, influence and support (Slaikeu, 1990) and that all crises require immediate intervention to interrupt the negative reactions to the crisis and help affected individuals return to pre-crisis functioning (Dass-Brailsford, 2007; James & Gilliland, 2005).

Teaching families, which are the points of transitions that can potentially lead to crises, is knowledge that spouses can employ to be proactive. For example, when a spouse knows that he or she needs to downsize, educating him or her about financial matters before problems become worse would be helpful. Explaining to families that all EOD spouses go through this continuous set of crises can minimize the crisis’ impact by knowing that this is a common experience. Even though they may not be able to prevent the crisis, they can be better prepared. Normalizing the experience, where spouses are taught to expect changes and ways to cope with them, can give people a sense of control and may minimize the impact of the crisis by obtaining the right kind of help at the right time.

In regards to which types of interventions are effective, there is some evidence that psychotherapeutic and case management interventions are effective in reducing caregiver symptoms in LOD (Nunnemann et al., 2012) but there is not much evidence in regards to EOD caregivers. There are a minimal number of EOD intervention studies; these include psychoeducational support groups (Banks et al., 2006; Deihl, et al., 2003; Marziali & Climans, 2009; Reah et al., 2008), and respite care in combination with caregiver education and support (Grinberg et al., 2007; Ikeda et al., 1996). Interestingly, out of the six international studies in this area, two are Canadian and were carried out at Baycrest Health Sciences (Grinberg et al., 2007; Marziali & Climans, 2009).
Findings from this study point to a need for interventions that help spouses with their sense of isolation, depression, feelings of being misunderstood and feelings of not being in control. The literature demonstrates groups to be an effective way to intervene, and this was corroborated through the findings in this study. Spouses who have participated in the online group sessions have found them to be invaluable since they were easily accessible, built community and were educational and supportive. It is a testament to the strength of this intervention that three years after the groups formally terminated, spouses continue to meet online via Skype. There is a need for this type of group to exist across the country through the Alzheimer's Societies, the Association of Frontotemporal Dementias and memory clinics. This is a cost effective medium to provide psychotherapeutic support, it is efficacious and meets spouses' needs.

The following section includes proposed forms of interventions, which have not been studied with the EOD population but which make sense, given this study’s findings and my clinical experience. The first modes of intervention are leisure activities groups. There is evidence in the LOD literature of the effectiveness of leisure-based groups whose sole purpose is recreational, and group modality allows for interaction with others in similar situations. Since EOD spouses have few opportunities to do pleasurable activities, this could be a helpful intervention. Although psychotherapeutic groups have their place, not everyone wants to discuss their problems in a formal setting. These activity based 'fun groups' could include walking clubs, bowling leagues, going to movies and doing recreational and interactive pastimes that are 'normal' for this group of people. Research findings indicate that leisure groups are supportive and are effective with caregivers of LOD patients (Bedini & Phoenix, 1999; Grosvenor, n.d.).
Telephone support is another form of intervention, since this group of spouses has minimal time to attend office appointments. There is a growing body of literature about the effectiveness of over the phone psychotherapy (Mozer, Franklin, & Rose, 2008). Additionally, there is evidence about the effectiveness of a care consultation intervention model, which is telephone-based, that helps caregivers by providing information about available resources and providing emotional support (Bass, n.d.). It has also been my clinical experience that spouses find telephone interventions beneficial. Although providing psychosocial support over the phone is not without its limitations (Hass, Benedict, & Kobos, 1996), for this population it may be a viable approach. Spouses find that having a contact person to call with questions/problems, to be a good form of intervention.

Other forms of intervention include building capacity, in particular in areas found to be problematic for spouses. First, given that spouses are very isolated and have a need to have a supportive network, teaching people how to develop these networks is important. Drentea, Clay, Roth and Mittelman (2006) developed an effective intervention model that helped Alzheimer’s spousal caregivers mobilize their social support network. Although this intervention model was effective with LOD spouses, it may be likely that it would have similar results with younger spouses. Furthermore, involving the family of origin at the point of diagnosis would be beneficial, since the loss of family support at this crucial time seems to be so pervasive. If families are included from the beginning and they have an opportunity to learn about the dementia and its effect on their family, they may be more likely to be involved from the earlier stages. The same applies to family friends, who could join family meetings and could participate in the network of support. A second area of capacity building is through social workers educating EOD spouses on the importance of financial planning, Power of Attorneys and where to obtain
information and support related to financial concerns. Third, as suggested by one of the participants, social work could help spouses compile a list of activities that spouses find meaningful, give them pleasure and remind them of the importance of self-care. This would help people expand their self-care repertoires and realize that there are options that are not time consuming and can be useful. The type of counselling which helps people how to best use their free time is called leisure counselling (Leitner & Leitner, 2005) and this type of psychoeducational intervention could be effective with EOD spouses.

Spouses wanted to preserve a sense of couplehood through the disease. One way to assist families with this would be by helping them create a repertoire of ‘together activities’, much like the list of self-care activities. I have found through my practice that asking couples what they enjoyed doing in the past, can be adapted as the illness progresses. One couple continues to hike outdoors, but the wife now keeps the hikes shorter, closer to home and stays by her husband at all times. As well, going to fitness centres could encourage both spouses to exercise as a couple. An activity such as indoor cycling is ideal since it does not require skill; each partner can work side by side at their own level without worrying that the ill-partner could lose their balance or get lost. By encouraging couples to exercise together, they could share a meaningful activity while keeping up their fitness’ level.

Although providing psychotherapeutic support groups for spouses of people with FTD and AD separately is preferable since FTD spouses have the extra burden of coping with disinhibited behaviours, it may be helpful to combine spouses of people with AD and FTD given the dearth of services. Anecdotally, Donna Margles, social worker at Baycrest Health Sciences Centre, conducted such a group, after having facilitated similar online support groups for FTD spouses only. She combined FTD and AD spouses for one of her groups at my request since I
was not able to find any resources for spouses dealing with early-onset AD and at that time, she did not have sufficient FTD participants to start the online group. I had seen that this mix of spouses has been successful through the FTD self-help group. Ultimately, Donna Margles found that combining both groups was not as effective as having only FTD spouses since dealing with the behavioural consequences of FTD was more problematic than AD. Nonetheless, when I spoke to one of the group members, whose wife had AD and had participated in this online group, he found the experience helpful. He agreed that there were difference based on the personality and behavioural changes of FTD; however, this online intervention was useful since there were still many commonalities related to life-stage issues. Support groups based on stage of life may be beneficial regardless of type of dementia when the alternative is not having sufficient participants or resources to run a group.

When to intervene.

Based on the EOD model of spousal caregiving, at what point a spouse is located in the trajectory matters. In the early phases, when someone is not ready to hear that his or her partner has a dementia, certain interventions are unlikely to be effective. I cannot offer a day program and counselling to a spouse that does not believe there is a problem, even when the medical team feels otherwise. What would be helpful at this point is to meet for a baseline assessment and establish rapport, so that when there is a crisis, the well-spouse knows who to call. It would also be appropriate to offer one-on-one supportive counselling at this stage, if the well-spouse felt ready. For those spouses that have been suspecting there were problems for a long time and are relieved to find out the cause of problems, this is a good opportunity to offer one-on-one
counselling. At this initial point, there is an opportunity to process the difficulties they have encountered and offers an opportunity for education and counselling.

Other times of transitions points, which are important times for social work intervention are the loss of a job, loss of driving privileges, or Children's Aid involvement. Interventions before problems become crises are crucial points to intervene to mitigate the crises' impact. Educating spouses that they can call for help available in their community, when they are worried, anxious or there are changes is important. Ideally, every EOD spousal caregiver should have a person from a health care team or Alzheimer's Society who is a point of contact. A health care professional early on in the disease process should identify this resource person. This would be someone that spouses can call for emotional support and education and to help advocate on their behalves.

Another crisis that necessitates intervention is the pre-admission and admission process to LTC. Spouses find this to be extremely difficult for several reasons. First, it is a separation of the couple as they know it and although they may be ready for it, it is painful nonetheless. Second, spouses are usually in shock at the age of other residents and worry how their partner would fit in. Third, from a financial perspective, LTC is expensive and to afford it most spouses need to downsize. This is an important time to discuss financial planning and priorities for the well-spouse in terms of how they will allocate their funds. Fourth, spouses need to learn to trust the nursing staff in caring for their partner and they need to walk the fine line between advocacy and forming alliances with the LTC staff. Fifth, it is common for spouses to feel guilt and believe that others are judging them for placing their partner. Finally, this is a time when spouses have more personal-time and after years of caregiving, it is common for the well-spouse to feel lost and unable to find new routines.
Intervention overview.

The findings from this study point to two major areas of social work intervention. The first one is at the macro level, or the structural systemic barriers that need to be broken down through education and advocacy to avoid people falling through the social safety net. The second one is in the clinical arena since there are very few current interventions for the younger sub-set that are evidence-based. In addition, knowing when it is an effective time to step in is as important as knowing how and what types of interventions are most effective for this group of caregivers. Finally, although clinical interventions are necessary, as Chemali and colleagues (2012) eloquently stated, "the interventions to date are not sufficient to tackle the problem when there is a lack of resources and absence of policy targeting the rights and needs of a younger population" (p 85). This quote sums up the current state of affairs for EOD spousal caregivers and for those of us who work with them.

Chapter Summary

As a theory empirically grounded in the data, the substantive theory generated in this research attempts to understand the experience of EOD spousal caregivers and was depicted in Figure 6.1. This model demonstrates the complexities of caregiving at a time in life that is not expected, when spouses have multiple roles to fulfill and are at the peak of their productivity. The conceptual model shows that caregiving changes over time and as the disease progresses, so do the caregiving experiences. It also illustrates how in spite of the constant crises that occur, spouses manage to survive and continue to adapt to their new circumstances. It also shows that over time, people move on with their lives and there is an end to the caregiving trajectory.
The model's relevance is not only in understanding this group of caregivers, but in providing types and points of intervention. Interventional approaches were proposed at a community and policy level and from a clinical perspective. Nevertheless, no amount of clinical interventions will change the reality that with a lack of appropriate resources, EOD spouses will continue to fall through the cracks.
Chapter 8

Conclusion

This study set out to understand the experiences of EOD spousal caregivers over the dementia trajectory spanning years of caregiving. I have been working with this population for 23 years and the dearth of theoretical literature on this subject, lack of knowledge, resources and interventions led to this research. This chapter presents a synthesis of the study’s findings and then links these findings to the implications for and contributions to social work practice. Finally, the study's limitations are considered.

Overview of Findings

The purpose of this overview is to integrate all of the findings into a cohesive synthesis of the experience of EOD spousal caregivers. The following findings describe the essence of this dissertation based on analyzing the data through the lenses of spouses' experiences imbued with my perspectives as per the constructivist grounded theory approach that informed this study. The findings are presented in two sections and include the EOD experience and coping strategies. This is followed by a synthesis of the study’s results, which become the foundation for the EOD spousal caregiving coping model.

Major themes - the EOD experience.

Life-stage.

The onset of dementia during middle adulthood has a deleterious impact on spouses' lives since participants are in an active and productive stage of life, have multiplicities of roles to fulfill and many still have dependent children. Changes in employment, none of them by choice,
have disastrous financial consequences. Intimacy between spouses is generally non-existent and the marital dynamic changes significantly. Loneliness is a pervasive feeling.

**Disease invisibility.**

People feel that their spouses’ dementias are invisible to the outside world, including the medical community. Their spouses look "normal" and dementia is seldom suspected, which leads to delayed diagnoses and creates severe stress for families. Well-spouses feel invisible and misunderstood too since their own families, friends and health care professionals do not acknowledge the difficulties they experience such as depression and stress.

**Continued uncertainty.**

The unpredictability of these dementias brings on anxiety associated with an inability to plan or predict which area of life will be affected next. Spouses have ambiguous feelings toward their partners. They resent having to take on a caregiving role so early in life, yet there is a sense of love and commitment that keeps them going.

**Falling through the cracks.**

Services are minimal or non-existent for either the well- or the ill-spouse. Systems such as pension/disability/income support plans, health care systems and other social and support services are inadequate to serve this younger group of dementia patients. For example, when people are under 65 years of age they do not qualify for most programs; those few programs that do exist are not suitable. This group experiences a triple financial crisis: patients' loss of income,
patients' inability to qualify for financial programs and spouses' cutting back/quitting their job to be a caregiver.

**Surviving chronic crisis.**

Surviving the continuous crises that spouses experience emerged as the main theme. The difficulties start early on, with initial symptoms that are unexplainable. At some point, spouses become aware of EOD difficulties and for subsequent years it is the job of the well-spouse to keep managing the daily challenges. These ongoing challenges are perceived as crises since peoples’ resources become exhausted and caregivers become worn down. In the later stages of the disease, spouses learn to manage these crises with more ease; that is, they adapt. By this phase, spouses have extensive experience with EOD, their depression is lifted and they reach out to their social networks, making this last stage somewhat easier.

**Coping.**

Overall, there were four major ways people coped. They included being a good advocate, reframing the way the disease was experienced, using self-care strategies, which was more evident as the disease progressed and finally, participants found support through spirituality and religion. Spouses that had good social networks fared better. Every participant tried to create a network of people and found that during difficult times other EOD caregivers were their strongest allies. There were a minimum amount of formal supports available to this group and the two most helpful ones included the FTD online support group and the FTD self-help group, which became people’s lifelines. The dearth of suitable formal supports made coping with EOD difficult; however, for those few individuals that actually received appropriate supports (e.g.,
high-quality day programs, positive experiences in LTC, good support groups and availability of counselling) these services were found to be extremely helpful.

**Substantive Theory: The EOD Spousal Caregiving Model**

EOD spousal caregiving can be interpreted as a trajectory that changes over time as the dementias progress. This journey is not experienced as linear and most importantly, the feelings associated with different phases (such as the earlier phases where denial, shock, relief, anger, anxiety, fear and depression) fluctuate. The dementia path is uneven and it is characterized by transition points that challenge spouses into having to survive continuous changes due to the impact of EOD. These changes are never welcome since they represent losses such as loss of employment, loss of a partner, financial losses and loss of social contacts. With each loss, there is a need to readjust to a new reality so that life can have some semblance of normalcy. Spouses attempt to maintain control over each new development and they are able to do this temporarily, until new crises occur. The phases of dealing with constant crises last for many years and the chronicity of dealing with ongoing problems creates a sense of living under continual stress. In the later stages, whether this means institutionalization, more care in the home or even after death of the partner, spouses regain a new sense of self and can move on to start thinking about a future.

**Synthesis of Results**

Results were classified as stemming from either a systemic (macro) or an individual/family (micro) perspective. From a systems' perspective, there is limited availability and accessibility of flexible, appropriate resources for care in the home, day programs, respite
services, counselling, LTC and minimal safety net provisions for families that encounter financial problems because of EOD. Moreover, since we do not have a National Dementia Strategy in place, it does not appear that this is likely to change in the near future.

EOD spousal caregiving has its own trajectory that changes over time as new challenges/crises occur. The trajectory is affected by a caregiver’s age, stage in life, gender, type of EOD and quality of social supports and resources. Transition points are the times when crises are most likely to occur since they are marked by new losses. Spousal depression was the most common negative mental health outcome, yet over time, the depression improved due to intervention strategies such as medication and counselling. Some coping techniques were more commonly used than others, but no one strategy was maladaptive in its own right. There were multiple coping tactics used and different individuals found each of them helpful at different points of the disease trajectory. There did not appear to be ‘effective’ versus ‘non-effective’ strategies, since individuals coped the best they could, given the circumstances and their own resources. In addition, spouses utilized different strategies at different points of the disease progression. Over time, spouses’ coping strategies became more adaptive and this could have been as a result of the ‘trial and error’ effect of managing the illness for many years, combined with the treatment of their depression. Feelings of love and/or having a sense of commitment allowed participants to persevere even when their spouses were no longer their partners.

**Study's Contribution to the EOD Caregiving Body of Knowledge**

Overall, the findings from the study corroborated much of the information available on studies about the EOD spousal population from both a systemic perspective (e.g., government,
community, health care, services and supports) and from the individual experiences of family caregivers; this is encouraging since this area of study is in its infancy.

First, there were some unique findings in this study through the examination of the caregiving journey as a process that changes over time, instead of looking at it as an experience at one point in time. Although this was a cross-sectional study, it attempted to explore various stages by interviewing spouses at various phases of caregiving.

To my knowledge, the finding that in the late stage, well-spouses start to cope and feel better has not been reported in the EOD literature, which previously stated that there is a linear positive relationship between years of caregiving and caregiver burden (Svanberg, Spector, & Stott, 2011; Williams et al., 2001). Perhaps, it is more of a curvilinear association, where caregiver burden peaks in the middle stage and finally, in the late stage, improves. This suggests that earlier intervention could change this curve.

Another contribution to the literature is the sex differences in the EOD caregiving journey. In the early stages, men caregivers seemed to have a more difficult time realizing and accepting that their wives had a dementia. Additionally, there were differences in that men looked after their wives at home for longer into the disease process and they seemed to have less guilt about the way they provided care and were more hopeful about the future. Perhaps the reason they appeared to experienced less caregiver burden was because they did not seem to have the same degree of financial difficulties, were physically stronger and felt they would have good jobs/careers after their spouse died. Although there have been gender differences reported in the EOD caregiving literature related to caregiver burden (Takano & Arai, 2005), there were methodological concerns with their study since they carried out a quantitative analysis based on only 24 participants.
This study also looked at contrasts between FTD and AD in terms of spousal perception of difficult behaviours in relation to the progression of the EOD caregiving stages. The differences that initially appeared to be problematic in the early-moderate stages of FTD (e.g., personality changes, disinhibition) were no longer a problem in the middle-late stages. In the moderate-late stages of FTD and AD, the behavioural difficulties were experienced by the well-spouses to be similar.

This study offers a Canadian perspective. Although most of the EOD research comes from Europe (mostly the United Kingdom), Australia, and the United States, spouses are essentially dealing with comparable concerns across countries. However, given that systemic/policy issues such as health care and financial safety nets are country specific, it is important to have a Canadian point of view. This study found that the lack of appropriate services results in people falling through the cracks of all systems, bringing about crises that could have been avoided if appropriate services were in place. It points out that there is much work to be done at all levels of intervention including initiatives at the clinical, community and societal levels.

Another contribution from this study is that it did not stop after the themes emergent from the data were analyzed, as most of the qualitative research in this area has done, but it continued to further interpret the data to produce a substantive theory about the experiences of EOD spouses. Even though this model is not predictive of other populations, it can be utilized as a guide to understand other similar populations such as spouses of people with related neurodegenerative conditions.

Finally, this investigation provided an extensive list of potential interventions at various levels of practice, which are based on the study's findings, my clinical experience and the
caregiving intervention literature. Best practices will only emerge when health care professionals collaborate with the people affected by these diseases and listen to them. Patients and their families are the experts in what is happening to them and what kinds of support they would find helpful. Their input is crucial for formulating interventions to address their needs at different points of the disease trajectory.

**Study’s relevance to my advancement of knowledge and practice.**

This study has confirmed most of the clinical knowledge I had about working with this population such as the difficulties in dealing with disinhibited behaviours, in addition to aggression and resistive to care behaviours. The findings associated to the multiple stressors of this particular stage of life were not surprising, nor where the findings that EOD caregivers fall through the cracks of most systems. However, in spite of my extensive experience with this group of caregivers, I discovered some surprising results.

First, I was distressed to find out the high proportion of families with children in the home, who had Children Aid’s involvement. Although all the referrals were appropriate, I did not realize the extent of stress that their involvement provoked given that their role was meant to provide support to the well-parent and the children. This has prompted me to explore not only child safety and previous Children Aid’s involvement in more depth with my clients, but also to refer to children’s mental health centres and the schools’ guidance counselling departments for children and family support.

Second, an unanticipated finding was the sex differences related to participants’ perception that the medical system favours men, and the observation that husbands receive more hours of care from the CCAC. The finding that men caregivers had an “advantage” over women
caregivers was something I had never considered. Furthermore, the fact that men seem to be much slower to realize that their wives have medical problems affecting their function was a new revelation to me.

Third, I was surprised to see an ‘underground’ group of spouses of people with EOD. I was impressed by the strength of the relationships that spouses of people with EOD had forged among themselves. Some of these relationships started through the online FTD group from Baycrest Health Sciences. Hearing participants discuss what this group meant to them was powerful since it made me realize that health care professionals can have a strong positive impact through appropriate interventions. Caregivers described group members to be their communities, and their sense of belonging helped counteract the alienation that they had been experiencing. This connectedness was also seen through the support network that members of the self-help group had formed. Since realizing the power of this group, I have been referring EOD spouses to this self-help group when the online support group is not available.

Finally, an unexpected finding was the amount of love and commitment these spouses had toward their ill-partner. In my everyday clinical experience I hear so much anger, resentment and pain, that I never truly understood the love, commitment, sense of responsibility or obligation that well-spouses experienced. Even when the circumstances were disastrous, spouses seem to feel a strong bond with their ill-spouse.

Implications for Social Work Practice, Education and Research

One of the aims of this dissertation was to focus attention on the spouses of people who develop a dementia under 65 years of age and to be a catalyst for research in this area. Without a clear understanding of the problems and circumstances that affect caregivers differentially, the
development and delivery of supportive interventions is difficult and ineffective. By understanding the variables that influence caregivers’ experiences, appropriate interventions prescribed at the right time can be developed. Much of the current thinking on interventions with spouses who are dementia caregivers has been based on models of stress and coping. The circumstances that affect caregiver outcomes also needs to be understood within a temporal context, because the nature of dementia caregiving changes over time and is affected by different contexts. If we recognize these contextual and temporal variables as affecting the EOD caregiving experience, then the way services are provided can adopt a longitudinal approach. Supportive services have to be available at particular stages of the dementia progression and at various points in the caregiving trajectory. As well, given that this population is under 65, more community organizations need to become involved in the provision of services. For example, places of employment for both the patient and the spouse need to be included, along with the school system and various respite programs, together with financial support systems, to name a few.

Social workers practice from a systemic perspective, where the unique situations of peoples’ lives are crucial in understanding their experience. Therefore, social workers need to focus on multipronged interventional approaches, which are systematic, integrated and multidisciplinary to offer appropriate interventions. Chapter 6 presented numerous proposed initiatives, both at the macro and micro levels. To ensure that these interventions can be developed and implemented, the first step is to advocate and disseminate information about EOD at all levels, both professional and public. This education encompasses governmental, financial, legal and health care systems as well as community services. A strong component of this
education includes making the link that EOD is a neurological disorder that affects not just older adults, but younger people who require specialized services and financial support.

From the findings, this study raises some questions about the direction of future research. Should people with EOD be differentiated by age or diagnosis? There are differences between the young-young EOD spouses and the older-young EOD spouses and therefore, it may be pertinent to distinguish between these two groups. In terms of diagnosis, there are differences between AD and FTD and focusing on the differences may lead to more adequate forms of support. However, considering the current absence of social provisions and interventions in general, such a focus may detract from the more important goal of the overall development of services and interventions.

EOD and spousal caregiving is a new, emerging area of research and thus, interventional studies are almost non-existent. An important area of future research is to study the efficacy of the proposed interventions explored in Chapter 7. The value of the proposed interventions is that they are based on spouses' needs, not only what health care professionals think would work, which has been the modus operandi up to this point. The dementia caregiving literature has found that multi-interventional approaches are most effective; therefore, another strength of these suggested interventions is the proposal of multiple approaches that can be applied at the same time (e.g., improvement of service delivery models, while providing psychotherapeutic groups and having available telephone support).

Another area that needs further understanding is looking at EOD from an intergenerational perspective, given the impact of EOD on entire families. The inclusion of children, adult children, siblings and parents in conjunction to spouses would provide a fuller understanding of how EOD affects the entire family system. This is an area that has not been
explored, with the exception of one very small study just published in March, 2014, which included only two families; one case had the perspective of a daughter, and the other the perspective of a brother and an uncle (Roach et al., 2014).

Finally, the newest area of caregiving research in LOD has focused on the increased risk of spouses developing a dementia. As it was explored in Chapter 2, Norton and colleagues (2010) have been spearheading this area of study. Vitaliano (2010) suggested that perhaps it was the length of exposure to the dementing partner that seemed to have such a deleterious outcome. If this is the case, are EOD caregivers, who have a longer duration of caregiving than LOD caregivers do, at higher risk of developing dementia? Would we see these findings in the younger population even though younger people have a lesser risk of developing dementia?

As the early, exploratory studies on EOD caregiving continue to emerge, the next step includes conducting more robust and larger scale evaluations (e.g., interventional randomized controlled trials with a large number of participants) to consolidate some of the elements of good practice suggested in Chapter 7. In order to accomplish this, more education, awareness and funding are needed to evaluate potentially effective interventions intended to reduce negative health outcomes of spousal caregivers and their families.

The ultimate objective for social workers in dementia care is to help people navigate the turbulent waters of living with dementia. To accomplish this, it is important to know what caregivers need and when they need services and this is not an easy task. In the end, the goal of the model presented in this dissertation is to predict what services and interventions work best with what types of caregivers given a specific EOD diagnosis at particular stages of the disease.
What Next? Dissemination Strategies

There are several findings from this study that I will implement at the completion of this dissertation. The first one is to discuss the findings within the Sam and Ida Ross Memory Clinic at Baycrest Health Sciences in order to obtain support for creating a new model of care for this population that includes social work assessment at the time of initial visit for all EOD patients and their families. The second step would be to share the information with the other four memory clinics in Toronto: Sunnybrook Health Sciences Centre, St. Michael’s Hospital, University Health Network and the Centre for Addiction and Mental Health. Third, I would offer to speak to EOD caregivers through presentations at the Alzheimer’s Society and the FTD/Early-Onset Dementia Self-Help group to share the study’s findings and how they may be applicable to their lives. Fourth, I will forward an information sheet with main findings to all study participants so that they can benefit from the body of knowledge they helped create. Fifth, I will present the findings at conferences related to dementia care. I have already agreed to speak at the Ontario Association of Social Workers at their annual conference in November 2014 and will continue to explore other venues to disseminate the study's findings. Finally, I will publish a series of papers drawn from this study’s finding to impart the information to a wider audience.

Limitations

This investigation utilized a convenience sample recruited through existent services such as a self-help group and a memory clinic, as well as by word-of-mouth. Therefore, this group of participants already had a support network as this is how they heard about participation in this study. Moreover, those spouses who were in severe distress at the time this study was advertised would not have contacted me since they would have been too overwhelmed at that time. Data
from spouses during a crisis would have added dimension and richness to the developing categories and the understanding of how these spouses cope with EOD during the more stressful times. In addition, other sub-groups of participants, (e.g., newer immigrants, spouses that had separated at any point during the disease trajectory) would have added more depth to the discussion since the stresses related to immigrating and marital separation would have affected their experiences in coping with EOD.

The other types of limitations were related to the application of the grounded theory approach. First, despite the effort of following the analytic grounded theory processes, modifications and different interpretations were inevitable. One of the reasons for not following the strategies in a uniform manner is that grounded theory has been fraught with numerous misunderstanding given the competing versions that exist. The lack of clear strategies, may mean that the analytic process was not conducted in a way that maximized the data's richness. Second, every effort was taken to follow the theoretical sampling guidelines; however, the sampling process was limited by the availability of potential participants. This contributed to the length of recruitment time, where it took nine months to interview 30 participants. In an ideal world, if time were not a constraint, the theoretical sampling process would have been more rigorous in that I would have scrutinized participants more carefully. Although the theoretical sampling method was applied to recruit participants, it is important to note that as this population of spouses is limited, the actual sampling process was limited by the availability of eligible and interested potential participants.
Conclusion

This study applied a grounded theory approach to explore how spousal caregivers experience having a partner with EOD through the disease trajectory. Although grounded theory does not intend to generalize its findings to the experience of all EOD spousal caregivers, it is clear from the narratives presented that spouses of people with EOD experience unique challenges attributable to their life-stage, to their invisibility and to the continued anxiety given the multiple uncertainties and unpredictability of events. Our systems and policies do not help this group of spouses since they are not set up to support younger people with dementia. Therefore, ill- and well-spouses fall through the cracks of social safety nets, which exacerbate their difficulties and perpetuate the chronic sense of crises they experience.

The essence of this study is summarized in the dissertation's title, "When Least Expected: Stories of Love, Commitment, Loss and Survival – The Experience and Coping Strategies of Spouses of People with an Early-onset Dementia". The first part of the title, "when least expected", refers to the ill-timing of the dementia, which is one of the most important issues for this group of caregivers and what separates their unique experiences from LOD caregivers. It addresses the temporal context of this study by introducing the perspective of time as a common thread. Time takes different dimensions in this study: the length of the disease trajectory, the time-limited yet chronic sense of crises over a long period, the lack of time for self and others, and the unexpectedness of dementia at this stage in life. The second part of the title, "stories of love, commitment and loss", also represents core issues. In spite of all the anger, anxiety, depression and loss the well-spouses face, there is an underlying theme of love and compassion for their partners, allowing them to persevere. Finally, coping with loss becomes this group's
narrative and in spite of the constant erosion to what they hold dear, their will to survive defines this resilient group of spouses.
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Appendices

Appendix A

Research Study: Living with Early-Onset Dementia:

The Experience of Spousal Caregivers

WHO: Spouses/ partners of people with an early-onset dementia (either early-onset Alzheimer’s disease or Frontotemporal dementia).

PURPOSE: To learn more from the experience of being a spousal caregiver of someone with early-onset Alzheimer’s disease or FTD.

WHAT: If you decide to join in this study, you will be asked to participate in one in-depth interview to discuss what it has been like to live with a spouse with an early-onset dementia like FTD. The interview will last no more than two hours.

BENEFITS: This study may benefit you and others in the future by learning more about the needs of people in your situation and advocating for better services.

WHERE: Interview will be done in your home, at Baycrest Centre or could be done on-line or over the phone.

Spouses who take part in this study will get $20 to thank them for their time and will also be reimbursed for travel expenses/parking.

CONTACT: Principal Investigator: Adriana Shnall, MSW, RSW, PhD Candidate (University of Toronto) Factor-Inwentash Faculty of Social Work Social Worker, Sam and Ida Ross Memory Clinic at Baycrest 416-785-2500, ext. 2307 or ashnall@baycrest.org
APPENDIX B

Participant

INFORMED CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Living with Early-Onset Dementia: The Experience of Spousal Caregivers

Principal Investigator: Adriana Shnall, MSW, RSW
PhD candidate, Factor-Inwentash Faculty of Social Work
University of Toronto
Social Worker, Sam and Ida Ross Memory Clinic, Baycrest
416-785-2500, ext. 2307
adriana.shnall@utoronto.ca

Thesis Supervisor: Dr. Lynn McDonald, Ph.D.
Factor-Inwentash Faculty of Social Work
416-978-5714
lynn.mcdonald@utoronto.ca

Informed Consent Process:
You are being invited to take part in a research study. Before you agree to participate in this study, it is important that you read and understand why this study is being done, what will take place and the benefits and risks associated with participation. I will discuss your rights to decide not to participate or stop at any time during the study. I will guide you through the process of informed consent by explaining the purpose of the study to you and ensuring that you understand what is being asked of you. Please ask me to explain any words you do not understand and I will make sure that all of your questions have been answered to your satisfaction before you sign this document.

Study Purpose:
The purpose of this study is to explore the experiences of spouses and partners of people with an early-onset dementia. The question I am interested in is how do you cope and manage with the daily problems of looking after a spouse with a dementia that develops at an early age. To obtain this information, I will first ask you some background information. I will then ask you some general questions about your experience in looking after your partner as well as some more detailed information about the stressors and supports you have experienced.

How do you become a participant?
For this study I am contacting spouses/partners of people who develop an early-onset dementia (either frontotemporal dementia or early-onset Alzheimer’s disease). If you agree to participate, I will discuss with you what your participation involves. This will give you the chance to ask questions or concerns that you may have regarding your participation in this study.
Nature of your involvement
If you agree to participate in this study, you will be interviewed by me, about your experiences in being the spouse and caregiver of someone with an early-onset dementia. This will include general questions and demographic questions as well as an opportunity to tell your story about what it is like to have your partner develop a dementia at an early age. This interview will take no longer than two hours. Ideally, it will be done face-to-face and I will either meet with you at Baycrest or wherever is most convenient to you. As well, there is the option to video-conference through a secure website. If none of these options are available, we will have a telephone interview. There will be no cost to you associated with this interview. I will take notes, as well as digitally record our interview for the purpose of transcribing it. All questionnaire and digitally recorded materials will be held in strict confidence with your personal information removed.

Participants’ rights & withdrawal
Your participation in this study is strictly voluntary. You can choose not to take part or you may stop the interview at any time without affecting your care. Your care at Baycrest or any other health care institution will not be impacted by your choice to participate or not. If you experience any negative symptoms at any time during the interview I will stop the interview and provide support or seek appropriate help as needed.

What are the benefits of participation?
Spouses of people with an early-onset dementia feel that there are not sufficient or adequate services and supports geared to their needs. This study will give you an opportunity to provide your insight into what it is like to be a partner of someone with an early-onset dementia and voice your opinion about what you would find helpful and how you feel your situation can be supported by professionals. The results of this study will help in advocating for more appropriate caregiver and patient supports through health and community services.

What are the risks from participating in this study?
It is my expectation that there should be no risks from participating in this study. However, due to the emotional nature of the information discussed during the interview, your feelings may intensify. If this happens, I will stop the interview and refer you to an appropriate counseling service.

Confidentiality
Every effort will be made to maintain your confidentiality during the study. For the purpose of this study, you will be identified with a study number only. No names or identifying information will be used. The recorded interviews can only be accessed by this researcher. Your name will not appear on the transcribed data which will be stored on a secure server by the principal investigator. All recorded information will be deleted after completion of this study (approximately 1 year).

If you have any questions about this study, please call the Principal Investigator, Adriana Shnall at 416-785-2500, ext. 2307 or thesis supervisor, Dr. Lynn MacDonald at 416-978-5714. If you
wish to contact someone not connected with this project, please call Dr. Ron Heslegrave Chair of the Research Ethics Board at Baycrest, 416-785-2500, ext. 2440.

**Participant Consent Form**

*Living with Early-Onset Dementia: The Experience of Spousal Caregivers*

By signing this form I confirm that this study has been explained to me and I have been given the opportunity to ask questions about participating and the questions have been answered to my satisfaction. I may continue to ask questions about the study at any time.

I understand and agree that a digital recording will be made of the interview and that a transcription of the interview will be prepared.

I have been informed of all the potential risks and benefits associated with this study.

I understand that all information will be kept confidential and that I will not be able to be identified in any publication or presentation of the results.

I understand that my participation in this study is entirely voluntary and that I am free to refuse to answer any questions or to stop the interview at any time and that this will not affect any current or future services that I, my spouse or any member of my family may receive.

My signature below means that I have been given a copy of the information and consent form and that I agree to participate in this study.

Participant Name_______________________ Date______
Participant Signature___________________ Date______
Person Obtaining Consent_______________ Date______
Person Obtaining Consent Signature_______ Date______
APPENDIX C
Patient Demographics Information
(to be administered by P.I.)

Circle those that apply

Spouse’s diagnosis: Frontotemporal dementia  Early-onset Alzheimer’s disease

When was your spouse diagnosed with an early-onset dementia:

Your spouse’s age:  Your age:

Your spouse’s gender: M  F  
Your Gender: M  F

Relationship status: married  common-law

Is this a first marriage? If not how long have you been together?

Living arrangement:

• Live alone
• Live with others (check as many as apply): Spouse
  Child(ren)  Ages:
  Parents/in-laws
  Others (please specify):

• If you do not live with your spouse, where is he/she?

Highest education level:
Elementary school  high school  trade/technical/community college
university postgraduate degree/studies

Employment status: (check as many as apply)

Working full-time  working part-time  self-employed  on contract/seasonal

on sick leave  unemployed  full time caregiver at home
Country of birth:

Canada Other___________

Primary language spoke at home:

English Other: _______________

Health care providers who are involved in your spouse’s care (check all that apply):

Family physician  neurologist  psychiatrist  geriatrician  
Memory Clinic, please specify:
RN  SWK  PSW  PT/OT  
other, please specify: ____________

Have you used or are you currently using any of these services:

CCAC  day program  community centre  private companion  
Alzheimer’s Society  long term care facility  
support group (please specify):  other (please specify):  

Have you found these services helpful?

Current Basic Activities of Daily Living: [scale from independent (1) to needs assistance to fully dependent (5)].

1. Bathing with sponge, bath, or shower  1___________5 (fully dependent)  
2. Dressing  1___________5 (fully dependent)  
3. Toilet Use  1___________5 (fully dependent)  
4. Ambulation/Transfers  1___________5 (fully dependent)  
5. Urine and bowel Continence  1___________5 (fully dependent)  
6. Eating  1___________5 (fully dependent)
**Instrumental Activities of Daily Living:** [scale from independent (1) to needs assistance to fully dependent (5) ]

7. Housework 1______________5 (fully dependent)

8. Medications as prescribed 1______________5 (fully dependent)

9. Managing money 1______________5 (fully dependent)

10. Shopping for groceries or clothing 1______________5 (fully dependent)

11. Use of telephone 1______________5 (fully dependent)

12. Transportation 1______________5 (fully dependent)

**Household income¹:**

<table>
<thead>
<tr>
<th>Income Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below $29,999</td>
</tr>
<tr>
<td>$30,000-$44,999</td>
</tr>
<tr>
<td>$45,000-$59,999</td>
</tr>
<tr>
<td>$60,000-$74,999</td>
</tr>
<tr>
<td>$75,000-$89,999</td>
</tr>
<tr>
<td>above 90,000</td>
</tr>
<tr>
<td>decline to answer</td>
</tr>
</tbody>
</table>

1. Are finances a concern?

2. Is your current household income adequate to manage your family’s needs?

3. How many people are supported by this income?

---

Footnote

¹ The question 'household income' was dropped after two interviews and the three questions that followed, related to finances, where the only ones included.
APPENDIX D
The Life Events Time Line

The arrow below represents your life since birth. Please indicate on the line the approximate location of each of the life events numbered 1-20 (some events may have occurred more than once). Add any events that you feel were significant numbering them 21, 22, 23, etc.

<table>
<thead>
<tr>
<th>Event Description</th>
<th>Life Event Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood/adolescence</td>
<td>1</td>
</tr>
<tr>
<td>Early-adulthood</td>
<td>2</td>
</tr>
<tr>
<td>Immigrated to Canada</td>
<td>3</td>
</tr>
<tr>
<td>Started living together</td>
<td>4</td>
</tr>
<tr>
<td>Married</td>
<td>5</td>
</tr>
<tr>
<td>Remarried</td>
<td>6</td>
</tr>
<tr>
<td>Birth of child (ren)</td>
<td>7</td>
</tr>
<tr>
<td>Adoption of child (ren)</td>
<td>8</td>
</tr>
<tr>
<td>Separated</td>
<td>9</td>
</tr>
<tr>
<td>Divorced</td>
<td>10</td>
</tr>
<tr>
<td>Widowed</td>
<td>11</td>
</tr>
<tr>
<td>Started working</td>
<td>12</td>
</tr>
<tr>
<td>Stopped working (took leave from work or retired)</td>
<td>13</td>
</tr>
<tr>
<td>My spouse got fired</td>
<td>14</td>
</tr>
<tr>
<td>My spouse stopped working/retired</td>
<td>15</td>
</tr>
<tr>
<td>EOD first symptoms</td>
<td>16</td>
</tr>
<tr>
<td>EOD diagnosis became a caregiver</td>
<td>17</td>
</tr>
<tr>
<td>Became a caregiver</td>
<td>18</td>
</tr>
<tr>
<td>Started receiving formal supports (e.g., day program, CCAC)</td>
<td>19</td>
</tr>
<tr>
<td>Placement to LTC</td>
<td>20</td>
</tr>
<tr>
<td>21</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td></td>
</tr>
</tbody>
</table>

Birth  present
APPENDIX E

Interview Guide

The following interview guide will be used in an open and flexible manner. Initial open ended questions are followed by probing questions. Not all questions will be used in every interview, but questions will be determined by the responses given and the direction that the participant establishes.

1. I want to begin at the time your partner was initially diagnosed with an early-onset dementia. Can you tell me what it was like for you?

   a) Who diagnosed it?

   b) How long did it take from the time that your spouse started exhibiting symptoms until he/she was initially diagnosed?

   c) How was this pre-diagnosis time for you?

2. What is your understanding of your spouse’s illness?

3. What is it like to live with a partner with a dementia?

4. What are the main caregiving activities in relation to your spouse?

5. What would a typical day look like?

6. How have your caregiving activities changed over time?
7. What kinds of behaviours do you find the most difficult to handle? (examples may include disinhibition, apathy, lack of empathy, bizarre behaviours, ), now and in the past.

8. What feelings do you have when thinking of yourself as someone married to a spouse with EOD? (examples may include feelings of anger, pain, hurt, loss, sadness, frustration, embarrassment, love).

9. How was your relationship before the onset of this disease?

10. When you become frustrated or angry, what do you do to manage your emotions?

11. What role does the support of family and friends play in your ability to cope?

12. Are you providing care for anyone other than your spouse?

13. What role does the support of community, services and health care professionals play in your ability to cope?

14. What helps you cope with the demands that you currently have?

15. What sustains you?

16. What worries you the most?

17. How do you find meaning or explain to yourself your current struggles and why this has happened to you and your family?
18. How have you changed as a result of your spouse’s diagnosis?

19. How has your family been affected by your spouse’s illness (your children, your parents, in-laws, siblings)?

20. Are you worried about your children and how this will impact on their lives?

21. Do you feel that there are other stressors, above and beyond your spouse’s illness that are impacting you and your family now?

22. How do you perceive your physical health to be?

23. How do you perceive your emotional health to be?

24. Are you seeking any help to help you cope with your situation?

25. Is there anything we have not covered that you would like a chance to discuss?
APPENDIX F

Notification of REB Approval

Date: June 28, 2012

To: Small, Adriana

Re: Living with Early-Onset Dementia: The Experience of Spousal Caregivers (REB #: 12-24)

Sponsor: VA
REB Review Type: Initial
REB Initial Approval Date: June 26, 2012
REB Expiry Date: June 26, 2013
Documents Approved: Study Protocol, Budget, ICF, Patient Demographics Information, Interview Guide, Advertisement Flyer

Documents Acknowledged:

The above named study has been reviewed and approved by the Baycrest Research Ethics Board. If, during the course of the research, there are any serious adverse events, confidentiality concerns, changes in the approved protocol or consent forms or any new information that must be considered with respect to the project, these should be brought to the immediate attention of the REB. In the event of a privacy breach, you are responsible for reporting the breach to the Baycrest REB and the Baycrest Corporate Privacy Office (in accordance with Ontario health privacy legislation – Personal Health Information Protection Act, 2004). Additionally, the Baycrest REB requires reports of inappropriate/unauthorized use of the information.

If the study is expected to continue beyond the expiry date, you are responsible for ensuring the study receives re-approval. The REB must be notified of the completion or termination of this study and final report provided. As the Principal Investigator, you are responsible for the ethical conduct of this study.


Sincerely,

[Signature]

Ron Feslgrave, Ph.D.
Chair, Baycrest Research Ethics Board
APPENDIX G

UNIVERSITY OF TORONTO

PROTOCOL REFERENCE # 27026

July 12, 2012

Dr. Lynn McDonald
FACULTY OF SOCIAL WORK

Ms. Adriana Shnall
FACULTY OF SOCIAL WORK

Dear Dr. McDonald and Ms. Adriana Shnall,

Re: Administrative Approval of your research protocol entitled, "Living with early-onset dementia: The experience of spousal caregivers"

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital:

- Graduate Student research - hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University's involvement requires ethics review.

Best wishes for the successful completion of your research.

Yours sincerely,

Daniel Gyetu
REB Manager