

**SPOUSAL CAREGIVERS OF PERSONS WITH YOUNG-ONSET DEMENTIA**

THE SOCIAL EXPERIENCES OF SPOUSES OF PERSONS WITH YOUNG-ONSET  
DEMENTIA: SOCIAL CHANGE, SUPPORT AND RESILIENCY

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## ABSTRACT

Research suggests that young-onset dementia (YOD) has a significant effect on the person with dementia and family members who provide care to the affected person (World Health Organization, 2012). In Canada, roughly one third of dementia caregivers are the spouse of a person with dementia (Cohen, Pringle & LeDuc, 2001), of which YOD spousal caregivers experience significant social impacts, including family conflict, social avoidance, and marginalization (Harris & Keady, 2004; Kaiser & Panegyres, 2007; Luscombe, Brodaty & Freeth, 1998; Rinfrette, 2010; Williams, Keady & Nolan, 1995). However, no qualitative study has examined the social experiences of YOD spousal caregivers within the Canadian context.

This qualitative research study examined the described social experiences of spouses who provide care to a spouse with YOD. A descriptive, qualitative approach (Sandelowski, 2000) was used to study the nature of these social experiences using in-depth, semi-structured interviews. Purposive sampling was used to recruit ten YOD spousal caregivers living in Ontario. Questionnaires were used to collect relevant demographic variables such as the age of the participant and their care partner, and whether the couple had children. Semi-structured interviews included open-ended questions on the participant's social experiences, including the nature of their social and recreational activities, the type of activities, and whether there had been any changes since becoming a caregiver.

Four themes relevant to the social experiences of YOD spousal caregivers emerged from the interviews: sources of social support, giving up activities in favour of new activities, adapting and maintaining in social and recreational activities, and social spaces as safe spaces.

Concepts of caregiver social adaptation, and choosing to give up social and recreational activities in favour of new ones builds upon existing research on theories of social support, activity restriction, caregiver adaptation, and avoidance previously described in the existing YOD and general dementia literature. Themes of giving up activities in favour of new activities, and social spaces as safe spaces also represent new themes not previously discussed in the body of dementia caregiving literature.

Previous, socially-relevant research on YOD spousal caregiving has focused primarily on examining and measuring social impacts, with little attention paid to caregiver perceptions of their social experiences in the Canadian context. The findings of this research study indicate that caregiving for a spouse with YOD entails complex social experiences, which extend beyond value-laden depictions of social outcomes recorded in the existing literature. These rich experiences challenge and expand our theoretical understanding of spousal caregiving for persons with YOD.

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I would like to dedicate this thesis to my Dad, for his selfless and ever-loving care of Mum. The deep sense of commitment and love you share with Mum is a living love story. Thank you for finding the strength and courage to make the tough decisions, and for holding us all together even when it was difficult to hold yourself together.

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## LIST OF ABBREVIATIONS

AD	Alzheimer's Disease
FTD	Fronto-temporal Dementia
LOAD	Late-Onset Alzheimer's Disease
LOD	Late-Onset Dementia
LTC	Long-Term Care
YOD	Young-Onset Dementia
YOAD	Young-Onset Alzheimer's Disease

## INTRODUCTION

Empirical evidence suggests that dementia is a particularly devastating disease for both the caregiver and the person with dementia. The Alzheimer Society's Rising Tide report (Alzheimer Society, 2010) argues that caregivers of persons with dementia spend 75% more time caregiving compared to persons providing caregiver support to individuals with other chronic conditions. The report also suggests that the demands placed on the caregiver are particularly severe in comparison to other chronic conditions (Alzheimer Society, 2010).

In Canada, an estimated 36% of dementia caregivers are the spouse of a person with dementia (Cohen, Pringle & LeDeuc, 2001). Spousal caregivers experience significant burden compared to other primary caregivers: they are less likely to have additional caregiver support, and more are frequently caring for persons with severe dementia (Canadian Study of Health and Aging [CSHA], 1994). Furthermore, approximately 33% of spousal caregivers are the sole source of informal care (CSHA, 1994).

Among those persons with dementia, young-onset dementia (YOD; onset before the age of 65) affects approximately 5-9% of the total dementia population (Van Vliet, De Vugt, Bakker, Koopmans & Verhey, 2010; World Health Organization [WHO], 2012). Among those persons who provide informal care to persons with dementia, YOD spousal caregivers are reported to experience greater caregiver strain than other informal caregivers (WHO, 2012). Although the existing YOD literature discusses the impacts of caregiving on the spouse, the nature of YOD caregiver social experiences has not been thoroughly explored.

The concept of this research on the social experiences of caregivers was sparked by personal experiences. As a daughter of a person with YOD, my perceptions of my father's dual role as spouse and caregiver to my mother with young-onset Alzheimer's disease prompted questions. I noticed many changes in my Dad's (and dually my Mum's) social experiences as the disease progressed including changes in friendships, decreased travel, and increases in singular pass-times.

Alongside these changes, I witnessed deficiencies in social services with regard to maintaining the general health of the younger caregiver (i.e. social health). This raised questions about the existing academic understanding of the young-onset caregiver experience. In my experience, the services available to us were generally not designed or suited to someone my Mum's age, and the caregiver supports (e.g. counseling, peer support groups, social networks, and etc.) were equally ill-fitting or insufficient. Support was generally second to the general shock over how young we all were (i.e. my parents and my sisters). Anger over what I perceived to be ageist notions of what dementia was, and what it looked like, highlighted the need for more research on this topic.

I began to suspect that the benefits of maintaining, promoting, or supporting the caregiver's social resources was wholly undervalued within the 'culture' of dementia

care, particularly with regard to the minority population of YOD caregivers. My need to seek answers to these questions led me to examine academic literature. Sadly, the answers could not be found within the existing body of literature on dementia caregiving. There were only a handful of research studies focused on examining the experiences of YOD caregivers, and none were situated within the Canadian context. This insufficiency was alarming considering the known health benefits of positive social support in buffering the effects of stress and depression (Koenig, 2008).

## LITERATURE REVIEW

### Dementia

Dementia is a broad term for a family of different types of diseases or disorders, which are characterized by intellectual and memory impairment as the disease progresses (Alzheimer Society of Ontario, 2007; Friedland & Wilcock, 2000). The effects of dementia can include impairment or decline in abstract thinking, judgement, personality, language and memory (Friedland & Wilcock, 2000). The effects of dementia ultimately interfere with various aspects of a person's life, including their work, social activities, and other daily activities which characterize a person's independence (Friedland & Wilcock, 2000).

Progression and reversibility of the disease varies depending on the type of dementia a person has (Friedland & Wilcock, 2000). Dementia can be acute or chronic in onset, and reversibility can vary between prolonged progression with no cure, and reversible with treatment (Friedland & Wilcock, 2000). However, most types of dementia are generally characterized as progressive, irreversible, and ultimately fatal (Friedland & Wilcock, 2000; Alzheimer Society, 2010). Short-term memory loss and the inability to learn new information are common early symptoms of dementia, often followed by aphasia,<sup>1</sup> apraxia,<sup>2</sup> and agnosia<sup>3</sup> as the disease progresses (Smith & Brechtelsbauer, 2011).

There are many different forms of dementia, and some are more frequent than others; examples include Alzheimer's disease (AD), Lewy body disease (LBD), and vascular dementia (Smith & Brechtelsbauer, 2011). Less common forms of dementia include frontotemporal lobar degeneration (FTLD) and Creutzfeldt-Jakob disease (Smith & Brechtelsbauer, 2011). AD is considered to be the most common form of irreversible dementia, while Creutzfeldt-Jacob disease is an extremely rare form of dementia (Friedland & Wilcock, 2000).

Because different forms of dementia can affect different regions of the brain (and affect the brain in different ways), the resulting symptoms may vary widely depending on dementia type. For example, AD may result in memory, movement, speech, behavioural, and judgement impairments (Friedland & Wilcock, 2000). By comparison, fronto-temporal dementia (FTD) may result in a loss of executive functioning, behavioural and relationship problems, social disinhibition, and mood changes (Smith & Brechtelsbauer, 2011). However, these different effects are not exclusive to a specific form of dementia, and can be seen in other types as well. Nonetheless, understanding the type or cause of dementia may help to determine the best drug treatment options, and may help to determine the duration or reversibility of the disease.

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<sup>1</sup>Aphasia: language impairment

<sup>2</sup>Apraxia: motor impairment

<sup>3</sup>Agnosia: inability to recognize objects

### *Prevalence*

Dementia is a significant health issue within the Canadian population. The prevalence of dementia (all types) among the Canadian population (all ages) was estimated to be approximately 1.5% in 2008 (Alzheimer Society, 2010). The number of Canadians diagnosed with dementia is expected to increase to 1.1 million people (2.8% of the population) by 2038 (Alzheimer Society, 2010).

As mentioned previously, dementia prevalence also varies among dementia types. However, not all estimates account for mixed dementias (e.g. AD with another co-morbid type of dementia), or atypical forms of AD (Feldman, Levy, Hsiung, Peters, Donald et al., 2003). The 2003 Canadian Collaborative Cohort of Related Dementias (ACCORD) study estimated that AD related dementias account for approximately 71.9% of dementias in Canada, which includes mixed forms of AD (Feldman et al., 2003).

## **Young-Onset Dementia**

### *Prevalence*

Young onset dementia (YOD; onset before the age of 65) accounts for approximately 5-9% of the total dementia population (Van Vliet et al., 2010; WHO, 2012), and can affect adults as young as 30 years of age (Mayo Clinic, 2009). The Rising Tide Report (2010) estimates that young-onset AD makes up 5-7% of the total Alzheimer population.

YOD prevalence by type is highly debated. A Canadian study by Feldman et al. (2003) found that AD was the most common form of YOD among the ACCORD study population sample. This is consistent with other YOD studies which also report AD as the leading form of dementia (Picard, Pasquier, Martinaud, Hannequin & Godfrey, 2011; Shinagawa, Ikeda, Toyota, Matsumoto, Matsumoto et al., 2007; Werner, Stein-Shvachman & Korczyn, 2009). FTD is also more prevalent among younger persons than persons with late-onset dementia (LOD; Feldman et al., 2003; Kaiser & Panegyres, 2007), accounting for 5-10% of cases of YOD (Feldman et al., 2003; Picard et al., 2011; Shinagawa et al., 2007). Furthermore, atypical forms of dementia are more prevalent among persons with YOD (Harris & Keady, 2004).

One study by McMurtray, Clark, Christine & Mendez (2006) compared the frequency and causes of YOD to LOD and found conflicting findings to those of Feldman et al. (2003) and Werner et al. (2009). McMurtray and colleagues (2006) found that vascular dementia was the most frequent form of YOD (28.8%) among the YOD subset of the population sample (McMurtray et al., 2006).

The differences in estimated prevalence of YOD types may be due to the different sampling techniques employed by researchers.

### *Diagnostic Issues*

Diagnostic issues related to YOD have been described by various researchers. One of the overarching issues associated with YOD is the length of time it takes to receive an official



diagnosis (Rinfrette, 2010). Often early symptoms of dementia are ignored by family, friends, and the person with dementia (Rinfrette, 2010), which results in a delayed start to the diagnostic process (Garre-Olmo, Genis Batlle, del Mar Fernández, Marquez Daniel, de Eugenio Huélamoet al., 2010; Shinagawa et al., 2007; Werner et al., 2009).

Primary care physicians – as the gatekeepers in the diagnostic process – often do not consider early symptoms to be the result of dementia (Van Vliet et al., 2010; Werner et al., 2009). Dementia is generally thought to be a disease of older persons, or a natural part of getting older (Alzheimer’s Association, 2006; Harris & Keady, 2004; Rinfrette, 2010).

Alongside the recorded ‘diagnostic hesitancy’ discussed in the literature, persons with YOD are more frequently misdiagnosed compared to persons with LOD (McMurtray et al., 2006; Werner et al., 2009). Often these early symptoms of YOD are misdiagnosed as stress (Luscombe, Brodaty & Freeth, 1998; Rinfrette, 2010; Werner et al., 2009), a normal part of aging (Rinfrette, 2010), psychiatric disorders (Garre-Olmo et al., 2010), or burnout, depression, or menopause (Werner et al., 2009). On average, the time to reach a diagnosis of YOD typically takes longer than LOD (Papageorgiou, Kontaxis, Bonakis, Kalfakis & Vassilopoulos, 2009; Van Vliet et al., 2010).

Persons with YOD and their families have described obtaining an official diagnosis as “frustrating,” and “confusing,” (Rinfrette, 2010, p. 120). The diagnostic process of YOD often involves a lengthy testing and evaluation period, sometimes lasting up to two years (Rinfrette, 2010). This is concerning considering YOD is typically thought to progress more rapidly (depending on type) compared to LOD (Papageorgiou et al., 2009). These diagnostic delays and misdiagnoses may present challenges to caregivers and the person with YOD. For example, a diagnosis from a physician is necessary in order for affected persons to receive income support benefits through Ontario’s Disability Support Program (Ontario Disability Support Program Act, 1997). This may result in significant occupational and economic issues for the person with YOD and their caregivers.

### *Occupational and Economic Issues*

Diagnostic issues associated with YOD are also accompanied by other unique age-related issues. These challenges are often a direct result of the roles associated with pre-retirement age. Unlike persons with LOD, younger persons with dementia are often still actively employed (Garre-Olmo et al., 2010; McMurtray et al., 2006; Van Vliet et al., 2010; Werner et al., 2009). As the disease progresses, their continued economic productivity may be reduced or cease entirely (Werner et al., 2009).

This loss of income may have further impacts if the person is the primary source of income for a family, or a significant economic contributor for their immediate or extended family. Often persons with YOD are still actively engaged in raising or supporting children (McMurtray et al., 2006; Van Vliet et al., 2010; Werner et al., 2009) and dependent parents (Werner et al., 2009). This economic impact has been called a double economic burden; the person with YOD may lose a significant portion of their income, while also not being eligible for some types of financial assistance (Werner et al., 2009), including full pension benefits (Garre-Olmo et al., 2010).

A study by Sperlinger and Furst (1994) found that 73% of the persons with YOD retired early due to the effects of their dementia. They also noted that 45% of those included in the study cited that work-related problems (often memory issues) were the first indication that there was something wrong (Sperlinger & Furst, 1994; Williams, Keady & Nolan, 1995). These occupational issues are often significantly different than those faced by persons with LOD (Sperlinger & Furst, 1994). Persons with YOD are more likely to move into LTC earlier than persons with LOD experiencing a similar level of impairment (Rosness, Haugen & Engedel, 2008), although reasons for this are not clearly discussed in the literature.

### *Emotional and Social Issues*

Along with the significant financial and occupational challenges associated with younger onset of dementia, persons with YOD also appear to experience feeling a loss of their independence as they begin to require assistance with independent activities of daily living (Rasmussen, 2002; Werner et al., 2009). Affected persons may experience role reversals, as their children become caregivers to them at a much younger age than their LOD counterparts, often while they are still parents to dependent children (Werner et al., 2009). They may also experience changes in their relationships with spouses, family members, or friends, and their plans for the future may be significantly disrupted (Werner et al., 2009) These feelings of lost independence, relationship changes, and role reversals, have been associated with emotional strain for the person with YOD (Werner et al., 2009).

Although these impacts are similar to those outlined in the LOD literature, Garré-Olmo and colleagues (2010) suggest that the social contexts of YOD differ significantly from the social contexts of older persons with dementia. They argue that persons with YOD are more likely to be working, have dependent family members, and have significant financial responsibilities (Garré-Olmo et al., 2010). The subsequent loss of the person's work may result in considerable social and emotional strain for the family members (Garré-Olmo et al., 2010). However, a detailed description of the nature of these strenuous social experiences has not been discussed in the YOD literature from within the Canadian context. This leaves little understanding regarding the derivation or nature of the various impacts of caregiving.

### **Caregiving**

As a person with dementia (LOD and YOD) regresses, they increasingly need help caring for themselves. The majority of caregiving for persons with dementia is provided on an informal basis, mostly by immediate family members (90%; Black, Gauthier, Dalziel, Correia, Hew et al., 2010; Alzheimer Society, 2010; Smale & Dupuis, 2004). There is considerable debate between researchers concerning what caregiving – as a concept – represents (Swanson, Perry Jensen, Specht, Johnson, Maas et al., 1997). The tasks associated with caregiving for a person with dementia are known to change as the disease progresses (Alzheimer Society, 2010; WHO, 2012). For this reason, the concept of

caregiving – in the context of dementia – is increasingly being thought of as a role. As a role, “caregiving is viewed as a simple extension of the roles customarily enacted by family members and/or others,” (Swanson et al., 1997, p. 68) including thoughts, behaviours, words, and nurturing activities. In the context of dementia, a broad definition of caregiving is more representative of the complex nature of informal caregiving.

The Rising Tide (2010) report discussed the unique challenges of providing informal care to persons with dementia. The authors reported that caregiving for a person with dementia is particularly demanding in comparison to other chronic conditions (Alzheimer Society, 2010). One significant difference had to do with the greater time commitment associated with caring for a person with dementia (Alzheimer Society, 2010; Smale & Dupuis, 2004).

Informal caregivers of persons with dementia experience multiple psychological-emotional, physical, economic-occupational, and social impacts. These effects also greatly contribute to various social issues. Caregiving for a person with dementia has been associated with disruption of relationships with the person with dementia (Deimling, Bass, Townsend & Noelker, 1989; Morris, Morris, & Britton, 1988; Smale & Dupuis, 2004), family members (Deimling et al., 1989; Smale & Dupuis, 2004), and friends (Smale & Dupuis, 2004; Williamson, Shaffer & Schulz, 1998). Family conflict (Deimling et al., 1989; Morris et al., 1988), social isolation (Brodaty, Green & Koschera, 2003; Bullock, 2004; WHO, 2012), and role strain (Deimling et al., 1989; WHO, 2012) are common social experiences cited in the dementia caregiving literature.

A comprehensive study of dementia caregivers in Ontario by Smale and Dupuis (2004) presented a profile of emotional support sources among caregivers; family members (55%), friends and neighbours (45.9%) represented the primary informal social resources described by caregivers. Findings from this study suggest that caregivers use informal social resources more often than formal support services (Smale & Dupuis, 2004), demonstrating the importance of these social experiences in mediating the emotional aspects of caregiving.

Despite the described benefits of social resources for dementia caregivers, Smale and Dupuis (2004) also found several social experiences to be significant sources of stress. Embarrassment regarding the behaviour of the person with dementia (25%), and having no one to share worries with (27.8%) were found to be very stressful for caregivers (Smale & Dupuis, 2004). Furthermore, more than 63% of caregivers found limitations in living their life (as a result of caregiving) to be a significant source of stress (Smale & Dupuis, 2004).

The study also described the impacts of caregiving on social lives (Smale & Dupuis, 2004). Caregivers of persons with dementia described multiple social impacts, including having less time for themselves (70.8%) and visiting friends and relatives less often (68%). Reduced participation in activities was also significant, including decreased social (66.5%), group/organized (65.6%), volunteer (63.9%), and recreation (55.8%) activities. Impacts on leisure activities were also described, and included being unable to go away on holidays (64.3%), changing vacation plans (58.7%), and reduced enjoyment in

recreation (46.2%) and leisure (44.4%) activities. Furthermore, the study also found that caregivers expressed feelings of guilt when spending time with friends (40.3%), rather than the person with dementia (Smale & Dupuis, 2004). These findings demonstrate the significant changes in social experiences associated with caregiving for a person with dementia.

These described social impacts demonstrate the complex experiences of persons providing care to a person with dementia. However, the available research (including the Smale & Dupuis, 2004 study) on caregiver social experiences, is not specific to YOD; this body of research represents the general dementia caregiver population.

## **Caregiving for a Person with YOD**

Much like the general dementia literature, research on YOD caregiving focuses primarily on the impacts of caregiving. However, there are some subtle differences in YOD caregiving.

Studies specific to YOD have been conducted since the early 1990s, with the vast majority of research conducted during the last twelve years. A total of twelve YOD caregiver studies were identified during the literature search (these are summarized in Table 1 [see Appendix A]).

In many ways, caregiving for a person with YOD is much like caring for someone with LOD. However, there are some recorded issues thought to be unique to individuals with YOD and their caregivers. In the case of YOD, 82% of persons receive assistance from an informal caregiver (Harvey, Rossor, Skelton-Robinson & Garralda, 1998). By comparison, an estimated 75% of older persons with dementia (i.e. LOD) make use of informal care (Nordberg, von Strauss, Kareholt, Johansson & Wimo, 2005). Family members are common sources of care (Bass, McClendon, Deimling & Muckherjee, 1994), with spouses and children representing the primary source of informal care for persons with YOD (Rosness et al., 2008). Although these sources of care are similar to those of persons with LOD, YOD spousal caregivers are more likely to be caregivers for longer periods of time, have less social support (Rinfrette, 2010), and be the sole caregiver (CSHA, 1994; Haase, 2005) in comparison to LOD.

Furthermore, spouses of persons with YOD report greater caregiver burden in comparison to LOD spouses (Kaiser & Panegyres, 2007; Rinfrette, 2010; Van Vliet et al., 2010). This burden experienced by caregivers of persons with YOD has been linked to perceived unpreparedness to adequately assume the caregiver role (Werner et al., 2009). Table 1 (see Appendix A) provides an overview of current YOD research related to the caregiving experience.

Of the twelve studies involving caregivers of individuals with YOD, the majority used a combination of qualitative and quantitative (i.e. mixed-methods) data collection methods and none of these studies used a purely qualitative design within the Canadian context. Although mixed-methods designs can be informative, purely qualitative approaches in

descriptive research can yield more detailed information about the nature of an individual's social experiences (King, Keohane, & Verba, 1994).

### *Emotional and Psychological Impacts*

Caregivers of persons with YOD experience similar impacts to caregivers of persons with LOD. Stress (Black et al., 2010; Kaiser & Panegyres, 2007; Luscombe et al., 1998; Rasmussen, 2002; Rinfrette, 2010), helplessness (Black et al., 2010; Rinfrette, 2010), grief (Kaiser & Panegyres, 2007; Luscombe et al., 1998; Van Vliet et al., 2010), depression (Kaiser & Panegyres, 2007; Rasmussen, 2002; Rinfrette, 2010; Van Vliet et al., 2010; Werner et al., 2009), anger (Kaiser & Panegyres, 2007; Rinfrette, 2010; Van Vliet et al., 2010) and emotional pressures (Black et al., 2010; Luscombe et al., 1998; Van Vliet et al., 2010) were similar emotional and psychological impacts reported by YOD caregivers.

However, there are several studies that note marked differences in the emotional and psychological impacts of caregiving between YOD and LOD caregivers. For example, one study by Van Vliet and colleagues (2010) found that YOD caregivers experience higher rates of stress compared to LOD caregivers. Further, two studies report greater rates of depression among spouses of persons with YOD (Kaiser & Panegyres, 2007; Werner et al., 2009).

In addition to these differences in rates of depression and stress, caregivers of persons with YOD also report some experiences not previously described in the LOD literature. One study by Kaiser and Panegyres (2007) found that caregivers of persons with YOD most frequently reported a reduced interest in sex as the leading emotional-psychological impact related to the caregiving experience. Additionally, suicidal thoughts were commonly reported among young-onset Alzheimer's disease caregivers (Black et al., 2010) and spouses of persons with YOD (Rinfrette, 2010).

Rinfrette (2010) discussed how caregivers frequently experienced *ambiguous grief*, while the person with YOD was still alive. Ambiguous grief refers to the ambiguous emotional effects of changing relationships where one person is "physically present but is psychologically absent," (Boss, 1999; Rinfrette, 2010, p. 80). This grieving process was linked to the ongoing changes in the individual with dementia, as they continued to decline. Rinfrette (2010) also found that ambiguous grief was closely connected to the loneliness cited by caregivers (especially spouses), which was also an upsetting factor related to caregiving for a person with YOD.

### *Physical Impacts*

Generally, the physical impacts associated with caregiving for a person with YOD are similar to those experienced by LOD caregivers, including physical morbidity (Black et al., 2010; Rasmussen, 2002), exhaustion (Kaiser & Panegyres, 2007), fatigue (Black et al., 2010), and stress hormones (Van Vliet et al., 2010). However, YOD caregivers frequently report higher rates of fatigue and exhaustion in connection with their caregiving tasks (Black et al., 2010; Kaiser & Panegyres, 2007), and lower overall global

levels of health (Van Vliet et al., 2010). Persons providing care to an individual with YOD experience multiple negative health outcomes and physical consequences, including the exacerbation of pre-existing health problems (Black et al., 2010; Rasmussen, 2002). As mentioned previously, the physical impacts of caring for someone with YOD are closely linked with other psychological-emotional, occupational-economic, and social experiences.

### *Occupational and Economic Impacts*

Economic and occupational experiences are frequently described as a significant source of stress for caregivers of persons with YOD. Financial strain (Kaiser & Panegyres, 2007; Luscombe et al., 1998; Van Vliet et al., 2010; Werner et al., 2009) and financial insecurities (Werner et al., 2009) are commonly reported in the literature on YOD and caregiving. This is not surprising considering that younger persons with dementia and their caregivers may still be actively employed during the onset and progression of the disease. They may be at the height of their careers, they may still be paying for/saving for their child's post-secondary education, and they may have little or no retirement savings (Harris & Keady, 2004). The various occupational and economic experiences described by persons providing care for someone with YOD, reveal the complex connections between other aspects of the caregiving experience.

### *Social Impacts*

The social impacts described by caregivers of persons with YOD within the existing body of research, reveals some commonalities with LOD caregivers. These impacts include social isolation (Garré-Olmo et al., 2010; Kaiser & Panegyres, 2007; Van Vliet et al., 2010) and activity restriction (Black et al., 2010; Brown & Roach, 2010; Kaiser & Panegyres, 2007; Luscombe et al., 1998). However, there are some differences in the frequency of social impacts reported in the literature between YOD and LOD caregivers. YOD caregivers frequently report lower levels of social support than LOD caregivers (Van Vliet et al., 2010). Possible reasons for these lower levels might stem from frequent reports of family conflict (Van Vliet et al., 2010), stigmatization (Luscombe et al., 1998; Werner et al., 2009), marginalization (Harris & Keady, 2004), social avoidance (Luscombe et al., 1998), and a perceived inability to relate to other persons within existing social networks (Van Vliet et al., 2010). Mobility restrictions and functional limitations associated with the person with dementia have also been described as key barriers to various social activities among caregivers of persons with YOD (Black et al., 2010; Kaiser & Panegyres, 2007). However, reasons for social restriction among caregivers of persons with YOD may be more complex, and may differ between caregivers.

A grounded theory study of persons with YOD and their families by Harris and Keady (2004) discussed eight specific themes that emerged in the data, which they felt represented the unique nature of YOD (in comparison to LOD). Of these themes, "changing relationships within the family structure" (p. 116) was cited as the most salient theme. The authors stated that diagnosis of the disease when the person with YOD

occupied multiple roles during family life cycle (e.g. spouse, parent to young children, child to aging parents), directly impacting the rest of the family (Harris and Keady, 2004). These changing family relationships were associated with extreme feelings of isolation and exclusion, notably the caregiver feeling as though they had no one to turn to or commiserate with (Harris and Keady, 2004).

More specifically, Harris and Keady (2004) argue that the stage in the family life cycle, coupled with the younger age of dementia resulted in unique challenges and stressors among caregivers which are not seen in LOD. They found that participants often cited changes in relationships with friends, which contributed to greater levels of social isolation and increase burden in comparison to LOD (Harris and Keady, 2004). The authors explained that many YOD caregivers felt as though some friends and family avoided them, due to a perceived inability to deal with seeing the person with YOD regress and change (Harris & Keady, 2004). Caregivers also described how they felt unable to maintain a friendship with someone who did not personally understand or have experience as a caregiver (Harris & Keady, 2004).

Although several studies have studied the impacts of YOD caregiving, few have focused on the social impacts alone. Of those studies that have examined the social impacts of caregiving, only a few studies have explored the caregiver experience, and none have sought to describe these experiences in the Canadian context using a purely qualitative design.

## **Social Experiences and Spouses**

The *social experience* is a broad concept used within the existing social science literature to describe an individual's perceptions of their interpersonal interactions. However, like many concepts, there are differing opinions concerning what this idea precisely entails. For example, an early comparative study of the social experiences of cancer patients undergoing treatment used *experiences* and *social experiences* interchangeably; the authors defined *experiences* as subjective elements of social encounters, and considered these to be either positive or negative experiences resulting from social interaction (Tempelaar, de Haes, de Ruiter, Bakker, Van de Heuvel, et al., 1989). The researchers divided the concept into two categories of positive and negative social experiences, with corresponding sub-definitions; through social interaction, positive social experiences resulted in social support and feelings of acceptance (i.e. positive social impacts), and negative social experiences resulted in various negative social impacts (e.g. stigmatization, victimization, etc.) during the course of the patient's treatment (Tempelaar et al., 1989).

In the general dementia caregiving literature, social experiences are sometimes discussed as caregiver outcomes or caregiver impacts, including such impacts as relationship changes and activity restriction (Donaldson, Tarrier & Burns). As Table 1 (see Appendix A) demonstrates, some research has been done relative to the social impacts of caregiving

for persons with YOD (Harris & Keady, 2004; Kaiser & Panegyres, 2007; Luscombe et al., 1998; Rinfrette, 2010; Williams et al., 1995).

Considering spouses are the primary source of informal care to persons with dementia (Cohen et al., 2001), and that YOD spousal caregivers experience greater social isolation and activity restriction than other dementia caregivers (Kaiser & Panegyres, 2007), understanding these social experiences is of particular importance. However, only three studies (Kaiser & Panegyres, 2007; Rasmussen, 2002; Williams et al., 1995) focus solely on spouses, and only two studies are concerned primarily with social impacts (Kaiser & Panegyres, 2007; Williams et al., 1995). For the purposes of this thesis study, the literature on YOD spousal caregivers' social outcomes proffers some insight into the overall experience of YOD spousal caregiving.

A mixed-methods study of spousal caregivers of persons with YOD by Rasmussen (2002) examined the influence of family life cycle variables and patient/caregiver characteristics on physical and psychological health outcomes. The study involved 33 spousal caregivers recruited through an Alzheimer's clinic in the United States, who completed a structured telephone interview, a demographic questionnaire, and four scaling instruments (i.e. a depression-mood scale, a social provision scale, a coping checklist, and a memory-behaviour checklist). Rasmussen (2002) found that spousal caregivers who reported greater social supports also had higher reported physical health ratings and lower levels of depression.

Although the study focused largely on psychological and physical impacts, Rasmussen (2002) did report some relevant social issues such as friends avoiding the spousal caregiver and the person with YOD, and new areas of social support not discussed in the existing literature. For example, Rasmussen (2002) cited pets, the internet, and spirituality were significant sources or social support for the caregiver.

The nature of these impacts were not thoroughly explored in the space of the telephone interview, which contained only two structured interview questions related to the challenges of caregiving. Rasmussen (2002) stated that participants were asked two questions during the interview: 1) *What is your greatest caregiving concern right now?* and 2) *Is there anything else you would like for this researcher to know about your caregiving experience?* Furthermore, Rasmussen (2002) did not indicate any potential probing topics, or even if this technique was used.

Kaiser & Panegyres' (2007) study of 100 spousal caregivers recruited from a Neurosciences Unit in Australia examined the psychosocial impacts of YOD using a demographic questionnaire combined with two scaling tools to measure burden and depression. The results of the questionnaire briefly highlighted social impacts including social isolation and activity restriction (Kaiser & Panegyres, 2007). Spousal caregivers frequently linked the functional decline to activity restriction (Kaiser & Panegyres, 2007). The results of the scaling tools revealed increased burden associated with social life and interpersonal relationships, and slightly greater levels of depression among wives than husband caregivers (Kaiser & Panegyres, 2007).



The most significant finding was the expressed need for more intervention or support services which would allow YOD spousal caregivers more time for themselves; the authors directly linked this to reduced experiences of caregiver burden (Kaiser & Panegyres, 2007). However, the study focused primarily on understanding the psychological impacts of spousal caregiving using the two measurement tools, of which social impacts was only a small part of these tools.

Williams and colleagues (1995) presented a personal case history of a spousal caregiver to a person with young-onset AD. This article is unique (in comparison to the other YOD caregiver literature), because it uses a single, personal narrative to highlight the experience of being a YOD spousal caregiver in lieu of more traditional data collection methods (e.g. scaling instruments). The primary author recounts her experiences, citing several socially relevant experiences including friends slowly turning away (Williams et al., 1995). The article describes this hurtful social experience as being treated as though the person had a contagious disease (Williams et al., 1995).

One limitation of the Williams et al.'s (1995) article is that it does not discuss social experiences in detail. Secondly, the article is a non-Canadian account of the caregiver experience, which may not be reflective of the YOD caregiving in the Canadian context (Williams et al., 1995). Furthermore, Williams et al.'s (1995) article represents only a single personal account, thus limiting the generalizability of the findings in relation to the larger YOD spousal caregiver population.

## Conclusion

Of the three studies relevant to spousal caregivers of persons with YOD, only one by Williams and colleagues (1995) used qualitative methods. Although descriptively rich, this study represents the experiences of a single caregiver of a person with young-onset Alzheimer's disease living in the United Kingdom (Williams et al., 1995).

Rasmussen's (2002) mixed-methods study used semi-structured interviews, demographic questionnaires, and scaling instruments to understand the impacts of caregiving on YOD spouses in the United States. Although this study did entail qualitative research interviews, only two structured interview questions related to the challenges of caregiving were asked. Neither of these structured questions specifically addressed the social experiences of caregiving.

Lastly, none of the YOD spousal caregiver studies (Kaiser and Panegyres, 2007; Rasmussen, 2002; Williams et al., 1995) were conducted in the Canadian context. A review of the literature highlights several insufficiencies in the scholarly understanding of caregiver experiences related to YOD. No previous study has undertaken an in-depth exploration of the social experiences of spouses of persons with YOD in the Canadian context. This lack of focused research represents a gap in our knowledge of YOD issues and experiences. Consequently, the research presented in this study was guided by a principal research question: *What are the social experiences of spouses of persons with YOD?*

## METHODS

### **Methodological Considerations in Research Design**

For the purposes of this thesis, *social experiences* were defined as a person's perceptions of how they think, act, and relate to their social world. This includes thoughts, actions, and feelings within the context of their social networks. Therefore, this descriptive, qualitative research study focused on understanding the social experiences of spouses of persons with YOD using semi-structured interviews.

#### *Qualitative Research*

Denzin and Lincoln (1998) state that qualitative research implies a focus on, “the socially constructed nature of reality...and how social experience is created and given meaning,” (Denzin & Lincoln, 1998, p. 8). Therefore, the researcher's concern is to explore the nature of social reality through in-depth analysis of social phenomenon or experiences.

King et al. (1994) suggest that the goal of qualitative research is to gain a comprehensive understanding of an event or case through in-depth evaluation. In this way, qualitative research designs are well-suited to answering research questions focused on gaining a deeper understanding or meaning from the point of the view of the research participants (Greene & Thorogood, 2009). Qualitative research approaches focus on participant perceptions, as well as “problem identification, hypothesis generation, theory formation, and concept development,” (Neergaard, Olesen, Andersen & Sondergaard, 2009, p. 1187).

In the case of this thesis, the objective of the research was to describe the social experiences of spouses of persons with YOD using their own words. Therefore, research methods that generate intensive information (such as semi-structured interviews) are better suited to research that strives to improve conceptual understanding of experiences or phenomenon (King et al., 1994), such as the case of this thesis study.

#### *Descriptive Research*

Descriptive research (a subset of qualitative research) is used primarily to provide a detailed picture of an event or case in order to challenge existing research, construct classifications, or clarify existing phenomena (contextually, sequentially, or mechanically; Neuman, 2006). Unlike exploratory research (which is concerned with understanding whether a phenomenon or case constitutes a legitimate avenue of future research), descriptive research is premised on a well-defined focus, and ends with an accurate, detailed description of that event or case (Babbie & Benaquisto, 2010; Neuman, 2006).

King et al. (1994) argue that inference is a fundamental aspect of scientific description, and the principal goal of good social science. The authors state that descriptive inference

involves making sense of unobserved and observed facts, which may lead the researcher toward new causal hypotheses or explanations (King et al., 1994). This is not to suggest that qualitative description is suited to generalizability, rather that descriptive research designs may uncover evidence for underlying causal explanations of a given phenomenon. As King et al. (1994) state, “without deep immersion in a situation [via thick description], we might not even think of the right theories to evaluate” (p. 39).

Qualitative, descriptive research on the insufficiently studied topic of YOD caregiver social experiences is an important step in theory development. The objective of this study was to provide detailed, accurate description in order to draw inferences about the nature of these social experiences. Therefore, a descriptive, qualitative approach (Sandelowski, 2000) was used to design the study. This method ensured a comprehensive and accurate summary of the social experiences of spousal caregivers, while simultaneously allowing for description in the participants’ own words. The descriptive, qualitative approach is ideal for open-ended, individual interviews (Sandelowski, 2000), and is considered to be the most comprehensive method for the study of social experiences (Denzin & Lincoln, 1998).

### *Semi-Structured Interviews*

Qualitative interviewing is a useful method for examining issues in great detail (Babbie & Benaquisto, 2010). Using interviews gives the participant (i.e. interviewee) more flexibility and freedom in responding to questions, and more control in directing the ‘flow’ of the conversation (Babbie & Benaquisto, 2012). The degree of control and flexibility relinquished by the interviewer is dependent on the chosen interview approach taken, which can range from structured to unstructured interviews (Robson, 2011). Consequently, the degree of structure also determines how in depth the response will be.

Structured interviews use pre-determined, fixed-ordered, fixed-question interview guides (Robson, 2011). The primary difference between survey-based questionnaires and structured interviews is that the questions asked in structured interviews are open-ended questions (Robson, 2011). In comparison, more loosely structured approaches such as semi-structured and unstructured interview designs allow for more flexibility in responses (Robson, 2011).

### *Critical Reflexivity and Insider Positionality*

Qualitative researchers within the social sciences recognize that complete objectivity in qualitative research is ultimately impossible; the various facets that make up our identity hold with them the potential to influence all stages of the research process (Greene & Thorogood, 2009). Greene and Thorogood (2009) state that it is impossible for research to be “untainted by values, and impossible for the researcher to stand outside those values and subjectivities” (p. 23). This concern with subjectivity is ultimately recognition of the nature of reality we are studying; perceptions of reality are variable between individuals, groups, cultures, and conditions (Jackson & Verberg, 2007).

In order to ameliorate concerns with research bias from positivist researchers who strive for ‘value-neutral social science,’ social science researchers employ methods of critical reflexivity to account for the inherent subjectivity of knowledge (Webb, 1993). Critical reflexivity is a process of critical thinking, where the researcher is continually mindful of the interactions between the researcher, the participants, and the data (Jackson & Verberg, 2007). Freshwater and Rolfe (2001) state the researcher should critically reflect upon “the personhood of the researcher, the research participants, the research context, and society as a whole,” (p. 529) throughout the entirety of the research process.

Jackson and Verberg (2007) argue that researchers must be reflexive, “so that readers of the research report are aware of how the researcher’s values, assumptions, and motivations may have influenced the framework, literature review, design, sampling, data collection, and interpretation of findings,” (p. 199). They and others further argue that being open about the role and subjectivity of the researcher in the research process, increases accuracy and relevancy of the research results (Jackson & Verberg, 2007; Webb 1993).

The use of critical reflexivity is ultimately a recognition of the place of the researcher in the research process. This interactive process is shaped by aspects of the researcher’s identity (e.g. personal history, gender, social class, ethnicity, and etc.), in conjunction with both the identity of the participants, and the characteristics that make up the context within which the research interaction occurs (Freshwater & Rolfe, 2001; Denzin & Lincoln, 1998). Additionally, Denzin and Lincoln (1998) argue that the researcher’s personal experiences should be viewed as a resource in social science inquiry. Qualitative researchers are encouraged to draw upon their personal experiences – albeit self-consciously – throughout the process of empirical inquiry (Denzin & Lincoln, 1998).

Critical reflexivity generally entails a two part process where the researcher first reflects critically on the nature of the research itself (i.e. ways that context can shape the research; Greene & Thorogood, 2009). Attention is then turned inward as the researcher reflects upon their own role or positionality within the process (and the ways that the researcher’s personhood can shape the research; Freshwater & Rolfe, 2001; Greene & Thorogood, 2009). In interview-based social science research, the researcher’s positionality also involves how the interviewee perceives or ‘places’ the researcher in suit with presumed social, cultural, engendered, ethnic, or institutional qualities (Greene and Thorogood, 2009). How a person frames the researcher may influence whether a person is willing to participate in the research, and may even influence the kinds of things that the participant shares with the researcher during the course of the interview (Greene & Thorogood, 2009). In this regard, the positionality of the researcher has the potential to influence the nature of the relationship between the participant and the researcher (and even if a relationship is possible).

O’Connor (2004) argues that the extent to which these dynamics of positionality serve “as an obstacle to the research is often determined by whether the researcher is considered an insider or outsider,” (p. 169). Insider/outside dynamics may entail certain benefits or disadvantages for researchers in certain situations or contexts (Greene & Thorogood,

2009; O'Connor, 2004). Furthermore, insider/outsider positionality may shift during the course of the research process (Herod, 1999).

My positionality as YOD caregiver (i.e. insider positionality) was made known to potential participants during recruitment. Critical reflexivity was used in order to reduce potential researcher bias as a result of my dual positionality as a researcher and an insider.

Firstly, field notes were taken in order to reflect upon the nature of each interview context. For example, it was noted in the field notes if a participant appeared to be comfortable speaking openly about sensitive topics with me (as a result of my 'insider' perspective) within the chosen interview environment. Secondly, these field notes included personal reflections on the general nature of my interactions with the participants throughout the course of the interview, and after the close of the interview. Specifically, I recorded whether I perceived that my positionality was having an effect on the nature of the interaction between myself and the participants.

Lastly, I employed critical reflexivity during the interview process; it was necessary to be constantly aware of my principal role as researcher during the interviews in order to reduce the possibility of influencing how the participants answered the research questions. Therefore, I limited how much 'insider' information I shared until after the interviews had been completed.

## **Methods**

### *Sample*

Because the population of interest was considered a hard-to-reach, or special population, a non-probability sampling technique was used to recruit participants: purposive sampling. Purposive sampling was used in order to ensure "information-rich" (Sandelowski, 2000, p. 338) cases were included in the study. This sampling technique allows for the selection of participants by the researcher based on 'typicality or interest,' relative to the objectives and the needs of the research project (Robson, 2011).

### *Inclusion/Exclusion Criteria*

All participants included in the study met the following inclusion criteria:

- Spouses providing informal care to their spouse with YOD
- Spouses currently residing in Ontario

Persons were excluded from the study if they met the following exclusion criteria:

- Spouses of persons with late onset dementia (LOD)

Initially, spouses of persons with YOD who were residing in long-term care (LTC) were not recruited. However, during the course of the study, several participants discussed earlier 'institutionalization,' concurrently with the perceived rapid progression of the YOD in comparison to LOD. The literature on YOD echoed this theme. In particular,

Rosness et al. (2008) found that younger persons were more likely to move into LTC earlier than persons with LOD with the “same degree of dysfunction” (p. 462).

In light of this information, the exclusion criterion was then modified in order to prevent further recruitment limitations among an already difficult to reach sample population.

### *Sources of Data*

Data collection involved three sources: a structured demographic questionnaire, semi-structured interviews, and post-interview field notes (i.e. a research journal). These methods were used sequentially.

#### 1) Demographic Questionnaire (see Appendix D):

A short, structured questionnaire was developed with the thesis advisor, drawing upon Rasmussen’s (2002) demographic questionnaire used in her study of the life cycle tasks of spousal caregivers of YOD. The questionnaire included demographic questions about the spousal caregiver, the care recipient, children, work status (of the spouse and person with YOD), and the time of diagnosis. Demographic questions included age, sex/gender, location, and occupation. The purpose of the questionnaire was for participants to describe their caregiving situations, and to keep the interview as short as possible. The questionnaire was given to participants to complete prior to the interview (to be completed at their convenience), and was used to provide descriptive information of the spousal caregivers.

#### 2) Semi-Structured Interview:

For the purposes of this study, a semi-structured interview guide (see Appendix E) was developed in order to allow for flexible topic development. The interview involved the participants describing what their caregiving situation was like, types of social and recreational activities they participated in, and whether there had been any changes in their social experiences since they had become caregivers. Probes related to travel, hobbies, interests, and relationships were included in the interview guide to ensure that the relative topics were covered during the course of the research interview. This guide was developed with the thesis committee. Interviews were used as the primary form of data collection (voice-recorded and transcribed), which allowed for accurate description of social experiences in the participants’ own words.

#### 3) Field Notes:

Poststructuralist theorists caution researchers against inferring meaning through language alone (Agger, 1991). Derrida (1997) argued that meaning found (or represented) using language is inherently unstable due to the subjective and imperfect nature of language. In other words, language is not an accurate representation of ideas or thoughts. This poses a problem in social research where the process of conducting research relies heavily (if not wholly) on communication between partners (Freshwater & Rolfe, 2001).

However, Agger (1991) argues that despite this imperfection in accurately conveying meaning through language, it is possible to approach understanding through a careful and

critical examination of language-based sources. To further account for these limitations, field notes were created in order to record observed behaviours (e.g. expressions, gestures, and etc.) not evident in the transcripts. Combined with the interview transcripts, these records of non-verbal communication were an important means of overcoming the potential pitfalls of language in qualitative research.

Field notes were written immediately after each interview. These notes included ideas about potential themes, remarks on the general nature of the interview, and any other relevant information that may not be evident from the voice recordings or the transcripts such as the researcher's impressions of the interview process. Additionally, several participants engaged in a discussion with me following the conclusion of the interview in order to hear my personal experiences as a child caregiver. I perceived this point of reciprocity as an indicator of the rapport and trust perceived by the participant.

Through the course of our open conversations following the interviews, several participants' shared additional stories or reflections not previously discussed during the formal interview. The voice-recorder was always turned off during these informal conversations. However, any additional or elaborative information relevant to the topic of social experiences was recorded in my field notes, for later consideration.

## **Procedure**

### *Identification of Recruitment Sites*

Identification of recruitment sites was done in two parts. Firstly, the Alzheimer Society of Hamilton-Halton, Brant, and Haldimand-Norfolk (HHBHN) assisted in recruitment within their organization. Additionally, the HHBHN Chapter approached other Chapters and relevant organizations. This process was initiated by the HHBHN Chapter Research Coordinator. However, the Chapters the Coordinator approached were not disclosed to the researcher.

The second part of the identification of potential recruitment sites involved a web-search of the Alzheimer Society of Ontario Chapter directories. Alzheimer Society chapters within South Western, South Central, and South Eastern Ontario were identified, and the individual chapter websites were reviewed to determine if these chapters had YOD appropriate support groups or services. For those websites that did not have information on the nature of the support services, the chapter office was contacted by phone or email for more information.

Those chapters that indicated they had YOD members or specific services for YOD members, were contacted individually (by phone or email) to discuss the nature of the thesis project, and whether the Alzheimer Society chapter would be willing to assist with recruitment. If the Chapter agreed, a mutually agreeable means of recruitment was arranged, using a support group presentation or a recruitment email (or a variation of these).

### *Participant Recruitment*

Assistance with recruitment was negotiated with several Alzheimer Society Chapters. The student researcher worked with each individual Alzheimer Chapter to begin recruitment in a way that was mutually agreeable. Three recruitment methods were used, depending on the preference of the participating Alzheimer Society Chapter, and the sampling method employed. Spousal caregivers who were interested in participating were provided with the student researcher's contact information, and invited to make contact with the student researcher if they were interested in the study.

After contact had been made by potential participants, the student researcher explained the purposes of the study and answered any questions (see Appendix B). The student researcher then asked if the person was interested in participating. If the person said no, they were then thanked for their time. If they were willing to participate, the researcher scheduled an interview at a time and location that was convenient for the person, and provided them with a copy of the demographic questionnaire. Participants were then given the option to return the completed questionnaire to the researcher prior to the interview, or on the day of the interview.

At the time of the interview, the student researcher reviewed the consent form (see Appendix G) with the participant and answered any questions they had about the study. The participants were then asked to review and sign the consent form if they were willing to participate. Participants were asked to sign two copies: one copy was given to the participant, and the second was retained by the researcher. Participants were also asked whether the interview could be voice-recorded by the student research.

### *Recruitment Procedures*

#### 1) Support Group Presentation (see Appendix B):

The support group leader at the participating Alzheimer Society Chapter gave a short, five minute presentation at a caregiver support group meeting. The support group leader briefly described the research topic and the objectives of the research study using a script. Support group participants were given a copy of the recruitment poster (with the student researcher's contact information; see Appendix F), and were invited to contact the researcher if they were interested in participating.

Additionally, support group leaders provided each group member with a 5 X 8 ½" index card which potential participants could fill out with their contact information. Following the presentation, the group leader asked everyone to return the cards. Those persons who were interested in participating in the research study were asked to check the "yes" box on the card, and write their contact information on the card. For those who were not interested, they were asked to check the "no" box on the card. The support group leader asked the group members to place all of the cards in a self-addressed, postage-paid, manila envelope provided by the student. The support group leader was then instructed to seal the envelope and drop it into a mailbox following the group meeting.

#### 2) Invitation Email (see Appendix C):



A letter was provided to the Alzheimer Society Chapters to use to invite spouses of persons with YOD to participate in the study. The letter identified the researcher, the purposes of the research study, and the procedures involved in the study. The Alzheimer Society representatives asked potential participants to contact the student researcher by email or telephone if they were interested in learning more about the study.

### 3) Participant Referral:

Participants who participated in the study were given a copy of the recruitment poster (see Appendix F) with their copy of the consent letter (see Appendix G) for their records. Although participant referral (i.e. snowball sampling) was not a recruitment method chosen by the researcher, this happened inadvertently; several participants passed along the poster to persons they knew who might be eligible and willing to participate in the study. Some of these individuals contacted the student researcher about the study.

## **Analysis**

### *Interview Analysis*

Qualitative content analysis was used to analyze the interview transcripts. For this thesis, conventional content analysis (codes derived from data; Hsieh & Shannon, 2005) using Elo & Kyngas' (2007) inductive content analysis approach was used to analyze the interview data. This process involves three coding steps: open-coding, creating categories, and abstraction (Elo & Kyngas, 2007).

Open coding allows for themes to emerge naturally from deep within the data, making it ideal for descriptive studies involving content analysis of interview transcripts. This process involves making notes and headings within the text during a first reading (Elo & Kyngas, 2007). The purpose of this process is to begin to condense the data into preliminary categories or codes, based on the research objectives (Neuman, 2006). This step in the analysis was done by hand, with notes being written in the side margins of the interview transcripts. Codes were created as they emerged in the open-coding phase. These codes were then collected in a coding book, which included preliminary insights and reflections surrounding the open-coding process (i.e. analytic memos). These notes proved to be an important reference during the grouping stage of coding.

The grouping and categorization stage of inductive content analysis follows the open-coding stage. Grouping and categorization generally involves grouping the data into categories based on the initial findings from the previous stage of analysis (Elo & Kyngas, 2007). The purpose of this process is to begin merging similar categories of data or creating new, broader categories to describe dissimilar data (Elo & Kyngas, 2007).

Given the semi-structured nature of the interview questions, mapping was a useful means of making sense of the themes that emerged from the data following the open-coding stage. As a visual learner, this technique was also useful to examine relationships within the thematic structure using the 'node structure' function of the NVivo qualitative

analysis software. NVivo 9 was used throughout the grouping and categorization stage of analysis, as well as the abstraction stage.

The process of abstraction stemmed naturally from the process of grouping and categorizing the data. This stage of analysis involves the researcher examining the previously created categories more deeply, and then beginning to formulate a general description of the phenomenon (Elo & Kyngas, 2007). This is a larger categorization process, where codes and sub-codes are grouped together into larger themes (or main categories) based on perceived relationships or similarities within the data (Elo & Kyngas, 2007). The abstraction phase of analysis allowed me to draw comparisons between codes and sub-codes (i.e. generic categories and sub-categories), and to consider relationships between ideas, and to scrutinize the nature of the themes on a deeper level.

I met with the Thesis Committee to discuss the emergent themes and sub-themes which I had developed following the open-coding and grouping/categorization processes. The purpose of this meeting was to make sense of my initial ideas about the nature of the data. By the end of the meeting, emergent themes were discussed and approved by the Committee. This was the beginning of the abstraction stage of inductive, qualitative content analysis.

### *Field Notes*

Conventional content analysis was also used to analyze the field notes. Like the analysis of the interview transcripts, this process began with open-coding. During the grouping and categorization stage, the coded field notes were used in conjunction with the coded interview transcripts to develop categories. The field notes were also important during the abstraction phase of analysis in order to ensure the resulting themes were representative of the nature of the described social experiences of YOD spousal caregivers.

### *Questionnaires*

Information from the demographic questionnaires was entered into a single Microsoft Excel sheet. The information was then analyzed using simple excel functions to calculate the mean and range of quantitative variables. Basic counts of qualitative variables were also taken (e.g. work status). The results of this analysis were used to generate a descriptive profile of the participants, the spouses with dementia, and their families.

## **Ethical Considerations**

### *Ethics Review*

Ethics approval was sought and approved by the McMaster Research Ethics Board. Participants were given a \$10 Tim Horton's gift card as a gesture of thanks for participating in the study.

Confidentiality of participants was protected throughout the entire research process. Alzheimer Society chapters were unaware of who participated in the study, and all

identifying information was removed or replaced with pseudonyms within the interview transcripts. Questionnaires were coded with numbers and kept separately from contact information.

To ameliorate any potential risks associated with participation in this research study, the letter of consent was reviewed thoroughly with the researcher prior to the interview. If the participant became upset at any point, the interview was stopped until the participant was ready to resume. All participants were made aware of their rights to stop the interview at any time, and/or withdraw from the research study. Contact information was also given to participants, and they were instructed to contact me, my advisor, or the MREB if they had any questions or concerns.

## FINDINGS

### Demographic Information and Description of Participants

All of the spouses who were recruited completed the study, resulting in a total of 10 spousal caregivers (6 females, 4 males). Caregivers' ages ranged from 42 to 66, with a mean age of 55 years ( $sd = 6.45$ ). All of the participants were married to partners of the opposite-sex, and only one participant had been married for less than 10 years (mean = 26.3 years;  $sd = 11.87$ ). Only one of the couples had been previously married (Joni). Table 2 provides a demographic profile of the participants.

**Table 2: Demographic Profile of Participants**

Participant	Age	M/F	Spouse	Age	M/F	Marital Status	Years Married	Children Y/N
Joni	49	F	Robert	62	M	Married	4	Y
Stevie	58	F	Donald	61	M	Married	32	Y
Nancy	42	F	Michael	61	M	Married	12.5	Y
Pat	66	F	Neil	67	M	Married	40	Y
William	55	M	Elizabeth	60	F	Married	30	Y
Anne	59	F	Stephen	66	M	Married	37	Y
Pete	57	M	Rachel	57	F	Married	31	Y
Linda	52	F	George	66	M	Married	21	N
Henry	54	M	Katherine	54	F	Married	18	Y
Matt	58	M	Lily	57	F	Married	37	N

Table 4 provides demographic information of the participants' family contexts. All but 2 caregivers had children (Linda and Matt), and caregivers had an average of 2 children. Children were primarily males ( $n=14$ ). The children ranged from 7-37 years of age, with an average age of 23 years ( $sd = 8.79$ ). Nancy and Henry were the only participants who still had all of their children living with them at their home. All of Nancy's children were particularly young in comparison to the rest of the participants; she had three boys who were 10 years old and under. Only two other participants – Pete and Henry – had children under the age of 18 still living at home. Several participants (Pat, William and Pete) had children over the age of 18 who were still living at home, and could be considered dependents.

**Table 3: Demographic Information of Family Context**

Participant	Spouse	Number of Children	M/F	Age of Children	Number of People Living at Home (not including the participant)	Spouse with Dementia living at Home?
Joni	Robert	4	M	25	1	Yes
			M	25		
			F	22		
			M	20		
Stevie	Donald	2	M	28	0	No
			F	26		
Nancy	Michael	3	M	10	3	No
			M	8		
			M	7		
Pat	Neil	4	F	37	1	No
			M	36		
			M	32		
			M	28		
William	Elizabeth	2	F	28	2	Yes
			F	26		
Anne	Stephen	2	F	35	1	Yes
			M	33		
Pete	Rachel	3	F	24	2	No
			F	20		
			M	17		
Linda	George	0	N/A *	N/A	1	Yes
Henry	Katherine	1	M	14	2	Yes
Matt	Lily	0	N/A	N/A	1	Yes

\*N/A = Not Available

All of the participants were currently employed, six on a full-time basis. Joni, Pete, Anne, Linda, and William worked full time outside of the home; Matt worked full time from home. Four participants indicated they had stopped working due to the demands of caregiving (Stevie, Nancy, Pat, and Henry). However, all four participants who indicated that they had ‘stopped’ working had in fact reduced working. Pat indicated that she had moved to part time work at home, moving towards retirement. Henry – who works from home – stated that he has had less time to work due to increased responsibilities at home associated with the effects of the dementia. Nancy moved to on-call, part time work due to her caregiving responsibilities for both her husband and her three young boys. Stevie indicated that she lost her full-time job (as a result of the demands of her caregiving), and has since moved to part time work from home.

### *Description of Persons with Dementia*

Persons with dementia ranged in age from 54-67 years, with an average age of 61 (sd = 4.33; see Table 3). They were primarily male (4 females, 6 males), and the majority were living at home with their spouse (3 were in LTC). Table 4 provides a description of the spouses with YOD. AD (n=6) and FTD (n=4) were the primary types of dementia affecting spouses at the time of the interview, although several participants described that their spouse had previously been diagnosed with something else, or that their diagnosis had changed over time. For example, Pete described how stress and then FTD were originally suspected before Rachel was formally diagnosed with AD with atypical presentation. Pat discussed a lengthy diagnostic process in which Neil was diagnosed with anxiety, depression, primary progressive aphasia, and FTD before a diagnosis of AD was finalized. The majority of the participants suggested that prior to their spouse’s diagnosis, they had suspected that their spouse was depressed.

**Table 4: Description of Spouses with YOD**

<b>Participant</b>	<b>Spouse</b>	<b>Spouse’s Dementia Type</b>	<b>Years Since Diagnosis</b>	<b>Spouse Working When Diagnosed?</b>	<b>Spouse Working Now?</b>
Joni	Robert	FTD	2	Yes	No
Stevie	Donald	FTD	4	No (already let go)	No
Nancy	Michael	AD	4	No (already let go)	No
Pat	Neil	AD	12.5*	No (already let go)	N/A
William	Elizabeth	AD	2	Yes	No
Anne	Stephen	FTD	2	No (quit before diagnosed)	No

Pete	Rachel	AD	4	No (quit before diagnosed)	No
Linda	George	AD	2	Yes (semi-retired)	No
Henry	Katherine	AD	0**	Yes	Yes
Matt	Lily	FTD	3	Yes	No

\*Spouse deceased for 2 years<sup>4</sup>

\*\*Recently diagnosed

Those spouses with FTD were primarily male (n=3); only one was female. Males and females were equally affected by AD (3 males, 3 females).

As Table 4 demonstrates, only one spouse with dementia was still working at the time of the interview (Katherine). However, Katherine was in the early-stages of the disease, and had only recently been diagnosed with AD. Henry stated that, “if she's working a year from now I'll be surprised,” indicating he was doubtful Katherine would be working much longer.

Six participants (Joni, Pete, Linda, William, Henry, and Matt) indicated that their spouses were working when they were formally diagnosed with dementia. Of these six, Linda stated that George was semi-retired at the time of diagnosis, but she suspected that his move to semi-retirement was the result of the effects of the disease.

Three participants stated that their spouse was let go from their jobs before officially being diagnosed (Stevie, Nancy, and Pat). All three of these participants linked their spouse's termination to the effects of the dementia, particularly a reduced capacity to cope with the demands of their jobs and deteriorating quality of their work.

Anne was the only participant who indicated that her spouse had quit his job prior to diagnosis. Like many of the participants, Anne linked Stephen's choice to quit to the effects of the disease.

## Results of Qualitative Analysis

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<sup>4</sup>I was not aware that Pat's husband had passed away until the day of the interview. Regardless of her husband's passing, Pat was still able to share her social experiences before the disease, as well as during the disease's progression in vivid detail. Although the interview took much longer to complete (in comparison to the other caregivers), Pat also provided some interesting insights into her experiences during the later stages of the disease. The most striking finding was that Pat still considered herself to be a spousal caregiver even after Neil's passing, suggesting that the caregiver role might not necessarily end upon the death of the spouse. For these reasons, I did not exclude this data in the proceeding analysis and discussion.

Interviews ranged from 45-60 minutes in length, and the interview questions and probes focused on caregiving and social experiences. Interview tapes were transcribed by a professional, medical transcriptionist with experience in academic transcription. Transcription took place concurrently with data collection so that the open-coding phase of analysis could begin prior to completion of data collection. This was important in order to ensure that saturation was achieved among the sample size.

The results of the qualitative analysis of interview transcripts highlighted four social themes (i.e. main categories) discussed by the participants. Within these themes were multiple sub-themes relevant to social experiences of the spousal caregivers. An overview of the thematic structure is presented in Table 5:

**Table 5: Thematic Structure**

<b><i>Theme 1: Sources of Social Support</i></b>	
<ul style="list-style-type: none"> <li>Continued Sources of Social Support</li> </ul>	<ul style="list-style-type: none"> <li>Including the Spouse with Dementia in Social Activities</li> <li>Providing Support to the Caregiver</li> <li>Helping the Caregiver with Caregiving Activities</li> </ul>
<ul style="list-style-type: none"> <li>Disappointing Sources of Social Support</li> </ul>	
<ul style="list-style-type: none"> <li>Unexpected Sources of Social Support</li> </ul>	
<ul style="list-style-type: none"> <li>Ideal Sources</li> </ul>	
<b><i>Theme 2: Giving up Social and Recreational Activities in Favour of New Activities</i></b>	
<ul style="list-style-type: none"> <li>Giving up Activities</li> </ul>	<ul style="list-style-type: none"> <li>Time Limitations</li> <li>Problems Associated with the Spouse’s Dementia</li> <li>Financial Strain</li> </ul>
<ul style="list-style-type: none"> <li>In Favour of New Activities</li> </ul>	
<b><i>Theme 3: Adapting and Maintaining Social and Recreational Activities</i></b>	
<ul style="list-style-type: none"> <li>Maintaining Social and Recreational Activities</li> </ul>	
<ul style="list-style-type: none"> <li>Adaptation in Social and Recreational Activities</li> </ul>	
<ul style="list-style-type: none"> <li>One Last Trip</li> </ul>	
<b><i>Theme 4: Social Spaces as Safe Spaces</i></b>	



## THEMATIC ANALYSIS

### Sources of Social Support

All ten participants discussed sources of social support. Although the nature of these social support sources were discussed in great detail, the majority of the described sources fell naturally into four categories: continued sources, disappointing sources, unexpected sources, and ideal sources of social support.

#### *Continued Sources of Social Support*

Eight caregivers discussed continued sources of social support. Participants who discussed continued sources of social support primarily spoke in terms of family and old friends. When Joni was asked about how her family and friends have been, Joni said: “they’re very, very supportive and, you know, they just take it all in stride and continue to include him in everything.” Similarly, William anticipated continual support from his family in the future when Elizabeth would move to LTC:

“When we get to that stage with Elizabeth I guess, we don’t have the same situation as my dad. Having this big community of friends. We have family and I expect that – they have been supportive all along; I don’t think there is going to be any changes in that.”

Continued social support was discussed in three forms: continuing to include the person with dementia in social activities, providing support to the caregiver, and helping the caregiver with caregiving activities.

#### Including the Spouse with Dementia in Social Activities

Five participants (Matt, Linda, Pete, Pat, and Stevie) described friends continuing to engage their spouse with dementia in social activities.

Matt said that his friends continued to invite him and Lily to their homes, and that these same friends had “stepped up” where family had not. Pat discussed how grateful she was for Neil’s friend Wilfrid, who continued to visit Neil in LTC, and engage with him in social activities even when Neil’s speech was impaired.

Linda stated how her husband George continued to play hockey because his teammates had made an effort to still include him:

“I emailed his captain and I said “I’m really leaving it up to you to tell me when it’s time to hang up the skates here” and he said “Absolutely not. George is great. He’s great on the ice. He’s great in the locker room. We love having him. He’s absolutely fine.””

For Linda, she expected her husband’s friends would continue to include George until he could no longer play safely. Additionally, Linda said her family would frequently stop in and have coffee with George during the day while she was at work.

Similarly, Anne's cousins also continued to play cards with her and Stephen despite the effects of the disease:

“The particular one [game] that we play he still does fairly well at. Near the end you can see he's getting tired and he loses focus and he'll play a wrong card or something, and he fumbles a lot with his shuffling, but they're wonderful and they just, you know, they just go with the flow.”

In addition to these less time intensive, ongoing social activities, Nancy described how her relatives overseas managed to arrange some money to have Nancy, Michael, and their children make one last trip to visit them. Pete described something similar. In the early stages of the disease, Pete's sister-in-law volunteered to take Rachel on a trip overseas to visit her extended family.

Six caregivers discussed how family continued to support them personally (Matt, Linda, Pete, Anne, Pat, and Nancy). Matt and Nancy both stated that although their relatives were limited in their capacity to help them more (due to geographic distance or health limitations), they still continued to provide them with emotional support over the telephone or by email. Pete described how Rachel's brother and sister allayed his fears when he made the decision to move Rachel to LTC. He said, “they were incredibly supportive, which was a worry of mine.”

Stevie also discussed how her friends of 20 years – Kate and William – continued to visit Donald in LTC. Prior to Donald's diagnosis of dementia, Stevie and Donald regularly spent Christmas Eve and New Year's Eve with Kate and William. For Stevie, Kate and William treated Donald in an expected way: “you know, they love him... they react the way I would hope someone who loves him reacts.”

### Providing Support to the Caregiver

Additionally, six participants (Linda, Pete, Anne, Pat, Nancy, and Stevie) described how friends continued to provide social support to the caregiver, primarily with managing the emotional impacts of their spouse's decline. Anne and Nancy talked about their old friends continuing to be there for them. Linda described how her old friends continued to be there for her, even when things became difficult:

“I didn't realize was that I wasn't coping and I had a major melt down in front of friends... they said “You've got to make that phone call.” And she said “I will go with you” she literally held my hand through the process of going in for our first meeting [at the Alzheimer Society] and then she attended the educational series with me and she started in the support group with me. So that was really great and then she said “You know you're good. I'm letting you fly little bird” and now I go by myself.”

Linda's friends provided ongoing support, even when Linda's ability to cope with the emotional impacts of caregiving became strenuous. Helping Linda find appropriate caregiver support was an extension of this ongoing social support.

Pete discussed how one specific friend had been particularly supportive of him, which he attributed to her own personal caregiving experiences with her father who lived with dementia. He was grateful for her advice, which he described as “incredibly pragmatic.”

### Helping the Caregiver with Caregiving Activities

Pete described how old friends continued to provide social support by offering to assist with caregiving activities. Pete explained that caregiving for Rachel early in the disease was manageable because they (as a couple) had so many friends to help. Although Rachel now required professional care in a LTC home, Pete remained thankful for this past social support.

Seven participants stated that family was a continual source of social support (Matt, Linda, Pete, Anne, William, Pat, and Nancy). Three caregivers (Matt, Linda, and William) said that their family had willingly assisted with caregiving activities for the spouse with dementia. Linda explained how her family “rallied” around them, and frequently offered to take George to appointments and other places. Surprisingly, both Matt and William described how their spouse’s parents had occasionally stepped in to assist with caregiving activities. William described how Elizabeth occasionally spends a few weeks at a time with her parents:

“Her parents are very elderly, they are 88 and 90... in spite of their advanced age they’re still mobile and active and they both have their driver’s licences... she’s gone down and stayed with them for one or two weeks at a time maybe two or three times she’s done that. That’s a good thing. It’s helpful for her because she’s going into a stress-free environment there.”

Matt’s 96 year old mother-in-law also offered to assist Matt with caregiving two days a week. Matt described how he would pick up his mother-in-law and bring her to Matt and Lily’s home to stay with them until Sunday afternoon. Although Lily’s mother did not drive, she was still able to assist with caregiving activities during those few days while Matt looked after the business and caught up on chores at the house.

### *Disappointing Sources of Social Support*

Contrasting continued sources of social support described by caregivers, many also discussed persons within their social support networks who had not lived up to the expectations of the spousal caregivers. In other words, disappointing sources of social support referred to persons whose behaviour or actions did not reflect their prior relationship with the couple. These ‘disappointing’ sources of social support were described by seven participants (Joni, Matt, Pete, William, Pat, Nancy, and Stevie) during the interviews. Disappointing sources involved a wide variety of people, including friends, family, neighbours, and co-workers.

The participants who talked about disappointing social support provided rationalizations or reasons why persons within their social networks had not been as wholly supportive as they had initially hoped. Reasons for their disappointment generally stemmed from

changes in behaviour towards the spouse with dementia, the caregiver, or the couple as a whole. These behaviours or treatments were perceived as negative, and effectively contributed to the caregiver's disappointment in the perceived quality (or lack thereof) of social support proffered. Two distinct reasons for disappointment were described: social avoidance and acting as if the person with dementia was dead or non-existent.

Four participants (Matt, Pat, Nancy, and Stevie) described how persons within their social support networks had avoided them, which led to social disappointment. Matt and Stevie both said that family members had avoided them and/or their spouse with dementia, which Matt described as "personal and hurtful."

Stevie also described a disappointing encounter with her sister-in-law, in which she avoided seeing Donald. Donald's sister did not live in Canada, and Stevie said her sister-in-law never called or asked about Donald. However, Stevie described how excited she was when her sister-in-law called and said she was coming to Canada to visit. This excitement was quickly replaced with disappointment when Stevie's sister-in-law avoided going to visit Donald in LTC.

"I asked his sister if she was going to come up and see Donald, and she said, 'I wonder if he'd remember me?' So out of my mouth I blurted, 'well, that's not the point,'...I think there's just people who understand the meaning of life, and there are people who do not, and I'm not sure why, and I spend time pondering why, and, you know, I think there are times when we don't get that answer and you have to let it go for your own well-being."

Just like Stevie, Pat resented her friend Betty because of a perceived lack of compassion for Neil and his declining state. Pat discussed her close friend Betty who would not visit Neil while he was in the hospital. Pat's incomprehension of Betty's rationale for not visiting Neil did not seem to reflect her experiences as a hospital volunteer in the intensive care unit:

"She told me once she didn't want to see Neil like that, that's why she didn't visit him and I don't accept – I've never accepted that as an excuse from people. It's – Who's sick here? Like let's get your priorities straight. It might be difficult for you but think how awful it is for them? And the fact that she worked in the hospital and saw sick people all the time you would think that she wouldn't be uncomfortable in that way. So, yeah she is still involved with me but I feel like something is still there, that I'm resentful of... So when June came or my friend Sophia would come with me- that's why I resent my friend Betty because here are people who didn't even know Neil that well who would come to the hospital with me."

Additionally, Pat stated that she knew she would have to 'confront' Betty at some point in the future about the change in their relationship. She described how she felt, "like it's always there. It's always there when I'm with her." The lack of compassion demonstrated by Betty ultimately led to a less-trusting relationship.

Avoidance by old friends which lead to disappointment was discussed by three caregivers (Matt, Pat, and Nancy). Pat described how a couple she and Neil used to socialize with began avoiding them after Neil made some embarrassing comments at a theatre. Pat invited them for dinner, but they made excuses for why they could not come. Nancy described how in addition to Michael's old friends avoiding them, her husband's old co-workers avoided seeing them. She said, "Not even his boss called – it was incredible."

One participant (Pat) discussed in great detail how many of her neighbours had avoided her and Neil. She said:

"Neighbours we've known – We've been here 28 years. I could see them being out front in their yards as we were walking down and disappearing before we – And I don't think I was reading into it because really, they didn't make any – a number of them who knew Neil didn't make an effort to speak to him."

Additionally, Pat described how one older neighbour (who had worked with Neil's father) had become friends with Neil. However, Pat began to notice that this neighbour would avoid seeing or speaking with Neil as the dementia progressed. Pat said that eventually, "he [the neighbour] would bring magazines over and hang them on the gate for Neil but not ring the bell to have any conversation with him." Considering how long Pat and Neil had been in the neighbourhood, and the positive nature of their previous relationships with their neighbours, this avoidance led to great social disappointment.

In Matt's case, he recounted a time when he tried to arrange one last trip out West for Lily to visit her 'niece.'<sup>5</sup> However, when it came time to make arrangements, Matt was told that Lily's niece was too busy and that they would have to stay in a hotel. Then Matt said that he was told if he and Lily came out West to see their niece, they would maybe meet her at a coffee shop. After this disappointing treatment, Matt gave up on the idea.

Five spousal caregivers (Pete, William, Pat, Nancy, and Stevie) discussed how disappointed they were with persons in their social networks who had acted as though their spouse with dementia was dead or non-existent. Family members who acted this way, were described by three participants (Stevie, Pete, and William). Stevie recounted how her sister-in-law called to make arrangements to pick up family heirlooms that had been bequeathed to Donald by his parents. This was shocking because Donald was still alive. Stevie also mentioned that none of Donald's siblings ever called to ask about him, or visited him in LTC.

Nancy echoed this tendency of persons to act as though the spouse with dementia was dead. In discussing Michael's co-workers, she stated that, "nobody called to ask me if he was alive."

Pete talked about how family members treated Rachel as though she did not exist. In Pete's case, he described how his father used to engage with Rachel in the earlier stages of the disease. However, Pete noticed that his father now would say things to him about

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<sup>5</sup> Lily and Matt's 'niece' was actually the daughter of an old friend, and not actually family.

Rachel as though she was not in the room. His Dad's tendency to talk over Rachel, or ignore her presence greatly annoyed Pete:

"I've been angry with my Dad... He'll say, "You know, she's losing a lot of weight," and I'll say, "You know, Rachel's standing right here.""

This tendency to pretend the person with dementia does not exist was reflected upon by William, who described it as "people's unwillingness to see past the disability to the person." Pat described a similar experience with her close friend Betty who continued to be friends with her, but "left Neil" entirely. For these five spousal caregivers, persons acting as though their spouse was dead or non-existent resulted in disappointment in a previously positive source of social support.

### *Unexpected Sources of Social Support*

In stark contrast to disappointing sources of social support, surprising sources of social support was the most salient theme within the context of support sources. All ten spousal caregivers described experiences when people within their social networks had provided them with increased or unexpected forms of social support. Stevie described these unexpected sources of support as, "little bits and pieces of people who can deal with it [the disease]." Unexpected sources of social support came from many diverse areas within the couple's social network, and included a variety of persons such as the couple's children, church members, neighbours, support group members, and friends.

Four spousal caregivers (Joni, Henry, Linda, and Pat) stated that their children and grandchildren had been surprising sources of social support. Henry explained that his relationship with his teenage son had grown. He stated that they had become closer and bonded over their shared experiences living with Katherine. He said, "He's a smart kid. You know, he understands all this stuff, or perceives it, so I guess we're closer inasmuch as I'm the one he can talk to, [he] can't really talk to- and she drives him nuts."

Joni also discussed how her relationship with her oldest step-son was better than it was before Robert's diagnosis. This was surprising to her, as Robert's sons had been forced to move in with their mother when Joni and Robert had to downsize their home (because of the dementia).

Surprising social support also came from other family members, and was discussed by Linda, Stevie, and Pete. Stevie discussed how surprised she was when her son Billy's future in-laws came to Canada to visit and asked to go to meet Donald in the LTC home. For Linda, her great-niece was a great source of social support for both her and George. She expressed her amazement over how Suzy interacted with George, despite her very young age, and George's continual decline:

"She loves Uncle George. Loves him. So he gets there at Christmas and "Uncle George, come into my living room." So there he is, there's pictures of him having a tea party with Suzy. \*laughs\* You know? It's amazing... She's so cute and she loves him so much that, it's great. I think the little ones are so good - well everybody is but especially Suzy. It's very special."

Five participants (Matt, Linda, Pete, Pat, and Stevie) stated that friends were surprising sources of social support. Stevie described a time when her friends came together and offered to look after Donald for the day so that she could have a break. An old friend of Pat and Neil's who was a performer, dedicated his performance to Neil and wrote Pat a long letter about all of the wonderful memories he had of Neil. Pat was deeply appreciative of this.

Linda became emotional when she began discussing the outpouring of support they (the couple) had received from their friends. Recently she had participated in the Walk for Memories (a fundraiser organized by the Alzheimer Society), and had been surprised by the generous "outpouring of love" old friends had shown her through pledges and other gestures of support. Linda described this support:

"Last weekend there was an article about George and I and the Walk in the local newspaper and I can't tell you the number of emails we got because of that... people are pledging - people that we have not been in touch with in years, have sent pledges... Guys from hockey that don't play anymore have sent pledges. A girlfriend of mine that I went to high school with and I haven't seen her since our high school reunion, which was probably 8 years ago, she sent a pledge. It's just amazing what happens..."

Six caregivers (Linda, Pete, Anne, Pat, Nancy, and Stevie) stated that their co-workers or employers (or their spouse's co-workers and employers) had been surprising sources of social support. Nancy described how her old co-workers have cooked meals for her, and have come over in the middle of the night to watch the boys when she's had to go to the hospital.

Four participants (Joni, Linda, Pat, and Nancy) stated that their neighbours were surprising sources. Linda described how the neighbours watch out for George during the day while she is at work. Despite Pat's experiences with neighbours avoiding her and Neil, Pat also talked about one of her neighbours – an occupational therapist (OT) – who would go out of her way to talk to Neil, even though his speech was impaired. She recounted her surprise, stating that this "meant so much to him and to me to have somebody, you know, willing to still treat him like he was a person."

Three participants (Linda, Pat, and Stevie) described pets as significant and surprising sources of social support. Pat stated that pets should be considered, "part of the social network." Certainly, all three participants who described their pets as surprising sources of social support agreed that their pets had provided them and their spouses with considerable enjoyment. Pat elaborated on her astonishment over how much social support her family dog provided to her and Neil:

"She's a big part of my life. Again I don't know what I would do without her. Talk about socializing. I mean ask how many people have – caregivers have pets who are keeping them sane. Really, what she did for all of us and for Neil. She was amazing with him because when he would get frustrated she would walk over and like with her nose just bump him and get his

attention and he would pat her and like completely divert him. It's probably some technique that they teach at school but she knew it instinctively."

Stevie also described the surprising importance of pets. She stated that having her dog forced her to get dressed and out the door in the morning to take her for a walk. Her dog's reliance on her was also reciprocal; she said that, "If I didn't have her I think I'd lie in bed a long time."

Peer support (i.e. support from other dementia caregivers) was the most surprising source of social support discussed by eight of the caregivers interviewed for this study (Joni, Matt, Linda, Pete, Anne, William, Pat, and Stevie). Several participants described how they had met new friends at support group meetings (Joni, Anne, Stevie, and Pat), and had even begun socializing with these new friends outside of the support groups. Anne discussed this in detail:

"I've met some really great people [through the Support Group] and we actually get together outside of the group as well... two of the girls and their husbands, and the six of us have actually got together, with our husbands so that's a good times... we went to one for a meal and then we went to a dinner theatre type show together, so that's really nice... like they're all around the same age... see out of everything bad something good comes of it"

Pat stated that attending a created support group (i.e. a support group that she had created with other YOD caregivers, not affiliated with a social service organization) had become her means of socializing. The surprising importance of peer support described by Pat and Anne, was echoed by Linda who called the support group her "lifeline."

Lastly, five participants discussed surprising sources of social support coming from other individuals. For example, Matt described how he hired a private personal support worker (PSW) after being disappointed with the PSWs provided to him by the Red Cross. This private PSW became a surprising source of social support to him and Lily, because she engaged more fully with Lily on the days she was in their home.

Linda, Pete, and Pat discussed the surprising amount of social support they received from their spouse's physicians (family doctors and specialists). This support was considered to be surprising because the participants described it as beyond the level of care typically associated with the duties of a doctor. For example, Pat talked about her husband's neurologist Dr. Sue who made herself always available to her patients. Dr. Sue had a nurse practitioner on call at all times when she herself was not available. Pat said that the level of access they had to Dr. Sue was "amazing." Furthermore, Pat said that Dr. Sue had even connected her with caregiver support services.

Linda had a similar experience with her husband's family doctor who was instrumental in facilitating his diagnosis, and his ongoing care. She described how lucky she felt to have his social support:

"He takes it very seriously... the doctor said to him "You know what? We're going to get your hip fixed and we're getting you to a specialist and



we're not messing around. "and I love that about him. He doesn't mess around... My doctor is relatively young. He's about 55 and I think maybe that's why he's more proactive. I don't know. Or maybe I'm just lucky."

Nancy – a recent immigrant to Canada – also described how lucky she felt that she ended up in Canada. She discussed many unexpected sources of social support such as other parents at her sons' schools, and even teachers who had gone out of their way to help her family. Particularly important to Nancy was the outpouring of support that came from members of her church. For example, Nancy talked about how her family's 'adopted grandmother' (a member of her church who was a close friend) had taken her and the boys to a theme park for a vacation. Other church members had surprised her at Christmas time by coming over to their home and decorating the outside of her house with Christmas lights. Not only were these unexpected sources of social support comforting to Nancy, but she stated that, "things like that encourage me about God."

### *Ideal Sources*

Although participants were not specifically asked to describe what an ideal source of social support should represent, two participants (Pat and Nancy) discussed this during the interview. For Pat, ideal social support meant that persons within her social network were providing social support to both her and Neil, and not just her alone. Pat painted a picture of ideal social support in the course of the research interview:

"I think for everybody if people could realize how little time they have to spend to really make a big impact. It would be nice if neighbours or friends, you know, even if they committed – like one – Wilfrid, once every 2 weeks but such a big thing for Neil and for me - For Neil because it was socializing. For me to know that Neil had somebody relating to him that was important. You know, if people would just walk around the block with him, I thought that would be nice. If somebody had gone down the trail with him. It would have meant so much, and not just in terms of me having the free time but knowing that he's doing something different with someone other than me because it became just me."

Nancy also discussed that ideal social support meant that people were engaging with Michael, even though he could no longer reciprocate verbally or physically. She hoped that people would support him just by being there for him:

"I suppose what I really want is somebody to look out for my husband too. I suppose because it's also something new in my circle, for them too. There's never been anybody with an illness like that, where they would visit."

## **Giving up Social and Recreational Activities**

### *Giving up Activities*

All ten participants described giving up social and other recreational activities due to various caregiving considerations. The reasons given for why participants gave up activities varied between individuals and the nature of the social or recreational activity described. However, all of the reasons given centred on different aspects of caregiving. There were some similarities in reasons given between individuals. These reasons included not having enough time, problems associated with their spouse's dementia, and financial limitations. Of these reasons, a lack of time was the most frequently cited reason for giving up social and recreational activities.

### Time Limitations

Eight participants described how time limitations had resulted in their giving up a social or recreational activity (Matt, Linda, Pete, Anne, William, Pat, Nancy, and Stevie). The majority of those activities that were given up due to time constraints were primarily singular activities that the caregiver participated in alone (without the spouse). For example, William stated that he no longer had time read books on the weekend (something he previously enjoyed) because he had so many chores to catch up on before the start of the next work week. Matt also gave up several hobbies due to time constraints.

Linda used to be a regular golfer and a skier. However, she described how she gave up golfing with her girlfriends, and weekend ski trips due to the lengthy time commitment associated with these activities. This was seen as time taken away from being with her husband George:

“I am a very social person and I would go out a lot with my girlfriends, go for dinner - I used to golf. Nine holes after work with girlfriends...I just don't feel like I can be gone that long anymore. I can't work all day and then golf at night and then come home at let's say 10 o'clock. Because it's - I don't think - I don't think he'd handle it that well.”

Pat explained how she gave up going out with her close friend because it became too difficult to “find the time.” Similarly, Nancy described how she no longer had the time to socialize with her girlfriends. She elaborated on this, stating that one of her close friends lived down the street, but she did not even have time to leave the house to say hello to her neighbours because she did not feel she could leave her three young sons alone.

Anne explained how she gave up volunteering with a community service organization. She stated that, “right now I'm just too busy.” Time limitations associated with caregiving and other responsibilities were echoed by Pete, who described juggling his parental responsibilities, work responsibilities, and caregiving responsibilities. He stated that he used to have brief ‘windows’ of time in order to cycle or go running. However, those windows disappeared when he “needed to be home at more regular hours,” in order to be home for his children and care for his wife. These time limitations resulted in Pete giving up these recreational activities, but they also extended to his participation in peer support groups. Pete spoke positively about attending peer support groups with other young onset caregivers. However, he stated that time constraints made it difficult for people of his age to attend these groups. As a result, Pete explained that balancing work

and other responsibilities lead to consciously giving up attending because of the amount of time it takes to attend a support group.

### Problems Associated with the Spouse's Dementia

Eight participants (Henry, Matt, William, Pete, Anne, Pat, Nancy, and Stevie) stated that they gave up social and recreational activities due to problems associated with their spouse's dementia. "Embarrassing" or "inappropriate" behaviours associated with the dementia were the most common disease issues described by participants. Both Matt and Pat said they gave up going to the theatre because their spouses' would interrupt the actors and the show by talking loudly. William described a similar experience where his wife Elizabeth offended a comic at a comedy show by sighing loudly, which resulted in an embarrassing public situation.

Stevie, Anne, and Pat discussed how reduced decision making associated with increased cognitive impairment presented safety concerns. These safety concerns associated with their spouse's dementia resulted in their decision to give up activities such as travel. For example, Pat gave up bicycling with Neil because he would no longer notice traffic hazards on the streets. Stevie recalled an experience with going through airport security where Donald ignored the security agent's directions. Stevie stated:

"[the officer] says, "remove your shoes," he looks at her, goes to pick up his luggage, and I could see her, like she's looking at him and she's- she let him go, if he had been anywhere in the world he would have been tasered I guess, so it got too dangerous after that, I just, no way."

Six participants discussed giving up travel entirely because of increased difficulty or safety concerns (Joni, Pete, Anne, Pat, Matt, and Stevie). Matt explained that he and his wife Lily were particularly avid travellers prior to her diagnosis, which he attributed to the fact that they did not have children, and therefore had extra money and time to participate in those activities:

"So usually once a year we would travel outside Canada, we got to see different parts of the world, and we'd travel once a year within Canada. We've seen a lot of Canada. So we're quite active. How has it changed? It all came to a grinding halt."

Joni also described how she and Robert used to travel several times a year. Although Joni and Robert had children, Joni also explained how those trips were "not happening anymore."

Stevie described giving up going to the gym because Donald could no longer be left alone. Similarly, Joni explained how she had to give up evening curling because, "it's hard to find someone to come in and stay with him that late in the night," and Robert could no longer be left alone.

Pete and Anne gave up activities that had become difficult or no longer enjoyable for their spouse due to their progressing dementia. For Pete, trips to the cottage became confusing for Rachel. He described how she would become confused and disoriented,

particularly with regard to sleeping arrangements. Pete stated that Rachel would not sleep at night, resulting in his decision to give up going to the cottage. Similarly, Anne gave up walking with her husband because Stephen would become cold easily, which made the activity unenjoyable for him.

### Financial Strain

Other participants explained how they had given up activities specifically due to the increasing financial burden they were experiencing (Henry and Nancy). Henry said that they had given up big trips in favour of the odd concert or small trip because he was concerned about their financial situation. Because Katherine's job represented the primary source of family income for their household, Henry was concerned about the small pension she would receive when she would be forced into early retirement: "I'm trying to make sure we're saving money, because I don't know what the future holds."

Nancy also described giving up activities due to limited economic resources. Like Katherine, Michael's job represented a major source of family income for Nancy's family. Now that he was no longer able to work and was living in LTC, Nancy had been forced to give up family trips with her children due to the financial strain associated with paying for two households (i.e. LTC and their family home).

Giving up activities due to financial constraints also extended to Nancy's children. She stated that she was no longer able to afford to enroll her children in recreational activities such as swimming and hockey.

### *In Favour of New Activities*

Six spousal caregivers (Henry, Joni, Matt, Pete, William, and Pat) described how they had given up social and recreational activities in favour of new activities that fit with their schedules and caregiving responsibilities, or that they could participate in with their spouses. Of these new activities, many were singular recreational activities or pass-times, and the majority involved physical exercise.

Three spouses (Joni, Matt, and William) explained how they had given up social activities in favour of new recreational activities. Joni – who had given up golf and curling due to scheduling problems and her husband's increasing dependency on her – had taken up puzzles and games for entertainment. She stated that she had, "to stay fairly quiet because as soon as I start trying to do things, he gets more agitated." As a result, she took up these activities to pass the time.

Matt and Lily had been fairly active campers before Lily was diagnosed with FTD. Matt also used to participate in river kayaking with friends. These activities were abandoned as Lily's dementia progressed. However, Matt explained that he had recently begun kayaking alone on a large pond nearby his home for exercise. Similarly, William had recently (the day of the interview) begun exercising in the morning before work. He stated that his daughter had asked him to purchase a treadmill, and he had made the decision he would start to work out in the morning before work. For both Matt and William, these new forms of recreational exercise were possible because they fit within

their schedules, and participating in them did not require them to leave their spouse alone for very long.

One participant (Pete) gave up multiple activities (e.g. entertaining, cycling) in favour of two activities he could participate in with his wife Rachel. These activities were ones which were mutually enjoyable for both persons, such as looking at tabloid magazines or photo-books together:

“Sometimes if you sit with her you can look at a Hello Canada, or a magazine or something, which is just hysterical for me, this is sort of what we've come to... but she'll look at a *Hello Canada* and just hairstyles, or dresses or something, and that seems to be [a] good sport... our eldest, had given her a Vanity Fair portraits book, so pictures of Marilyn Monroe or something, and that seemed to be of interest.”

Additionally, Pete described how he had taken to giving Rachel a bath each night at the LTC home where she lived. Rachel's LTC home was a new facility, equipped with a state-of-the-art tub, which Pete was allowed to use. Pete spoke fondly of this new activity with Rachel:

“She's great, she's so appreciative of that and it's a tender moment, I like the fact that we can still have that tender time I do those things and I think staff probably thinks it's great because it's one less thing that they have to do... sometimes you know we take candles into the bathroom, I said “It's like a spa.” You know, she laughs, just because you know- lots of people gave her for Christmas those nice bubble stuff.”

For Pete, this new nightly activity with Rachel was not only one he could participate in with Rachel, it was also an extension of his perceived role as a caregiver. He attributed being able to participate in this new activity with Rachel to his age: “I'm young- I mean it's not like I'm 83 and I can't give my wife a bath.”

Lastly, six participants (Henry, Joni, Matt, Pete, William, and Pat) described giving up social and recreational activities in favour of singular pass-times and activities. Of these new, singular activities, four caregivers (Henry, Matt, Pete, and William) had taken up a sport or an exercise-based activity. Henry had recently taken up sports such as squash. Although he was receiving treatment for a back injury (and was not playing at the moment), he had hoped to resume playing squash once his doctor cleared him. Regardless, Henry explained that he tried to exercise at least six days a week.

Pete had taken up running again. However, he stated that starting to run was different than it was before Rachel's diagnosis; now he ran alone.

Two caregivers (Joni and Pat) described giving up activities in favour of new, singular activities. Pat's new activities were numerous. She described taking up woodworking and advocacy activities (relevant to dementia), as well as professional development courses. She had also begun cataloguing her husband's model train collection, which she described as extensive:

“Neil’s train table downstairs – As his disease progressed he started rewiring things, but they did not work and his train never seemed to be going... So, I did a database of all his trains. He had over 300 different trains, - By colour and by railroad name and by type and by car and so on. I knew that that was one thing that would be very difficult for me to let go of so... I talked to somebody at the model railroad store... and he came out and helped get the wiring all set up. It hasn’t really become a hobby of mine but I could see it happening.”

## **Adapting and Maintaining in Social and Recreational Activities**

All of the caregivers interviewed for this study described their efforts to maintain and/or adapt so that they or their spouse could continue participating in activities. This may or may not include new activities that the couple could participate in given the new challenges associated with the progression of the spouse’s dementia. Maintaining social and recreational activities referred to efforts on the part of the caregiver to continue participating in previously enjoyed social and recreational activities, or efforts to keep the person with dementia involved in these activities. Adaptation referred to changing an activity or way of participating in an activity so that the spouse or the person with dementia could continue to participate in it. It also referred to modifying different aspects of the couple’s life (e.g. schedule) in order to incorporate new activities. Sandwiched between adaptation and maintaining social and recreational activities, was an emergent theme of ‘one last trip.’

### *Maintaining Social and Recreational Activities*

The spousal caregivers who participated in the study also described efforts to maintain existing recreational and social activities. Maintaining activities – like adaptation – involved maintaining activities that the caregiver was involved in, activities the spouse with dementia was involved in, and activities the couple experienced together.

Eight spousal caregivers (Henry, Joni, Matt, Linda, Pete, Anne, Pat, and Stevie) discussed how they had maintained existing social and recreational activities while providing care to their spouse with YOD. Linda stated that she still continued to attend her book club, which met once a month. Anne maintained physical fitness activities such as going to the gym and attending aerobics classes. Both Matt and Pat stated that they both enjoyed and continued cycling.

Stevie explained how she made an effort to maintain her social relationships with friends. She continued to engage in social activities such as short trips and going to lunch with her girlfriends. The importance of maintaining these social relationships was evident during the interview:

“I do keep contacts with my friends, to this day, I don’t isolate here, I, with the people who mean a lot to me and who are good for my soul I don’t want to ever let the year go and say, “oh my god I never contacted them.”

Three participants (Linda, Anne, and Nancy) for this study discussed maintaining social and recreational activities for the spouse with dementia. Nancy described how Michael used to go for breakfast with his friends on the weekend. Although he eventually became too afraid to go (due to incontinence), she stated that he maintained this activity for a while after his diagnosis.

Linda discussed how George had taken up golf when he retired, and still maintained this activity. For George, golf was both a recreational activity and a social activity which he did with his brother and some friends. Anne’s husband Stephen continued to cook (an activity he enjoyed). However, Anne was not sure how much longer he would enjoy this activity. She stated that he “gets flustered, especially if he has to follow a recipe or something.”

Nine spousal caregivers (Henry, Joni, Matt, Linda, Pete, Anne, William, Pat, and Stevie) talked about experiences of maintaining social and recreational activities that the couple participated in together. Henry discussed how he and Katherine would work together to prepare meals. He recounted this ongoing activity fondly:

“We usually go out as a family Friday nights for dinner and then Saturday Katherine and I will work together to make a meal at the house, you know, or we try to eat Vegetarian, if not Vegan, and that proves to be a challenge, but it's fun, we like doing that.”

Henry also said that the entire family (including Katherine and their son Billy) frequently attends musical concerts, as music was something Henry said both Katherine and Billy had a great interest in. Similarly, Linda also stated that she and George still made use of their subscription to the symphony.

Five participants (Henry, Linda, William, Anne, Pat, and Joni) stated that they had continued to maintain regular social activities with their families. For example, Henry said that the entire family still continued to visit his father in the United States, and make weekend trips to visit his in-laws out of town. Anne and Stephen continued to play cards with her cousins, and participate in various family functions a few times a year. Pat recounted how they continued to spend holidays together:

“We still had the Christmas and Thanksgiving and all the holidays together and his birthday and my birthday so, we still maintained those things.”

William talked about how he, Elizabeth, his daughters, and his sister still continued to spend time together. During the interview he talked about how they had all gone to the theatre together the past weekend.

### *Adaptation in Social and Recreational Activities*

Acts of adaptation in social and recreational activities generally involved adapting an existing activity, or making changes in the couple's life to allow for participation in new or existing activities. This theme of adaptation was discussed in terms of adaptation related to the spousal caregiver's social and recreational activities, adaptation related to those activities of the spouse with YOD, or activities together as a couple.

Five spousal caregivers (Joni, Matt, Linda, Pete, and Stevie) discussed adapting so that they could participate in various social and recreational activities. Joni described how she was going to change the curling league she played in so that she could play in the early evening. The early evening was better because she could more easily find someone to come and stay with Robert.

Matt had begun using respite services, which he called "little windows" of time he used to catch up with friends out of town, or go to the symphony and theatre. Making use of the respite services now allowed him to engage in social and recreational activities. Linda had also found little windows of time. Although she had given up regular skiing and lengthy ski trips, she had recently made a short trip to a girlfriend's ski condo. She said that she drove to her friend's condo on Sunday night, spent Monday during the day skiing, and then drove home in time to make dinner for her and George Monday evening. This change in when and how long she went skiing was a simple adaptation: "I didn't feel like I was gone that long and he [George] was fine."

Six participants (Matt, Linda, Anne, Nancy, William, and Pat) discussed adaptation in order to continue or begin social and recreational activities for their spouse with YOD. Matt and Anne had both enrolled their spouses in a day program so that they could (as Linda described it), "get out more and see different people." Matt had also foregone PSWs through the Red Cross, and hired a private PSW who engaged more fully with Lily by doing laundry and cooking with Lily. This simple change led to increased socialization for Lily.

When Pat's husband Neil lost his license and could no longer go 'yard-saling' (something he enjoyed), he had begun using his bike. They ended up buying him a backpack so that he could carry things, and continue to participate in this activity.

Nine caregivers (Joni, Matt, Linda, Pete, Anne, William, Pat, Nancy, and Stevie) described how they had adapted in order to participate in social and recreational activities together as a couple. Pete had begun a daily routine with Rachel involving walking to Tim Horton's after dinner. Although she had begun needing help with feeding, he found that they were still able to have a coffee together before she would go to bed at the LTC home.

Anne discussed her plans to go on a trip to visit their friends in the United States. Although many types of travel were no longer possible with Stephen, this short trip was possible because there was a small motel near their friends' place where Stephen could rest comfortably, and the area they would be travelling to was fairly "contained." She was prepared for the flight there, and said she would need to empty Stephen's pockets for him before going through security.



William discussed how he and his wife Elizabeth had begun lawn bowling because it was an activity that Elizabeth could easily participate in. Although William described his reluctance to participate in an activity with a group of people who were primarily older adults, he also stated that this was one of the few resources available to them in which Elizabeth could socialize and participate in a recreational activity. He stated:

“I’ll do that once or twice a week. It’s just around the corner from our house. We can walk over together... But those are the resources that are available. You don’t have resources for – or you don’t have those kinds of things for middle age people because we’re all at work.”

Nancy recounted how Michael used to love cartoons. He was no longer able to participate in physical activities with the boys such as pool, or have conversations with them. However, Nancy recently noticed that he would watch the television when the boys would turn on cartoons during their visits. Now she and the kids watched cartoons together with Michael at the LTC home, because it was something he could participate in.

Lastly, Stevie, Matt, Linda, Pete, and Pat talked about making adjustments to how they socialized (as a couple) with their friends. For example, Stevie explained how Donald’s behaviours at their dinner parties had become embarrassing and stressful for her. As a result, she began only having very close friends over who understood the situation. Linda also described adapting to George’s changing needs during social activities. One of these social activities was to go a few times a year to dinner and the symphony with a group of friends. She stated:

“There is 8 of us now and usually we would go up for dinner first and then go to the symphony. If he’s not having a good day then maybe we won’t go for dinner and we’ll still go to the symphony or maybe we won’t go at all. Depends on how he is.”

Linda’s willingness to adapt according to George’s changing needs allowed them to both enjoy social activities together as a couple.

### *One Last Trip*

Five spousal caregivers (Matt, Pete, Anne, Pat, and Nancy) discussed how they had taken ‘one last trip’ together. Taking one last trip fell (thematically) between maintaining and adapting. In many ways, taking another trip was a way of maintaining an activity that the couple had previously enjoyed together. However, it could also be considered an act of adaptation because the purpose of taking one last trip was a recognition of the limitations of their spouse’s progressing dementia. After taking one last trip, they would adapt by discontinuing extensive travel.

Anne described how she had contemplated taking one last trip almost immediately after Stephen was diagnosed:

“Well I knew, when he got diagnosed immediately I thought, “Well I don’t know how long he can travel.” So we usually went away somewhere every year for the last while, so we went on a Mediterranean cruise.”

She later described her disappointment over how little regard Stephen paid to the trip. Although she had initially intended this trip to be the last, Stephen's complacency (which was not his usual reaction to vacations) solidified her decision to give up travel.

In Matt's case, he explained that he gave Lily the choice to decide where their last trip would be. He recounted how he said to her, "Make a wish Lily, what would you like to do?" This was the last trip they went on.

Pete explained that his family had never before done a major trip together (probably due in part to the younger age of his children). In the first year that Rachel was sick, Pete decided that they would go on a trip together as a family before it became too difficult for Rachel to go. He said that the trip "worked okay," but that the airport was really confusing for Rachel.

For Nancy, her husband Michael's doctor had been the one to suggest that they make one last trip as a family to fly home (Nancy and Michael were not originally from Canada) and visit their families. Nancy described how, "God and my relatives got together and we got some money to go and that was the last." After that last trip, her parents and some of his family came to Canada to visit them.

Not all of the spousal caregivers decided consciously before their last trip that it would be their last. Joni discussed how she tried to adapt to her husband's increasing needs by bringing her son Billy with them on a cruise to help her with Neil's care. However, she now fondly spoke of this one last trip as "the cruise from hell," and described in detail how stressful the trip had been:

"It was terrible. I mean, he was pretty far along. We couldn't keep track of him and... this was also not a nice trip for me because again when you get into the socializing, he couldn't talk properly but he thought he could. So he was always trying to engage people in conversation but he was making absolutely no sense. I got to the point where I'd try to position myself between him and some person who might speak to him."

After this last trip, Pat no longer went on long vacations with Neil. Much like the other participants who described going on one last trip together, the end of the trip signalled Pat's adaptation to social and recreational activities that fit Neil's changing activity parameters.

## **Social Spaces as 'Safe Spaces'**

Of the ten participants, seven (Joni, Linda, Pete, Anne, William, Pat, and Stevie) described how certain social spaces were 'safe spaces' in which they could talk freely or not worry about how their spouse with YOD was perceived. These were social spaces where the spousal caregiver did not feel as though they were being judged, or simply places that were comfortable for them.

All of spousal caregivers who referred to certain social spaces and safe spaces, discussed support groups, or persons they had met at support groups as safe spaces. Joni discussed how she had become involved in a young-onset support group through the Alzheimer Society. After the interview tape had been turned off, she described [recorded in field notes] how her support group was a safe place to share her feelings and stories about being a caregiver with other people who understood what she was experiencing. During the interview she said, “I have made some new friends who are also in the same situation, which has been really nice.” Furthermore, when Joni and Robert moved, she made sure that she could still attend the same support group.

Linda described the support group as a safe space where she could laugh at the amusing aspects of caregiving for a spouse with YOD:

“We’re in a safe room and everybody understands what we’re going through. Friends empathize but they can’t really understand – they don’t know what we’re living. – We can say anything and we know we’re not going to be judged. Nobody is critical and that we understand and you know, we laugh a lot because you have to. Actually you know, sometimes when you think about it, it’s just funny. Some of the stuff that they do... We’ll go, “Oh god, my husband did the same thing! What is that?”

These support groups described by participants varied between ones held by the Alzheimer Society, support groups run by other organizations, and created groups (not associated with an organization). Pete, Pat, and Stevie were three participants within this study who had described how they had ‘created’ support networks with other caregivers. The purpose of these created groups was to create safe spaces that were applicable to their experiences as YOD caregivers. For Pat and Stevie, the function of these created safe spaces was also socialization. For example, Pat stated that her support group had become her socialization. Both Pat and Stevie discussed how their created support groups involved sharing a meal with other group participants.

Several participants described how they had made new friends within these safe spaces. Joni, Anne, Pat, and Stevie all said they had made friends with people at their support groups, and continued to socialize with them outside the group. Anne talked about how two friends she had made at her support group frequently got together with their spouses for dinner and other activities.

Pat spoke extensively about her friendship with a woman she met at a support group. For Pat, socializing outside of the group with another caregiver (June) and her spouse was a safe space for both the caregivers and the persons with YOD:

“We decided that it might be nice for us, because weekends were always long with the guys – That we would get together because we both understood –Like social situations become very difficult when you are with people who don’t understand what that person is doing. Who might get embarrassed so it seemed very comfortable to meet, Neil and I with Benny and June.”

Pat's perception of the safe space she and June had created for themselves, also extended to their husbands with YOD. She described how socializing in this safe space was enjoyable for her husband Neil. She explained:

“We would order in Swiss Chalet and meet at her house or here on a Sunday evening. That really felt so good to be doing something with Neil, and... I remember them leaving and saying, “That was good.“ and you see, he could say these short phrases once in a while and you just thought “Well that's good because he actually was - He thought he was being sociable”

## DISCUSSION

The previous section presented the research findings on the described social experiences of YOD spousal caregivers living in Ontario in order to identify significant themes. The results of analysis highlight the importance of social experiences for spouses of persons with YOD. Indeed, much of the analysis echoes the key findings in the existing literature on the importance of socialization, recreation, and leisure activities in reducing stress in the lives of spousal caregivers. Many of the spousal caregivers spoke explicitly of the importance of these social experiences as coping methods, which aided in their ability to continue to meet the emotional and physical demands of caregiving for their spouse. However, the preceding analysis also demonstrated several new, emerging themes, not previously discussed in the existing caregiving literature. Themes of social adaptation and maintaining activities were salient themes described throughout the included accounts of the participants interviewed for this study.

This chapter will discuss the research findings through a reflection on existing literature. This discussion highlights the social experiences of YOD spousal caregivers as a highly relevant and information-rich aspect of the caregiver experience, which extends beyond simple ‘impacts.’ The described experiences in this study are far more complex than those discussed in the existing literature. First, the emergent themes will be discussed and compared with the existing YOD and general dementia literature to assess the theoretical significance of these findings. Because this research has both theoretical and practical significance, I will then discuss these findings in social service practice, with an emphasis on practical application. Secondly, four considerations relevant to the interview context will be explained. Lastly, the limitations of this qualitative study will be considered and addressed in full.

### **Thematic Discussion and Theoretical Significance**

This section presents a discussion of the themes that emerged during the analysis of the interview transcripts. The significance of emergent themes of social support, giving up activities, adapting and maintaining social and recreational activities, and social spaces as safe spaces are discussed in conjunction with relevant YOD and general dementia literature. This thematic discussion highlights the theoretical and significance of these research findings.

#### *Sources of Social Support*

Social support is a widely discussed topic in the existing dementia literature. In the context of YOD research, it is important to note that caregivers experience “lower levels of social support than LOD caregivers,” (Van Vliet et al., 2010, p. 1095). Social support is not the same as a relationship. The concept of a *relationship* entails an ongoing association or enduring social interactions between two people (Reis, 2001). A relationship is different from a social *interaction* because it is ongoing, and entails a bond

between the two individuals based on history, feelings, and awareness of the relationship (Reis, 2001). An *interaction* by comparison is a single social event between persons (Reis, 2001).

Frese (1999) offers a useful definition of the concept of social support. He states that social support is “characterized by affective support (i.e. love, liking, and respect), confirmation (i.e. confirming the moral and factual “rightness” of actions and statements), and direct help (e.g. aid in work, giving information or money),” (Frese, 1999, p. 179). For those persons whose experiences are contrary to these various aspects of social support (e.g. disrespect, wrong actions or statements, and etc.), logically they would no longer consider these persons within their social networks to be sources of social support. These aspects were reflected in the accounts of expected, surprising, and ideal sources of social support described by the spousal caregivers in this study.

Particularly important were unexpected sources of social support. This was the most salient topic that emerged during the analysis of social support sources. Unexpected sources came from persons such as the caregiver’s children, community service workers, former co-workers, and children’s teachers.

Much like expected sources of social support, the unexpected sources discussed by the participants generally involved direct help with caregiving tasks. What was unique to this category was the degree to which these sources provided social support in comparison to expected sources. Several participants described how unexpected sources of social support exceeded expectations of the support provided by close family and friends.

Additionally, this support generally came from persons the caregiver would not have suspected would come forward to provide assistance. Expected sources were typically considered to be family members or close friends of the spousal caregiver and the person with YOD. Although unexpected sources did occasionally include family members such as children, the nature of the caregiver’s relationship with persons who were considered to be unexpected sources was far more diverse. For example, Nancy described how other parents from her sons’ schools had offered assistance, and how former co-workers had told her to call them day or night if she needed any help.

Not surprisingly, disappointing sources of social support described by YOD spousal caregivers were not reflective of the qualities of social support contained within Frese’s (1999) conceptualization of social support.

Harris and Keady (2004), Williams et al. (2002), and Rasmussen (2002) all found that YOD caregivers described how friends and family had failed to maintain contact with the caregiver and the person with YOD or avoided them entirely. Rasmussen (2002) described how losses of social support were considered barriers to caregiving for YOD caregivers.

A predominant feature of disappointing sources of social support was that the spousal caregivers had described negative experiences in which their spouse with YOD had been mistreated in some way. The perceived mistreatment involved persons ignoring the spouse with YOD, excluding them, or treating them as though they were dead or non-

existent. More specifically, the spousal caregivers viewed these experiences as negative because their spouse had been *dehumanized*.

Brannelly's (2011) research on professional dementia caregivers (e.g. social workers, nurses, etc.) discusses the concept of *dehumanization* as a part of the phenomenon of 'social death.' Brannelly (2011) argues that 'social death' (as opposed to 'social life') occurs when persons with dementia are no longer perceived to be "worthy of social participation [and are then] deemed to be dead when they are alive," (p. 662). Social death entails *dehumanization* of the person with dementia as a protective function (Brannelly, 2011). Brannelly (2011) posits that dehumanization occurs when a healthy (sometimes younger) individual creates a distance between themselves and the 'unhealthy' person with dementia in order to avoid relating to themselves in a similar position, or to avoid empathizing with that position. The result of this protective distance is that the person with dementia is positioned as less than human (i.e. dehumanization; Brannelly, 2011).

Although Brannelly's (2011) theory of social death and dementia was described in relation to formal dementia caregivers, this research reflects the described experiences of YOD spousal caregivers and their social networks in this thesis. This research suggests that disappointing sources of social support may involve the perceptions of dehumanization of the spouse with dementia.

Caregivers frequently described disappointing sources of social support, including examples of persons within their social networks who had begun avoiding both the spousal caregiver and the care partner. Reasons for 'avoidance' were suggested by a few caregivers, such as persons finding it too painful to see the disease. One caregiver (Nancy) suggested that facing them entailed recognizing their own mortality: "I suspect that they are closer to his age and didn't want to face it head on that they could be staring at themselves, you know?"

Kastenbaum (2004) offers a theoretical explanation for this occurrence. He states that persons who are dying/terminally ill are viewed as contaminated with the *aura of death* (Kastenbaum, 2004). Therefore, "we ourselves lose status, [and] we become less valuable if we become too closely associated," with the person who is dying (Kastenbaum, 2004, p. 101). Kastenbaum (2004) calls this associated loss *status contamination*. Interestingly, this theory closely resembles the proposed explanations of social avoidance described by the spousal caregivers within this study. Further, *social contamination* may represent a form of dehumanization unique to YOD spousal caregivers.

Despite the disappointment the spousal caregivers felt towards persons within the social networks who did not live up to the perceived expectations of their pre-disease relationships, understanding the nature of this disappointment was important to several caregivers. Six participants (Joni, William, Matt, Stevie, Pete, and Pat) attempted to explain or rationalize why persons who initially provided positive social support began to avoid the couple, or act as though the person with dementia was dead or non-existent. Participants often stated that they believed persons had become uncomfortable with the effects of the dementia. For example, William stated that Elizabeth had significant

memory problems which caused her to frequently repeat herself. Others pointed to ‘changing social dynamics’ as a probable reason for these negative behaviours towards the couple and the person with dementia. Pete thought that people no longer, “knew what to do with her [Rachel],” in social situations. Matt described how he felt persons within their social networks were uncomfortable with modifying their behaviour in order to interact within Lily. Additionally, he stated that, “friends and family, neighbours, you know, don't see enough of that person to be comfortable, so they become uncomfortable. So they draw back.”

Participants suggested that the reason persons avoided them or acted as though the spouse with YOD was dead or non-existent was because it was “too painful” to see them continue to decline. Matt stated that much of the family had found it too painful to provide them with social support. Pat said it was difficult for friends to talk with Neil. Pete also explained that it was difficult (emotionally) for people to engage in the way they used to: “I think it's hard to watch people, it's hard what you're doing [the researcher i.e. to study YOD].”

Despite the insight provided by caregivers as to why social support sources become disappointing sources, Joni did not claim to know exactly why these negative behaviours towards the couple come to pass. To Joni, understanding the reasons for these changes were only best guesses: “who’s to say why it changes, is it the dementia, is it because he’s not working anymore, is it because we moved?”

### *Giving Up Social and Recreational Activities in Favour of New Activities*

Giving up social and recreational activities in favour of new activities has not been discussed in the YOD spousal caregiving literature. However, the existing dementia literature on caregiving frequently discusses *activity restriction* as a common occurrence. For example, Kaiser and Panegyres (2007) stated that functional decline of the person with YOD has been linked to activity restriction for spouses. A personal case history by Brown and Roach (2010) challenges the idea of activity restriction; they state that activity restriction is a complex internal negotiation between the co-occurring roles of spouse, YOD caregiver, and parent to a dependent child. This suggests a deeper dimension of activity restriction among spouses of persons with YOD.

The concept of *activity restriction* implies that the caregiver was unable to participate in an activity. In the space of this thesis study, participants described experiences revealed a deeper level of complexity. The YOD spousal caregivers frequently described how they had given up certain social or recreational activities in favour of new activities. Comparatively, *giving up* is premised on choice; the caregiver made a conscious choice to give up an activity rather than being unable to participate any longer (i.e. activity restriction).

This is not to suggest that the choice to give up an activity was not premised on the participant’s perception of that activity no longer being possible. Indeed many of these decisions to give up an activity were the most logical choice, or maintaining the activity was perceived as impossible (e.g. financial barriers). However, regardless of whether a



participant felt that they were unable to continue participating in a social or recreational activity, giving up the activity (in this space of this thesis) was an autonomous act grounded in choice.

For example, giving up travel was a common experience described by the spousal caregivers interviewed for this study, and often was preceded by the care partners taking one last trip together. Common reasons for giving up travel included problems related to the spouse with dementia, such as disorientation, problems going through the airport, fear of losing the spouse, and so on. Regardless of why they had stopped travelling, participants continually stated that they had made the choice to give it up.

Several YOD spousal caregivers described how they had given up social and recreational activities that did not include the spouse with dementia, in favour of new ones with the spouse. For example, William had previously enjoyed quiet pastimes such as reading. He had taken up lawn bowling with his wife (despite his discomfort with socializing with primarily older adult members) because it was an activity they could participate in together. A study of all dementia caregivers by Smale and Dupuis (2004) found that 40-45% of caregivers felt guilty participating in activities that did not include the person with dementia. Although reasons such as being afraid to leave the person with dementia alone, and time and financial constraints were cited as reasons for giving up activities by the YOD spousal caregivers in this study, feelings of guilt may be a factor in some caregivers' choices to participate in new activities that included the spouse with YOD. However, none of the caregivers in this study specifically cited feelings of guilt as a factor in choosing a new activity, so the applicability of this theory may be limited in the context of this study.

Pat described taking up multiple new singular activities (such as her husband's model railroad collection). She had stated that she had more time now to participate in activities than she did before Neil had passed away. Additionally, Pat had also said that she had been moving slowly into retirement. Whether or not her ability to participate in more activities (compared to the other participants) was a function of no longer being a caregiver, or whether it was a function of being semi-retired, was not clear (and cannot be determined in this type of study design). Nonetheless, Pat – like the other participants – had described giving up activities throughout the progression of the illness in favour of new activities.

Not all of these new activities included the spouse with dementia, or even other people. As discussed in the analysis section, six spousal caregivers gave up activities in favour of new, singular activities. Of these new activities, a large majority were exercise-based. For example, William had recently begun running on his treadmill in the morning, and Henry had begun kayaking again. Smale and Dupuis' (2004) study offers some insight into why these participants chose new, exercise-based, singular activities (as opposed to social activities). Smale and Dupuis (2004) found that approximately 70% of dementia caregivers in their study stated that they had less time for themselves since they had become a caregiver. This research, coupled with the findings in this study which highlight how caregivers gave up social activities in favour of singular activities, suggests that

caregiving may be connected with reduced opportunities for socialization among YOD spousal caregivers.

### *Adapting and Maintaining Social Activities*

Adaptation has been discussed in the space of the existing dementia caregiving literature. However, the concept of caregiver adaptation is not always termed *adaptation*, nor is there a generally accepted definition of what this concept represents. Gaugler, Davey, Pearlin and Zarit (2000) discuss LOD caregiver adaptation as a necessary task involved in the caregiving process. The authors found significant evidence to suggest that the duration of care is associated with greater emotional and psychological adaptation, and subsequently more effective acts of adaptation (Gaugler et al., 2000). Rinfrette (2010) described the YOD caregivers' propensity to be more amenable to adaptive behaviours as 'increased flexibility,' which she viewed as a positive outcome of YOD caregiving.

Comparatively, Corcoran (2011) associates acts of adaptation as a characteristic of a 'facilitating style' of dementia caregiving, which involves focusing on the emotional health of the person with dementia. A *facilitating style* of caregiving involves the dementia caregiver choosing one-on-one, cooperative activities together with the person with dementia, which are both meaningful and enjoyable for the person with dementia (Corcoran, 2011). Facilitation of these activities may involve adaptation of activities for both the caregiver and the person with dementia.

Although the general dementia literature primarily discusses emotional and psychological adaptation among caregivers (e.g. Gaugler et al., 2000), the results of this thesis suggest social adaptation is also relevant in the context of YOD spousal caregivers. Most caregivers employed problem-solving strategies in order to adapt and maintain activities whenever possible. The ability to adapt seemed to depend on factors such as resources (e.g. economic, social, and emotional), and the abilities of the spouse with dementia. Additionally, the capacity of the caregiver to continually adapt seems to be hindered by the receptiveness/capacity of members of the social network to comfortably accept changes (including the continued deterioration of the person with YOD).

Furthermore, until the spouse with YOD was no longer able to fully participate and/or find enjoyment in the adapted activities, caregivers generally continued to find ways to adapt and maintain activities. It must be noted that several caregivers continued adapting activities for their spouse with YOD, even when the activity was no longer enjoyable for the caregiver. This sort of 'trade-off' seems to indicate a resiliency "threshold" (as demonstrated through adaptation), which placed the perceived enjoyment of the spouse with YOD, above the individual caregiver's level of enjoyment. In other words, many of the caregivers were happy if the spouse with YOD was happy; personal feelings over the most mediocre activities were generally put aside if the spouse with YOD was able to meaningfully participate in an activity.

This form of resiliency – although extreme – is equally admirable, and concerning; the dutiful act of social preservation (of the care recipient) on the part of the caregiver suggests the individual's capacity for adapting and maintaining care recipient activities

may push the limits of healthy adaptive behaviours, especially if we consider cases where the caregiver has continued to promote social activities that provide the care recipient with enjoyment, but also elicit considerable amounts of stress in the caregiver. This over-resiliency serves as a caution to community service providers, namely to demonstrate the insufficient attention paid to the emotional state and stress levels of the caregiver, even when the perceived state of the care recipient is considered acceptable.

According to Iwasaki and Smale (1998), negative life events have an initial impact on a person's psychological well-being. However, a person's ability to adapt to these changes ameliorates the impact of the negative event on the person (Iwasaki & Smale, 1998). In the case of the participants in this study, spousal caregivers were continually adapting as their spouse's dementia continued to progress. However, the degree to which adaptation and maintaining activities serves to ameliorate the impact of the disease's progression on psychological well-being is a matter of debate.

Although Henry had not described acts of adaptation, he did discuss maintaining social and recreational activities. Particularly important to him was swimming, playing slo-pitch, and his various volunteer positions, which he was still able to maintain. This capacity to maintain activities (rather than adaptation) might reflect the early stage of Katherine's dementia.

### *Social Spaces as Safe Spaces*

Of those spousal caregivers who participated in the study, seven discussed certain social spaces as safe spaces. Peer support groups were the most common safe spaces, and they were discussed by each of these seven participants. Generally, a space was considered 'safe' if the participant could relate to – based on a degree of commonality – to other persons who were occupying that social space. Although many participants discussed some flaws with some of the existing peer support groups available to them (to be discussed later), those participants who described a support group as a safe space indicated a common feature: these support groups contained other YOD caregivers.

The last two criteria outlined by the general dementia caregivers in Fung and Chien's (2002) study of effective peer support, may explain why participants in this study perceived groups with other YOD caregivers to be safe spaces. Fung and Chien (2002) found that caregivers viewed effective support groups as spaces where they could share their feelings and concerns, gain insight into current caregiving problems, feel as though they were not alone with their problems, and hear persons with similar situations discuss similar problems.

Similarly, YOD spousal caregivers in this study did not feel alone in their problems, and they could relate to the situational problems of other YOD caregivers. If these criteria were met, a support group space was deemed to be a safe space. Pete's experiences with LOD caregivers at a support group, who vocalized their shock over the young age of Pete and his wife Rachel, singled him out as a being different from the rest of the group members. Again, if we consider Fung and Chien's (2002) criterion of an effective support

group being a place where persons did not feel alone with their problems, it is not surprising that this peer support space was not considered to be a safe space.

Further, this perception of social safety among other YOD caregivers may explain why several of the participants created their own YOD specific groups, and/or sought out other mediums such as video-support groups (e.g. Matt) in order to connect with other YOD caregivers. In a study by Rinfrette (2010), the researcher stated that some of the YOD caregivers included in the study experienced positive outcomes, of which expanded social networks (vis-à-vis caregiver peer and mutual support) were often cited. Furthermore, although Rasmussen (2002) found that the YOD spousal caregivers in her study sought out alternative forms of support through the internet, neither of these two studies described caregivers creating their own peer support groups. Furthermore, none of the existing YOD literature on caregiving has discussed YOD caregivers initiating the creation of YOD specific support groups, nor has this literature discussed the concept of ‘safe social spaces.’

### *Implications of the Research Findings*

This section compared the findings of this thesis study to the existing dementia literature (both LOD, YOD, and general dementia research) in order to assess the theoretical significance of this research. Although much of this research echoed previous YOD and general dementia caregiving research, a significant portion of the participants’ described experiences highlighted new, socially relevant aspects not previously discussed. Further, many of the themes expanded upon phenomenon or experiences already described in the literature. These research results demonstrate that many of the social experiences of spousal caregivers of persons with YOD are unique in comparison to other dementia caregivers. Additionally, these experiences are far more complex than the ‘social impacts’ discussed in the body of caregiving literature.

### ***Expanding Existing YOD Research***

Themes of social support and adapting and maintaining social and recreational activities provided greater theoretical insight into the existing research on YOD spousal caregiving, and YOD caregiving in general. The described experiences recorded in this study affirm that aspects of YOD spousal caregivers’ social experiences have not been thoroughly understood, and have primarily been discussed in terms of social impacts. Therefore, the expansion of several theoretical aspects of YOD caregiving literature will be discussed.

Sources of social support largely reflected the existing YOD literature on spousal caregivers. These findings parallel much of the existing research on the nature of positive and negative social support, particularly Rasmussen’s (2002) study of YOD spousal caregivers. The sub-theme of disappointing sources of social support among YOD spousal caregivers affirms the experiences of dehumanization, social death (Brannelly, 2011), and avoidance (Harris & Keady, 2004; Rasmussen, 2002; Williams et al., 2002) recorded in both the general dementia literature, and the YOD caregiving literature.

However, these thesis findings also serve to expand upon our existing understanding of sources of social support, specifically in terms of disappointing and ideal sources of social support. Kastenbaum's (2004) concept of *status contamination* among persons with terminal illnesses is also applicable in the case of disappointing sources of social support among YOD spousal caregivers. The theme of giving up social and recreational activities was similar to activity restriction described in the YOD caregiving literature (e.g. Kaiser & Panegyres, 2007). However, as the previous sections demonstrates, giving up social and recreational activities for YOD spousal caregivers often involves a conscious choice on the part of the caregiver. Although perceptions of activity restriction may be considered by spousal caregivers before making a choice, the choice still exists.

Adapting and maintaining social and recreational activities provides a better theoretical understanding of the concept of adaptation among YOD spousal caregivers. This concept has been previously described as *increased flexibility* (Rinfrette, 2010), *facilitating style* (Corcoran, 2011), or emotional and psychological adaptation (Gaugler et al., 2000; Iwasaki & Smale, 1998) in the larger body of dementia research. However, the majority of these adaptive practices have been described in terms of emotional or psychological adaptation, and not adaptation of social or recreational activities. The results of this thesis analysis serve to expand our theoretical understanding of the concept of caregiver adaptation to include *social adaptation*. These thesis findings provide increased theoretical understanding of the YOD caregiving literature on social avoidance.

### ***The Unique Experiences of YOD Spousal Caregivers***

The described social experiences of spouses of persons with YOD included in this thesis not only bolsters our existing theoretical knowledge of caregiver social experiences, they also reveal new, theoretically significant accounts not previously described in the existing YOD literature. Themes not previously discussed in literature included giving up social and recreational activities in favour of new activities, and social spaces as safe spaces. These findings demonstrate that many social aspects of the YOD spousal caregiver's experiences are unique to this role (in comparison to other YOD or general dementia caregivers).

The social experiences of spousal caregivers of persons with YOD are complicated by factors associated with the younger age of the caregiver and person with dementia. Younger caregivers are presented with unique financial challenges. A diagnosis of dementia before the age of 65, may entail loss of primary income, ineligibility for early retirement, forced retirement, and loss of employment. These financial challenges may apply to either (or both) the caregiver and the person with dementia. Caregivers may also have dependent children still living at home, and may also have work responsibilities. The financial, parental, and occupational responsibilities (particularly those described by Pete and Nancy) associated with this younger age group, represent unique issues which older spousal caregivers may not have to contend with when negotiating social activities and relationships while acting as a caregiver.

Caring for a person with YOD often requires a significant time commitment, which impacts workforce participation (Van Vliet et al., 2010). Work-related problems can

include decreased income associated with lost earnings of both the person with YOD and the informal caregiver (Black et al., 2010; Delany & Rosevinge, 1995; Luscombe et al., 1998; Rinfrette, 2010), coupled with the increased direct and indirect costs of caregiving (Delany & Rosevinge, 1995; Rinfrette, 2010). Together these problems can have a significant impact on social and recreational activity participation.

The theme of giving up social and recreational activities for new activities was complicated by many financial and occupational factors (as described by the participants), in addition to problems associated with *activity restriction* already described in the existing YOD and general dementia literature. The act of giving up these activities in favour of new activities is however unique to this thesis study. No previous dementia caregiver study has discussed YOD spousal caregivers giving up social and recreational activities in favour of new activities.

Social spaces as safe spaces was also a theme, not previously described in the existing YOD literature. This theme – as described by the participants – also provides significant insight in terms of practical application. The practical significance of social spaces as safe spaces will be described in the next section.

## **Practical Significance**

### *Peer Support as Social Support*

It is evident from the preceding analysis that peer support can become an important form of social support for spouses. Particularly, social interaction with other caregivers of persons with various forms of YOD outside of a peer support group seemed to be a common means of social support for many caregivers interviewed through this study. In the case of YOD spousal caregivers, affective peer support can become a significant source of social support under the right conditions.

Support groups comprised primarily of LOD caregivers were criticized by participants for two reasons: 1) the information was not relevant to their situation; or 2) they could not relate to the older caregivers or younger caregivers who were caring for a parent (or grandparent) with LOD. Not surprisingly, a support group space was considered a *safe place* if they contained other YOD caregivers. As argued earlier, YOD spousal caregivers classify a social space (such as a peer support group) as a ‘safe space’ based on how well they can relate to other persons residing in that space. When the caregiver could not relate to those persons in a support group, the capacity of the support group to provide social support was limited.

These insufficiencies and inaccessibility of peer support groups discussed by participants, prompted several participants to seek out or create alternative peer support methods or resources relevant to their experiences as spousal caregivers of persons with YOD. For some of those caregivers, this meant creating informal peer support groups with other YOD caregivers. Additionally, those YOD caregivers who created informal peer support groups, social relationships were formed with other members.

Given the apparent technical proficiency of several of the participants in this study (and demonstration of this proficiency while arranging interviews), coupled with the perceived insufficient, inaccessible, or inappropriate support group models of the past, new methods of providing peer support needs to be addressed by community service providers. The findings of this research study suggest that peer support with other YOD caregivers can lead to increased socialization and opportunities for positive social support among YOD spousal caregivers.

### *Community Caregiver Supports*

Many of the dementia caregiver support services provided in Ontario focus primarily on relieving dementia caregivers of caregiving tasks, or focus specifically on psychological health and well-being (e.g. counselling; Smale and Dupuis, 2004). For example, Smale and Dupuis' (2004) study of general dementia caregivers in Ontario found that 44% of caregivers who were interviewed made use of adult day programmes, and 33% used homemaker services. Of those same caregivers interviewed, participants "reported making social visits and providing companionship (82.9%) and creating opportunities for recreation (79.9%) such as scenic drives and dining out," (Smale & Dupuis, p. 23) with the person with dementia.

Although these caregiver supports are important, the promotion of social and recreational activities for both the person with dementia and the caregiver are equally important. Research suggests that dementia caregivers (in Ontario) with greater social resources use formal community support services less than caregivers with fewer social supports (Smale & Dupuis, 2004). Therefore, community caregiver support providers need to consider the holistic benefits of creating opportunities for social and recreational activity participation for dementia caregivers.

The promotion of social activities and supports for caregivers – which are known to have significant health benefits (Koenig, 2008) – are not necessarily being addressed by community caregiver support providers. The findings of this thesis study reveal a gap in community support provision for dementia caregivers, which require further assessment of the effectiveness of community caregiver supports for YOD spousal caregivers.

## **Considerations Relevant to the Interview Context**

Ritchie and Lewis (2003) state that the context in which the research is collected is an important consideration in any qualitative research study. The authors argue that contextual factors or variables have the capacity to influence the nature of the data, or the researcher understands of that data during the analysis (Ritchie & Lewis, 2003). Therefore, three contextually relevant aspects of the research interview must be assessed: insider perspective, observed emotional strain, responding to questions, and stages of dementia.

### *Insider Perspective*

Positionality was important in the space of the interview. As I discuss earlier in this chapter, social spaces in which a participant feels as though feelings of mutual understanding and commiseration are possible with other persons, contribute to a space being termed a *safe space*. I initially suspected that many of the participants perceived our interaction during the interview process as an interaction between persons with a shared history; a sense of mutual understanding seemed to contribute to instant rapport-building between myself and the spousal caregivers. Pete affirmed my suspicions, and alluded to the idea of the interview space as a safe space. He stated that, “I know your history, you've probably been there, you do have to laugh at the stuff.” This statement conveyed a perceived sense of mutual understanding between his experiences and my experiences (as a child caregiver) in giving up relationships with people who ‘don’t get it.’ Laughing together over the absurdity of these negative relationships appeared to be a significant part of qualifying his feelings.

Indeed, many of the participants – after explaining something troubling – would say, “well, you know,” or, “I’m sure you’ve been there.” The differences in age between myself and the YOD spousal caregivers seemed to be irrelevant; it was our shared roles as YOD caregivers that affirmed our mutual understanding. I argue that my role as a YOD caregiver led to the interview space being considered a safe space, and this perception of social safety contributed to more detailed and candid accounts of the social experiences of the spousal caregivers.

In order to avoid potential researcher bias, I forewent any discussion about my personal experiences as a child caregiver until after the interviews had been concluded. Although the participants were aware of my dual-positionality, it was important for me to avoid potential conversation prompts (before and during the interview process) that could influence the direction or topic of the interview for the participant (beyond the questions and topics outlined in the interview guide).

### *Emotional Strain*

The limitations of written speech (i.e. transcripts of interviews) presents some issues with regard to observing and considering non-verbal cues and occurrences throughout the course of the interview, particularly observed emotional strain. Examples of non-verbal indicators of emotional strain observed during the interviews (and recorded in my field notes) included becoming choked up, being at a loss for words (long pauses), abrupt changes in topic, fidgeting, tearing up, and crying. These observed behaviours were noted in the field notes for later consideration. Prevalent among the sample was an increase in emotional strain when participants began to speak specifically about the perceived changes in their marital relationship with their spouse, and (if applicable) the perceived emotional effect that their spouse’s deterioration had on their children.

All participants exhibited some sort of behaviour-based, increased emotional response when discussing the changes in their marital relationships. Several participants became quite upset when discussing the perceived impact of the disease on their children, and the deteriorating relationship between their children and their spouse. Whether this increased



emotional strain is indicative of these topics being more stressful for participants to discuss (compared to changes in hobbies or friendships), or whether these observed emotional behaviours is simply a function of talking about generally upsetting experiences for a prolonged period of time, is not clear. However, the prevalence of this increased emotional strain across all interviews, involving the same topics of discussion, is nonetheless significant. It is also not surprising that topics of close, personal relationships might elicit an increased emotional response from participants.

### *Responding to Questions*

Seven participants responded to interview questions in a similar manner; when asked about the participant's experiences, their answer typically involved a discussion of their spouse's experiences. For example, when Henry was asked what a typical day was like for him, he immediately responded by telling me about his wife Katherine's daily routine. Similarly, when Stevie was asked if she participated in any recreational activities or sports, she began telling me about her husband's recreational activities and sports.

Responding to questions directed at the caregiver with a discussion of the experiences of the caregiver's spouse was a common behaviour that was noted in the interview field notes. Occasionally probes were used in order to direct the participant to talk specifically about their individual experiences (rather than the spouse with YOD). However, those seven participants who responded to questions in this way also frequently discussed their social experiences together with their spouse with YOD. In other words, the caregiver considered their social experiences and their spouse's social experiences to be mutual experiences.

Whether this behaviour is a reflection of the caregiving partnership, or whether it is a function of being married, is debatable. Nonetheless, the fact that these described experiences are approached by caregivers as mutual experiences suggests a new dimension to the caregiver relationship. None of the existing dementia caregiving literature reviewed for this study has made this same observation, nor has it been discussed.

## **Research Limitations**

### *Design Limitations*

Although a qualitative, descriptive design was the most appropriate means of examining the social experiences of spouses in depth, there are some limitations to qualitative description in social research. Namely, it is difficult to accurately account for the 'why' questions, or emerging questions of causality that may arise during the course of analysis. However, given the under-developed nature of the topic of social experiences of YOD spousal caregivers, the intent of this research project was never specifically to approach explanation or causation.

Additionally, in-depth interviews are commonly criticized for being recorded accounts of what people say, and not necessarily what they do in practice (Greene & Thorogood, 2009). In other words, interviews are not accurate representations of experiences; rather they are accounts of the social world (Greene & Thorogood, 2009). However, this does not mean the use of interviews in social research should be discounted. As Greene and Thorogood (2009) argue, language is a primary means of communication between persons, making it an ideal means of obtaining primary accounts of personal experiences or beliefs. Therefore, in-depth interviews may be the best means of understanding the experiences of an individual person for the purposes of social research. For this reason, coupled with other factors such as time, geographic location, and budgetary constraints, semi-structured interviews were the most suited means of obtaining primary accounts of social experiences relevant to the topic of study, and the research objectives. In the case of this study, these information-rich accounts of social experiences generated a deeper understanding of the YOD spousal caregiver's perceptions regarding these experiences.

### *Population Sample*

The size and the nature of the sample population included in this study limit the generalizability of the research findings. The study sample included only ten participants who were interviewed about their experiences as YOD spousal caregivers. Although, this small sample size does not allow for generalizations to be made about the larger YOD spousal caregiver population, the goal of this thesis study was not to make these generalizations. Rather, the purpose of the research was to describe the specific social experiences of those participants included in the study.

Additionally, the nature of the population sample was complicated by the different types of YOD spousal caregivers who were recruited. Due to the difficulty with recruiting sufficient participants to be interviewed for this study, coupled with the time limitations of this Master's thesis, the inclusion criteria were modified to include YOD spousal caregivers whose spouses were also in LTC. This allowed for increased and timely recruitment of YOD spousal caregivers.

Furthermore, one participant was recruited for the study whose spouse had recently passed away. This was not originally outlined in the inclusion/exclusion criteria for this study, which should have been addressed. Although this recruitment was unintentional (it was not known that the spouse had passed away until right before the interview), the account of this participant was not discarded. Although, this limits the generalizability of the research findings, this decision was made based on the recruitment difficulties I experienced and the limited timeframe to complete the research study.

This, coupled with funding limitations also needed to be taken into consideration. Conducting interviews required a significant amount of travel. Although every effort was made to use the most economical means of travel, a large portion of the research budget was used to cover travel expenses. These limited financial resources and coupled with the short research study timeline made recruitment of more than ten participants impractical.

### *Theoretical Saturation*

Purposive sampling in qualitative research entails that sample size is determined based on *theoretical saturation* rather than a predetermined, statistically significant number of cases (Ritchie & Lewis, 2003). Theoretical saturation is determined when, “no new analytical insights are forthcoming,” (Ritchie & Lewis, 2003, p. 81). This technique assures that the included sample is diverse, which was the case with the sample used in this thesis study.

The research committee initially suggested that ten YOD spousal caregivers should theoretically provide sufficient data necessary to achieve saturation. This number was used as a reference during the execution of the research study. During the course of interviewing the last two participants for this study, no new insights emerged in the participant accounts of their social experiences. It was therefore determined that theoretical saturation had been achieved.

### *Recruitment Challenges*

Additionally, practical aspects of the recruitment and data collection process had to be taken into account with regard to the inclusion and exclusion criteria. Firstly, the initial target sample (i.e. caregivers of person with YOD living at home with the spousal caregiver) was difficult to reach. This produced some challenges with regard to recruitment. Secondly the relatively short timeline of my thesis study, necessitated changes to the inclusion criteria in order to ensure a sufficient amount of research data were collected relative to YOD spousal caregiver social experiences.

### *Validity and Credibility*

Research validity is understood as the correctness or precision of the research findings in a study (Ritchie & Lewis, 2003). In qualitative research, validity is sometimes referred to as the *credibility* of the research results due to the subjective nature of qualitative research analysis (Ritchie & Lewis, 2003). In order to ensure the credibility of the results of this thesis study, qualitative content analysis involved multiple readings of the interview transcripts and field notes, and all emergent themes and codes were discussed and approved by the thesis committee prior to the final stage of analysis. Emergent themes included an examination of external theoretical perspectives from the existing body of YOD and general dementia literature.

All stages in the research process were documented in thesis log-books. This documentation provided written records of any changes or modifications to the research process by the student researcher, or changes initiated by the thesis committee. Documentation of the research process allowed for improved reporting of the research process during the writing of this thesis.

Additionally, unlike observational research or scaling methods of research, the source of data in this thesis study were literal accounts given from the target population. By comparison, the use of first-person accounts (i.e. semi-structured interviews with

participants) greatly improves the credibility of the research findings because it ameliorates the possibility for researcher subjectivity in interpreting the meaning of the research findings.

### *Critical Reflexivity*

To account for the potential effects of insider/outsider positionality on the research process, O'Connor (2004) asserts that self-reflexivity (as a part of critical reflexivity) is necessary to ensure the research results are valid and rich.

The idea for this thesis was ultimately born from my position as a child caregiver, and the academic perspective I developed through my undergraduate training in religious and cultural studies. In the context of this thesis, my dual position as student researcher and child caregiver was important throughout the entire research process. During recruitment, I was open about my dual-positionality as a child caregiver. This information was freely disclosed to the Alzheimer Society staff and to potential participants.

However, there were some disadvantages to this dual position. Participants provided candid accounts of their experiences, which I could personally relate to. Although this provided more detailed accounts, conducting interviews and analyzing interview transcripts generated a great deal of emotional fatigue for me as a caregiver. The result of this compassion fatigue made it difficult for me to spend more than a few hours conducting interviews or analyzing interview transcripts on a given day.

My dual role as student researcher and child caregiver required that I rely on critical reflexivity to control for sub-consciously imposing my personal beliefs upon participant accounts. O'Connor (2004) echoes the agency of dual-positionality, and argues that reflection which includes both experience and theory holds the potential to expand knowledge and understanding, provided self-reflexivity is observed. However, my dual-positionality allowed me to cast a more discerning eye upon the interview transcripts, resulting in richer inferences.

## CONCLUSION

The purpose of this research study was to describe the social experiences of spouses who provide care to a spouse with YOD. Previous research on the social experiences of YOD spousal caregivers, and the general YOD caregiving research in general have primarily discussed social experiences as a series of caregiving impacts. As the literature review demonstrates, socially-relevant research on YOD spousal caregiving has examined and measured social impacts (e.g. activity restriction, changing social relationships, and etc.), with little attention paid to caregiver perceptions of their social experiences within the Canadian context.

This gap in the YOD caregiving literature prompted the development of the research question: *what are the social experiences of spousal caregivers of persons with YOD?* The design of this thesis study aimed to answer this research question in the space of a qualitative research study. This was accomplished through an analysis of demographic questionnaires, semi-structured research interviews, and interview field notes.

The results of this study indicate that caregiving for a spouse with YOD entails complex social experiences. While it is clear that YOD spousal caregivers experience some similar social impacts compared to their LOD counterparts, there are some notable differences as well. In addition to these similarities, YOD spousal caregivers also have unique social experiences which are different from those social experiences of other dementia caregivers.

Four major themes were identified and discussed in the previous chapters of this thesis: Sources of social support, giving up activities, adapting and maintaining in social and recreational activities, and social spaces as safe spaces. The findings within the themes of social support and adapting and maintaining social and recreational activities serves to bolster and expand our theoretical understanding of YOD spousal caregivers and their social experiences. Concepts of social contamination, caregiver social adaptation, and choosing to give up social and recreational activities builds upon existing research on theories of social support, activity restriction, caregiver adaptation, and avoidance previously described in the existing YOD and general dementia literature.

However, themes of giving up activities in favour of new activities, and social spaces as safe spaces also represent new themes not previously discussed in the body of dementia caregiving literature. These emergent themes require further theoretical understanding through the development of future research studies.

In addition to the theoretical significance of the research findings, practical implications were discussed. The theme of social spaces as safe spaces was applied to the practical delivery of effective peer support. Suggestions were made in order to promote peer support as an effective form of social support. Additionally, implications for holistic development of community caregiver support services (specifically inclusion of caregiver social opportunities) were also discussed.

Although YOD spousal caregivers share some social impacts with their LOD caregiver counterparts, they also experience larger, complex social experiences that have not been previously noted. Additionally, their social experiences during caregiving may influence their choice to participate in social and recreational activities, who they socialize with, how they engage in socialization, and may even influence their future interpersonal relationships after the spouse with YOD has passed away.

The results of this thesis study demonstrate that the social experiences of YOD spousal caregivers is a highly relevant and information-rich aspect of caregiving that extends beyond minimalistic depictions of social impacts recorded in the existing literature. These rich experiences challenge and expand our theoretical understanding of spousal caregiving for persons with YOD.

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## APPENDIX A – Table 1

**Table 1 – Summary of Existing YOD Literature**

<b>Author(s)</b>	<b>Study Design</b>	<b>Population Sample</b>	<b>Sample Size (n=)</b>
<i>Luscombe, Brodaty &amp; Freeth (1998)</i>	Cross-sectional (self-report survey)	Convenience sample (Support Groups & Clinicians)	102
<i>Sperlinger &amp; Furst (1994)</i>	Mixed-Methods (Semi-structured Interview; Scaling Instruments)	Convenience sample (Clinician Referral)	15
<i>Black, Gauthier, Dalziel, Keren, Correia, Hew &amp; Binder (2010)</i>	Quantitative Design (Structured Surveys)	Convenience sample (Website Referral)	221
<i>Werner, Stein-Svachman &amp; Korczyn (2009)</i>	Literature Review	none	None
<i>Arai, Matsumoto, Ikeda &amp; Arai (2007)</i>	Quantitative, Comparative Study (Self-Administered Survey; Scaling and Index Instruments)	Purposive Sample (Hospital Database)	68 dyads (136) EOD = 14 (28) LOD = 54 (108)
<i>Williams, Keady &amp; Nolan (1995)</i>	Personal Case History	none	1
<i>Kaiser &amp; Panegyres (2007)</i>	Cross-sectional, cohort analysis (Questionnaire; Scaling and Index Instruments)	Convenience Sample (Neuroscience Clinic Database)	100
<i>Rasmussen (2002)</i>	Mixed-Methods	Purposive Sample	33

	(Semi-structured Interview; Questionnaire; Scaling Instruments)	(Alzheimer's Clinic Referral)	
<i>Rinfrette (2010)</i>	Mixed-Methods (Semi-Structured Interview; Scaling Instruments)	Purposive Sample (Alzheimer's Association Referral)	20 Spouses = 12 Children = 7 Sibling = 1
Van Vliet, De Vugt, Bakker, Koopmans & Verhey (2010)	Systematic Review	none	None
Delany & Rosenvinge (1995)	Cross-sectional, Mixed-Methods (Semi-Structured Interview; Questionnaire; Scaling Instruments)	Purposive Sample (Multi-agency and group referral)	27 Spouses = 21
Harris & Keady (2004)	Cross-Sectional, Grounded-Theory, Mixed-Methods (Interview and Focus Group; 2 separate data sets)	Purposive Sample (Multi-agency referral)	Persons with = 23 Carers = 15

**Table 1 – Continued**

Author(s)	Inclusion-Exclusion Criteria		Impacts			
	Inclusion	Exclusion	Social	Occupational – Economic	Physical	Emotional - Psychological
<i>Luscombe, Brodaty &amp; Freeth (1998)</i>	<ul style="list-style-type: none"> <li>• Carers of younger persons with dementia (less than 65 years of age)</li> <li>• Persons with dementia diagnosed before 65 years of age</li> </ul>	<ul style="list-style-type: none"> <li>• Persons with dementia over 64 years when surveyed</li> <li>• Persons with AIDS-related dementia</li> </ul>	X	x		x
<i>Sperlinger &amp; Furst (1994)</i>	<ul style="list-style-type: none"> <li>• Carer currently caring for someone diagnosed presenile dementia (diagnosed before 65)</li> </ul>	<ul style="list-style-type: none"> <li>• Carer who previously cared for a person diagnosed with presenile dementia, who is now in long-term care</li> <li>• Dementia secondary to another disease (e.g. AIDS)</li> <li>• Very early-stage dementia</li> <li>• Carer visibly distressed</li> </ul>		x		
<i>Black, Gauthier, Dalziel, Keren, Correia, Hew &amp; Binder</i>	<ul style="list-style-type: none"> <li>• Carers aged 44-64 (i.e. baby-boomers)</li> <li>• Providing care for someone with Alzheimer's disease</li> </ul>	<ul style="list-style-type: none"> <li>• spousal caregivers</li> </ul>	X	x	x	X

(2010)						
<i>Werner, Stein-Svachman &amp; Korczyn (2009)</i>	<ul style="list-style-type: none"> <li>Published literature on early-onset dementia</li> <li>Persons with dementia and caregivers</li> <li>Clinical and social aspects of early-onset dementia</li> </ul>	<ul style="list-style-type: none"> <li>late-onset dementia (over 65)</li> </ul>	X	X		X
<i>Arai, Matsumoto, Ikeda &amp; Arai (2007)</i>	<ul style="list-style-type: none"> <li>Caregiver/patient dyads</li> <li>Co-residing family caregivers</li> <li>Outpatients at Ehime University Hospital (Japan) between June 2004 and December 2005</li> <li>Meet diagnostic criteria for dementia</li> </ul>	<ul style="list-style-type: none"> <li>Caregiver and patient not living together</li> </ul>				X
<i>Williams, Keady &amp; Nolan (1995)</i>	<ul style="list-style-type: none"> <li>Carer of a person with younger-onset Alzheimer's disease</li> <li>Spouse</li> </ul>	none	X	x		x
<i>Kaiser &amp; Panegyres (2007)</i>	<ul style="list-style-type: none"> <li>Spouses of persons with young-onset dementia</li> </ul>	none	X	x	x	x
<i>Rasmussen (2002)</i>	<ul style="list-style-type: none"> <li>Spousal caregivers of persons diagnosed with mild to severe cognitive impairment</li> <li>Degenerative symptoms of persons with cognitive impairment began before the age of 65</li> </ul>	<ul style="list-style-type: none"> <li>Person with dementia - history of physical disability which included neurologic sequelae and/or significant brain injury</li> </ul>		x	x	x
<i>Rinfrette (2010)</i>	<ul style="list-style-type: none"> <li>Participant has a family member with</li> </ul>	<ul style="list-style-type: none"> <li>Family member with dementia</li> </ul>	X	X	x	x



	<p>diagnosed early-onset dementia</p> <ul style="list-style-type: none"> <li>• Participant is a caregiver for the person with EOD</li> </ul>	<p>exhibited symptoms after 65</p> <ul style="list-style-type: none"> <li>• The diagnosed cause of EOD was alcohol consumption</li> </ul>				
<p><i>Van Vliet, De Vugt, Bakker, Koopmans &amp; Verhey (2010)</i></p>	<ul style="list-style-type: none"> <li>• Informal caregivers and children of persons with early-onset dementia</li> <li>• Psychological or psychosocial impacts</li> </ul>	<ul style="list-style-type: none"> <li>• Mixed groups of LOD and EOD</li> <li>• Articles focused solely on caring for people with Huntington's disease, or on dementia after acquired brain damage, HIV, alcohol abuse, or Down syndrome</li> </ul>	X	x	x	x
<p><i>Delany &amp; Rosenvinge (1995)</i></p>	<ul style="list-style-type: none"> <li>• Primary informal caregiver to a person with dementia</li> <li>• Person with dementia must be under 65 years of age during the study</li> <li>• Person with dementia must have a clinical diagnosis of Alzheimer's disease or Multi-Infarct Dementia</li> </ul>	<p>none</p>		X		
<p><i>Harris &amp; Keady (2004)</i></p>	<ul style="list-style-type: none"> <li>• Persons with: diagnosed YOD</li> <li>• Carers: caring for or have cared for a person with YOD (diagnosed)</li> </ul>	<p>none</p>	X	X		x

## APPENDIX B –Recruitment Script and Return Card

My name is Stacey Hawkins. I am a graduate student at McMaster University. The Alzheimer Society and your group leader has generously given me a few moments to talk to you about a research study I am doing on the social experiences of spouses of persons with early-onset dementia. This research is part of my Master of Arts (MA) thesis in Health and Aging Studies at McMaster University.

Early-onset dementia refers to people with dementia who were diagnosed before the age of 65. I am hoping to speak with spouses who care for a persons with early-onset dementia who are still under the age of 65. I also have a personal interest in this study; I am a caregiver for a person with early-onset dementia. I am working with the Alzheimer Society Chapters of [Hamilton and Halton, Haldimand Norfolk, Brant, Niagara, Oxford, Toronto] to make contact with spouses who help to care for persons with dementia who are under the age of 65. I'm interested in better understanding how this affects relationships with family members, relationships with friends, and social activities.

If you are interested in taking part in the study, you will be asked to participate in an interview, where I will ask some questions about your friendships, social activities and work relationships. You will also be asked to complete a short questionnaire which asks some descriptive questions about you such as your age, occupation, number of children, etc.). The interview questions and questionnaire would be mailed to you prior to the interview so you know the specific questions I'll be asking. The interview should take only 30- 45 minutes to complete, and will be voice-recorded. It will be arranged at a place and time that is convenient for you. Any names or identifying information given throughout the process will be changed or removed in order to protect everyone's privacy.

The Alzheimer Society will not be aware of your participation in the study. Also, your participation in this research study is voluntary and your decision will in no way affect the services provided through the Alzheimer Society.

I have handed out a copy of the recruitment poster with my contact information, as well as a blank 5 X 8 ½" card to everyone here today. I have also left your group leader with a self-addressed, manila envelope. If any of you are interested in learning more about the study, or even if you have any questions, you can check the "yes" box and write your contact information on the card and I will contact you. At that time, I can tell you more about the study and then you can decide whether or not you want to take part. For those who are not interested, you can simply check the "no" box on the card. After I leave, your group leader will collect all of the cards in the manila envelope, seal it, and mail it to me.

If you have any questions, do not hesitate to contact me. I want to thank you all for allowing me to come today and share a few minutes of your time. It was nice talking to you all.

Would you like Stacey to contact you?

Yes

No

If “yes,” please provide the following information:

Name: \_\_\_\_\_

Telephone: \_\_\_\_\_

When is the best day and time to call?

\_\_\_\_\_

\_\_\_\_\_

*Thank you for filling out this card.*

## APPENDIX C – Invitation Letter

### Sent on behalf of the Researcher

Stacey Hawkins, BA, MA (Cand.)  
Masters Candidate in Health & Aging  
McMasterUniversity

Carrie McAiney, PhD  
Thesis Supervisor  
Assistant Professor  
McMasterUniversity

Study Title: **Spousal Caregivers and the social impacts of caregiving for persons with young-onset dementia.**

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Dear «Title»«Name»,

Stacey Hawkins, a McMaster University graduate student, has contacted the«OrganizationName» asking us to inform you about a study she is doing on the social experiences of spouses of persons with young-onset dementia (onset of the disease before 65 years of age). This research is part of her Master of Arts program in Health and Aging Studies at McMasterUniversity. The following is a brief description of her study. If you are interested in getting more information about taking part in Stacey’s study, please read the brief description below and contact her directly at her telephone number or her McMaster email address:

**Tel: 289-396-7615** or [hawkisa@mcmaster.ca](mailto:hawkisa@mcmaster.ca)

Stacey Hawkins is inviting you to take part in a 30-45 minute, voice-recorded interview and complete a brief questionnaire at a convenient time and place of your choice. Stacey hopes to learn more about how your experience as a spouse of a person with young-onset dementia affects relationships with family members, friends, and social activities. More generally, Stacey is hoping to discuss your social experiences and your role as a care partner. She has asked us to attach a copy of her information letter that gives you full details about her study.

Your participation is confidential, and the«OrganizationName»will not know whether you choose to participate or not.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted you may contact:

McMaster Research Ethics Board Secretariat  
Telephone: (905) 525-9140 ext. 23142  
c/o Office of Research Services  
E-mail: [ethicsoffice@mcmaster.ca](mailto:ethicsoffice@mcmaster.ca)

Sincerely,

«Name»

«Title»«AddressBlock»

## APPENDIX D - Demographic Questionnaire

PARTICIPANT #:	
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### SPOUSES OF PERSONS WITH YOUNG-ONSET DEMENTIA

#### QUESTIONNAIRE:

**Thank you for taking the time to complete this survey. The goal of this research study is to better understand the social experiences of spouses who care for a person with young-onset dementia (also called early-onset dementia). The information you provide in this survey will help the researcher understand you and your spouse, as well as provide some information on your relationships. When you have completed this survey, please attach it in an email, and send it to the researcher at [hawkisa@mcmaster.ca](mailto:hawkisa@mcmaster.ca) . You may also return the survey to the student researcher on the day of your interview.**

**Please do not put your name on the survey. Each survey is given a number to keep the responses confidential.**

#### INFORMATION ABOUT YOU AND YOUR SPOUSE:

1) How old are you?

\_\_\_\_\_ Years

2) What is your gender? (please type an "X" next to the appropriate response)

Male

Female

3) How old is your spouse?

\_\_\_\_\_ Years

4) What is your spouse's gender?

Male

Female

5) Are you and your spouse married or living common law?

married

common law

6) How many years have you and your spouse been married or living common law?

\_\_\_\_\_ Years

7) Do you have any children?

yes

no

If you do have children, please indicate their gender and age in the table below. If you need more space, please use the other side of this paper.

<b>Child</b>	<b>Gender</b>	<b>Age</b>
Child 1	<input type="radio"/> male <input type="radio"/> female	
Child 2	<input type="radio"/> male <input type="radio"/> female	
Child 3	<input type="radio"/> male <input type="radio"/> female	
Child 4	<input type="radio"/> male <input type="radio"/> female	
Child 5	<input type="radio"/> male <input type="radio"/> female	

8) How many people currently live in your home (not including yourself)?

\_\_\_\_\_ People

9) How long ago was your spouse diagnosed with dementia?

Approximately \_\_\_\_\_ years ago

10) At the time your spouse was diagnosed with dementia, was he/she working?

Yes

No

11) Is your spouse currently working?

Yes

No

12) What is your current work status? (Check all that apply)

I am a full time homemaker

I work outside the home full-time

I work outside the home part-time

I am retired

I am unemployed and looking for work

I am currently on a leave of absence from work

Other \_\_\_\_\_

*Please explain*

13) Have you had to stop working to care for your spouse?

Yes

No

***Thank you for your help.***



## APPENDIX E – Interview Guide

PARTICIPANT #:	
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### INTERVIEW QUESTIONS

1. Could you tell me a little about your caregiving situation for your spouse?

#### PROBING TOPICS

- What type of care do you provide?
- What's a typical day like?

2. Has your spouse been formally diagnosed with dementia by a doctor?
3. Tell me about any changes in your social life since your spouse's diagnosis?
4. Thinking back to the time before your spouse's diagnosis, what types of activities did you enjoy participating in?

#### POSSIBLE PROBING TOPICS (venues or types of social activities):

- work
- clubs
- sports
- volunteer
- leisure – dinners, movies, concerts, etc.
- travel

5. Did you participate in any of these activities with friends or family members? Which ones?
6. What did you enjoy about these activities? What meaning did they have for you?

7. After your spouse was diagnosed with dementia, did your participation in these activities change? If so, how?

Probes:

- Types of activities
- Frequency of participation (how often)
- Who you participate with
- Level of enjoyment/meaning
- Relationship with family members or friends

**For those who have experienced a change in participation, go to question #8.  
For those who have not had a change in their participation, go to question #11.**

8. What do you think led to this change?

9. How do you feel about these changes?

10. How have your family and friends reacted to these changes?

11. Are there any activities that you participate in now that you didn't participate in before your spouse was diagnosed with dementia? If yes, describe:

*I am also interested in understanding any changes in your relationships with those closest to you that have happened since your spouse's diagnosis with dementia.*

12. Have your relationships with your family members changed since your spouse's diagnosis?

**For those who have experienced a change in their relationships with family members, continue with the next questions. For those who have not had a change in their relationships, go to question #16.**

13. Can you describe what these relationships were like before your spouse's diagnosis?

POSSIBLE PROBING TOPICS:

- a. How are these relationships the same?
- b. How are these relationships different?

14. Why do you think these relationships have changed?
15. How do these changes make you feel?
16. Have your relationships with your friends changed since your spouse's diagnosis?

**For those who have experienced a change in their relationships with friends, continue with the next questions. For those who have not had a change in their relationships, go to question #20.**

17. Can you describe what this relationship was like before your spouse's diagnosis?

POSSIBLE PROBING TOPICS:

- a. How are these relationships the same?
- b. How are these relationships different?

18. Why do you think this relationship has changed?
19. How do these changes make you feel?
20. Is there anything else about your social experiences that we did not discuss, which you feel is important for me to understand?

Thank you for your time.

## APPENDIX F – Recruitment Poster



### **PARTICIPANTS NEEDED FOR RESEARCH ON CAREGIVING FOR PERSONS WITH EARLY- ONSET DEMENTIA**

We are looking for volunteers to take part in a study of *social experiences of spousal caregivers of persons with early-onset dementia.*

You would be asked to describe your relationships with your family member, friends, co-workers, and your spouse.

Your participation would involve completion of 1 questionnaire and 1 interview session, lasting 30-45 minutes.

In appreciation for your time, you will receive a \$10 Tim Horton's gift card.

For more information about this study, or to volunteer for this study, please contact:

Stacey Hawkins  
Department of Health and Aging  
McMaster University  
905-525-9140 Ext. 27035  
Email: [hawkisa@mcmaster.ca](mailto:hawkisa@mcmaster.ca)

**This study has been reviewed by, and received ethics clearance by the McMaster Research Ethics Board.**

## APPENDIX G – Consent Letter

### LETTER OF INFORMATION / CONSENT

#### *Social experiences of spousal caregivers of persons with young-onset dementia.*

#### **Investigators:**

##### **Student Investigator:**

Stacey Hawkins, MA candidate  
Department of Health, Aging and Society  
McMaster University  
Hamilton, Ontario, Canada  
(905) 525-9140 ext. 27035  
E-mail: hawkisa@mcmaster.ca

##### **Faculty Supervisor:**

Dr. Carrie McAiney, PhD  
Department of Psychiatry and Behavioural Neurosciences  
McMaster University  
Hamilton, Ontario, Canada  
(905) 525-9140 ext. 36722  
E-mail: mcaineyc@mcmaster.ca

#### **What are we trying to understand?**

You are invited to take part in a study of spousal caregivers of persons with young-onset dementia (under the age of 65 years). I am hoping to better understand the social experiences of spousal caregivers to see how these experiences compare with the experiences of spousal caregivers of persons with late-onset dementia (over the age of 65 years).

#### **What will happen during the study?**

With your permission, a questionnaire will be filled out, and an interview will be arranged at a time and in a location of your choice. The interview will last approximately 30-45 minutes. With your permission, the interview will be voice-recorded. I will be asking personal questions about your daily life, social activities, and relationships. I will also ask you for some background information such as your age, occupation, number of children. Some questions that might be asked include:

- Do you have any hobbies or activities that you enjoy? How often do you participate in them?
- Can you describe your relationships with friends since you spouse/partner's diagnosis?

- Can you describe your relationship with your spouse/partner before his/her diagnosis?  
Can you describe your relationship now?

**Are there any risks to doing this study?**

The risks involved in participating in this study are minimal. You may find it upsetting to discuss your caregiving experiences, or you may worry about how the interviewer will react to what you say. If at any time you need to take a break, feel free to let the interviewer know. Also, it should be noted that you are not required to answer questions that you do not want to answer or that make you feel uncomfortable. If you wish to end the interview and withdraw your consent, you may do so at any time. If you become upset during or after the interview, you may request that the student researcher provides you with the name and contact number of a support person (e.g., counselor) at the Alzheimer Society.

**Are there any benefits to doing this study?**

There are no direct benefits to you as a participant. However, your participation could give important information about the social experiences of caregiving for persons with young-onset dementia. This information could aid in the development of programs and services that take into account the needs of caregivers of persons with young-onset dementia.

**Payment or Reimbursement**

As a token of appreciation for the time spent participating, you will be given a \$10 Tim Horton's gift card.

**Who will know what I said or did in the study?**

You are participating in this study confidentially. Every effort will be made to protect your confidentiality and privacy. I will not use your name or any information that would allow you to be identified. However, we are often identifiable through the stories we tell. Pseudonyms (made-up names) will be used in place of your real name(s), and consent forms will be coded. Only I will have access to the codes. The information you provide will be kept in a locked desk that only I have access to. All information stored on a computer will be protected by a password, and kept in a locked office. Once the study has been completed, the interview transcripts will be stored without any identifying information, and kept in a locked cabinet. The recorder used to audio-tape the interviews will be kept in a locked storage area.

**What if I change my mind about being in the study?**

Your participation in this study is voluntary. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed (unless you indicate otherwise). If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect your services you receive through the Alzheimer Society.

**Information about the Study Results**

I expect to have this study completed by approximately February of 2012. If you would like a brief summary of the results, please let me know how you would like it sent to you.

**Questions about the Study**

If you have questions or need more information about the study itself, please contact me at: hawkisa@mcmaster.ca or 905-525-9140 x27035.

This study is being funded by the Alzheimer Society of Hamilton-Halton, Brant, and Haldimand-Norfolk.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance (#2011-147).

If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

McMaster Research Ethics Secretariat  
Telephone: (905) 525-9140 ext. 23142  
c/o Research Office for Administrative Development and Support  
E-mail: ethicsoffice@mcmaster.ca

**CONSENT**

I have read the information presented in the information letter about a study being conducted by Stacey Hawkins, of McMaster University.

I agree that the interview can be voice-recorded.

- Yes                       No

I would like to receive a summary of the study’s results.

- Yes                       No

If yes, please send them to this email address:

\_\_\_\_\_

or to this mailing address:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time.

I have been given a copy of this form.

I agree to participate in the study.

Signature: \_\_\_\_\_

Name of Participant (Printed) \_\_\_\_\_