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The Lived Experiences of Female Informal Caregivers for Individuals with Young-onset Dementia

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THE LIVED EXPERIENCES OF FEMALE INFORMAL CAREGIVERS FOR INDIVIDUALS WITH YOUNG-ONSET DEMENTIA

by

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THESIS

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Acknowledgments

To my participants - a paragraph, a page, or a novel of gratitude would never do justice for the appreciation I have for all of you. You opened your hearts and poured your souls into my research, sharing your journeys about providing care to your loved ones with young-onset dementia. You are all extraordinary women. I hope my words do yours justice and allow for the heartfelt emotions provoked and your passion to increase awareness of young-onset dementia to shine through. I wish the ten of you, and all others providing informal care for individuals with young-onset dementia a voice and place to be heard - thank you!

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Finally, to my fur friends, Lenny and Buster - thank you for the companionship over the last two years. You never failed to leave my side as I spent countless hours sitting at my desk, forever my biggest fans.

Inclusive Language

It is important to recognize the synonymous nature of a few terms used throughout this master's thesis. To begin, the primary researcher uses the term young-onset dementia (YOD) to denote individuals diagnosed with dementia under the age of 65; however, this term is interchangeable with early-onset dementia (EOD). Throughout this thesis, the primary researcher uses the term caregivers (CGs) to represent all female participants providing care to their loved ones with YOD. This term is interchangeable for carers, care partners, or care providers as used within a few quotes by participants when describing their various roles. These terms are also evident within the literature. Person-centered language is critical when interacting with individuals with dementia and their families. Through the use of person-centered language, I acknowledge as the primary researcher (H. O'Neil) the effect language can have on the thoughts and actions of individuals living and caring for dementia (Alzheimer Society, 2017).

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ABSTRACT

Objective: Informal CGs for individuals with dementia experience an increased risk of compromised health. However, CGs of individuals with young-onset dementia (CGs-YOD) are more likely to have longer caregiving durations, less social support, and heavier caregiver burdens than those caring for people with LOD (Arai et al., 2007). Further, there are limited resources available to CGs-YOD, increasing their likelihood of negative health outcomes associated with CGs roles. This qualitative study investigated the experiences of female informal CGs-YOD specifically examining the effect of providing informal care on CGs overall health and well-being.

Methods: The theoretical orientation used to guide the research was interpretive phenomenology in order to ensure an accurate representation of the lived experiences of female informal CGs-YOD was provided. Background questionnaires were administered, followed by one-on-one semi-structured interviews, and follow up interviews. Subsequently interviews were transcribed verbatim. Field notes, member checks, and triangulation were used to enhance the credibility of the study.

Results: From the analysis three themes emerged: (1) “Are we essential?”, (2) “I don’t wish this life for anybody”, and (3) “I don’t belong here”. All participants emphasized the life altering nature of their caregiving roles and the importance of advocating and spreading awareness to help fight the stigma associated with YOD.

Conclusions: Overall, this study provides knowledge on the lived experiences of female informal CGs within the Canadian healthcare system and the challenges and barriers associated with providing informal care for individuals with YOD. Their stories can provide comfort for other individuals currently providing care for loved ones with YOD.

CHAPTER 1: REVIEW OF THE LITERATURE

1.1 Introduction

With population aging the number of individuals with dementia and their informal caregivers (CGs) continues to rise. Dementia, the most common type of neurodegenerative disorder, consists of memory loss, and difficulties with thinking, problem-solving or language interfering with activities of daily living (Alzheimer's Association, 2020; Prince et al., 2013). Individuals with dementia are classified as having either young-onset dementia (YOD) or late onset dementia (LOD) based on age at diagnosis (YOD <65, LOD >65) (Alzheimer's Society Canada, 2020). Informal CGs are individuals who provide unpaid care to family members or friends who are unable to care for themselves (Williams et al., 2010). Over half of Canadian informal CGs for individuals with dementia are women (57%), with three-quarters between the ages of 45 to 65 (Sinha, 2013). Caring for a family member or friend with dementia is an arduous task which can lead to stress, increased risk of morbidity and premature mortality. However, informal CGs for individuals with YOD (CGs-YOD) are more likely to have longer caregiving durations, less support, and heavier caregiver burden than those caring for LOD (Arai et al., 2007). Further, CGs-YOD lack a myriad of resources, which increases their likelihood of negative health outcomes associated with their caregiving roles. Likewise, CGs-YOD face other challenges resulting from diagnosis timing. For example, some YOD carers are more likely to be employed and have younger children, causing caregiving duties to disrupt family functioning (Arai et al., 2007; Svanberg et al., 2011). Unfortunately, research involving informal CGs-YOD is still in its infancy stages (Ducharme et al., 2013; Lockeridge & Simpson, 2012; Van Vliet et al., 2010), limiting the understanding of this population's needs and signalling the need for more research.

The purpose of the current study was to examine the lived experiences of female informal CGs for individuals with YOD. As such, this chapter covers previous literature in regard to informal caregiving in Canada; dementia in Canada; YOD; prevalence of females as informal CGs; effects of caregiving for individuals with YOD; and the disconnect between the services available and the needs of female informal CGs-YOD.

1.2 Magnitude of the Problem

1.2.1 Definition of Caregiving

Despite being examined for years by health professionals, there is still no one single definition of caregiving used due to its complex nature (Hermanns & Mastel-Smith, 2012). That being said, two main forms of CGs have been identified, namely formal and informal. Formal CGs are trained professionals who are paid for providing care (e.g., nurses and personal support workers), whereas informal CGs are classified as individuals who provide unpaid care for family members or friends unable to care for themselves, because of a chronic illness, injury, or physical/cognitive conditions (Lum et al., 2011; Williams et al., 2010). Despite formal and informal care often occurring in tandem, due to the close relationship of informal CGs with their care recipients, informal CGs frequently provide emotional and instrumental-tangible support (i.e., transportation, delivery of essential items, contacts support groups, etc.), while formal CGs provide primarily physical care (i.e., bathing, dressing, feeding, etc.) (Williams et al., 2010).

Individuals can be classified as primary or secondary informal CGs. Primary informal CGs are persons who are primarily responsible for the individual’s care (Barbosa et al., 2011), whereas secondary informal CGs provide support to the primary CGs rather than the care recipients (Williams et al., 2010). Thus, for the purpose of this paper, an informal CG will refer to a family member or friend who self-identifies as being primarily responsible for the care of a person with YOD.

1.2.2 Dementia: An Introduction

Internationally, an estimated 55 million people are living with dementia, a number surpassing the total population of Canada, making dementia a global health crisis (Alzheimer's Association 2020; WHO, 2022). Dementia is an umbrella term for disorders associated with a variety of signs and symptoms (e.g., memory loss, alterations in mood and behaviour, difficulties with judgement/ reasoning) caused by abnormal brain changes. There are many types of dementia including Alzheimer's disease, Lewy body dementia, Vascular dementia, and Frontotemporal dementia (see Appendix A: explanation of forms of dementia listed). Signs and symptoms differ depending on the type of dementia; however, one common characteristic is the progressive nature of the disease, with the severity of the signs and symptoms increasing as more brain cells deteriorate (Alzheimer's Association, 2020). In addition to the different types of dementia, depending on age at diagnosis, individuals are classified as having either YOD or LOD. YOD is diagnosed before the age of 65 and comprises approximately 3% of all Canadian dementia cases (Canadian Institute for Health Research, 2020). LOD is diagnosed in individuals over the age 65 and occurs more frequently than YOD (Mendez, 2017).

In Canada in 2014 it was estimated more than 402,000 or 7.1% of the population aged 65 and older had some form of dementia, with over 76,000 new cases of dementia occurring each year (Canadian Institute for Health Research, 2021). As previously indicated, only 3% of Canadian dementia cases or approximately 5-6% of dementia cases globally are a result of YOD (Canadian Institute for Health Research, 2020; WHO, 2021), meaning in Canada in 2016 approximately 16,000 Canadians under the age of 65 had some form of YOD (Alzheimer's Association, 2020).

Further, the number of individuals living with dementia is expected to more than double by the year 2031 (WHO, 2021), including the number of individuals being diagnosed with YOD (Alzheimer Society Canada, 2016). Therefore, with the prevalence rate of YOD on the rise, it is essential for individuals, health care workers, policy makers and society as whole, to recognize YOD is not just LOD at a younger age (Mendez, 2017). Further appropriate resources and support services are warranted for these individuals and their informal CGs. Thus, differentiating YOD from LOD and the effects of YOD on informal CGs will be discussed next.

1.2.3 Young-onset dementia

As previously indicated, YOD is dementia that occurs in individuals under the age of 65 (Kuruppu & Mathews, 2013; Mendez, 2006). The diagnosis of YOD is typically a lengthy process, with individuals experiencing on average a three-to-four-year delay in diagnosis, taking approximately a year and half longer for individuals with YOD to gain a diagnosis in comparison to older adults (Greenwood & Smith, 2016; Mendez, 2006). Thus, the diagnostic process is a long, difficult, and frustrating experience (Alzheimer's Association, 2020). Moreover, the extensive delays in diagnosis lead to an underrepresentation of YOD cases, which in turn leads to a misunderstanding of the services needed, leaving many individuals with YOD and their CGs receiving inadequate support (Vieira et al., 2013). The cause of YOD is relatively unknown; however, it has been suggested there is a genetic component associated with the development of YOD (Alzheimer's Association 2020; Mendez, 2017; Rogers & Lippa, 2012). As previously mentioned, there are many types of dementia including Alzheimer's disease, Lewy body dementia, Vascular dementia, and Frontotemporal dementia (Appendix A). This is no different for individuals with YOD; however, YOD has a larger degree of variation in terms of the type of dementia experienced and therefore is more likely the result of a rare dementia in comparison to

LOD (Jefferies & Agrawal, 2009; Mendez, 2006; Vieira et al., 2013). As indicated in *Figure 1,* Alzheimer's disease (AD) and Vascular dementia are the most prominent forms of LOD making up nearly 80% of all cases. Similarly, AD and Vascular dementia are the most common forms of YOD; yet they make up less than 50% of all cases, indicating the large degree of heterogeneity between individuals with YOD. Further, Frontotemporal, and other forms of dementia are much more common in individuals with YOD in comparison to those with LOD (Jefferies & Agrawal, 2009). As indicated within *Figure 1,* 25% of YOD cases are a result of a rare [other] dementia with only 2% of LOD cases being caused by this type. Thus, the vast degree of differences between the types of dementia within individuals with YOD in comparison to those with LOD has implications for programming, since signs and symptoms differ depending on the type of dementia (Appendix A) (Alzheimer's Association, 2020; Jefferies & Agrawal, 2009; Vieira et al., 2013). Moreover, as indicated by Mendez (2006) differences within the specific types of dementia (e.g., AD) between younger and older adults also exist. For example, individuals with young-onset Alzheimer's often experience more prominent cognitive deficits in addition to memory loss unlike older individuals with AD (Mendez, 2006). Thus, these differences emphasize the needs of individuals with YOD vary from those with LOD, indicating specific resources are warranted for families faced with YOD.

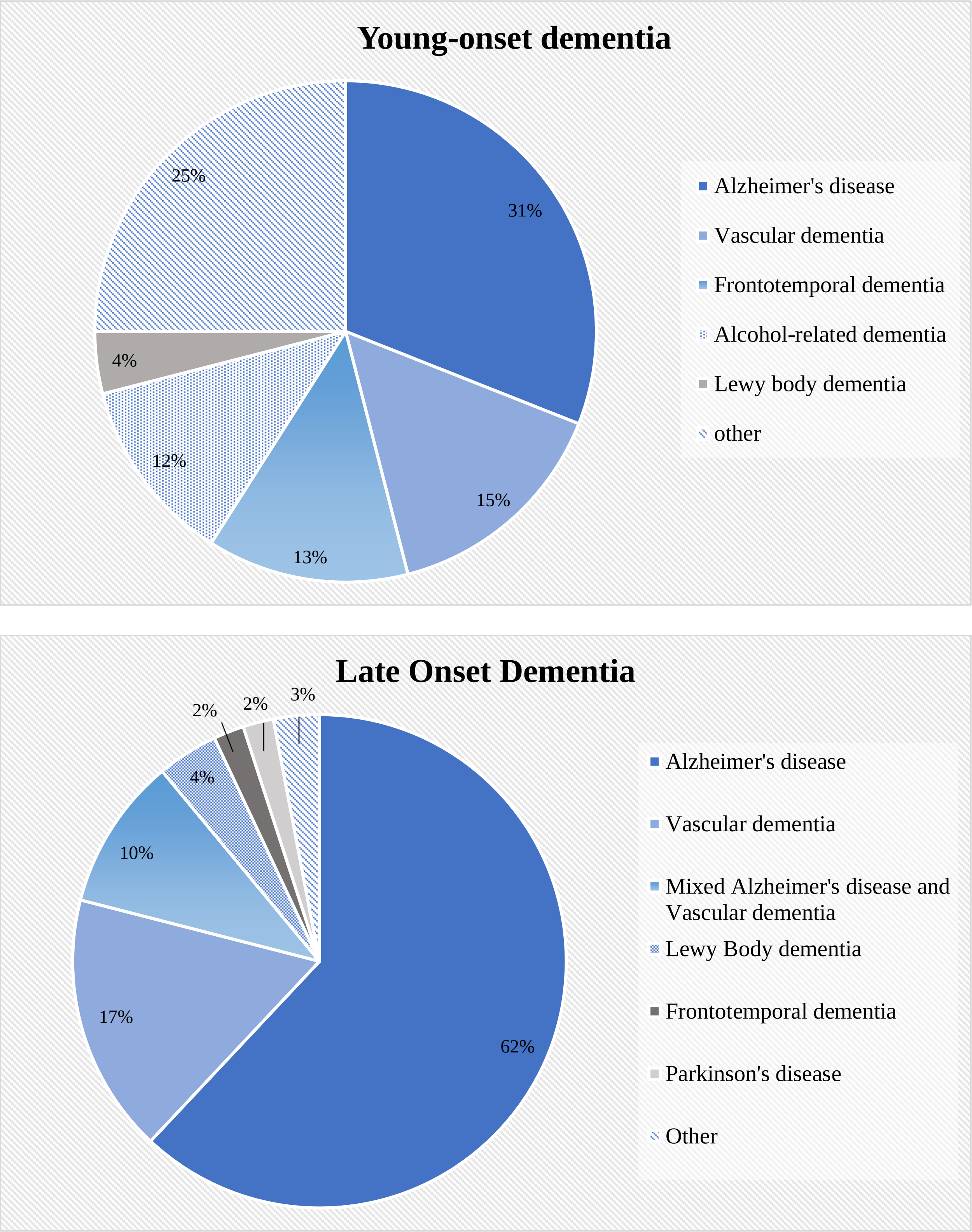

Figure 1: Adapted from Jefferies & Agrawal 2009

Although there is currently no cure for YOD, pharmacological and non-pharmacological (psychological) interventions do exist. The medications administered depend on the type and severity of dementia. For example, an individual with mild-moderate dementia may be prescribed Donepezil, whereas an individual with moderate-severe dementia may be prescribed Memantine, with treatments specifically targeted at emotional and behavioural symptoms (Jefferies & Agrawal, 2009; Kuruppu & Mathews, 2013). Non-pharmacological treatments focus on management of psychological and behavioural symptoms and may include interventions such as music, art, and recreation therapy (Jefferies & Agrawal, 2009).

Finally, YOD is unique in comparison to LOD due to the timing of the diagnosis and the progression of the disease. Younger individuals with dementia often experience a higher degree of psychosocial problems including unexpected loss of independence, difficulty juggling active responsibilities (job, family), grief, and inability to cope with the illness in comparison to those with LOD (Mendez, 2017). Further, YOD typically has a more aggressive clinical course and shorter relative survival time compared to LOD (Mendez, 2017; Seltzer & Sherwin, 1983). Thus, the literature has emphasized the importance of future research to help understand YOD and the importance of YOD specific services, as general dementia services are often inadequate and do not meet the needs of these individuals and their CGs (Jefferies & Agrawal, 2009; Mendez, 2017).

1.3 Young-onset dementia and Informal Caregiver Statistics

The role of informal CGs has become increasingly important within Canada, as CGs help to reduce the demands placed on the health care system (Turner & Findlay, 2015). In 2012 it was reported over 8 million Canadians provided informal care to family members or friends (CARP, 2020). Specifically, these informal CGs were primarily women (57%) between the ages of 45-65

(Sinha, 2013). Similarly, in 2019 it was reported over two thirds of CGs for individuals with dementia were women (Alzheimer's Disease Facts and Figures, 2019).

In Canada, 747,000 live with Alzheimer's disease and other dementias, with only 16,000 having YOD (Alzheimer's Society Canada, 2020). Although there are fewer Canadians diagnosed with YOD the needs of these individuals are just as significant. Economically, the annual cost of care for individuals with dementia in Canada is approximately 15 billion, expecting to rise to 153 billion by 2038, with informal CGs being responsible for approximately 70% of care related costs (Alzheimer's Disease Facts and Figures 2019; Chang et al., 2015). Moreover, it is expected the cost of care for individuals with YOD is even higher than those with LOD due to the timing of the diagnosis (Greenwood & Smith, 2016). In Singapore the median annual costs of care for an individual with YOD is approximately $15,815 (USD) compared to $8,396 (USD) for those with LOD (Kandiah et al., 2016), emphasizing the significant financial burden CGs-YOD experience. No similar study could be found in the North American context.

In 2019 it was estimated informal CGs for individuals with dementia spent 17 billion hours providing unpaid care for family members or friends. However, CGs-YOD often spend even more time caring than CGs for individuals with LOD (CGs-LOD), since persons with YOD often experience severe cognitive impairments while still living at home in comparison to older individuals (Canadian Institute for Health Research, 2020; Centers for Disease Control and Prevention, 2020). Thus, these numbers indicate the strain of dementia, specifically for informal CGs-YOD.

Finally, the number of people with dementia is rising and so is the need for informal CGs. Globally, an estimated 55 million people are living with dementia which is expected to rise to 65.7 million by 2030 and 115.4 million by 2050 (Alzheimer's Association, 2020; Prince et al., 2013; WHO, 2022). Similarly, it is projected by 2038 2.8% of the Canadian population will have some form of dementia, including those with YOD, increasing the incident rate to approximately one new case of dementia every two minutes (Alzheimer's Society, 2010; Chang et al., 2015). In sum, as the number of people living with dementia continues to rise, an increasing number of people will be expected to meet the demands as informal CGs (Canadian Institute for Health Information, 2022; Sinha, 2013).

1.4 Gender and Caregiving

1.4.1 Female Population in Canada

Within Canada there are approximately 19 million females consisting of 50.4% of the total population. Although this majority is small it has been consistent for over three decades, with rising life expectancy favouring women over men. In 2020 the median age of women in Canada was 41.9 with 32.4% of women being between 45-69 (Statistics Canada, 2020). Moreover, more than a quarter of the female population resides closest to home, with 39% of females living in Ontario. Further, it is expected by 2061 there will be over 21.2 million women and girls living within Canada. Thus, like the general population, the female population is aging along with the baby boom cohort. The baby boom cohort consists of individuals born between 1946 and 1965 (Urquijo & Milan, 2015) who are between 55-74 years old in 2020. Thus, this large cohort of women was one of the first generations to experience an increase in "labour participation amongst women in Canada" (National Institute of Ageing, 2018). However, despite the influx of women in the labour force there has been no change to the proportion of men and women taking on unpaid caregiving roles. The majority of CGs are primarily women. Further, women who host multiple roles (e.g., perform paid and unpaid work) do not displace or diminish their responsibilities, rather they perform the "second shift" and work longer hours ensuring they fulfill all tasks (Moyser & Burlock, 2018). However, by working these extended hours they put themselves at risk for adverse health effects. Thus, with the number of women performing paid and unpaid work simultaneously on the rise, the baby boomers aging, and the prevalence rate of Canadians living with chronic conditions, including dementia intensifying, it is essential for the voices of these women to be heard and their needs to be met (Moyser & Burlock, 2018; Urquijo & Milan, 2015). The effects of providing care on women’s health with be discussed next.

1.4.2 Females Providing Care

Bordonada et al. (2018) investigated the unique lived experiences of adults who identify as primary informal CGs, specifically aiming to gain a better understanding of how primary informal CGs make sense of their experiences. Phenomenology guided this qualitative study with interviews, conducted with 6 women. Snowball sampling was used to recruit participants living in the northern region of the United States who identified as primary informal CGs. Participants ranged in age from 55-75 years, with caregiving duration ranging from 6 months to 12 years. Three participants were employed full time, two participants were employed part time and one was retired. Each woman participated in a one-on-one semi-structured interview with the primary researcher. The results indicated all participants accepted their roles as CGs, with love being the motivating factor behind performing various caregiving duties. Nevertheless, the results accentuated the major effects caregiving had socially and emotionally, emphasizing the importance of support and practicing self-care. Thus, the results of this study shine light on the importance of appropriate support services for female informal CGs, helping to combat the multifaceted effects of providing informal care (Bordonada et al., 2018).

Using a cross-sectional design, Argimon et al. (2004) explored health-related quality of life in carers of people with dementia (age of persons with dementia not specified) (52% AD, 25% Vascular dementia, 23% mixed dementia) in comparison to carers of the general population. Participants were recruited from 37 primary health care centres in Spain. Carers of people with dementia were recruited (n=181, 141 females and 40 males, mean age 63) and were matched based on gender and age to three carers of the general population (n=543). All participants' health-related quality of life (HRQoL) was assessed using the SF-36 questionnaire, a generic instrument used to assess physical and mental health, consisting of 36 questions and eight SF-36 sub-scales (i.e., physical functioning, physical role, bodily pain, general health, vitality, social functioning, emotional role, and mental health). The results indicated female CGs for individuals with dementia reported significantly lower health in seven of the sub-scales, with the exception of physical functioning in comparison to carers of the general population. Further, 37.6% of female CGs for individuals with dementia indicated their health was significantly worse than the previous year, in comparison to only 26.2% of general carers (p=.007). Conversely, there were few differences between the male CGs for individuals with dementia and the male control group. Thus, the results of this study emphasized the significant effect dementia caregiving can have, specifically with respect to female carers HRQoL.

As previously indicated, women in Canada take on the majority of caregiving tasks. In 2018 a report conducted by the National Institute of Ageing (NIA) indicated 54% of Canadian informal CGs were women. Further, within the report it indicated that not only do more women hold roles as an informal CGs, but they also provide more hours of care and sustain the roles as CGs for longer durations in comparison to men (NIA, 2018). Specifically, Sinha (2013) indicated women typically spend upward of twenty hours per week providing care, with their male counterparts reporting providing less than one hour of care per week. Therefore, due to the extended hours of care women provide in comparison to men, they were more likely to feel the financial, social, and physical effects associated with demands of their caregiving roles (NIA, 2018).

1.5 Effects of Caregiving

1.5.1 Caregiver Burden

CG burden has been defined as “distress CGs experience as a result of providing care” (Koopman et al., 2020) and can be one of most serious complications associated with being informal CGs (Adelman et al., 2014). CG burden can be further sub-divided into two classifications, objective burden (e.g., time and costs associated with providing care) and subjective burden (e.g., CGs perception of the situation) (Flyckt et al., 2015; Montgomery et al., 1985) which have the ability to cause an array of adverse health effects such as depression, anxiety and decreased quality of life (Etters et al., 2008). Previous studies have indicated numerous risk factors associated with burden among informal CGs (Adeleman et al., 2014; Koopman et al., 2020; Prevo et al., 2018). These risk factors include demographic characteristics (e.g., female gender, advanced age, being employed), relationship with the care recipient (e.g., spouse or parent), number of hours spent providing care, health of the informal CG, financial situation, and level of social support (Adelmen et al., 2014; Koopman et al., 2020). Papastavrou et al. (2007) investigated the relationship between family CGs for individuals with dementia and their reported levels of psychological burden. Results showed female CGs experienced a higher degree of burden, personal strain, and depression in comparison to their male counterparts (Papastavrou et al., 2007). These results were consistent with other studies indicating female gender increases the likelihood of experiencing CG burden (Adelmen et al., 2014; Argimon et al., 2004; Prevo et al., 2018).

Chou (2000) developed a conceptual model to help individuals better understand the elements of caregiving directly related to CG burden. Specifically, CGs experience burden when they feel a sense of overload in one or more of the following domains: (1) physical strain, (2) emotional strain, (3) social strain, and/or (4) financial strain. Thus, Chou's (2000) conceptual model of caregiving burden can be utilized to help gain a better understanding of the effects of YOD on female informal CGs. In fact, various studies (e.g., Flynn & Mulchay, 2015; Lui et al., 2020) have utilized this model to better understand the CG burden effects.

1.5.2 Caregiving and COVID-19 Pandemic

Tsapanou et al. (2020) explored the effect of COVID-19 pandemic on older adults with mild cognitive impairments (MCI)/ dementia (mean age 79, 36 MCI, 58 dementia, gender and type of dementia not specified) and their CGs. Participants were recruited from various Alzheimer's societies and private neurological practices in Greece. Two hundred and four CGs (75.6% women, mean age 59) agreed to participate and completed a self-reported questionnaire regarding individuals with MCI/dementia and themselves as CGs, with questions specifically examining changes during the pandemic (e.g., physical, psychological, routine activities etc.). Results indicated 78.8% individuals with MCI/dementia experienced a significant overall decline as a result of the COVID-19 pandemic, with communication, mood, movement, and compliance with the new measures (i.e., hygiene/protective measures) being amongst the top four domains affected. Further, CGs reported experiencing an increase in CG burden specifically in relation to physical burden (64.7%) and psychological burden (80%). Additionally, only 40.3% of CGs had some support during this time due to the various restrictions implemented. Therefore, the on-going COVID-19 pandemic has amplified the effect of MCI/dementia on individuals and their CGs and decreased the number of support services available.

1.6 Effects of Caregiving for Individuals with Young-onset Dementia

1.6.1 Negative Effects

For a comprehensive summary of all methodologies, explanations of the methodologies and results of all studies with negative effects of caregiving please refer to Appendix B.

Currently, there is limited information on the effects of caring for younger individuals with dementia. However, in general it has been said informal CGs for individuals with dementia are referred to as the "invisible second patients" due to the adverse health effects associated with their CG roles (Brodaty & Donkin, 2009; Van Vliet et al., 2010), resulting in their caregiving experiences being inherently negative. For example, Aria et al. (2007) conducted a study examining the experiences of informal CGs-LOD in comparison to CGs-YOD, specifically aiming to identify the problems CGs face. Participants were selected from 92 different caregiving-patient dyads and data were collected through means of various self-administered questionnaires (more detail located in Appendix B). The results indicated CGs-YOD were more likely to experience an increased burden since they were less likely to be prepared for their caregiving roles, due to the timing of the diagnosis. Further, due to the rarity of YOD it was more likely for CGs-YOD to experience a lack of services available, leading to isolation of these individuals. Similarly, in a study which explored the lived experiences of spousal CGs-YOD, Ducharme et al. (2013) found partners of individuals with YOD faced extreme hardships following the diagnosis of dementia. The rarity of YOD has created stigma surrounding the disease. This stigma led to participants keeping their spouses' diagnoses confidential, exacerbating their feelings of loneliness. Additionally, the results further indicated participants grieved the loss of "normal life" and felt helpless when trying to plan for their futures, with a paucity of appropriate resources accelerating these effects. Conversely, a large-scale, prospective, longitudinal study by Millenaar et al. (2016) compared overall well-being of CGs-YOD (n=220) to CGs-LOD (n=108). All CGs were assessed at baseline and took part in four follow up assessments over the course of 2 years (more detail in Appendix B). Unlike Aria et al. (2007) the results indicated few differences between CGs-YOD and CGs-LOD. More specifically, CGs in both groups reported high levels of physical and psychological complaints, mild depressive symptoms, a low sense of caregiving competence, and low HRQoL. However, a statistical significance between the two groups did exist. CGs-YOD experienced more difficulties within daily life resulting from the physical and psychological effects of caregiving in comparison to CGs-LOD, despite both groups reporting high levels of physical and psychological complaints (Millenaar et al., 2016). Thus, future research should further investigate the differences between CGs-YOD to CGs-LOD, to help better understand the lived experiences of both groups.

Using a qualitative interpretive phenomenological design, Kimura et al. (2015) explored the psychosocial consequence of YOD among CGs. Nine CGs-YOD (7 women, 2 men) were interviewed using open-ended questions, allowing for individuals to express their true feelings towards their caregiving roles. Researchers concluded CGs-YOD experienced strain specifically in relation to the following five domains: (1) psychological and emotional; (2) physical; (3) financial and professional; (4) social; and (5) support services. Similarly, Flynn and Mulcahy (2015) examined the four aspects associated with caregiving burden namely physical, emotional, social, and financial. Within both studies researchers concluded CGs-YOD experienced significant social effects due to the time commitment associated with their caregiving roles and limited social supports available (Flynn & Mulcahy, 2015; Kimura et al., 2015). Further, the financial effects of caregiving for individuals with YOD was highlighted by all participants.

More specifically, participants indicated financial hardships stemming from early retirement for both CGs and individuals with YOD (Kimura et al., 2015), the individuals with YOD being the family breadwinner, and costs associated with having children completing their educations at the time of diagnosis (Flynn & Mulchay, 2015). These results emphasized the heightened financial effects CGs-YOD experienced due to the timing of the diagnosis. However, some inconsistencies existed between the experiences of CGs-YOD. Kimura et al. (2015) reported CGs-YOD experienced decreased physical health resulting from their caregiving roles, whereas Flynn and Mulcahy (2015) indicated few CGs experienced physical effects; thus, future research is warranted. Moreover, Kimura et al. (2015) suggested the psychological and emotional strain associated with caregiving stems from feelings and emotions intrinsic to the caregiving situation (e.g., guilt, grief, depression, anger, loneliness, fear for the future), while Flynn and Mulcahy (2015) reported emotional effects with respect to family dynamics, dependent children, and acceptance of the diagnosis. Therefore, although inconsistencies exist within the literature it is apparent CGs-YOD experience a myriad of physical, social, emotional, and financial effects.

Few studies have considered gender when examining the effects of caregiving for younger individuals with dementia (Kaiser & Panegyres, 2007; Lockridge & Simpson, 2012; Luscombe et al., 1998; Papastavrou et al., 2007). Research conducted by Kaiser and Panegryes (2007) studied spousal CGs of individuals with YOD, with the intentions of gaining a better understanding of the effects of caregiving on psychological well-being. A cross-sectional cohort analysis was conducted with spousal CGs of patients with YOD at the Neuroscience Assessment and Care clinic in Western Australia. A questionnaire consisting of two sub-sections was sent to 120 spousal CGs-YOD (more detail in Appendix B). Section one of the questionnaire included the Zarit Burden Interview, while section two consisted of the Beck Depression Index (BDI).

The ZBI and BDI are valid and reliable assessments tools and commonly used when examining CG burden (Gallicchio et al., 2002; Xiong et al., 2020). Of the 120 questionnaires administered 100 were usable (i.e., 20 were incomplete). The results of the ZBI reflected the degree of subjective and objective burden experienced by CGs. Specifically, CGs expressed feeling burdened by the dependency of their spouses, decreased overall health, and diminished social lives. Likewise, consistent with previous research, wives caring for their husbands reported a higher degree of emotional distress (i.e., grief) in comparison to husbands caring for their wives (Kaiser & Panegyres, 2007; Luscombe et al., 1998). Similarly, female CGs experienced higher rates of depression in comparison to male CGs (Kaiser & Panegryes, 2007). Finally, female CGs were less likely to ask for help and more likely to utilize emotion-focused coping techniques which have been found to unwittingly exacerbate the effects of caregiving rather than combat them (Lockridge & Simpson, 2012; Luscombe et al., 1998; Papastavrou et al., 2007). The results indicated the importance of specific resources for female CGs-YOD to help decrease negative effects associated with caregiving. However, it is important to recognize the scarcity of YOD literature in general, not only related to gender.

Due to the timing of the diagnosis, CGs-YOD are more likely to have dependent children which creates additional stressors and effects in comparison to CGs-LOD. For example, Gelman and Rhames (2018) explored the effect of YOD on parenting and children experiences. In-depth semi-structured interviews were conducted with four spouses (all wives) and eight children aged 16-20 of individuals with YOD (3 AD, 1 Frontotemporal dementia). Interviews with each participant ranged from 1-2 hours in length and focused on evolving parent-child relationship since the diagnosis. All interviews were transcribed verbatim and analyzed using thematic narrative analysis (Braun & Clarke, 2006; Riessman, 2008), with three core themes emerging:

(1) “Changes in family structure and role”- in all families the mothers took over both parental roles and children became care takers for their fathers; (2) “Muting of experience to protect mother”- all children indicated they did not express their feelings of worry or stress to their mothers; and (3) “Divergent perspectives on YOD’s impact”- due to all children hiding their emotions from their mothers, mixed results were reported between the children and spouses of individuals with YOD (Gelman and Rhames, 2018). The results of this study highlighted the noteworthy effects YOD can have on individuals, their primary informal CGs, and their dependent children, further emphasizing the importance of specific resources for families faced with YOD.

A 2016 report from the Alzheimer’s Association revealed 28% of people who cared for individuals with dementia were more likely to struggle financially than those who did not provide care. Further the annual out of pocket costs for individuals with dementia ranged from $1000 to $100,000 with the spouse or partner covering the majority of the expenses (Alzheimer’s Association, 2016). Since YOD occurs at such a young age, individuals are often forced to retire early, have less money in savings accounts (O’Neil & Fletcher, 2021) and spouses/partners often must take time off work to care for their loved ones (Flynn & Mulcahy, 2015), all factors which augment financial stress among these families. Also, due to the intensified financial effect for younger individuals with dementia, financial hardships have been reported as one of the most difficult factors associated with having and caring for an individual with YOD (O’Neil & Fletcher, 2021). Yet, a paucity of financial assistance is available to these individuals and their families. In addition, programs typically do not address the needs of families faced with YOD. A qualitative case-study examining the lived experiences of an individual with young-onset AD and his family indicated they were victims of ageism when reaching out to various community programs (O’Neil & Fletcher, 2021). Within Ontario seniors are given the opportunity to participate in exercise programs free-of charge to help maintain various symptoms associated with AD; however, due to age being a restricting factor, younger individuals with dementia are either excluded from these programs or do not qualify for the financial assistance, thus exacerbating the effects associated with dementia for younger individuals and their families (Government of Ontario, 2021; O’Neil & Fletcher, 2021).

1.6.2 Positive Effects

For a comprehensive summary of all methodologies, explanations of the methodologies and results of all studies with positive effects of caregiving please refer to Appendix C.

Although the majority of the effects from the experiences associated with informal caregiving for individuals with dementia have been negative, a few studies have positive effects (Flynn & Mulcahy, 2015; Semiatin & O’Connor 2012). Semiatin and O’Connor (2012) examined the relationship between self-efficacy and positive aspects of caregiving for individuals with late onset AD. Fifty-seven CGs (39 spouses, 15 children, 3 siblings) of individuals with AD were recruited from caregiving intervention centers. Participants were assessed at baseline to ensure they adhered to the strict inclusion and exclusion criteria (baseline assessments administered can be observed in Appendix C). Analysis of the one-on-one interviews revealed positive experiences related to caregiving, such as bringing the family together and satisfaction of helping others. Likewise, there was a negative relationship between distress (e.g., physical, and psychological) and CGs reporting positive aspects of care (Semiatin & O’Connor, 2012). Hence, CGs who were able to recognize the benefits associated with their caregiving roles reported lower physical and psychological distress in comparison to CGs who perceived their roles as solely negative. Similar findings were expressed within Flynn’s and

Mulcahy's (2015) qualitative analysis of the effects of YOD on family caregivers. Further, the importance of maintaining a positive attitude following the diagnosis of young-onset AD was emphasized within the O'Neil and Fletcher (2021) qualitative case study on an individual with young-onset AD and his family (See Appendix C), thus indicating CGs-YOD can also experience benefits from their caregiving roles.

Positive aspects associated with providing informal care are underrepresented within the literature, limiting our comprehension of the experiences of CGs-YOD. Gaining a better understanding of the factors associated with positive aspects of caregiving may provide insight about the provision of quality care for individuals with YOD (Carbonneau et al., 2010). Thus, it is imperative for future research to explore positive aspects of caregiving specifically for female CGs-YOD to aid in the development of appropriate resources. The current programs and resources available within Canada for individuals with dementia and their CGs will be discussed next.

1.7 Programs and Resources

1.7.1 A Disconnection: The Needs of Female Informal Caregivers Vs. Current Services

Within Canada, most support programs and resources are designed for older adults with dementia, with limited programs designed specifically for individuals with YOD (Young-onset dementia Facilitators Resource Manual, 2018). Thus, people with YOD typically struggle to find appropriate community services that meet their unique needs (Withall et al., 2013).

Ducharme et al. (2014) utilized a mixed method approach to better understand the unmet support needs experienced by Canadian CGs-YOD, specifically within Quebec. CGs-YOD were recruited (n=32), and data was collected using The Family Caregivers Support Agreement (FCSA) tool which consisted of various questions within four broader sections: (1) "helping you care for your relative”; (2) how to make life better for your relative (individual with YOD); (3) how to make life better for themselves as a CGs; and (4) “getting quality help” (Ducharme et al., 2014, p. 3). CGs were asked to rank “whether the information would be helpful for them, whether it was already being received, or whether it did not apply to their situation” (Ducharme et al., 2014, p. 3). Finally, CGs were giving the opportunity to add any information believed to be important, that was not addressed within the questionnaire. Over 50% of CGs, in 16 of the 30 FCSA needs investigated, reported their needs were unmet. More specifically, the most prominent findings were associated with the need for more information (78% of CGs), the need for help finding/applying for financial assistance (72% of CGs), means to make the individual with YOD feel valued (72% of CGs), and ways to decrease stress as CGs (75% of CGs). Overall, the results of this study helped shine light on the various unmet support needs of Canadian CGs-YOD and the importance for psychosocial interventions to help CGs cope with the various effects associated with their caregiving roles (Ducharme et al., 2014).

As previously indicated, there are limited programs within Canada specifically for individuals with YOD and their CGs, with a “one size” (Ducharme et al., 2014) fits all approach currently being applied to most interventions for individuals with dementia and their CGs. However, despite this “one size” fits all approach some services go as far as to exclude individuals under the age of 65 (Van Vliet, 2012; Withall, 2013). Further, the services that are inclusive are typically irrelevant for younger individuals with dementia, since programs are tailored for much older, more frail individuals (Withall, 2013). As such, CGs experience increased burden due to limited time away from caregiving duties and limited appropriate support services available. Thus, in order to develop support programs specific to this at-risk population, Withall (2013) advised consultations with CGs-YOD so their needs could be clearly articulated for health care workers, policy makers and society as a whole.

1.8 Female Caregivers for Individuals with Young-onset Dementia: The Gap in the Literature

Currently there is a lack of information about the experiences of female CGs-YOD, which poses as a threat to their well-being. CGs-YOD are often not prepared for their spouses to retire, as a result of YOD, causing families to face severe financial hardships (Flynn & Mulchaly, 2015; Kimura et al., 2015; O’Neil & Fletcher, 2021) which potentially exacerbates other aspects of their lives, including physical and mental health, social support, food insecurity and access to safe accommodations (Flynn & Mulcahy, 2015). As a result of the limited understanding of the needs of female CGs-YOD there is a corresponding lack of resources available, further exacerbating their caregiving duties and increasing CG isolation for families faced with YOD (Arai et al., 2007). It is apparent increased understanding and awareness of the lived experiences of CGs-YOD could provide serious implications for programming (Withall, 2013). Further, Brodaty and Donkin (2009) contend psychosocial interventions tailored to the specific needs of CGs help reduce depression and CG burden; however, many interpersonal teams who work with these CGs still believe a “one-size” fits all model works, grouping CGs-YOD with CGs-LOD causing these services to be irrelevant for YOD clients (Ducharme et al., 2014). In addition, Chaston (2010) argued a lack of awareness and information is destructive when trying to provide care for individuals with YOD and their families. Nurses and other health care workers are in the optimal position to provide support and help educate families about dementia and providing care (Cabote et al., 2015). Unfortunately, individuals are reluctant to do so due to the lack of information available. As such, there is a gap in the literature regarding the experiences of female CGs-YOD that needs to be addressed.

1.9 Purpose and Research Questions

The goal of this research study was to provide in-depth information about the lived experiences of female CGs caring for individuals with YOD, by specifically examining the effects of caregiving on CGs, and the barriers to the provision of care. The three primary research questions that guided this qualitative study included:

1. What effects does caregiving have on women CGs' overall health and quality of life?
2. What are the challenges associated with being female CGs for individuals with YOD? and
3. What effects do programs/resources or lack of programs/resources have on CGs?

Implications for this research include recognizing the substantial effect caregiving for individuals with YOD can have on female informal CGs, as well as helping to guide the development of specific resources to help sustain the health and well-being of this at-risk population.

CHAPTER 2: METHODOLOGY

2.1 Participant Recruitment

In order to gain rich information about the lived experiences of female CGs, individuals had to be experiencing the phenomenon firsthand (Patton, 2015) to participate in this study. The primary researcher recruited 10 female informal CGs for individuals with YOD. As such, participants were recruited using purposeful sampling, namely criterion and snowball sampling. Purposeful sampling was used to recruit participants who were considered information-rich and were able to provide in-depth descriptions of their experiences (Creswell, 2013). Snowball sampling was employed by asking the participants if they knew of any female informal CGs of individuals with YOD (Patton, 2015). Lastly, criterion sampling was implemented to ensure all participants “met some criterion” (Creswell, 2013, p.158).

Participants were recruited through word of mouth and advertisements to societies and support groups for individuals with YOD or dementia in general, in Canada. All participants were assessed using specific inclusion and exclusion criteria to ensure they were information rich and could provide a comprehensive understanding of the effects of being female informal CGs for individuals with YOD. The inclusion criteria for each female informal CG was as follows: (1) must live within Canada; (2) must consider herself a primary informal CG for an individual with YOD; (3) must be untrained and unpaid for her services; (4) must be a family member, close friend, or significant other to the individual with YOD; and (5) must be in some form of contact with the individual with YOD weekly. To elaborate on point three, individuals who were employed as health care professions (e.g., personal support worker, nurses, occupational therapists, etc.) within their professional lives, but demonstrated informal acts of care for individuals with YOD were allowed to participate. Expanding on point five, the informal CG did not have to live with the individual with YOD, meaning the person with YOD could have been a resident of a long-term care home or lived within another setting. However, the informal CG must have communicated with the individual on a weekly basis and provided some form of support. Furthermore, the reasoning for including CGs-YOD who may have only communicated with the individual with YOD on a weekly basis was because of the ongoing COVID-19 pandemic. During numerous lockdowns, restrictions prohibited CGs from visiting long-term care facilities, thus if these individuals were excluded challenges with recruitment and reaching saturation may have been faced due to the rarity of YOD.

In terms of the individual with YOD, the inclusion criteria consisted of: (1) being formally diagnosed with dementia before age 65; (2) and has someone who provides care for them. Additionally, individuals with any form of YOD (Alzheimer's disease, Frontotemporal dementia, Vascular dementia, Lewy body dementia etc.) and severity (mild, moderate, or severe) were eligible to participate in this study. Due to the rarity of YOD if the inclusion criteria for informal caregivers was restricted to one form of YOD (e.g., mild AD) challenges with recruitment and reaching saturation may have occurred.

2.2 Research Tools and Procedures

2.2.1 The Qualitative Method and Paradigm

To gain a thorough understanding of the lived experiences of female informal CGs for individuals with YOD, the most appropriate methodology to use was qualitative in nature, as it allowed for a holistic understanding of a particular experience or phenomenon. Specifically, this methodology was grounded within a constructivist paradigm. As stated by Ponterotto (2005) constructivists "hold that reality is constructed in the mind of the individual, rather than it being an externally singular entity" (p.129). Creswell and Creswell (2018) further described constructivists as individuals who strive to understand subjective experiences and who recognize that their own background influences their interpretations. Therefore, the primary researcher believes multiple realities exist (i.e., relativist ontology) and to understand these realities, the lived experiences of multiple individuals needed to be understood (i.e., subjectivist epistemology) (Ponterotto, 2005). Thus, qualitative inquiry with a constructivist paradigm base allowed for the stories, experiences, and voices of female informal CGs-YOD to be understood and heard. Therefore, this was an appropriate methodology for this particular study, since its purpose was to understand the lived experiences of female informal CGs-YOD.

The theoretical orientation used to guide this research was phenomenology. As described by Creswell "a phenomenological study describes the meaning for several individuals of their lived experiences of a concept or a phenomenon" (Creswell, 2007, p.57). Patton (2002) thoroughly described phenomenology as

> *How human beings make sense of, experience and transform experience into consciousness, both individually and as shared meaning. This requires methodologically, carefully, and thoroughly capturing and describing how people experience some phenomenon –how they perceive it, describe it, feel about it, judge it, remember it, make sense of it and talk about it with others (p.104).*

Specifically, interpretive phenomenology was used, meaning the researcher's own beliefs and understandings played a part in the interpretation of the participants' views (Lverty, 2003). In order to do this, "one must undertake in-depth interviews with people who have directly experienced the phenomenon of interest; that is, they have 'lived experience' as opposed to 'secondhand experience'" (Patton, 2002, p.104). Female information CGs-YOD have lived experiences rather than secondhand experience of being CGs.

One one-on-one semi-structured interview, and one follow up interview via email or Zoom with each participant, a background questionnaire, field notes, and member checks were used to collect information pertaining to CGs' lived experiences. Analyses of the information collected allowed for the true "voices" of participants to be conveyed, enabling readers to fully understand the essence of their experiences.

2.2.2 Ethics

Prior to data collection, all tools and procedures were approved by the Wilfrid Laurier University Research Ethics Board. Upon recruitment and prior to participating in this study, all participants were sent an informed consent statement to read and sign. All participants were allowed to refuse to answer any questions, ask questions prior, during, or after any interview session, or terminate their participation at any point in time. All potential ethical ramifications were outlined within the consent form (Appendix D).

2.2.3 Background Questionnaires

Once the consent form was signed, a background questionnaire was sent to all participants to be completed. The background questionnaire consisted of: (1) demographic information (e.g., date of birth, education, employment, marital status, children); (2) perceived health (e.g., overall health, any known illnesses/conditions); (3) descriptions of the relationship with the individual with YOD and the health of the individual with YOD; and (4) information concerning role as a CG (e.g., activities completed for the individual with YOD) (Appendix E). The information obtained from the background questionnaires provided context prior to the interviews and assisted with rapport building between the interviewer and the interviewee.

2.2.4 Interviews

Each participant took part in a one-on-one semi-structured interview and a follow up interview conducted by the primary researcher. Interviews were arranged at a time convenient to the interviewee and were conducted via Zoom (n=8), or over the phone (n=2) for interview number one, and via Zoom (n=2), over the phone (n=0) or via email (n=7) for interview number two. One participant failed to complete interview number two due to personal health reasons. The length of the interviews was dependent on each participant's responses and interviews were audio recorded for further analysis. Interview one lasted an average of 79 minutes with the shortest and longest being 41 minutes and 130 minutes respectively. Interview two lasted an average of 21 minutes with the shortest and longest being 20 minutes and 22 minutes respectively (Table 1 on page 42). Likewise, all interviews were transcribed verbatim. To maintain confidentiality/anonymity of all participants, pseudonyms were used in the place of the participants' names. Any other identifying information was removed from the transcripts to protect the anonymity of participants.

Prior to each interview the primary researcher reminded all participants of the purpose of the study, and that they were able to choose not to answer any question, take a break, or discontinue the interview at any point in time. The primary researcher also introduced herself helping to build rapport with the interviewees.

To capture the lived experiences of these informal CGs, the primary researcher conducted one semi-structured interview and a follow up interview via email or Zoom. Interview one consisted of 19 open ended questions focusing on the effects and challenges associated with being an informal CG and if at all, any coping mechanisms or resources utilized. The beginning of the interview included background questions and demographic information helping to capture the lives of the informal CGs. The interview then moved into questions pertaining to their roles as CGs and the effects of caregiving on their everyday lives. The interview then discussed the health of the informal caregivers pre- and post their caregiving roles and any challenges or barriers faced as CGs. Finally, the interview ended discussing if at all, any coping mechanisms utilized by CGs (Appendix F). The follow up interview via Zoom or email (method was dependent on interviewee's choice) concluded with questions regarding their caregiving roles, changes to their caregiving journeys, and advice they would give others CGs (Appendix F).

Throughout the interview process, probes were utilized when participants' answers required elaboration or further information was warranted. As described by Flick (2009), probing allowed the researcher to gain a deeper understanding of what was being said, through questions of comprehension and confronting the interviewee with any inconsistencies presented. Further, each interview was audio-recorded through a password protected device, transcribed verbatim, and read over to monitor saturation. Saturation indicates that no new data are being identified (Saunders et al., 2018) and thus, when the primary researcher felt saturation had been achieved, recruitment of participants ceased, and the data obtained were further analyzed.

2.2.5 Field Notes

Data collection was further enhanced by handwritten field notes. The researcher took notes prior to, during, and after each one-on-one interview. Prior to each interview field notes were taken indicating the date, time, location, and atmosphere of all interviews. During the interviews field notes were recorded helping to highlight participants' reactions, body language, and emotions in response to specific questions. These notes then assisted with post interview data analysis. For example, when analyzing transcripts, I would review my field notes to remind me of any emotions provoked, and key topics discussed. Finally, the primary researcher recorded reflexive thoughts after the completion of each interview, also known as journaling (Janesick, 1999). Although the primary researcher is not an informal CG-YOD, she has previous experience interacting with an individual with YOD and his immediate family. Thus, it was important for her as the primary researcher to separate her own experiences from the participants’ ensuring the data collected were an accurate representation of the female informal CGs-YOD. For instance, after each interview I would debrief by journaling and express any of my own thoughts and opinions regarding any information disclosed. I would then refer to my journal when reviewing transcripts and writing the results, ensuring my own thoughts and experiences were separate from participants. The field notes added more context to the interviews helping to ensure richness of the data collected and assisted with the analysis process.

2.2.6 Member Checks

After transcription, each participant was sent a copy of her transcript giving her the opportunity to “correct, amend, or extend” (Lincoln & Guba, 1985, p.236) any information disclosed during the interview process. This process helped to ensure participants had the ability to control the information included within future research papers, posters, or presentations presented by the primary researcher. All member checks were sent to each participant in a format most convenient to her (e.g., physical hard copy sent via postal mail (n=0), or an electronic copy via email (n=19)). Each participant was given two weeks to return the member check to the primary researcher and the primary researcher then used the information provided within any further data analysis. The primary researcher received 16 member checks from her participants. All CGs returned their member check for interview one, and six CGs returned their member check for interview two. Within the member checks CGs provided several pieces of additional information, and some grammatical edits. Three CGs did not return their member check for interview two and provided no explanation. It is important to recognize there were only nine member checks for interview number two as one participant failed to complete interview two due to personal health reasons. After the two-week period allotted for reviewing member checks, the primary researcher proceeded with the transcripts as is. Thus, member checks helped to increase the accuracy of the data, as well as build rapport and trustworthiness between the primary researcher and all participants (Holloway, 2005).

2.2.7 Triangulation

The purpose of triangulation is to utilize multiple sources of data to "build a coherent justification of themes" (Creswell & Creswell, 2018) during data analysis. Within the current study data and investigator triangulation (Padgett, 2012) were employed. Data triangulation was used to increase the credibility of the results by incorporating multiple modes of data collection, namely background questionnaires, field notes, one-on-one semi-structured interviews, and member checks. Additionally, investigator triangulation was utilized by having the primary researcher and her supervisor individually analyze, compare, and interpret the data (Patton, 2015). This helped to strengthen the findings from the analysis. Finally, an intercoder agreement was implemented to ensure there were no inconsistencies in codes between the primary researcher and her supervisor (Creswell & Creswell, 2018).

2.3 Trustworthiness: Credibility, Transferability, and Confirmability

Lincoln and Guba (1985) contest that trustworthiness is an essential component when determining the worth of a particular study. Trustworthiness can be established through the implementation of the following four concepts, (1) credibility; (2) transferability; (3) confirmability; and (4) dependability (Lincoln & Guba, 1985). Each of these concepts will be discussed.

2.3.1 Credibility

As described by Lincoln and Guba (1985) credibility is the process of creating confidence in the data presented. Patton (1999) contends the following three factors help to establish credibility: (1) rigorous techniques for gathering high quality data; (2) ensuring credibility of the researcher; and (3) philosophical belief in the value of qualitative inquiry.

As previously stated, credibility was achieved within the current study using multiple modes of data collection (see 2.2.5 Field Notes, 2.2.6 Member Checks, and 2.2.7 Triangulation). By implementing rigorous modes of data collection, it helped to ensure greater integrity of the data and allowed for trust to be built between the primary researcher and all participants (Lincoln & Guba, 1985). Open communication was made with all participants throughout the research process enabling them to be active contributors throughout the data collection process.

Additionally, the primary researcher was an asset in the qualitative research process and was considered an integral tool (Sanjari et al., 2014). To ensure a comprehensive understanding of qualitative methodologies and theoretical approaches, the qualitative researcher completed multiple research methods courses. Further, she completed an extensive literature review on YOD and the multifaceted effects of caring for individuals with YOD, which was reviewed by her supervisor. The researcher also utilized field notes to support the analyses of other data collected. Further, the primary researcher conducted reflexive ‘journaling’ to ensure neutrality by recognizing her own biases brought to the study (Janesick, 1999).

Finally, the primary researcher utilized a qualitative methodology to fully examine the lived experiences of female informal CGs-YOD. This design allowed for the true “voices” of all participants to be heard.

2.3.2 Transferability

Padgett (2012) describes transferability as the ability of the study’s findings to be generalized to other contexts. In order to achieve this one must obtain a “thick description” of the topic of interest. Within the present study, to ensure high-quality data was collected all participants had to be information-rich cases and had to be selected (or not selected) based on the inclusion/exclusion criteria. This way, findings from this study are applicable to healthcare professionals, government officials responsible for allocating funding, and support services such as the Alzheimer’s society in how to better meet the needs of CGs-YOD. Further, by implementing this method, it helped to ensure saturation was achieved, increasing the credibility and transferability of the study (Padgett, 2012).

2.3.3 Confirmability

Padgett (2012) states “confirmability is achieved by demonstrating that the study’s findings [were] not imagined or concocted but, rather, firmly linked to the data” (p. 204). Further, Lincoln and Guba (1985) contend confirmability is the degree of neutrality within a study, or how the participants’ responses shape the data, and not the motivations of the researcher. Thus, to establish confirmability, field notes (2.2.5) and triangulation (2.2.7 data and investigator triangulation) were utilized (Lincoln & Guba, 1985; Padgett, 2012). The use of these methods allowed for the lived experiences of each participant to be understood and shape the data within the study.

2.3.4 Dependability

Korstjens and Mosr (2018) states “dependability is the stability of findings over time” (p. 121), and involves the participants perceptions’ of the “findings, interpretation, and recommendations” (p. 121). Further, Lincoln and Guba (1985) contend dependability is comparable to reliability in quantitative research and is the degree of stability, consistency, predictability, and accuracy of the results. Thus, to establish dependability, the primary researcher included a complete audit trail indicating every step she and her supervisor took in order to collect (i.e., background questionnaires, field notes, interviews, member checks), analyze (see 2.4 data treatment and Appendix G), and interpret the results. Each step is explained in detail throughout the methodology section of this paper, allowing for this study to be easily replicated.

2.4 Data Treatment

2.4.1 Qualitative Analysis: Phenomenology

The theoretical orientation used to guide this study was interpretive phenomenology. Since this research examined the lived experiences of females providing informal care for individuals with YOD, interpretive phenomenology was the most appropriate theoretical orientation to use, as it allowed for the phenomenon (i.e., caregiving) to be examined and understood, while recognizing the researcher's own beliefs and understandings played a part in the interpretation of the participants' views (Lverty, 2003; Van Manen, 1990).

Within this study the primary researcher used numerous steps in order to conduct an in-depth analysis of the data collected from the background questionnaires, interview transcripts, field notes, reflexive journaling, and member checks. The information presented within the background questionnaires helped provide context prior to the interviews, increasing the credibility of the results. Likewise, field notes and transcripts were analyzed numerous times, ensuring richness of the findings. Finally, data collection and data analysis were performed concurrently helping to capture the ebbs and flows associated with caregiving for individuals with YOD and to monitor saturation.

A step-by-step analysis of the data was conducted by the primary researcher. Specifically, Braun and Clarke's (2006) six steps to thematic analysis were utilized. “Thematic analysis is a method [used] for identifying, analyzing, and reporting patterns/themes within the data” (Braun & Clarke, 2006, pg. 79). This process consists of six key phases: (1) familiarize oneself with the data; (2) creation of initial codes; (3) search/develop themes; (4) review the themes; (5) define and name themes; and (6) produce the report (Braun & Clarke, 2006). To begin, for the primary researcher to familiarize herself with the data she read, then re-read and highlighted key statements, ensuring she had a thorough understanding of all information. Then, the primary researcher re-examined what she had highlighted within all transcripts to identify any similarities throughout the data. Once similarities had been identified the primary researcher was able to use that information to develop common themes. Further, the primary researcher created a colour coded chart of the different themes enabling subthemes to emerge. The primary researcher then named all themes and identified verbatim quotes from each interview that corresponded respectively. The primary researcher utilized vision boards to organize all themes, sub-themes, and their respective quotes (Appendix G), culminating with the production of the final report. Throughout the entire data collection process investigator triangulation was used by having the primary researcher meet with her advisor (who read and analyzed all of the data), as well as present findings to a qualitative lab group.

Table 1: Interview number, duration and mode utilized

	Interview #1	**Interview #2**
Via Zoom	n=8	n=2
Over the Phone	n=2	n=0
Via Email	N/A	n=7
Average Length	79 minutes	21 minutes
Longest Interview	130 minutes	22 minutes
Shortest Interview	41 minutes	20 minutes

Note n=9 for interview #2. One participant failed to complete the second interview due to personal health reasons and thus the total is nine.

CHAPTER 3: RESULTS

3.1 Introduction to Participants

The purpose of this study was to examine the lived experiences of primary informal caregivers for individuals with young-onset dementia (CGs-YOD). Each of the ten women self-identified as primary informal CGs-YOD participated in a one-on-one semi-structured interview and a follow up interview, scheduled via Zoom, over the phone or by email (follow-up interview only). Women who ranged in age from 28-75, included wives (n=5), significant others (n=1), sisters (n=1), or daughters (n=3) to individuals with young-onset dementia (YOD). Education levels varied from college diplomas (n=4), undergraduate degrees (n=4), and master's degrees or higher (n=2), with employment status varying from stay-at-home caregivers (CGSs) (n=4) to employed full-time (n=6). Women's perceived health status ranged from fair to excellent with various conditions influencing their abilities to manage their caregiving roles. Five of the women provided informal care within the home (i.e., lived with the individual with YOD), while the remaining five reflected on their experiences providing care at home, as well as their current caregiving roles for their loved ones in long-term care (LTC). Further, seven of the women were from Ontario, one from Alberta, one from Manitoba, and one from Newfoundland and thus, geographical differences were considered throughout the entire data analysis process (Table 2).

Although individuals with YOD were not interviewed it was important to gather their demographic information, as the type of dementia and duration of the disease may have had an influence on the CG's experiences. Five of the individuals with YOD were men and the remaining five were women, and their ages ranged from 56 to 76 at the time of data collection. On average the individuals with YOD were diagnosed 9 years ago with the most recent diagnosis and longest time since diagnosis being 2 years and 36 years, respectively. As previously mentioned, five of the individuals lived at home with their primary informal CGs, while the remaining five lived in LTC. Further, CGs reported six of the individuals had Alzheimer's disease, two had Frontotemporal dementia, one had Vascular dementia, and one had a mixed other form of dementia (i.e., overt dementia in multiple sclerosis). However, it is important to recognize the forms of dementia cannot truly be identified until after death during an autopsy (Deture & Dickson, 2019; National Institute of Aging, 2022) (Table 3).

Table 2: Demographic information for female informal caregivers

Primary Informal Caregiver	Age	Number of children	Current Employment	Highest level of education	Marital status	Perceived health status	Current health conditions	Relationship to individual with YOD
“Debra”	61	0	Retired/stay at home caregiver	College Diploma	Married	Good	Bi-polar	Wife of “Joe”
“Jasmine”	58	2 (adult)	Stay at home caregiver	Graduate Degree	Married	Fair	Low thyroid, Recovering from post-viral pancreatitis	Wife of “Don”
“Amanda”	29	0	Full-time	Undergraduate	Single	Good	N/A	Daughter of “Sally”
“Mindy”	75	2 (adult)	Retired	College Diploma	Married	Excellent	Osteoporosis	Wife of “Max”
“Denise”	49	1 (adult)	Full-time and Part-time	Undergraduate	Common Law	Good	Yes (would not specify)	Significant other of “Maria”
“Kate”	66	2 (adult)	Retired	College Diploma	Married	Excellent	Type 2 diabetes, controlled	Wife of “Colin”
“Nicole”	28	0	2 Part-time jobs	College Certificate	Common Law	Good	N/A	Daughter of “Kathy”
“Millie”	59	2 (step-children)	Other	Undergraduate degree	Common Law	Excellent	Depression, Anxiety, Leukocytic colitis	“Wife” of “Vince”
“Carly”	46	2 (15 and 10)	Full-time	Masters	Married	Good	N/A	Daughter of “Krista”
“Michelle”	65	2	Full-time	Undergraduate degree	Married	Good	Diabetes, Asthma, Sarcoidosis)	Sister of “Ruth”

Table 3: Demographic information for individuals with young-onset dementia

Individual with YOD	Age	Type of dementia	Living Situation	Date of Diagnosis (MM/YYYY)	Other Chronic Health Conditions	Primary Informal Caregiver (PIC)
"Joe"	56	Alzheimer's disease	In home with PIC	04/2017	Sleep Apnea, high blood pressure	"Debra"
"Don"	60	Vascular dementia	In home with PIC	12/2018	Depression	"Jasmine"
"Sally"	59	Frontotemporal dementia	Long-term care	10/2018	Asthma	"Amanda"
"Max"	74	Alzheimer's disease	Long-term care	09/2008	N/A	"Mindy"
"Maria"	56	Frontotemporal dementia (behavioural variant)	In home with PIC	09/2012	N/A	"Denise"
"Colin"	67	Alzheimer's disease	In home with PIC	09/2020	Controlled high cholesterol	"Kate"
"Kathy"	62	Alzheimer's disease	Long-term care	08/2014	High cholesterol	"Nicole"
"Vince"	60	Atypical Alzheimer's disease	In home with PIC	07/2019	N/A	"Millie"
"Krista"	76	Overt dementia in M. S	Long-term Care	1986 (does not remember specific date)	N/A	"Carly"
"Ruth"	62	Alzheimer's disease	Long-term Care	10/2015	Diabetes	"Michelle"

PIC: Primary informal caregiver

3.2 Themes

All female informal CGs-YOD reflected on their experiences as CGs and the effect their caregiving role had on their overall health. Generally, all CGs had similar experiences, which resulted in the emergence of three salient themes: (1) “Are we essential?”, (2) “I don’t wish this life for anybody”, and (3) “I don’t belong here”. Theme 1 described the up-hill battle within the healthcare system for individuals living and caring for YOD. Theme 2 addressed the complex nature of being a CG and the unimaginable loss associated with YOD. Theme 3 focused on CGs feelings towards current supports offered and the desire to increase awareness about YOD to help CGs maintain their own quality of life while continuing to provide care to their loved ones with YOD. The themes and their respective sub-themes summarized in Table 4 will be discussed in turn. For more detailed information pertaining to the themes and their respective sub-themes in relation to the research and interview guide questions please refer to Appendix H on page 145.

Table 4: Themes and subthemes of the lived experiences of female informal caregivers for individuals with young-onset dementia

Theme	Sub-Theme
1. “Are we essential?”	I. “Missing, missing, missing” II. “This system does not make it easy” III. “It doesn’t look that much different for us” vs. “It was so detrimental”
2. “I don’t wish this life for anybody”	I. “Filling the void” II. “Loss while living” III. “Shattered ego”
3. “I don’t belong here”	I. “Drained cup” II. Advocacy: “rather than sit and let it happen to us”

3.3 “Are we essential?”

This theme pertained to the emphasis all CGs placed on the essential nature of their caregiving roles despite the limitations within the healthcare system, limitations CGs for individuals with LOD or other conditions may not face. The first sub-theme explained the areas “missing” in the lives of CGs and the individuals with YOD. The second sub-theme indicated ageism and the heightened struggle CGs and individuals with YOD faced due to the timing of the diagnosis. Finally, the emergence of the third sub-theme arose from issues from Covid-19 and the effect Covid had on individuals with YOD and their CGs.

3.3.1 “Missing, missing, missing”

A commonality existed throughout the individual journeys of all CGs. The phrase “missing, missing, missing” by Mindy, epitomized the shortcomings CGs and individuals with YOD faced, namely, lack of knowledge on YOD, miscommunication during and after the diagnosis of YOD, and lack of respect CGs and individuals with YOD received when interacting with healthcare professionals. “I didn’t even know young-onset dementia existed until my partner was diagnosed” said Denise, a CG who emphasized the lack of knowledge surrounding the disease leading to “this misconception of what [young-onset] dementia is” (Denise). Millie, a former healthcare professional stated “I didn’t know a lot about young-onset dementia to be honest…. [just that dementia] it’s mostly elderly”. Likewise, prior to the diagnosis of her sister Michelle stated, “we called it [dementia] the old-timers’ disease”. Similar sentiments were expressed by Nicole, Debra, and Amanda when asked what they knew about YOD or dementia in general prior to the diagnosis of their loved ones.

> *Virtually what everybody else thinks, that its only for…older people.* ~ **Nicole**
>
> *NOTHING! Nothing at all* ~ **Debra**

> *…not a whole lot….in my undergrad as an elective I took…. geriatric nutrition and so I started learning about dementia there…. I didn't know very much about dementia…at that point*~ **Amanda**

Mindy, another former healthcare professional, also stated the following:

> *Well, I worked in long-term care, so I started there in '75 and people only talked about senility then right…and it was a long time before the umbrella name of dementia came to be one that we understood…. but really…. it's only the last 10, 15 years that we've become… a lot more knowledgeable. But we need to be more knowledgeable!* ~**Mindy**

Thus, despite the various educational backgrounds all women felt as though there was a paucity of knowledge concerning dementia as a whole prior to beginning their caregiving journeys. However, it was not only the CGs themselves who believed they had a lack of knowledge surrounding YOD. All women vehemently expressed the many challenges they faced within the healthcare system due to the lack of knowledge many healthcare professionals had concerning YOD. Denise described the diagnostic process as "a damn nightmare" and Jasmine expressed "that no one takes you seriously". Amanda concurred by sharing:

> *So, I felt like I was…researching like I was googling but was digging deeper than these health care professionals that were specialized in these fields.* ~**Amanda**

Debra added:

> *But the neurologist gave us the answers and fluffed him off. And we ended up going to four other neurologists and…the fifth [one] finally…diagnosed him.* **~Debra**

Two CGs expressed the following in relation to age and gaining a diagnosis:

> *….it was a nightmare. And for people with young-onset, if you talk to them and I've talked to enough of them, it's a nightmare because they're so young.* **~Denise**
>
> *…. [after] the pet scan, [the geriatrician] said that…. there were definitely leads to dementia but then also said oh "he's so young and still so capable, you know, we can't tell"* ~ **Kate**

CG Amanda indicated the need to advocate for her mom despite feeling as though she was "just a random kid" and stated the following regarding the knowledge of healthcare professionals:

> *It was very frustrating….it just kind of makes you lose faith in our healthcare system…. Finally getting an appointment with a neurologist to have my concerns brushed away…. Her neurologist wouldn't believe [me] that she had dementia, she was saying it was depression, said it was the medication she was taking…. It felt like "I told you so" after it was realized that she was not "reacting to a med" or "had depression". I felt like… you're the doctor, you should know this. And I felt like I had to step up and advocate for [my mom] because she wasn't capable [of] advocating for herself.* ~**Amanda**

This trend of "missing" information/knowledge extended beyond the diagnostic process, specifically for those CGs whose loved ones had now advanced and were living in LTC. Michelle commented on the knowledge of the LTC staff where her sister with YOD resided. "Very poor…I have to say. They have some knowledgeable people…. but the PSWs definitely need more training" (Michelle). Similarly, Nicole added "I feel like even some of them [LTC staff] aren't particularly well-trained in dementia care either". Kate, a CG whose husband was more recently diagnosed indicated "I feel like anyone working with people with dementia should have training and a firm understanding of dementia and all that goes with it". Amanda stated, "we just don't feel right. Nobody [in] there to look after her, or just be there with her". Mindy also expressed "…. I am reluctant to not go everyday as I worry, [my husband] won't be properly cared for". In relation to proper care, two CGs indicated concerns regarding medication being administered to their loved ones with YOD.

> *…. but the resident didn't prescribe it properly….so he upped the dose after two weeks. Well, I discovered later you don't up the dose, probably for a couple of months….it was terrible, terrible.* ~**Mindy**

> *…. they had her so medicated it was like…she was nothing. It's like she was gone. I had to feed her and stuff like that, and I have pictures of before and after…. you [would] think she was on her death bed because her eyes were glazed over, and she was just [pause] not well at all.* ~**Michelle**

After advocating for her sister's medication intake to be reduced CG Michelle stated:

> *I am going to be honest with you, I think she would have died if I hadn't [had] gone in [and] intervened…. [but] once they [started] weaning her down, within the week I was*

> *there you would not believe the difference in that woman. I'm telling you, she sat up, smiling, tried to chitter chat to me.* ~**Michelle**

This quote emphasized the essential CG role concerning the health of Michelle's sister with YOD, a circumstance that occurred with other CGs as well.

Aside from medication, three of the five CGs providing care to their loved ones in LTC indicated issues with general routine care within various healthcare settings, care that compromised the health of the care recipients (CRs). For example, Michelle stated "leaving her dirty for a long time" was one means of inadequate care provision. Mindy concurred after reflecting on her experience with a specialized hospital.

> *And he was still in the same clothes from the day before just pacing the hall, like a deer with his eyes in the headlights….they said they knew how to look after [him], but they didn't have a clue….and what I learned after [the situation] was the LHIN had recommended that [the specialized hospital] have a one-on-one for [Max] but the hospital decided he didn't need that…so there [are] somethings I have hard time forgiving them for because…it was horrible.* ~**Mindy**

Similarly, Nicole added

> *There's no stimulation…. I feel like because she is…so reliant on care* and support and *stuff…. that they [LTC home] don't necessarily involve her in much…. [like] if she can't be involved in a group activity with, like doing things on her own, they just don't involve her.* ~**Nicole**

Likewise, Michelle stated

> *They don't have time to be watching her, so it's easier… so I will say this straight out, so it's easier to medicate her and just have her shoved back in a corner.* ~**Michelle**

Only Carly provided positive thoughts regarding her mom's care in LTC.

> *…. the workers are well supported. It's a not-for-profit [organization]. I have a good relationship with them. They know me. I know them. So that's been positive, like to actually feel like I'm part of the team of people caring for [my mom] rather than being it.* ~**Carly**

Unfortunately, for several women "missing" information/knowledge was not the only aspect they identified as void in the healthcare system. "The people who have lived through it know how difficult it is, but no one else seems to want to listen or understand," said Jasmine. "The person living with dementia and their partners are the two experts. They need to be valued and heard, and be front and center" expressed Denise; however, this was not the case for several of the women whose knowledge about their CRs was dismissed by health care professionals. Many CGs expressed the challenges they faced due to the lack of communication and guidance provided by various healthcare professionals. "It's just recommendations… not knowing what to do or where to go" (Millie) in a "system [that] is broken so badly (Michelle). Mindy concurred with the following:

> *Healthcare professionals not being able to…to find resources to help was…. pretty frustrating.* ~**Mindy**

Additionally, Nicole indicated the lack of guidance she received from healthcare professionals following her mom's diagnosis of YOD.

> *…but no one really, …. explicitly was like, you know, there are resources out there for you, very few mind you…. but if you need, you know, check it out.* ~**Nicole**

These sentiments were similar to Amanda who shared:

> *I wish there [was] more support and education on frontotemporal dementia (FTD). My family doctor and neurologist didn't seem to know how to proceed or where to direct us. There was so much uncertainty.* ~**Amanda**

CG Kate struggled to accept her husband's diagnosis and took many months "to process and deal with it" (Kate) prior to even "thinking about reaching out" (Kate).

> *I thought they said when we were in [the hospital] that the Alzheimer's society would reach out to us, but they never did, nobody ever contacted us.* **~Kate**

Similarly, when discussing accessibility of the limited supports available Millie added the following:

> *…. even the Alzheimer's society they're not suggesting [a] list of people, you know, professionals that you could see or where you could go [for help].* ~ **Millie**

Due to the lack of support and guidance provided within the healthcare system CG Nicole "[took] it upon [herself] to do her own research and get involved" (Nicole). Likewise, Debra expressed:

> *....no one, no one, no one talked about young-onset because at [the] Alzheimer's [society] no one has it...so if it wasn't for [City H friendly event] we would [have] never found out about the group [that includes both LOD and YOD].* ~**Debra**

Mindy highlighted the following when discussing her knowledge on YOD.

> *I guess mostly self-taught, looking up things and reading books.... you know, just advocating for [Max's] quality of life.* ~**Mindy**

Beyond the lack of knowledge and communication, respect was another aspect missing within the healthcare system as perceived by most CGs. "The lack of respect and regard for families is, is truly profound" exclaimed Mindy when explaining her feelings towards the LTC facility. "Definitely barriers in the health system where people don't …. automatically recognize the role of the caregiver" expressed Carly who further went on to explain:

> *I think it's a double-edged sword. On one hand, I can really respect that autonomy is honoured and protected. On the other hand.... I think caregivers should be able to talk directly to healthcare providers.... without having to dance and just being 100% honest.* ~**Carly**

Yet not all CGs conveyed similar sentiments. Many CGs did not feel the autonomy of their loved one was honoured and protected, rather the care being provided "was so inappropriate for young-onset" as expressed by Mindy. Amanda expressed the following:

> *I would get frustrated because the staff...they would just treat [my mom] like a ninety-year-old with Alzheimer's, she was 56 with frontotemporal lobe dementia [FTD] .... when she first went in [to the home], there would be PSWs calling her mom.... cause they do that, and I was like, right away.... her name is [Sally], you guys are probably the same age, what the fuck!* ~**Amanda**

Similarly, Mindy stated "…in long-term care he just gets treated like an old person". Denise emphasized the lack of respect from the doctor who granted her partner with her official diagnosis of YOD.

> *…. when we finally went to see a geriatrician….she's like, "I know what you have. You have FTD [frontotemporal dementia]". And I'm like hallelujah somebody has figured it out. What pill can she take? And so, when she came back and she said, "it's, it's not curable." Like its…. "[I am taking] your driver's license right now. You need to go home and get your affairs [in order]" …. the presentation was terrible.…. You don't tell people, go home, and get ready to die.* ~ **Denise**

Further when asked if she could go back in time and change anything about her journey as a CG for her partner with YOD, Denise stated:

> *I wouldn't have listened to the doctor so much…to be honest with you. Because they, they're [pause]…not the be all to end all…. They didn't listen very well.* ~**Denise**

Conversely, Millie a former healthcare professional stated:

> *My nurse practitioner (NP)…. [she] didn't know but was more than willing to look and ask and stuff, so that was great. And we have a very collaborative relationship. She honors what I know and vice versa.* ~**Millie**

Despite Millie being the only CG who felt as though her thoughts and opinions were respected by healthcare professionals, she was able to recognize how lucky she was and could only imagine how difficult it would be for others who were not as fortunate to have a healthcare professional honouring what they knew.

> *…. You would feel very isolated to be honest if you didn't have a regular….GP [general practitioner] or NP [nurse practitioner] or um…somebody who you had a relationship [with], that was willing to go to bat for you. Holy crap! I don't know, it [would be] very isolating, even more scary.* ~**Millie**

Beyond these negative experiences, CGs were left thinking sentiments such as: "what can we do to change it?" as Michelle shared. "There is a lot more stigma attached to [YOD]" (Denise), we need to be "mainstreaming dementia into society rather than the, you know, what we do in our societies…. just like we factor them out" (Carly). Thus, all CGs emphasized the importance of continual education for healthcare professionals and society on YOD to further ease the process for those living and caring for YOD.

> *We obviously need more education out there. This is not necessarily as rare as what people think it is…. I wish I would have known what dementia was and that there [were] so many variants of it you know. What it looked like, and it could hit people at different ages…. it's not just the quote-un-quote older person disease.* **~Denise**

"Missing", was the one word which best summarized the experiences of CGs and CRs in their journeys with dementia and interacting with health care systems.

3.3.2 "This system does not make it easy"

This sub-theme discussed the struggle CGs faced because of the timing of the diagnosis and the limited resources available for their loved ones with YOD. "I retired at 55 to care for [my husband] ….it has brought our lives to a crashing halt…we live in limbo" (Jasmine). CGs expressed the challenges faced due to their loved ones being diagnosed with dementia at such a young age, specifically financially.

> *We were in a better [financial] situation before she [was diagnosed] …when we were 10 years younger…it's just absolutely terrible!* ~**Denise**

Jasmine added:

> *…. because of his early retirement, we have lost a lot of money because people don't take him seriously as somebody that has an illness that prevents [him] from working. Our GP [general practitioner] looked at us when we asked her the last time [and] said "well I can see maybe because of the anxiety levels he would have trouble holding a job" …(sigh)…somebody that gets up at 10 o'clock and is asleep by 4 cannot really hold a job.* ~**Jasmine**

Debra stated:

> *Since 2015 he hasn't wanted to work…and he gets a disability pension but that is only a thousand a month. So, drugs cost a hundred and forty alone…. and then my drugs (medication for bipolar) [pause] and the house isn't paid for and [pause]… young onset … you are not prepared to retire because he is not 65. [pause] So financially it is the worst.* ~**Debra**

Further Debra added:

> *…. if you have [an] RRSP you cannot take out the money before age 65 without a 50% tax penalty…. This is something else that is difficult for individuals with young-onset dementia … save all your life for retirement and if you must retire early, you are heavily taxed.* ~**Debra**

Mindy had no issues financially, despite the numerous expenses she endured due to her husband living in LTC.

> *I'm very grateful that…that money has not been an issue …I was always prepared to spend…what I needed to…to try to have some quality of life for the both of us.* **~Mindy**

In addition to the diminished income multiple CGs and individuals with YOD faced, CGs emphasized the increased costs associated with YOD.

> *…. well medication every month is hundreds. We don't have…any type of, you know [pause] [benefits] so just even like dental, medical, [and] she has mobility [issues]…chiropractor, you know that sort of stuff…we pay out of pocket for all that.* ~ **Amanda**

> *She's topped up for $155 a month which is way under what we need, but I supply everything else...so I don't get anything financially from anybody.* ~**Michelle**

Although for CG Mindy "money had not been an issue" (Mindy), she stated:

> *you know, we have to pay for care…. I mean…I can't say that I'm suffering…[pause]but is that what you want to spend your money on? No.* ~**Mindy**

Yet, despite the increased costs, most CGs highlighted "the government doesn't provide much support for in home and community services" as shared by Nicole. Carly further emphasized this by stating:

> *There's sort of that aging in place paradigm where everyone's supposed to go home and stay at home as long as possible, but the actual, both kind of social discourses around it….and the actual resources in the community, you find some gems that are fantastic, but in terms of sustainable, predictable… network of support, it just doesn't exist.* ~**Carly**

Likewise, CGs noted the limited availability of services available, such as home care. One of the CGs expressed "good luck actually finding [help]…you might be approved for X amount of hours, but there isn't [enough PSWs to do the work]" (Denise). Nicole concurred:

> *…. we needed extra hours…. with PSWs and they just couldn't, they already told us multiple times that we had too many hours. And we're like… "are you kidding?" How do people [function], I mean in other circumstances, without multiple supports? If I wasn't available for help with my stepdad…. he wouldn't be able to work. It [is] just really, incredible that there is not a lot of additional support.* ~**Nicole**

Similarly, when asked one thing she wished she had as a CG for her husband with YOD Debra stated:

> *….it would be nice to have… [a live in] PSW and live on a one floor house [but] those are just…impossible dreams.* ~**Debra**

Moreover, due to the lack of services available many CGs felt as though their loved ones with YOD did not have the support they needed.

> *I would say that he does not have the support he needs.* ~**Jasmine**

Additionally, Mindy and Denise expressed the challenges associated with finding support due to their spouses being under the age of 65.

> *…. there was [a] seniors' kind of assessment center at [Hospital D] but you had to be 65 to be eligible, and of course [Max] wasn't. And I remember trying to search out all kinds of ways to get help. I wanted to be able to care for him…and I knew I needed help to do that.* ~**Mindy**

> *It's been a real challenge, a real challenge, harder to get programs and resources*. ~ **Denise**

Denise further explained how some programs tried to exclude her partner not because she was under the age of 65, but rather because she had frontotemporal dementia (FTD), a form of dementia often associated with fluctuations in behaviour more common in those with YOD.

> *…. getting her into a day program, you know unless we live near [a big city] something like [place X], they don't necessarily take…people that have FTD, especially with the behavioural variant.* ~**Denise**

Fortunately, Kate's husband attended one of the few day programs specific to YOD in Canada and discussed how beneficial the program had been for herself and her husband.

> *The [day program] he goes to every Tuesday, he loves that. He absolutely loves it….so happy we made the connection with that group*. ~**Kate**

Nevertheless, despite being fortunate enough to attend one of the only day programs in Canada specific to YOD, barriers still existed regarding program accessibility for Kate and her husband.

> *…. he probably would be going twice a week but…that hour drive in and out… its [difficult].* ~ **Kate**

Most CGs discussed paying out of pocket to ensure their loved ones received the care and support they needed. For example, CG Jasmine expressed the support her husband with YOD required.

> *He has a therapist…. but we are paying a hundred and sixty dollars for each visit with her…so no support on that.* **~Jasmine**

Likewise, after discussing the limited services provided by the LTC facility, Nicole stated:

> *We have hired external therapy, like recreation therapy…for someone to come in play guitar and sing with my mom…but the home would never provide anything like that.* **~Nicole**

Many CGs were disappointed by the lack of support and resources provided by the government, as demonstrated by the following quotes:

> *They don't understand the toll it takes; they just don't understand.* ~**Mindy**
>
> *It's been extremely hard because…. I mean…there was absolutely nobody to support [us].* ~**Carly**

Further, Carly stated the following when asked one piece of advice she would give others faced in a similar situation.

> *Maximize supports if you have them. Try to get as much government aid as possible. Don't be afraid to be assertive and pushy about your specific needs related [to] early-onset.* ~**Carly**

This quote from Carly stresses the minimal support she had received as a CG and the importance she placed on support, so others did not have to endure the same journey.

Additionally, when asked if she had any form of respite care, CG Denise stated:

> *Not really* ~**Denise**

CG Amanda even went to say “I just wish there was…three more people like me to share the load” emphasizing the significant strain the paucity of support and resources had on her as a CG for her mom with YOD. Denise shared similar sentiments:

> *Canada needs to smarten up and figure this out…because it costs our medical system…. a lot more money to put her in respite care. Canada is so far behind the eight ball, it’s time to get with the program already. You should be throwing us a bone, throwing us something…. but Canada expects your loved ones to do it…. See, that’s the difference. Like when you have kids, they’re like “well can’t your daughter do this?” like she can’t actually…. it’s crazy the expectation that our government has on our friends and our loved ones to help us out and [they] don’t want to give us help at all.* ~**Denise**

Similarly, Jasmine and Michelle provided:

> *Is it appropriate to save money on our health care by burning out women, by putting the caregiving role on people and removing them from their productive roles within society? Why is it they are disposable?* ~**Jasmine**

“The [government system] is not good” but explained her hesitation by stating:

> *I, I don’t want to run them down because I have to depend on them. But on the other hand, it is not good…. It’s sad, but it’s the reality.* ~**Michelle**

These statements further emphasized the significant strain all CGs experienced resulting from their caregiving roles and the limited support available. Also, Mindy stressed the importance of the public understanding these shortcomings.

> *We have to, we’ve got to let people know about this, because…we’re going to need all the help we can get.* **~Mindy**

In sum, Jasmine’s views reflected the viewpoint of all CGs and the way they felt used by the system.

> *….and as caregivers, as women in this society and certainly the way the health system is set up…they want to exhaust you as a caregiver, completely, totally use you up before they will step up and care for someone with dementia.* ~**Jasmine**

Emphasizing the thoughts of all CGs, in which they believed “this system does not care about me” (Jasmine) nor does “this system make it very easy” (Mindy) for individuals with YOD and their CGs.

3.3.3 “It doesn’t look that much different for us” vs. “It was so detrimental”

Since March of 2020 Covid-19 has been a challenge for many individuals across the world. This was no different for women providing informal care to their loved ones with YOD. However, there was a clear divide between CGs who lived with their loved ones with YOD and CGs whose loved ones lived in LTC.

Four of the five CGs who provided care to their loved ones at home mentioned Covid-19 affected their overall health (e.g., physically, mentally, socially) and caregiving roles. Millie, the fifth CG providing care to her husband with YOD did not mention Covid when reflecting on her experiences. Kate discussed she had been in a “funk” and stated:

> *I am kind of coming out of it now, that funk you know, but I was thinking…. I was depressed…. I wasn't doing anything, which wasn't good for me.* ~**Kate**

Kate then went on to explain

> *The funk, I was in, I just had no drive, no desire to do anything. But I think it was Covid, I didn’t want to expose us or anyone else, so it was just easier to stay home.* ~**Kate**

Similarly, Debra discussed the effect Covid had on her motivation to exercise.

> *I should exercise. I used to exercise…now I have gained weight back since Covid, I haven’t cared.* **~Debra**

Debra also expressed the lack of socialization she experienced since the start of the pandemic due to no longer running weekly programs for seniors within her community.

> *I turned to my seniors for a form of friendship. Now they are out of my life due to Covid.* ~**Debra**

Likewise, Denise stated “I don't have one [a personal life]” as a result of caregiving but recognized the role of Covid and further expressed “Covid didn’t help”, when discussing the non-existent nature of her current personal life outside of her caregiving role.

Covid also affected the women’s CRs. For example, Debra and Jasmine discussed the effect of Covid on the health of their husbands.

> *But physically he hasn’t exercised since Covid, and that, I, I, I am surprised, his friend exercises on Zoom, because Alzheimer’s has Zoom sessions, but he is just, he won’t exercise.* ~**Debra**

> *…and of course everything that was in place to support people disappeared…I mean as we tried to sort out what was safe, what wasn’t safe, how to manage these things, what would be effective managing these things….but I am listening to the same story from absolutely everyone, that the lack of stimulation, the lack of exercise has suddenly made a quantum drop…in my spouse’s ability to go…and we saw it here too.* ~**Jasmine**

Debra shared her husband’s frustrations resulting from Covid’s effects.

> *There are other programs that [Joe] was forced to stop because of Covid.* ~**Debra**

Interestingly, when discussing her partner with YOD, Denise mentioned

> *Covid didn’t affect her as far as isolation, like it did with other people, cause she’s like “yayy I don’t have to be around anybody” …like you know, she loves it.* ~**Denise**

Yet, despite Covid exacerbating the effects of caregiving for several women, Jasmine stated:

> *…but you know with this pandemic it doesn’t look that much different for us because everyone I know is dealing with the same thing, they just don’t have the caregiving portion on top, but their social lives have been bashed in the exact same way.* ~**Jasmine**

This quote emphasized the effects CGs experienced because of Covid were not entirely unique to only those providing informal care to individuals with YOD.

In comparison, four of the five women who provided care to their loved ones with YOD in LTC, expressed the hardships faced because of Covid and not being able to see their loved ones for months at a time.

> *It's horrible, Hailey (primary researcher). It's horrible. Just you know, not being there…to hug her and love on her, even though you see her on video, it's not the same. It's just really not the same.* **~Michelle**

> *It was so unbelievably challenging trying to have a meaningful visit through a window.* **~Nicole**

Two CGs further discussed the "significant decline" (Nicole) in their loved one's abilities, the heightened frustrations associated with not being considered "essential" (Mindy) and the lack of rights to physically see their loved ones.

> *…during Covid…when I couldn't go in for five months, I eventually had window visits and I noticed his hand were like this (clenches fist together) …I mean they don't see this stuff right…and now he's got pressure sores between…I'm the one that found his fingers…so are we essential? Yeah, we're essential.* **~Mindy**

> *It was so detrimental, like for her and for us…. we weren't allowed in at all, which we saw a significant [decline in her] …speech and just overall capacity.... It was incredibly frustrating and irritating because initially…. we had to be outside. She was inside and we had to talk through [a] phone, but like my mom at this point, doesn't know how to use a phone or understand….so we [were] just staring at each other through a window.* **~Nicole**

Likewise, Amanda commented on the lack of quality care her mom received during this time.

> *She just [does not] have quality care because it is just not possible right now…. more and more staff are testing positive everyday so [they] are short staffed…so then you know she is getting less quality care, everybody is burnt out, everybody is scared, everybody is tired.* ~**Amanda**

Despite restrictions being lifted by the end of data collection and CGs being able to enter the various LTC facilities, two CGs emphasized the ongoing effects of the pandemic on their CRs mental health.

> *…. She hasn't seen my whole face in like three years. Like that's so disturbing! ...COVID has just been so detrimental.* **~Nicole**

> *Hugging my mom and crying into my mask. Holding her hand and it smelling… like yeast from not being washed while in the nursing home's care.* **~Amanda**

In addition, Nicole echoed Amanda's sentiments in respect to routine care during the pandemic.

> *…. she is not being bathed, a normal, healthy person when they're not clean it affects all aspects of their mood, you know, just capacity…it was outrageous.* **~ Nicole**

Carly, the fifth CG whose CR lived in LTC did not mention Covid when reflecting on her experiences as a CG; however, it is importance to recognize Carly's mom did not move to LTC until the fall of 2021 and was still living at home during the early stages of the pandemic. Thus, CGs whose loved ones lived in LTC faced many challenges as result of Covid provoking many emotions for CGs; however, Mindy emphasized "it's only exposing what's the norm, really, it's making it much more visible." Covid was not the sole cause of the challenges contributing to lack of quality care, rather Covid made these issues "much more visible" (Mindy).

In sum, two situations prevailed for the CGs with respect to Covid: (1) "it doesn't look that much different for us" (Jasmine), a commonalty between the CGs who lived with their loved ones with YOD, verse, (2) "it was so detrimental" (Nicole) for CGs whose loved ones lived in LTC, who felt the pandemic had created havoc for their CRs.

3.4 "I don't wish this life for anybody"

This theme encompassed the aftermath following the YOD diagnosis and onwards on CGs and their CRs. The first sub-theme focused on time and the challenges CGs experienced in relation to maintaining quality of life for their CRs. The second sub-theme emphasized the significant loss associated with YOD and indescribable grief CGs, CRs, and family members experienced. Subsequently, the third sub-theme explored the emotions and hardships associated with caregiving for individuals with YOD.

3.4.1 "Filling the void"

This sub-theme pertained to challenges CGs experienced regarding time and "filling the void" (Debra) in the lives of their loved ones with YOD. "The boredom…. like what do we do?"

as said by Mindy. Most CGs expressed the challenges associated with "how to fill the days" (Mindy) and ensuring their loved ones were not "sitting on the couch and playing games for eight hours" as expressed by Millie specifically during the early days immediately following the diagnosis. Further, CG Debra discussed the "apathy" associated with YOD.

> *He's content to just do nothing…he has that I don't care attitude.* ~**Debra**

Family members did not want their CRs to live this way. Kate concurred by emphasizing the lack of "initiative" her husband with YOD had "to do anything" and stated:

> *He's just content, you know, sometimes I look over and he's just sitting in the chair staring off into space.* ~**Kate**

CGs did not want their CRs wasting away since a lack of stimulation directly relates to decreased cognitive function and overall quality of life. So, to combat this, Jasmine and Carly emphasized the importance of planning activities and making sure their CRs were stimulated.

> *We might set up a task for him to do…. I bought…some bobbins that didn't turn the way that they were supposed to. So, I gave him a drill bit to…file down the inside of the bobbin and gave him a piece and he spent… [pause] almost three hours getting them clean on the inside so that they spun perfectly.* ~**Jasmine.**

> *We tried to have something she did every day, other than kind of sit and watch TV.* ~**Carly**

Millie concurred when discussing the importance of monitoring the amount of time her husband with YOD spent playing computer games.

> *You've been playing that game for…. two hours, maybe now is enough [pause]…Suggesting if there's a task that needs to be done…. I guess thinking up of a chore, [pause] and maybe sometimes if I've got something on and he'll be here by himself, maybe pre-planning that someone comes over or he goes somewhere.* **~ Millie**

Nicole expressed similar sentiments when reflecting on her role as a CG for her mom prior to her moving to LTC.

> *…. when I first came home, it would probably be, [pause] just kind [of] like taking her out. So, she'd get out of the house, maybe walks or, [pause] like going to Tim Horton's or going to the park, [pause], to the movies, [pause]…initiating like games or crafts or activities.* ~ **Nicole**

Mindy, a CG who was employed full time when her husband was diagnosed with YOD, emphasized how difficult it was to arrange activities for her husband while she went to work, due to the lack of programs available specific to his interests as a man in his 50's.

> *The boredom…the boredom, the boredom, the boredom, and you can only watch so much TV and you know, people say they can get cooking classes, well we're talking about a guy here [laughter]…. like the day programs are a lot of that or art, [Max] was an athlete so…[pause]…trying to find things to do…. that was a huge problem…. you know, how to fill the days because [Max's] his hobbies were…running and sports.* ~**Mindy**

This quote from Mindy, accentuated the importance CGs played when examining the quality of life of individuals with YOD, while further demonstrating the lack of support CGs experienced.

Millie discussed the decrease in friends her husband experienced since his diagnosis and the heightened challenges associated with "keeping him busy".

> *His circle of friends has shrunk tremendously…[pause] a lot of those old-time buddies…[pause] I believe out of fear, I don't know for sure [but] they're avoiding him.* ~**Millie**

However, aside from "keeping [her husband] busy", Millie expressed the importance of respecting her husband and ensuring he felt comfortable in all situations.

> *…. Keeping him busy socially…[pause]…as well as you know being okay, if he says, "this is too much for me".* ~**Millie**

This quote emphasized the countless factors (e.g., interests, comfortability etc.) CGs for individuals with YOD needed to consider daily when striving to maintain as much quality of life for their loved ones with YOD.

Additionally, CGs emphasized the significant amount of time and energy it took to "coordinate" (Nicole) alternative care when they could not be with their loved ones.

Amanda and Nicole expressed:

> *I made like a full schedule…from her waking hours there would always be someone there between like friends, family, and [pause]…paid help…. it was a lot of work, like scheduling everyone, paying everyone.* **~Amanda**

> *I would also have to coordinate going out/leaving the house with when a PSW was there or when my stepdad would be home, because she couldn't be left alone much.* **~Nicole**

Aside from planning alternative care, Kate discussed having to pre-plan meals for her husband if she would be out for the day, as he no longer had the capacity to remember when to eat.

> *If I am away for the day, I need to make sure he has something for lunch he can microwave or [have] already prepared. If I don't, I'll come home, and he won't have eaten.* **~Kate**

Likewise, Denise stated

> *If I go out and have a life, which I haven't because of Covid, but you know, if [my partner] is at home and in bed…I have to make sure she's settled, and the phone is you know, right there.* **~Denise**

On top of the myriad of care tasks CGs had to perform daily, they also had to "fill the void" for their CRs. Filling the void helped increase quality of life of CRs as well as contribute to the peace of mind of CGs.

3.4.2 "Loss while living"

This sub-theme highlighted the indescribable grief and loss CGs, individuals with YOD, and family members experienced because of YOD. "Grief is a given feeling in this situation. It is ambiguous, with no definitive ending per se rather continuous losses of your person" explained Nicole. Similarly, Millie indicated "ambiguous loss is huge for me" and stated:

> *Ambiguous loss for example is the loss of our/my dreams and plans for the future; the loss of my best friend and partner; the loss of shared roles and responsibilities; and the progressive losses in the life of the person with dementia that are occurring now and will [occur] in the future.* **~Millie**

Corresponding to the words of Millie, all CGs expressed feelings of grief in relation to the loss of their loved ones; the loss of their futures together; the loss of shared roles and responsibilities; and the progressive losses in the lives of the CRs. Each area of grief experienced by CGs will be discussed in turn.

All CGs were asked to describe their loved ones before and after the diagnosis. The majority of CGs emphasized their unconditional love for their CRs; however, CGs expressed these sentiments in past tense. For example:

> *…. we were best friends. We loved each other to death. He was the love of my life.* **~Millie**
>
> *She was my rock. She was my lifeline.* **~Denise**
>
> *He truly was a lovely man.* **~Mindy**

The past tense of the sentiments provided by Millie, Denise and Mindy indicated CGs grieved the relationship they once had with their loved ones, as well as the person the CRs used to be. Likewise, all CGs were asked to describe their relationship with CRs before and after the diagnosis. Millie stated:

> *…. he's been my biggest support for my whole life. And now he's not, or now he doesn't have the capacity to be for the most part.* ~**Millie**

Similarly, Denise added:

> *The empathy isn't there anymore. Passion isn't there anymore, [pause] or just a lot of things that she used to be able to do that she can't do anymore. And it's just so heartbreaking.* ~**Denise**

In relation to passion, all CGs who provided care to their significant others with YOD (i.e., husbands or partners) indicated the loss of intimacy following the diagnosis of YOD. Denise, Millie, and Mindy provided the following:

> *…. the intimacy is gone…. she lost her libido and, [pause] then at the same time when your relationship changes and it's from partners to care partners…. there's an awkwardness. So, it just…it's non-existing now.* ~**Denise**

> *…. there was no physical intimacy whatsoever…[pause] and that's a bit coming from me [be]cause I just can't wrap my head around…[pause] making out with my person I look after, you know*? **~Millie**

> *[pause] in terms of intimacy, I guess that, you know, gradually diminished, I mean, for me…I always have this feeling…that, you know, he wasn't all there so, it wasn't a balanced [relationship].* **~Mindy**

Similarly, "our sex life ended…so that made life difficult, that strained things" stated Jasmine. Debra also expressed changes in the relationship with her husband "sexually" but did not expand further. The other four CGs who provided care to loved ones (i.e., sisters or mothers) did not have an intimate relationship with their CRs; however, these CGs also expressed alterations in their relationships following the diagnosis. Amanda, a CG who provided care to her mom with YOD expressed the following regarding her mom's ability to provide comfort and support to her as her daughter.

> *A lot of hurt and just…confusion… she wouldn't text me, or call me, so I was like "wow does my mom not care about me?.... cause my mom was sooo loving growing up and soo supportive… and then…like I would [be] crying in front of her and she would be smiling.…breaks your heart….* **~Amanda**

Nicole expressed similar sentiments regarding her mom with YOD.

> *It's easily the most difficult thing to experience, to see your mom, this beautiful person, just completely lost in her own sick brain…. I know my mom is virtually nowhere inside that body anymore. Her personality maybe, but she doesn't respond to "Mom" at all anymore either…. For the past 8 years she has been losing parts of her and with that her role/identity as my mother.* ~**Nicole**

Mindy concurred when discussing the emotions of her son following her husband's diagnosis of YOD.

> *You know, [our son] felt like he was being rejected…that was [pause] that was pretty awful.* ~**Mindy**

Further, CGs emphasized the change in dynamics of the relationships with their CRs. For example, Amanda, Nicole, and Mindy provided:

> *It's like she's…. a baby, I hate to use that comparison but...*~**Amanda**

> *I like to say babysit, I know it's probably a rude term, but [pause], it is what it is.* ~**Nicole**

> *It's more like he's my child…. [pause]…. I don't know [how] else to describe it.* ~**Mindy**

Due to the change in relationships/dynamics resulting from YOD, Debra and Jasmine expressed the following to try to explain the new normal:

> *Differentiate the disease into two different people. Our loved one[s] and the stranger that comes to visit.* ~**Debra**

> *I've come into a three-way relationship, which is a good way to look at it…with [my husband] and his dementia.* ~**Jasmine**

Yet, despite the significant grief CGs experienced, most CGs emphasized the lack of support they received from family members and friends.

> *….my stepmom has been a lot more supportive to me than my dad has. [pause] which has also kind of put a strain on my perception of him and the situation because…I'm losing my mother and my father isn't there for me.* ~**Nicole**

Millie provided the following about her husband's children.

> *…. they're not lashing out at him that much anymore. So that has changed. They're not blaming him for stuff…but they're also not being supportive.* ~**Millie**

Denise added:

> *You lose a lot of friends, you lose family.* ~**Denise**

Thus, the quotes provided by Nicole, Millie and Denise indicated CGs were not only grieving the loss of the CRs but also friends and family due to the lack of support they received. Interestingly, Kate indicated the increased support her husband and herself had received from their one son since the diagnosis, but support from other family members was non-existent.

> *I know our oldest…has backed off…like he was on the council in town and with his work…. just because he wants to be available.* ~**Kate**

It was also important to note CGs were cognizant of others who grieved the loss of CRs. CGs indicated grief experienced by other family members despite the lack of support they received from some of these individuals. For example, Mindy and Amanda stated:

> *The kids grieve [Max]…. Occasionally I do feel deflated and teary when I process the situation that my husband has [had] to endure and its impact on our family.* ~**Mindy**
>
> *My granny [grieves] cause like she understands what's going on…. [it's] been extremely hard for her [to see my mom like this], I would say it definitely contributes to [her] depression.* **~Amanda**

Nicole provided the following about her stepfather:

> *I guess for a long time he would choose not to think about her eventual progression and the end. I'm not sure how you can live in denial when this is all unfolding in front of you, but that is [how he copes].* ~**Nicole**

This quote indicated the grief Nicole's stepfather experienced in relation to his wife with YOD. Similarly, Michelle stated:

> *[Daughter A] said "I can't go see [Ruth] because it hurts my heart too much. And I said "it's going to be worse for you than her…. but later when your mom dies, you're not going to have that quality time".* ~**Michelle**

Nicole provided similar sentiments regarding her sister who lived in a different country.

> *She has pretty much been away for the entirety of it…. I don't really care, and I honestly feel like my sister wouldn't be able to handle [the caregiving role] ….But I just feel secondary emotions for her like when our mom passes. She's going to have all this guilt and terrible weight on her shoulders for not being here.* ~**Nicole**

In sum, despite some friends and family being unsupportive, CGs were able to recognize the grief and hardships they also experienced.

In addition to grieving the loss of their loved ones, many CGs indicated grief in relation to their futures with the CRs. "Your dreams of growing old together and things that you want to do, like travel…come to an abrupt end" expressed Denise. Nicole concurred when discussing the effect of her mom's YOD on her stepfather.

> *Profound sadness. Accepting that his life partner that he thought he'd grow old with and travel with has dementia. Not only grieving his partner but having to care for her.* **~Nicole**

Millie added "I've had to deal with, [the] future of retirement, what plans have to be modified" but emphasized how thankful she was, she did not have young kids and could only imagine how challenging it must be for others.

> *…. but I don't have to think about you know having young children and getting them to school and making meals necessarily and working myself and those kinds of things. I, I, I honestly cannot imagine.* ~**Millie**

Denise and her partner Maria did have children living at home when Maria was diagnosed and emphasized the significant challenge they experienced.

> *We weren't retired at the time [of diagnosis] ... our daughter wasn't out of the house; we still had a mortgage…. I was in my thirties and [Maria] was in her forties. So typical for that age, right. But [pause] not typical of the average person that has…has dementia.* **~Denise**

This quote from Denise emphasized the significant strain and loss specific to those with YOD in comparison to older adults with dementia. Further, Nicole indicated the effect providing care for her mom had on her dating life as a woman in her twenties.

> *…. if you tell someone that you still live at home [pause] it's a little bit off putting.* ~**Nicole**

Amanda expressed her "resentment" towards other people her age because of her caregiving role and the grief associated with the loss of her youth.

> *It's an ongoing grieving process over and over with every change, and then not knowing what's going on and then the frustration and… like at that age too. I had just graduated, so I had resentment like I wanted to…be working and like I wanted to be doing my internship, I wanted...be like my friends and ...have the same worries and joys that they did and not be…like toileting my mom.* ~**Amanda**

Similarly, Carly emphasized the substantial effect her caregiving role had on her career.

> *It was a profound effect. I couldn't work full-time anymore. It changed the trajectory of my personal life.* **~Carly**

Additionally, grief in relation to the loss of their loved ones and their future together was not the only form of grief CGs experienced. CGs also expressed the loss of shared roles and responsibilities with their loved ones with YOD. Kate stated:

> *You go from being a partner, sharing responsibilities, goals, to being a caregiver who is on call 24/7. He's, my responsibility. I not only have to make sure he's loved, [but] his needs are met, he's safe, he's comfortable, and he's entertained and cared for….and I feel like I should be doing more for him…. but then I am doing things that I don't really want to do.* ~**Kate**

Jasmine shared:

> *So, [pause] in addition to looking after him there is all the things, he used to do for the household that he can no longer get done so I have to do [it].* ~**Jasmine**

CG Jasmine further emphasized the effect of YOD, and the increased roles and responsibilities associated.

> *I am increasingly isolated, both by circumstances of caregiving and by the disease that is taking my spouse away bit by bit. At 55 I became a caregiver and lost my career and in many ways my identity as a person and a couple.* **~Jasmine**

Nicole and Denise concurred with the loss of their own identities as a result of their caregiving roles.

> *I've seen myself as a caregiver for so long ….it is currently part of my identity. [pause] so I have thought of like…. what is my life going to be after this?* ~**Nicole**
>
> *…. your identities end up being morphed…. And even like, you're talking to me today, but a lot of times I'm just, I'm [Maria's] partner…. So it was like, I don't have my own identity.* **~Denise**

Denise further emphasized:

> *I need to carve out a life for myself. Like the reality is, she does have dementia. She is getting worse (emotional) and it [needs] to be on the priority list.* ~**Denise**

Grief also extended to the CRs following the diagnosis of YOD and onward, as expressed by the CGs. Mindy stated:

> *So…he had to…essentially retire because he couldn't drive… And [I] guess probably couldn't do the job anymore. But he was…he was 61 and certainly hadn't planned to [retire], probably planned to work till he was seventy.* ~**Mindy**

Similarly, Kate said:

> *I think it was happening before [retirement]…he had a couple of issues at work that, you know, he struggled with.* ~**Kate**

In addition to grieving the loss of their careers, Amanda discussed the physical abilities her mother mourned.

> *The disease it slowly…like paralyzed her body I guess, it started with her right leg, so she would kind of drag that when she was walking and then fell more, and then her right arm…and then more her left leg and then her left arm.* **~Amanda**

Carly expressed similar sentiments regarding her mom's physical and cognitive abilities.

> *An increasing siloed approach…. she could operate in tiny silos and then the rest of it, she couldn't problem solve. She couldn't….be flexible in her thinking.* ~**Carly**

Nicole indicated the emotional hardships her mother experienced.

> *She did ask my stepfather to kill her…. I think it was [because of the] emotions surrounding the dementia diagnosis. It's worse than cancer she would always say. Or that she wouldn't wish this on her worst enemy. But I can imagine many people with a diagnosis of cognitive decline would feel the same. There's a reason MAiD [Medical Assistance in Dying] exists.* **~Nicole**

This sentiment by Mindy echoed Nicole's thoughts.

> *As it progressed, he, you know, began to express wanting to die…*~**Mindy**

CG Denise recognized the need to cope with the losses by looking for any positives in the situation such as new talents. "There's a lot of [talents] that [my partner] doesn't have anymore" stated Denise, but emphasized "she has different talents now" and further indicated:

> *It's about tapping into their hidden gems and, you know, rolling with the punches.* ~**Denise**

Similarly, Carly added:

> *I don't think there's any ideal solutions when somebody has dementia and you just kind of make the best of each moment you can.* ~**Carly**

This quote by Carly emphasized the importance for CRs and CGs enjoying the remaining quality time despite the associated grief of the process.

Thus, CGs, CRs, and family members grieved from the time of diagnosis onward as summarized by the words of Jasmine: "…The nature of dementia is that it is going to rip pieces out and there is a constant grieving process for what you have lost" so as CGs "yes you can grieve but you still have to chop wood and carry water". Life continues albeit not the lives anticipated by CGs, CRs and/or other family members.

3.4.3 "Shattered ego"

"Overwhelming" (Carly), "Terrible" (Nicole), "Lonely" (Denise), "Challenging" (Kate) and "Shitty…because it all sucks" (Amanda), are the words CGs used to describe their experiences/feelings with caregiving for YOD. This subtheme sheds light on the overwhelming emotional toll CGs experienced that often bled into other aspects of their lives. Most CGs emphasized the toll their caregiving had on their overall health (i.e., physical, mental, social) and well-being. "….it brought me such anxiety…I had never experienced before in my life" as stated by Michelle. Similarly, Millie who was open about her previous mental health challenges indicated:

> *I've had to go back on anti-depressants…and antianxiety medication. [pause] and I have been medication free for well gosh, 10 years.* **~Millie**

Kate, Amanda, and Nicole added:

> *Not knowing what time, we have left is difficult.* **~Kate**

> *Just a lot of sadness…. My mood gets low. It's sad and drains "my cup".* **~Amanda**

> *It was and continues to be an incredibly challenging situation to navigate emotionally. I lose my mom more and more as each day, month, and year passes. How do you handle the first time your mom doesn't remember who you are? How many of your friends' bathe and toilet their mom?... The ambiguity is relentless and painful.* ~**Nicole**

Debra and Mindy expressed similar sentiments regarding the turmoil YOD caused.

> *It feels like my feet have been removed from under me. It feels like I would rather die first than to deal with this. I cannot stand it any longer.* ~**Debra**

> *I feel very [pause] disappointed, [pause] I feel [pause] sad, I feel [pause] so much is wrong that doesn't need to be wrong, that it makes me…think how much energy do I have to fight this battle? Like why do I have to do this all the time? Why is it so difficult?* **~Mindy**

Michelle emphasized the struggle to walk in her shoes, a struggle only another CG would comprehend.

> *…you will never know…how terrible it has been. Nobody knows the struggle…unless you're there. The other women can tell you, it's difficult…The tears that flow when you go and see her.* ~**Michelle**

Similarly, Nicole and Amanda stated:

> *This type of situation is heartbreaking. I find now more often I have trouble keeping my composure when I am with her. If something goes a little awry, I don't have the capacity to handle the situation myself – I usually have a PSW take over and I leave. It's too hard to see her like that.* **~Nicole**

> *It was really hard of course and just…. seeing some of the stuff and being in some of the situations, I don't think at any age you would want to be in…with your parents and see them like that.* **~Amanda**

Undeniably having to watch loved ones degenerate and become different versions of themselves was "heartbreaking" and unbearable for CGs.

Debra further discussed her husband's "sundowning", a symptom associated with his dementia causing him to be "irritable" and having "no patience" and the effect on her own mental health.

> *He can 'showtime'…act like nothing is wrong for a period of time…. He is Mr. Nice guy to strangers and family…. but not to me…he yells. I feel the loneliness…. 'I am not fun to live with'…that phrase was like a knife stabbing my heart. How do I stop from wanting to cry? .... Two years ago, I wanted to spend more time with him…now I want to spend time away from him.* ~**Debra**

Likewise, Jasmine and Millie further emphasized the colossal effect of YOD on them and their relationship with their CRs.

> *Quite possible I would have left my husband and my marriage. The toll of this is so much greater than I ever thought.* ~**Jasmine**

> *To be frank I might not have stayed in the relationship.* ~**Millie**

The bluntness of these sentiments indicates the extent of the devastation YOD can create in the lives of CGs. Similarly, Carly added:

> *[it] put a lot of stress on our relationships. [pause]…[if] anything it caused us to have to examine questions of existential and whatever faith-based beliefs. [Something] we wouldn't have needed to do until we were much older.* ~**Carly**

Carly further emphasized the effect of providing care for her mom while raising two young children.

> *We called it "The Nana factor" …. Because there's a constant crunch and pressure on time and just on personal energy and resources. There's a constant process of having to weigh priorities because…you know…we can't just be a typical normal family…. I would never wish this upon anybody. I don't see other people. I mean…. I don't see people doing this. It's very isolating.* ~**Carly**

Social isolation contributed to the overwhelming emotional toll CGs experienced. "It [YOD] made people run because they just don't understand it. They don't believe it…they don't know how to react to it" expressed Denise. "Certain friends are avoiding completely [pause]…[they] don't know what to do" concurred Millie. Due to the lack of awareness on YOD, many CGs felt alone in their journeys further exacerbating the effects of their caregiving roles.

> *I see less of friends, I see less of family, it has intensified…life.* **~Jasmine**

> *…. What happens is people just stop inviting you to things…instead of being understanding and supportive.* **~Denise**

Amanda added:

> *It was hard and frustrating because…. I have two cousins, but they live far away, but like I wished my brothers were more involved…there was only so much time and energy to do everything…. My psychologist has said I have post-traumatic stress disorder (PTSD) from being a caregiver. I took a leave from my internship [and] didn't get back.* ~**Amanda**

Denise, a CG who had her own physical health concerns stated "…it's just not manageable for me anymore" and further expressed "we will be moving to [place X] so that I will have a better support system". Likewise, Carly and Millie further emphasized the lack of support received and social isolation experienced.

> *I honestly don't think that it impacted other people a whole lot, because there wasn't really anyone who came to help.* ~**Carly**

> *…. I just have to ask [for help], which is different, people aren't offering but I ask anyway.* **~Millie**

Mindy emphasized how thankful she was to have her new partner [Tom], who was also a CG for his wife with YOD, as she would not be able to bear the emotional toll of her caregiving role without him.

> *So [pause] if I didn't have this relationship with [Tom] I probably would have crawled under the covers and put a pillow over my head by now (crying).* ~**Mindy**

This quote from Mindy emphasized the substantial toll of her caregiving role on her mental health, feelings other CGs experienced as well. Further, due to the substantial toll of providing care for an individual with YOD Amanda recognized the effect it had on her relationship with friends.

> *I wouldn't have the capacity to hang out with friends as much.…I wouldn't have, like the mental state to listen to my friends' issues when they would be…complaining about a guy and it's like…to me I would say you are lucky that that is your biggest problem.* **~Amanda**

Similarly, Millie provided:

> *In a small community like that, there's sometimes a lot of drama here and I just don't have the freaking time for it. So, I walk away.* ~**Millie**

Thus, the quotes from Amanda and Millie further emphasized the effect of providing care for an individual with YOD on all aspects of life.

Despite the substantial negative toll CGs experienced, they were also asked if at all, any silver linings emerged from their caregiving roles. Nicole stated:

> *I did the best I could. I believe it strengthened [my] relationship [with my mom] and provided me with fond memories together. It was a very intimate time together. I wouldn't change it for the world.* ~**Nicole**

Amanda and Denise added:

> *I would say I have an increased awareness about mental health and have grown psychologically.* **~Amanda**

> *There's a reason why I was chosen, why I am not sure, but a lot of care partners unfortunately end up sick or leaving. And [Maria] will tell you with me by her side she's been able to live her best life.* **~Denise**

Carly indicated "my physical and emotional health is 100% improved" since her mom had transitioned to LTC and further added:

> *As my parent has been in long term care 8 months now, my role has continued to change significantly. I visit her approx. every 2 days. But I feel that my outlook has significantly changed, and I am able to focus upon myself, including trying to relook at my career, the financial implications (negative) of caring for her in our home and how much generally it took out of me to do so. I remember some of the more difficult incidents (e.g., when she was distressed or deeply confused) and said hurtful things, or when there were significant clean up issues that were out of the ordinary (e.g., due to toileting), and I remember how overwhelmed I felt. I had not expected to feel so differently today, as the immediate care needs are no longer on my shoulders.* ~**Carly**

This quote from Carly emphasized the significant toll of her caregiving role and the immense benefit the LTC home has provided.

Further, Jasmine was able to identify a small positive throughout her journey as a CG for her husband and stated:

> *There are going to be challenges in any life, but the challenges of this process are enormous and they are devastating…but in that there can be such amazing things happen….and you gotta hang on to those [amazing things] and [you have to let] the negativity bias go, because that negativity bias will allow for you to go down deep, deep, deep, and stay there…so find those little shiny gold nuggets out of all that sand…and keep looking.* ~**Jasmine**

But for many CGs it was hard to find those "shiny gold nuggets". "I can throw you positives, [but] at the end of the day, it's really difficult" as stated by Carly. Mindy concurred and said, "so I'm really struggling to be able to find a positive out of all this", and Nicole added "there's not really any light at the end of the tunnel". Amanda concurred and stated the following:

> *I don't think I'm in a place to put a positive spin on things. Maybe one day, but still too much in the grief to be positive. It has made me realize how much other things just don't matter. To not work my life away until I'm 65, thinking I'll be promised retirement and health.* ~**Amanda**

In sum, CGs-YOD experienced an inordinate amount of stress and emotional turmoil because of their caregiving roles which effected many other aspects of their lives.

3.5 "I don't belong here"

This theme encompassed the lack of belonging (i.e., within current support groups and within society) CGs articulated because of their caregiving roles. The first sub-theme expressed CGs feelings towards current supports offered and coping mechanisms utilized. The second sub-theme emphasized CGs desire to increase awareness about YOD to help CGs maintain their own quality of life while continuing to provide care to their loved ones with YOD.

3.5.1 "Drained cup"

"I want to be able to live and not be…crippled by this period of my life" said Jasmine, as CGs-YOD "we suffer in silence," said Denise. All CGs discussed the lack of appropriate resources available for CGs further exacerbating the effect of their caregiving roles. "…. They never seem to address the issues that I needed address[ed]" expressed Carly, when discussing the various support services, she had accessed as a CG for her mom with YOD. Nicole expressed similar sentiments.

> *I was in a couple of support groups [and] I don't feel they [pause], satisfy my needs so much anymore because…. I just feel…. they want to fix the situation or tell me, you know…. maybe [how to] fix it or get over it, you know, that kind of thing, which I'm kind of like, I'm not looking for you to tell me what to do. I just want you to listen to me and empathize and just understand that, you know, this isn't a very clear-cut situation…. [But] I found people just complained a lot and I'm just like, I'm really sad…I don't want to talk about all this.* ~**Nicole**

Mindy and Millie emphasized the increased negative effect support groups had on their mental health.

> *Gripe sessions really, we're all frustrated and…[pause]…I'm not blaming the Alzheimer society, you know, I mean, I still could go to stuff there, but I have no interest, I'm just too tired of it.* **~Mindy**

> *…. I participated a bit … but then you get a bit bogged down, and you don't want to know any more about it for a while …***~Millie**

Denise provided the following regarding the appropriateness of a program she and her partner with YOD attended.

> *…. it was terrible. It was terrible. They were singing wheels on the bus. We're like, we are never coming back. We were so, excuse my language, pissed. We were so pissed off…. It was just really insulting.* ~**Denise**

Further, CGs expressed feeling a lack of belonging when reflecting on their experiences within various support groups. "…. We just don't have anybody to go to, that are truly walking this path…it's not the same" stated Denise, and further expressed:

> *We did go to some meetings, and I [also] went to some care partner meetings. Once again, everybody was like 30 years older than I am. I just couldn't…. They're retired, their grandkids have kids, like you know…. They still go on trips because they can afford to, they have pensions, you know, just totally different than [Maria] and I.* ~**Denise**

Debra concurred when discussing the composition of the support groups she attended.

> *I can't relate to their money stories because they are all rich…. Because they are all 80 and they saved their money, they're [pause] retired…rich, rich, rich.* ~**Debra**

Nicole echoed the words of Debra and Denise and expressed how uncomfortable she felt attending support groups with CGs who were much older.

> *…but I was so unbelievably uncomfortable because everyone was older than me. And they're all just like, what the hell are you doing here? Not like rude, but they weren't aware of young onset, right. So, I was like incredibly uncomfortable, [pause], really emotional because I was like, no one in here knows. I mean, they know, but like it's a different situation because…. I don't have the rest of my life with my parent. They already have had their opportunity.* **~Nicole**

Millie and Kate further emphasized feeling as though they did not belong within various support groups, since there CRs were in the beginning stages of their journeys with YOD.

> *I have tried that, but [pause] it's too difficult for me because maybe because I know too much…. they're putting their partners in care or they're struggling with the end before the care. And I'm not at that place. I'm not naive enough to know that it's, [pause]…not going to happen but…. I don't want to be there right now.* **~Millie**

> *…. they were….in care home settings and, [pause]…I'm not there yet. I don't, you know, I don't want to go there yet.* **~Kate**

Likewise, Denise expressed the challenges she had experienced when seeking support, as a result of living in a rural community.

> *…. I'd like to do pottery or painting, or you know, something like that [but] they don't do any of that stuff up here.* ~**Denise**

Kate added:

> *I wouldn't mind, [pause]…if there was something in the area that I could, you know, get into …just [a] support group, you know, talk to other people that are kind of dealing with some issues like this…. but I haven't been able to find anything specifically for [young-onset].* ~**Kate**

Aside from the lack of appropriateness and acceptance CGs experienced within support groups, Carly indicated “I really have no ability whatsoever to go to a support group” and further expressed:

> *I get that most dementia services, and even in long-term care, they're all organized around a model of, you know, somebody 65 to 70 and they're slightly older adults [who] have dementia or something like that. But even the visiting hours in long-term care and their COVID testing schedule, this is organized around a certain model of dementia, which doesn't fit early onset dementia in my experience. So, [pause] between raising children and trying not to completely lose an entire career life and earn some money and care for my mom and have a relationship with my husband.* ~**Carly**

Conversely, Jasmine belonged to a support group for CGs for individuals with dementia in general and emphasized the support group’s ability to “normalize feelings of betrayal of…horror that sometimes arises, because some of these situations are so bizarre”. This quote from Jasmine stressed the importance of her support group as it allowed for her to feel as though she was not alone in her journey.

Despite feeling “unbelievably uncomfortable” within her own support group, Nicole added the following about her experience with the individuals at the Alzheimer’s society.

> *Discussing the gravity of life with Alzheimer’s and how entirely valid my feelings and emotions are at any given point I believe help me be a better caregiver. It allows me to give myself more grace and that what I am feeling is common.* ~**Nicole**

Similarly, CG Mindy emphasized the importance of social support and stated:

> *One [of] the positive things has been the support of other spouses and [pause] without the support of other…. people in the same journey, it would be an impossible road…. I don’t know how one would really survive the journey.* ~**Mindy**

Although CG Denise did not feel she had adequate social support as a CG for her partner with YOD she stated “…. it’d be really nice to connect with somebody else that has FTD [frontotemporal dementia]. Like its verrryyy hard!”. Likewise, Nicole and Amanda had the same wish regarding the support they wish they received as CGs-YOD.

> *I just, if I had one thing, I wish they would ask me how I am regarding the situation…. I do find that a lot of the time….a lot of people are like, how is your mom? And I am like, how am I? You know, so I do find that they kind of just completely skip over that.* ~**Nicole**

> *Ask the caregiver how they're doing. I often get asked "how's your mom". She's looked after. What about me?* ~**Amanda**

Thus, the quotes from Nicole and Amanda emphasized the importance of social support. Nevertheless, despite many CGs emphasizing the importance of social support, Mindy highlighted "….and again the importance of social support is…. really, truly not recognized", further emphasizing the importance to increase awareness of YOD to help ease the process for CGs and CRs. Together with the need for support, was the need for self-care.

"You can't give a hundred percent [to yourself], if you are giving someone else hundred percent" said CG Amanda. "Sometimes, you need to practice self-care before you can be there for your loved one" added Nicole, and further emphasized the importance of practicing self-care and the effect it had on her ability to provide care for her mom with YOD.

> *I know myself and I listen to what my mind and body tell me. I also know that if I am unwell, it will reflect in my actions and attitude when I visit my mom – so despite "wanting/needing" to visit her, I have learned that I should not go if I don't feel emotionally or mentally capable of handling the visit.* ~**Nicole**

For CG Millie "trying to put in self-care for myself…. is probably the most difficult thing to do". She further explained:

> *I am so busy with doing his stuff and the daily household things that it has not become automatic for me. Often it may mean that I have to arrange others to take him to appointments etc. in order for me to leave [and practice self-care].* ~**Millie**

Mindy, Debra, and Carly indicated the forms of self-care they utilized to help manage their roles as CGs-YOD.

> *My gift to myself was a personal trainer, because I knew that in order to care for [Max] I needed to care for myself.* ~**Mindy**

> *…Well every day I go in my journal and it gives a question of the day and I write about that…I just write my thoughts*. **~Debra**

> *Everything I do is organized around making sure I get fresh air and exercise…. [I] stay grounded in the very specific task that I need to do and not let my[self-become] overwhelmed or isolated or disappointed or depressed by the circumstances [around] me and [allow myself to stay] focused in each moment.* **~Carly**

"I utilize [block therapy] to keep my body healthy, as well as I incorporate meditation, and yoga at the same time"; however, "not so positive coping is I started smoking again and sometimes I cope with alcohol" expressed Millie when discussing the various coping mechanisms, she utilized to help manage her caregiving role. Amanda expressed similar sentiments.

> *For a while I would smoke and drink more….and I was like "well why not like I could get dementia when I am 55, why would I care?" My mom was healthy her whole life and didn't smoke, didn't drink and look at her… I definitely had a bad attitude for a little while.* ~**Amanda**

In sum, CGs-YOD experienced many hardships with limited appropriate resources available; however, as CG Amanda's therapist said "you need joy in your life, like you have so much heaviness…you need to…do something fun" emphasizing the importance for CGs-YOD to practice self-care and make themselves a priority too!

3.5.2 Advocacy: "rather than sit and let it happen"

This sub-theme focused on CGs desire to increase awareness surrounding YOD and advice for others faced with similar sentiments. "I've been given an opportunity to advocate rather than just like sit and let it happen to us" said CG Nicole. Most CGs stressed the importance they placed on advocacy to help make the journey easier for others and to increase awareness on YOD. "I always said to [Max], if we could, you know, through this, do anything to improve this for others, [I would]" expressed Mindy. CG Carly voiced similar sentiments and expressed the goal her family had as CGs for her mom with YOD.

> *We saw ourselves as wanting to be part of our culture, as wanting to…be out in the world providing care and trying to be sort of showing what accessibility and inclusion look like.* ~**Carly**

Similarly, Nicole and Kate highlighted the importance they placed on sharing their experiences with others.

> *I try to save space for advocating for the disease by providing my time to help others, share awareness with personal stories and volunteer my experience with a parent with Alzheimer's disease to the Alzheimer's society.* **~Nicole**

> *I had to get the message out there, I guess, about dementia and that, you know, with the way people are treated…makes a big impact on…how they react and how they feel.* **~Kate**

The lack of knowledge held by numerous individuals Millie had encountered "impelled [her], to want to educate people more" helping to ease the journey for others. Yet, advocating for increased knowledge and awareness did not only have the potential to benefit others who may be faced with similar situations, rather CG Nicole indicated the benefit being an advocate had on her journey as CG-YOD.

> *…. honestly advocating and putting it out there has really helped because I've met quite a few people now that are in [pause] the same situation with…. early onset, or, you know older people that have a parent with Alzheimer's.* ~**Nicole**

However, not all CGs were given the opportunity to build connections through advocating, and thus "we…. need more education out there…. [so, we are] able to engage with people that are actually going through the same things that we are," said Denise. Aligning with the words of Denise, CGs were asked in an ideal world what type of support they would have liked to receive as a CG-YOD. "…. some type of outdoor/walking or exercise group for caregivers…. It's good for mental health to socialize, exercise and be outside," said Nicole. Denise concurred.

> *In an ideal world, yeah, a group or people, it doesn't even have to [be a group] certainly people with young-onset dementia [pause] but, it would be amazing [to connect] because you could develop friendships and support one another.* ~**Denise**

Mindy indicated she would have liked to have access to the following:

> *Perhaps assistance from a social worker on a regular basis to express concerns or discuss challenges…. financial support for music therapy, trained "buddies" for [Max].* ~**Mindy**

Similarly, Amanda provided the following regarding formal education she wished she would have received and financial assistance she would have benefited.

> *What to expect as part of the disease progression and feelings I might go through to normalize it. Actual support/a counselor to reach out to when I'm struggling. Someone to ask questions to and to be compensated [as] a caregiver.* ~**Amanda**

Jasmine also expressed the desire for financial assistance (specifically, "universal income") and further stated:

> *Universal income…. would mean a world of difference. I am losing my income, and [Don] has retired early because of this illness, so we lost his income as well. My pension is suffering as I have no work income deductions going into my pension, and we will lose [Don's] pension early because of his prognosis. He had to take his pension early at a heavily discounted rate (-36%).* **~Jasmine**

Also, after self-educating herself on caregiving in different parts of the world, Carly provided the following about financial assistance:

> *I've learned more about carers in different parts of the world (e.g., Carers [in the] UK [United Kingdom] and some of the initiatives in Australia). It makes me realize how far behind we are, in Canada, in supporting caregivers. It inspires me to want to do more - I realize how little support I've had compared to what was possible…. I stopped working to care for my mom and so [because of that I] did not get EI Maternity benefits - but in other countries, I believe that I would. This needs to change!* ~**Carly**

In addition to mental health supports and financial assistance, Mindy provided the following:

> *I wish the "system" would be more resilient and nimbler to respond in a timely way to changes in the situation. I tried my hardest to seek help but [Max] was often ineligible as he was under 65….If there is up to date research [on YOD], I would like healthcare professionals to know and plan accordingly….It is so important [for healthcare professionals] to listen to the caregivers and have regard and respect for the information they are sharing….We need to find a better way to provide quality of life for these individuals….age appropriate facilities would be awesome!* ~**Mindy**

This quote from Mindy accentuates the importance for specific resources for individuals with YOD and their CGs.

“You are not in this alone!” (Kate); “take care of yourself” (Mindy); “get plugged in” (Denise); “do things to release your anger…exercise!”(Amanda); “….you can only do what you can, you don’t want to burn yourself out” (Nicole); “take [it] one day at a time, make yourself a priority… [and] ask for help” (Millie), and “make a plan for yourself…. think about the long term and how your life will develop and still have meaning and joy” (Carly), are just a few pieces of advice CGs provided for other faced in similar situations. “Just don’t wait until 65, just don’t wait for the old age pension to begin living life...because life happens before then,” said Debra. Similarly, Denise shared the importance that “it’s not the end. There’s so much living yet to do”. Millie concurred and explained strategies she had implemented to keep living even after her husband’s diagnosis of YOD.

> *Living day to day, and trying to keep a balance, and looking at things, [pause]…for a moment and not trying to control, not trying to change what you can’t control [pause] embracing…ensuring that you are breathing.* **~Millie**

Nicole added:

> *…. finding outlets, understanding the emotions involved in the situation…. comprehending that [pause] you are experiencing grief and loss.* ~**Nicole**

In terms of outlets, Mindy emphasized the importance of “[becoming] very familiar with the services at the Alzheimer’s society [and to] share with your friends and family to ensure as much support as possible.” Nicole concurred and stated, “having others to help support you while you are caregiving can make the journey easier” but further emphasized:

> *Also being present in the moments with your loved one, but also not being ignorant to the hard fact it is a progressive degenerative disease, and your person will change and there will be constant battles and hills. But nothing will make it easier.* **~Nicole**

Despite acknowledging YOD is a progressive degenerative disease, Denise emphasized the importance “to meet the person where they’re at, instead of trying to take them with you” and further stated:

> *Your loved one may lose some abilities, but you need to keep your eye open for those hidden gems…. So they might not get to do one thing, but they sure as heck have something else there that they're able to offer…. which means focusing on their abilities…not their disabilities.* **~Denise**

Similarly, Debra who had her own mental health concerns, articulated the following:

> *[my health concerns] are just a small part of me…just like dementia is [only] a small part of [Joe].* **~Debra**

This quote from Debra indicates she saw glimpses of her [Joe] helping to ease the journey as her husband progressed with YOD.

In sum, Nicole’s views reflected the viewpoint most CGs had regarding easing the process of YOD caregiving for others.

> *It’s going to be tough, scary, and very sad. Frustrating, draining and potentially rewarding. It all depends on the relationship you had prior to and your coping methods. Maintaining healthy habits and social life is important and have a support system whether it is your closest friend, family member or from a support group…. It’s good to know what your loved one would want at the end, rather than having to make decisions when you can no longer discuss their wishes with them…. You need care options and supports.* ~**Nicole**

CHAPTER 4: DISCUSSION

4.1 Comparison to previous literature

The purpose of this study was to understand (1) the effects of providing care for individuals with YOD on female CG's overall health and quality of life, (2) the challenges associated with being CGs-YOD, and (3) the effects of programs/resources or lack of programs/resources on CGs. To answer the first research question, the effects of providing care for an individual with YOD, CGs indicated substantial psychological consequences, specifically in relation to grieving the loss of their loved ones and their futures together. CGs also indicated effects on their physical health which resulted from the lack of time available to implement self-care. Finally, CGs indicated the effect of YOD on their relationships with friends and family. Relative to the second research question, CGs emphasized numerous challenges experienced within the healthcare system, specifically in terms of the knowledge on YOD and the information/resources available. Further, CGs indicated the financial challenges associated with a dementia diagnosis at such a young age, and the challenges linked with having a loved one with YOD and the Covid-19 pandemic. Finally, in terms of the third research question, CGs emphasized the lack of appropriate resources available to CGs-YOD and the importance of advocacy to help ease the process for others faced with similar situations. Thus, predicated on the lived experiences of female informal CGs-YOD, this research uncovered three major themes, discussing the aftermaths of providing care, the challenges, and barriers CGs-YOD experienced, and coping mechanisms/ support services utilized.

Theme 1: "Are we essential?"

Theme 1 described the experiences of CGs and CRs within the healthcare system. CGs indicated various negative experiences within the healthcare system, with communication of healthcare professionals being one factor influencing their negative experiences. CGs emphasized inappropriate means of communication displayed by healthcare professionals during the diagnosis, and lack of communication/guidance following the diagnosis. Prorok et al. (2016) indicated similar results with CGs and persons with dementia (PWD) emphasizing the inappropriate demeanor of various healthcare professionals in relation to the style of communication, the content communicated, as well as challenges regarding system navigation. Likewise, within a study conducted by Connell et al. (2004), CGs indicated being appreciative of finally getting an official diagnosis; however, CGs stated the presentation of the diagnosis was inappropriate and conducted in an insensitive way. Within the current study, CGs emphasized the lack of compassion and empathy physicians exhibited towards them as CGs and their CRs during the diagnosis and onward. Further, CGs stressed the substantial effect the lack of guidance within the healthcare system had on their roles as CGs. Nevertheless, it is important to recognize Connell et al. (2004) and Prorok et al. (2016) examined CGs and PWD of all ages (i.e., not just those with YOD and their CGs), thus indicating challenges associated with communication and system navigation may not be unique for those providing care for individuals with YOD. As such, more research on CGs and YOD is warranted.

Barca et al. (2014) emphasized the lack of recognition adult children experienced during the diagnosis of a parent with YOD, and further highlighted the neglect adult children felt by healthcare professionals and social services. Within the current study, Amanda, a daughter providing care to her mom with YOD, stated her concerns as a CG were brushed away and did not feel as though her concerns were valued or heard by her mom’s GPs (general practitioners) or neurologists. However, it was not only Amanda who felt this way. Most CGs within the current study (i.e., not only the adult children CGs) felt as though their thoughts and opinions were not valued, and their voices were not being heard. Future research is critical to help educate healthcare professionals on the signs and symptoms associated with YOD to aid in the identification/diagnosis of YOD. Further, health care providers need to be educated about the value CGs possess in terms of “knowing” the CRs. As such, one novel finding from this study is the emphasis CGs placed on their knowledge of CRs. This idea regarding the immense knowledge CGs have and the importance for healthcare professionals to value CGs knowledge has yet to be discussed within the literature regarding YOD.

All CGs in this study stressed the lack of knowledge healthcare professionals had regarding YOD, resulting in challenges and frustrations during the diagnosis, understanding treatment/care options and seeking support. Several studies have indicated the importance for healthcare professionals to have a better understanding of what YOD is and the effects of providing care (Barca et al., 2014; Bruinsma et al., 2020; Couzner et al., 2022; Spreadbury & Kipps et al., 2018). Couzner et al. (2022) conducted an international Delphi study using an online survey platform with YOD experts (e.g., neurologists, social workers, nurse practitioners etc.,) from Australia, Canada, the United Kingdom (UK), Netherlands, and Norway about the information believed to be essential for health professionals regarding YOD. Results indicated experts believed it is critical for healthcare professionals to have a broad understanding of knowledge pertaining to YOD identification, diagnosis, treatment, and ongoing care. CGs within the current study highlighted the significant strain they experienced as a result of the lack of knowledge of healthcare professionals. This information by Couzner et al. (2022), in addition to the information from the current study regarding the lived experiences of CGs and CRs, needs to be utilized to educate and inform healthcare professionals about YOD to help ease the journeys for those living and caring for YOD. The Canadian health care system needs to do better.

A paucity of research has been conducted regarding the experiences of individuals with YOD in LTC. In this study, CGs who provided care to CRs living in LTC stressed various issues regarding care quality and emphasized the inappropriate nature of the care their loved ones received. CGs indicated their loved ones were excluded from activities as it was easier for staff to “shove them in a corner” than attend to their specific needs. One CG also discussed the inappropriate use of medication the LTC facility administered to her loved one with YOD. LTC nurses report that caring for individuals with YOD is more burdensome than individuals with LOD, due to their behaviours such as agitation and aggression often associated with FTD and Vascular dementias, two forms of dementia more common in those with YOD (Jefferies & Agrawal, 2009). Due to these behaviours and the strength of individuals with YOD, nurses are often urged to “manage” these behaviours evidently resulting in unnecessary use of psychotropic drugs (Van Duinen-van den IJessel et al., 2018), or exclusion/social isolation. Excessive use of psychotropic drugs is highly inappropriate and needs to be stopped due to their potential harmful effects. Nurses, PSWs, and other healthcare professionals need to be educated and trained in YOD care, ensuring person-centered care is a priority and the health and quality life of these individuals are at the forefront. Further, future research is warranted regarding the perception of healthcare workers (e.g., nurses) on the burden of individuals with YOD in comparison to those with LOD. Van Duinen-van den IJessel et al. (2018) is one of the few studies to examine this phenomenon.

Carter et al. (2016) explored individuals with YOD and the need for specialist care. Age-appropriate care/support for YOD is problematic nationwide due to the focus of most dementia services being for individuals with LOD. Overall, there is a poor understanding of the ideal models of care for individuals with YOD; however, within the Netherlands a “national YOD care program" (Carter et al., 2016) has been implemented and funded by the government since 2006. This care program allows CGs for individuals with YOD to receive financial assistance for YOD services. More specifically, LTC facilities/care homes have YOD specialized units allowing for individuals with YOD to live together. All staff have specialized training in YOD care, helping to mitigate the excessive use of psychotropic drugs. Further, these specialized units offer specific activities for individuals living with YOD to help keep PWD stimulated and thus maintain as much quality of life possible (Carter et al., 2016). Stimulation, or the lack thereof, was a major concern of CGs providing care to CRs living in LTC within the current study. CGs indicated the lack of stimulation provided by various LTC facilities across Canada as being detrimental to the overall well-being of their loved ones with YOD. Research needs to continue to examine the experiences of individuals with YOD in LTC in Canada, increasing the understanding of the needs of these individuals, in the hopes of one day developing a care model such as the one currently being implemented in the Netherlands.

CGs emphasized the financial strain associated with a diagnosis of YOD, with most CGs indicating having to retire early or take a leave of absence from work to provide care for their loved ones with YOD. However, CGs emphasized not only the loss in income due to early retirement, but also, the financial penalty associated with accessing their pensions early or not meeting the criteria for disability related financial assistance. One CG stated the "Canadian government is so far behind the eight ball in terms of support" and provides limited financial assistance to those living and caring for YOD. The cost of living with YOD is largely unknown but is predicted to have a greater effect in comparison to those living with LOD due to the timing of the diagnosis (Kandiah et al., 2016; Mayrhofer et al., 2021). Various research studies examining individuals with YOD and their CGs have indicated financial concerns (Flynn &

Mulcahy, 2015; Kimura et al., 2015; O'Neil & Fletcher, 2021); however, this topic continues to be under researched. Mayrhofer et al. (2021) attempted to fill the gap in the literature by understanding the financial impact of a YOD diagnosis on individuals and families in the UK. Results indicated individuals with YOD experience "the triple effect of income losses" (Mayrhofer et al., 2021) namely loss in income, depleted savings, and unexpected care costs, which in turn increases CGs anxiety surrounding paying for care in the future. Within Canada there is limited financial assistance available to individuals living with YOD and their CGs. For example, the Disability Tax Credit can provide up to $40,000 in income tax relief, but it excludes individuals who are able to perform activities of daily living (Disability Credit Canada, 2022). Due to the nature of YOD, many individuals are still able to perform activities of daily living in the early to middle stages and are thus excluded from this funding. Additionally, within the current study CGs indicated up to a 50% tax penalty for taking money out of a Registered Retirement Saving Plan (RRSP) prior to age 65. Canadians who need to take money out of an RRSP early face three major consequences: (1) missing out on the advantages of compound interest (i.e., lose the opportunity to earn money while its invested), (2) having to pay tax on RRSP withdrawals, and (3) permanently losing RRSP contribution room (Sun Life, 2022). CGs for individuals with YOD are currently given no financial assistance, do not qualify for many financial support networks, and are heavily penalized for accessing funds early. Money needs to be allocated for research regarding YOD, education pertaining to YOD, and provided to CGs to help decrease the financial challenges associated with YOD.

Although evidence is emerging regarding Covid-19 and the effect of the Covid-19 pandemic on individuals with dementia and their CGs, limited research has examined individuals with YOD and their CGs specifically. The current study provides insight into the effect of the

Covid-19 pandemic on individuals with YOD and their CGs both at home and within LTC. CGs who provided care to individuals at home reported increased social isolation, restricted access to support, and decreased physical and mental health because of the pandemic. Cations et al. (2021) indicated similar results. CGs and individuals with YOD reported difficulties managing behavioural and psychological effects as a result of boredom, isolation, decreased access to supports, and stress stemming from the pandemic. Results from the current study and the results of the study conducted by Cations et al. (2021) are comparable to numerous studies examining the effects of Covid-19 on individuals with LOD and their CGs (Giebel et al., 2021; Hanna et al., 2022). As such these results indicate the experiences with Covid are not necessarily unique to individuals with YOD and their CGs, as indicated by CGs within the current study when reflecting on their experiences.

The experiences of CGs whose CRs lived in LTC throughout the Covid-19 pandemic were inherently negative. CGs indicated issues regarding routine care, and the effects of not being able to see their loved ones for many months, on the physical and psychological health of the CRs and them as CGs. However, most CGs for CRs living in LTC emphasized the pandemic has only exacerbated the issues within the LTC system and allowed for them to be much more visible. Phillipson (2020) strongly emphasized the ways in which the LTC system has failed to keep individuals protected and safe due to care homes “being too big; inadequately staffed; and financially insecure” (Phillipson, 2020) during the ongoing Covid-19 pandemic. Phillipson (2020) stressed the current model of LTC facilities is broken and suggested various steps to take action for change. One step was for researchers to re-evaluate the future of LTC facilities. Thus, research needs to further examine the current experiences of individuals with YOD in LTC to ensure their needs are at the forefront during this re-evaluation.

Theme 2: “I don’t wish this life for anybody”

Theme 2 described the ongoing repercussions CGs and CRs experienced because of YOD. CGs indicated challenges associated with maintaining CRs’ quality of life following the diagnosis and onward. When individuals are diagnosed with YOD many changes occur which are often challenging for individuals and their CGs to accept (Busted et al., 2020; Caddell & Clare, 2011; Clemerson et al., 2013). Some of these changes include but are not limited to: disruptions to the life cycle as a result of being forced to retire early, losing a sense of self/identity, social isolation/disconnect from others, and feeling powerless over life (Busted et al., 2020; Caddell & Clare, 2011; Clemerson et al., 2013; O’Neil & Fletcher, 2021). Due to the myriad of changes individuals with YOD experience, PWD have reported decreased psychological health and overall quality of life following the diagnosis of YOD (Busted et al., 2020; Draper & Withall, 2016). Within the current study CGs emphasized CRs experiencing an indescribable amount of boredom, evidently decreasing their quality of life (QOL). To mitigate the boredom and decreased psychological health individuals with YOD experience, research has concluded services for individuals with YOD need to be age-appropriate (Beattie et al., 2002; Mayrhofer al., 2018); but there is limited evidence indicating what “age-appropriate” means in practice (Bell, 1995; Heiser, 2002; Mayrhofer et al., 2018), resulting in a paucity of services available. Within the current study CGs indicated the substantial challenge they endured in relation to “filling the days” due to the limited services available specific to the needs of the CRs. To address this issue, Kinney et al. (2011) implemented a pilot program specific to individuals with YOD. The results of this study found the program specific to YOD provided respite care to CGs and gave individuals with YOD purpose, and a place to connect and build friendships. In turn, this enhanced the QOL of both CGs and individuals with YOD. Similar sentiments were expressed by Kate, the only CG within the current study whose CR attended a day program specific to YOD. Future research implementing pilot programs for individuals with YOD is warranted, in order to gain a better understanding of what “age appropriate” services for individuals with YOD means in practice. These programs also have the potential to help decrease the psychological effects associated with YOD for the individuals and their CGs.

CGs emphasized the continual grieving process associated with having loved ones with YOD. CGs grieved in terms of the loss of their loved ones, the loss of their futures together, the loss of shared roles and responsibilities (Svanberg et al., 2011; Wawriczny et al., 2017), and the progressive losses in the lives of the individuals with YOD (Lindauer & Harvath, 2014). Research has indicated the culmination of these losses together creates what has been defined as pre-death grief (PDG) (Kobiske et al., 2018). In a study conducted by Kobiske et al. (2018), examining CGs-YOD, PDG, and perceived stress, it was found PDG accounted for 42% of CGs stress. The results of the study conducted by Kobiske et al. (2018) correlated to the results of a previous study indicating CGs’ well-being is negatively affected by the grief associated with YOD and the demands of the caregiving role (Paun et al., 2015). CGs-YOD are at risk for serious long-term physical and mental health consequences. Programs and resources focusing on PDG experienced by CGs have the potential to decrease these effects, and thus future research is warranted in this area.

There is a paucity of literature that has examined the effect of providing care for a parent with YOD on adult children. In this study, three CGs identified as adult children caring for their mothers with YOD. Amanda, Nicole, and Carly all identified a change in the relationship with their mothers following the diagnosis and onward. CGs expressed they were parentified, with

CG Amanda indicating her mom was like “a baby” to whom she provided care (Svanberg et al., 2010). Further, Amanda and Nicole emphasized the significant amount of grief, anger, and resentment experienced as a result of being in their twenties and providing care to their moms with YOD (Svanberg et al., 2010). Sikes and Hall (2017) expressed similar results, whereby adult children CGs, like spousal CGs, experienced a significant amount of grief and sadness; however, adult children CGs also expressed feelings of envy and resentment towards others whose parents were healthy or had a curable disease. The results of the current study, in combination with the results from Sikes and Hall (2017), clearly indicates the profound sadness adult children experience. It is imperative these individuals have access to grief counselling in order to help decrease the negative psychological effects associated with their caregiving roles. Lasty, within the current study CG Carly indicated the effect of her mom’s YOD on her two young children; however, little to no research has examined the effect of YOD on young children and, thus future research is warranted to determine the effects on families.

All CGs providing care to their spouses/partners with YOD expressed the inordinate change in their relationships as a result of YOD. CGs expressed the loss of intimacy, and the limited support available leaving CGs vulnerable and alone. Limited research has examined the effect of YOD on spouses, specifically in relation to intimacy. For older adults with dementia (LOD) mixed results have been established regarding a diagnosis of dementia and sexual intimacy. Kuppuswamy et al. (2007) examined 50 couples consisting of one partner with dementia. Varied results were found with some couples enjoying a healthy sex life following the diagnosis of dementia, others who struggled to accept changes, and lastly others who accepted the loss of intimacy following the diagnosis of dementia. Within the current study, CGs who were spouses/partners to CRs emphasized the significant toll no longer being intimate with their life partners had on them and their CRs. The results of the current study in terms of the effect of YOD on intimacy is novel, with no other studies examining this phenomenon. Awareness needs to be raised regarding the potential effect of YOD on intimacy. Further healthcare professionals need to be educated, so they can provide support/guidance to both CGs and CRs as they navigate these critical changes in their relationships following a diagnosis of YOD.

Bruinsma et al. (2020) examined CGs for individuals with FTD which resulted in CGs emphasizing the lack of recognition, acknowledgement, and understanding of healthcare professionals, further exacerbating the effect of their caregiving roles. CGs perceived physicians had challenges recognizing CGs concerns due to the individuals with FTD being able to present themselves well and perform well on neurological testing (Bruinsma et al., 2020). Within the current study, CGs emphasized the ability of their loved ones to “show time” or “hostess” and act like nothing was wrong for a period. The ability of the CRs to hostess resulted in friends, family, and physicians not seeing the effects of YOD on the CRs like the CGs did. This resulted in CGs becoming increasingly isolated with little to no support available both formally and informally (Bruinsma et al., 2020). However, it is important to recognize all CGs within the current study (i.e., not just those providing care to individuals with FTD) emphasized the lack of support received due to family, friends, and healthcare professionals lack of awareness of YOD. Healthcare professionals should actively seek out the knowledge CGs possess regarding their CRs. Particularly in the case of YOD (e.g., FTD), CGs can provide insight into the behaviours of CRs, rather than what is revealed during “showtimes”. These findings further emphasize the novel results of this study in terms healthcare professionals valuing what CGs know in regard to their CRs.

Theme 3: "I don't belong here"

Theme 3 described CGs' perceptions on the current support services available. CGs-YOD have the ability to live meaningful lives when the appropriate physical and social support services are in place (Herron & Rosenberg, 2017). There is a lack of literature examining support services for CGs-YOD, with minimal research focusing on individuals with YOD (Kinney et al., 2011; Mayrhofer et al., 2018). CGs within the current study expressed feeling as though they did not belong within support groups, due to the different stage of life they were in, in comparison to older adults providing care to LOD. This corresponds to previous research where CGs and CRs have indicated feeling out of place and would have preferred to have their own support groups tailored to their specific needs (Bakker et al., 2006; Giebel et al., 2020). Yet, support groups designed specifically for individuals with YOD come with an assortment of challenges, including not having enough individuals with YOD in a specific region to form a group (Giebel et al., 2020). Within the current study CGs expressed challenges associated with geographical regions. Some CGs lived in rural areas of various provinces across Canada and expressed their interest to participate in activities such as art or pottery to help mitigate the effects of their caregiving roles; however, nothing was available in their regions. Likewise, Kate indicated her husband would attend the YOD specific day program more often giving her additional respite care; however, it was an hour drive to and from the program and was not feasible. Other than Kate's experience, CGs from the current study were from different provinces, no differences were indicated in terms of support available besides those living in rural verse urban communities. Women living in rural areas of Canada are at a heightened risk of experiencing poor physical, mental, and social health because of limited access to various healthcare services (Leipert, 2005). No research to date has examined the potential heightened effect of providing care to individuals with YOD while living in a rural community. Research needs to examine the lived experiences of these individuals ensuring they have access to the support services necessary to help maintain their own health and QOL.

CGs in this study emphasized the importance of self-care despite not always having time to implement it. Self-care has been identified as a critical component in one's management of well-being; however, no research was found that examined self-care and CGs-YOD, with limited research examining CGs-LOD (Wang et al., 2018). CGs-LOD have indicated limited time to attend doctors' appointments, take their own medications, and partake in social activities because of their caregiving roles, adversely affecting their own health. Further CGs-LOD reported not practicing self-care due to a lack of motivation, awareness, skills, and knowledge on self-care; however, self-care has been found to positively influence the health of CGs-LOD (Wang et al., 2018). Therefore, another novel finding from the current study was the importance CGs placed on self-care and the ability for self-care to help mitigate the substantial toll CGs experienced. It is essential for future research to explore self-care as a mean of coping for CGs-YOD. By increasing the awareness and education on the potential benefits of practicing self-care may help to close the gap between the needs of CGs-YOD and the current support services available since self-care can be practiced independently at any time throughout the day.

Lastly, CGs within the current study emphasized their passion to advocate and spread awareness about YOD. Amidst all the hardships, CGs stressed the importance of increasing awareness and education to help ease the process for others faced with similar situations. This is a consistent finding across numerous studies examining the lived experiences of individuals with YOD and their CGs (Barca et al., 2014; Cartwright et al., 2021; Sikes & Hall, 2018). The voices of these individuals need to be heard and action needs to be taken.

4.2 Limitations

Within this research some limitations exist that need to be addressed. This study examined the lived experiences of female informal CGs for individuals with YOD within Canada. CGs consisted of spouses (n=6), daughters (n=3), and sisters (n=1) to individuals with YOD. Due to this, the experiences of CGs-YOD were not necessarily similar. The recruitment of only CGs with the same relationship to the CRs (e.g., daughters) with YOD may potentially allow for greater information regarding the effect of providing care to CGs' overall health (i.e., physically, socially, financially, psychologically etc.); however, it is important to recognize the experiences of each CG were intricate and unique. Further, in terms of racial diversity, although this information was obtained within the background questionnaires it was not disclosed. Limited participants identified with different cultural backgrounds and due to the rarity of YOD, it was essential to keep this information anonymous to ensure anonymity of all participants. Nevertheless, it is important to recognize the lived experiences described by CGs may be influenced by the culture in which they identify. Lastly, 10 CGs-YOD were recruited to participate in this study consisting of one semi-structured interview and one follow up interview via Zoom or email. One participant only completed the first interview due to personal health issues, and thus did not disclose any information regarding advice for others or current support services available (Theme 3). Further, seven of the CGs completed the second interview via email while the remaining two were interviewed by the primary researcher via Zoom. The differences in the style of the second interview may have created inconsistences in the richness of the data, as probing was not possible during the interviews via email (although member checks were provided to participants).

Next, CGs were from different provinces (Ontario n=7; Alberta n=1; Manitoba n=1; Newfoundland n=1) and lived within a variety of different settings (e.g., urban vs. rural). Overall, most of the experiences CGs-YOD were similar; however, when examining the current support services or the lack of current support services available differences existed due to location (i.e., urban versus rural) but did not differ between provinces. The recruitment of CGs from only urban or rural areas may potentially allow for greater information regarding the current resources available for CGs and individuals with YOD. Regardless, all CGs, except for Kate, experienced deficits in current resources, and emphasized more resources were warranted.

Further, the information presented in this study is reflective of the experiences of the PIC and no other family members or the individuals with YOD. Information obtained from other family members and individuals with YOD could potentially allow for greater understanding of experiences of YOD. For example, the recruitment of multiple cases with CGs caring for individuals with YOD and young children versus other situations would allow for greater understanding of CGs' experiences. Further examining YOD cases in comparison to LOD cases or between YOD cases and LOD cases (i.e., examine multiple cases consisting of individuals with YOD and their CGs or likewise for LOD) could allow for a greater understanding of CGs experiences.

Likewise, this study only reflects the experiences of the PIC within the healthcare system and not the PWD or healthcare professionals. Information obtained from individuals with mild YOD (i.e., PWD who are still able to communicate) and healthcare professionals may allow for greater understanding of the knowledge of healthcare professionals on YOD.

Lastly, five of the women provided informal care within the home (i.e., live with the individual with YOD), while the remaining five reflected on their experiences providing care at home, as well as their current caregiving roles for their loved ones in LTC. Due to this, some of the information pertaining to their caregiving roles was retrospective in nature and may have resulted in reduced recollection of information. Additionally, community based CGs did not have experiences with LTC and thus could not provide any additional context.

There is no “one size fits all” approach to reach data saturation since there is no one universal design for qualitative inquiry (Fusch & Ness, 2015). However, it has been said when “no new data, no new themes, and no new coding” (Fusch & Ness, 2015, pg. 1409) have emerged then data saturation has been achieved. However, within qualitative research there is no set pre-determined number utilized to indicate data saturation, with Bernard (2012) stating the number of interviews necessary to reach data saturation is not quantifiable and is completely independent to population and research topic. Similarly, Patton (2002) contends there are no specific rules when determining sample size and power in qualitative research. “Sample size depends on what you want to know, the purpose of the inquiry, what’s at stake, what will be useful, what will have credibility, and what can be done with available time and resources” (p.244). Nevertheless, the primary researcher believes data saturation was achieved due to the redundancy in the data occurring halfway through the data analysis process (Saunders et al., 2018). Yet, it is important to recognize the skill of the primary researcher may have had an influence on the data being collected (Mason, 2010). The primary researcher has engaged in qualitative research for two and half years and her skills may have had an effect on the quality of data being collected; however, to account for this, data triangulation and investigator triangulation were utilized (Fusch & Ness, 2015). The primary researcher and her supervisor both identified redundancy in the data, approximately halfway through data analysis, with no new data emerging. Lastly, the primary researcher contended saturation was achieved with the majority of the themes presented due to the thick and rich descriptions provided within (Fusch & Ness, 2015) this phenomenological study.

4.3 Implications

This study provides substantial contribution to the literature surrounding the effects of providing informal care for individuals with YOD, and the experiences of CGs in numerous aspects of their lives (i.e., interacting with healthcare professionals, support received, coping mechanisms utilized). As the population ages and the number of individuals living with YOD rises, so does the number of individuals who will be unpredictably capitulated into the roles of providing informal care. With this, CGs-YOD will need assistance navigating the healthcare system, accessing supports/resources, and recognizing the importance of practicing self-care to maintain their own health and QOL. Further, this study provides information for healthcare providers concerning how to better meet the needs of younger individuals with dementia and their CGs.

Additionally, this research is critical for policy makers and health care professionals. This study supports previous research, clearly indicating individuals with YOD are financially disadvantaged with limited support services available. Individuals with YOD are often forced to retire early, with CGs often having to leave their jobs in order to provide care to their loved ones with YOD (see for example: O'Neil & Fletcher, 2021). This study emphasized the significant financial burden associated with YOD and the limited support services available. CGs and individuals with YOD face discrimination, and do not qualify for the same financial assistance as older adults with dementia. The Canadian government relies heavily on informal caregivers and their families but does not want to provide financial assistance to these individuals. It would be beneficial for policy makers to create a framework similar to those currently being implemented within Europe (for example see: Carter et al., 2016) that allows CGs to be financially compensated for providing informal care. In addition, funding needs to be allocated to further aid in research regarding YOD and educating our Canadian healthcare providers.

Likewise, this study provides valuable information for the Alzheimer’s society and other networks who currently provide support for individuals with YOD and their families. This research stressed the importance of further education of YOD and increasing awareness of YOD for healthcare providers and society. Alzheimer’s societies and other support networks need to make information pertaining to YOD easily accessible and provided at the time of diagnosis. Additionally, this research provides insight into the specific needs and desires of CGs-YOD in terms of beneficial support. Alzheimer’s societies and other support networks need to use this information to design resources and support groups tailored directly towards the needs of CGs-YOD.

Moreover, the implications of this study are of importance for family members and friends of CGs-YOD. This research indicates the value of social support and the ability for social support to help decrease the negative health effects (e.g., physically, psychologically etc.) associated with providing informal care for an individual with YOD. Family members and friends can use this information to gain a better understanding of what YOD is, the effects of YOD, and how they can help decrease the negative effects associated with providing informal care.

Lastly, individuals who are currently providing care for someone with YOD (or have in the past) can sympathize and relate to the experiences of the CGs. These findings may help others take comfort and know they are not alone, and that many others are facing a similar phenomenon. Their stories and experiences emphasize the importance of self-care and social support for those providing informal care for YOD.

4.4 Suggestions for future research

Some suggestions for future research include (1) examining CGs, individuals with YOD, and healthcare professionals to further increase knowledge surrounding YOD and the Canadian healthcare system, (2) evaluating current resources for individuals with YOD and their CGs, allowing for a greater understanding of “what works” in practice regarding programs/services, and (3) designing, implementing, and evaluating a program specific to the needs of informal YOD-CGs. Each of these research areas will be discussed.

Currently, most of the research surrounding dementia focuses on individuals with LOD and their CGs. Within recent years, studies have started to zone in on individuals with YOD and their CGs; however, the area is still relatively void of information. The current research examining YOD primarily focuses on the diagnostic experience of individuals with YOD and their CGs. Further, research has explored the effect of YOD on the individuals, the CGs and their families in comparison to LOD. Limited research has examined the experiences of individuals with YOD and their CGs within the healthcare system. It would be beneficial to study individuals with YOD, CGs-YOD, and healthcare professionals to understand the perceptions of all individuals in relation to the experiences of individuals with YOD in the healthcare system. Further, it would be valuable to examine individuals with YOD, CGs-YOD, and healthcare professionals during various points throughout one’s journey with YOD (e.g., diagnosis, accessing services, within LTC etc.). Additionally future research should continue to explore the novel findings of this study and examine the potential benefit of healthcare professionals valuing CGs’ knowledge in relation YOD. Further, most research addressing services for individuals with YOD has focused on the individuals with dementia, overlooking the needs of primary informal CGs. It is important to understand the needs of CGs and their experiences within current support services available in order to develop programs tailored specific to their needs. Lastly, pilot programs addressing the specific needs of CGs-YOD should be implemented to allow greater insight into "what works" in relation to programs/resources specific for CGs-YOD. The incorporation of individuals with lived experiences would be an asset when designing the support services, helping to ensure the needs of these individuals are being met (Mayrhofer et al., 2018). Likewise, these pilot programs should consider the novel findings of this study and incorporate self-care as a mean of support for CGs-YOD. Further, these programs designed to help CGs-YOD need to be adequately funded, as without funding, the strain on CGs and the healthcare system will be considerably increased. Thus, it is imperative to continue to use qualitive research methods when studying individuals with YOD and their CGs. The voices of individuals with YOD, CGs, researchers, and health care providers can allow for a more holistic understanding of the YOD experience, and the various effects associated.

4.5 Conclusion

This study adds to the previous literature surrounding the effects of providing informal care for individuals with YOD and the disconnect between the current services available and the needs of this at-risk population. All individuals within the current study conveyed the substantial toll their caregiving roles had on their physical, psychological, social, and financial health, with limited accessible resources available. Additionally, CGs were able to provide insight into the complex issues existing within the Canadian healthcare system for individuals with YOD and their CGs.

In conclusion, this study demonstrates the perpetual hardships associated with providing informal care for a loved one with YOD. Through the stories of these ten women, it is clear there is “no light at the end of the tunnel” in regard to how physically, emotionally, and psychologically taxing it is to provide YOD care; nevertheless, the study has given CGs the opportunity to increase awareness and help fight the stigma associated with YOD. Thus, the results and implications of this study could not be summed up better than by Jasmine, who used poetry to express her experiences as a CG-YOD:

> *I see myself and all my pain in a hundred thousand other faces. I feel the hope in a hundred thousand other smiles. I hear the quiet strength in a hundred thousand other sighs. I sweep up my shattered ego that can no longer cry “I hurt”. And gently hold our breaking hearts together.* **~Jasmine**

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Glossary

EOD	Early-onset dementia
YOD	Young-onset dementia
AD	Alzheimer’s disease
FTD	Frontotemporal dementia
CGs	Caregivers
CGs-YOD	Caregivers for individuals with young-onset dementia
CRs	Care recipients
LTC	Long-term care
PIC	Primary informal caregiver
PWD	Persons with dementia
QOL	Quality of life
PDG	Pre-death grief
HRQoL	Health related quality of life

Appendix A

Table a: A Comparison of the Different Types of Dementia

Type of Dementia	YOD Prevalence	LOD Prevalence	Explanation of condition (signs, symptoms, characteristics)
Alzheimer's Disease	31%	62%	▪ Changes occur in the brain that control learning, difficulty remembering newly learned information ▪ Difficulty speaking, swallowing, and walking ▪ Disorientation, mood/behaviour changes, inability to recognize friends/family
Vascular Dementia	15%	10%	▪ Decline in thinking skills, blood to regions of the brain become reduced or blocked depriving them of oxygen ▪ Confusion, disorientation, poor balance, numbness or paralysis on one side of the face/body, physical stroke symptoms
Frontotemporal Dementia	13%	17%	▪ Group of progressive disorders causing nerve cell loss in the brain's frontal and temporal lobes ▪ Changes in personality/ ability to socialize
Lewy body dementia	4%	4%	▪ Changes in thinking, reasoning, visual, hallucinations, delusions, dizziness, slowness and gait imbalances similar to Parkinson's disease
Other	25%	3%	

NOTE: All information is from Alzheimer's Association *Types of dementia* webpage and Jefferies & Agrawal (2009).

Appendix B

Table b: Summary of Negative Effect Studies on Caregivers for Individuals with YOD

<table>
<tr><th>Researchers</th><th>Aria et al. (2010)</th><th>Ducharme et al. (2013)</th><th>Millenaar et al. (2016)</th></tr>
<tr><td>Qualitative or Quantitative</td><td>Quantitative</td><td>Qualitative</td><td>Quantitative</td></tr>
<tr><td>Location</td><td>Japan</td><td>Canada (Quebec)</td><td>Netherlands</td></tr>
<tr><td>Participants</td><td>92 patient-CG dyads, 68 used for analysis (14 YOD patient-CG dyads, 54 LOD patient-CG dyads)</td><td>12 spouses of individuals with YOD (8 women, 4 men)
(9=AD, 3=mixed dementias)</td><td>CG patient dyad YOD N=220
CG patient dyad LOD N=108</td></tr>
<tr><td>Age of Participants (mean)</td><td><table><tr><th></th><th>YOD</th><th>LOD</th></tr><tr><td>Patient</td><td>60.5</td><td>78</td></tr><tr><td>Caregiver</td><td>61.5</td><td>70</td></tr></table></td><td>Age range not given
Women X=52, men X= 60</td><td><table><tr><th></th><th>YOD</th><th>LOD</th></tr><tr><td>Patient</td><td>61.6</td><td>80.2</td></tr><tr><td>Caregiver</td><td>59.02</td><td>64.3</td></tr></table></td></tr>
<tr><td>Methods</td><td>*Patients were assessed in terms of cognitive function, psychological disturbances and severity of dementia
Caregivers completed a series of self-administered questionnaires</td><td>Semi-structured interviews</td><td>Baseline assessment and four follow up assessments</td></tr>
<tr><td>Methods in detail</td><td>Sociodemographic status, number of hours spent providing care, duration/length of being a caregiving, and number of hours relieved from caregiving duties per day</td><td>Focused first symptoms, diagnosis, main difficulties, evaluation of relations within the family</td><td>Primary outcomes
1. CG competence
2. Psychological and physical complaints
3. Depressive symptoms
4. Health related quality of life</td></tr>
<tr><td>Main Conclusions</td><td>CGs-YOD significantly younger, more likely to have a job, less prepared for CG role, limited resources</td><td>Difficulties associated with accepting their spouses’ disease</td><td>CGs in both groups significant effects as a result of their caregiving role</td></tr>
</table>

NOTE: Table 2 is organized based on the order of which the articles were discussed within the contents of the paper and extends from page 20-25. All literature was accessed via Wilfrid Laurier University Library and Google scholar. Some of the key words used to access the literature include but are not limited to: young-onset dementia, young-onset dementia, effects of dementia, caregivers, support services, effects of dementia on the family, effects of dementia on children.

Table b Continuation: Summary of Negative Effect Studies on Caregivers for Individuals with YOD

Researchers	Kimura et al. (2015)	Flynn & Mulcahy (2015)	Kaiser & Panegyres (2007)	Luscombe et al. (1998)
Qualitative or Quantitative	Qualitative	Qualitative	Quantitative	Quantitative
Location	Brazil	Ireland	Australia	Australia
Participants	9 CGs-YOD (7 women, 2 men)	7 family CGs for individuals with YOD (2 women, 5 men)	100 Spouses of individuals with YOD, (54% women) (FTD N=42, AD N=36, PPA N=6, OTHER N= 16)	102 CGs-YOD
Age of Participants (mean)	34 to 66 years old X=51.2	31-65 years old Mean age not specified (29% were between 31-55, 71% were between 56-65)	49-73 years old x=62.3	Not provided
Methods	One-on-one semi-structured interviews utilizing interpretive phenomenological analysis	Semi-structured interviews	1. Zarit burden interview (ZBI) 2. Beck-depression Index (BDI)	Cross sectional questionnaire survey
Methods in detail	10 questions focusing on the diagnostic process; changes to routine; family situation; the future; difficulties associated with the disease; CGs current situation.	Face to face semi-structured in-depth interviews were conducted with each participant.	ZBI →22 item scale assessing burden associated with functional/ behaviour impairments, and home care situation BDI→21-item questionnaire including socio-demographic characteristics of patient/ Caregiver	33-item self-reported questionnaire addressing demographic characteristics; diagnostic procedure; family history, finances, family relationships, service uses and satisfaction of services
Main Conclusions	CGs-YOD experience physical, psychological, social, and financial effects, and a lack of services	Diagnosis of YOD effects the entire family unit. All CGs indicated a lack of services	Spouses for individuals with YOD specifically wives experience a variety of psychological, social, and financial effects	Difficulties with gaining a diagnosis, all members of the family effected by YOD

Table b Continuation: Summary of Negative Effect Studies on Caregivers for Individuals with YOD

Researchers	Lockridge & Simpson (2012)	Papastavrou et al. (2007)	Gelman & Rhames (2018)	O’Neil & Fletcher (2021)
Qualitative or Quntitative	Qualitative	Quantitative	Qualitative	Qualitative
Location	England	Greece	United States	Canada
Participants	6 Spouses of individuals with YOD (3 women, 3 men)	200 patient-CG dyads, 172 used for analysis (40 men CGs, 132 women CGs)	4 wives of individuals with YOD 8 Children of individual with YOD	1 Case (Individual with young-onset AD, wife, sister, and mother of individual with AD)
Age of Participants (mean)	52-70 years old X=63	Care recipients age range =52-97 years, CG age range and mean not provided	Wives 43-51 years old Children 16-20 years old	50 to 89 years old
Methods	Semi-structured interviews	Four instruments implemented during an interview conducted by the primary researcher	Semi-structured interviews	Background questionnaire, Semi-structured interviews
Methods in detail	Semi-structured interviews focused on experiences of CGs-YOD, and coping strategies implemented by the carers.	Four instruments, (1) MBPC assessing cognitive and behavioural status of the patient; (2) Burden interview assessing caregiver burden; (3) CES-D assessing depression in the past week; (4) Ways of coping questionnaire addressing coping strategies CGs utilize	One-on-one, face-to-face interviews were conducted with each participant; interviews were recorded	One-on-one, face-to-face interviews were conducted with each participant; interviews were recorded
Main Conclusions	CGs-YOD typically develop emotion and problem-focused coping strategies leading to negative effects	Female CGs need specialized training to help understand how to manage behaviours of dementia & how to cope with feelings as a caregiver	YOD effects all members of the family however the impact may be perceived differently	Significant financial effects associated with young-onset AD

Appendix C

Table c: Summary of Positive Effects on Caregivers for Individuals with YOD

Researchers	Semiatin and O’Connor (2012)	Flynn & Mulcahy (2015)	O’Neil & Fletcher (2021)
Qualitative or Quantitative	Quantitative	Qualitative	Qualitative
Location	United States	Ireland	Canada
Participants	57 family CGs for individuals with AD (39 spouses, 15 adult children, 3 siblings/friends)	7 family CGs for individuals with YOD (2 women, 5 men)	1 Case (Individual with young-onset AD, wife, sister, and mother of individual with AD)
Age of Participants (mean)	43 women X= 70 age range= 44-88 years old 14 men (age range and mean not provided) Individuals with AD X=80 range = 64-92	31-65 years old Mean age not specified (29% were between 31-55, 71% were between 56-65)	50 to 89 years old
Methods	Structured interview followed by a series various measures assessing positive aspects of caregiving, caregiving self-efficacy, caregiver depression, patient neuropsychiatric symptoms	Semi-structured interviews utilizing descriptive qualitative methodology	Background questionnaire, Semi-structured interviews
Methods in detail	Structured interview to gather CG and patient history and demographic information. Positive aspects of caregiving were assessed using the nine-item positive aspects of caregiving scale	Face to face semi-structured in-depth interviews were conducted with each participant.	One-on-one, face-to-face interviews were conducted with each participant; interviews were recorded
Main Conclusions	Caregivers who report higher self-efficacy, are more likely to recognize the positive aspects of their caregiving role	CGs-YOD emphasized the importance of the development of services for individuals with YOD and their families. Positive aspects of caregiving recognized	All participated were able to recognize the silver linings associated with young-onset AD

NOTE: Table 3 is organized based on the order of which the articles were discussed within the contents of the paper and extends from page 25-26. All literature was accessed via Wilfrid Laurier University Library and Google scholar. Some of the key words used to access the literature include but are not limited to: young-onset dementia, young-onset dementia, effects of dementia, caregivers, support services, effects of dementia on the family, effects of dementia on children.

Appendix D

Wilfrid Laurier University Informed Consent Statement

INFORMAL CAREGIVERS FOR INDIVIDUALS WITH YOUNG-ONSET DEMENTIA

Principal Researcher: Hailey O'Neil, MKin
Advisor: Dr. Paula C. Fletcher
Department of Kinesiology and Physical Education

You are invited to participate in a research study about the lived experiences of female informal caregivers and the effects on perceived health and overall quality of life. Specifically, female informal caregivers will be providing care to individuals with Young-onset dementia. The goal of this research is to gain a better understanding of the effects of caregiving on the women and the need for appropriate services.

The principal researcher, Hailey O'Neil, is an MKin student at Wilfrid Laurier University and is conducting this research for her thesis. Her research advisor, Dr. Paula Fletcher, is a professor in the Department of Kinesiology and Physical Education.

Information

Female informal caregivers (CG) for individuals with Young-onset dementia will be recruited to participate in this study. All participants will meet the following criteria: (1) the informal caregiver must live within Canada; (2) the informal caregiver must consider herself as the primary informal CG for an individual with or in the process of being diagnosed with Young-onset dementia (YOD); (3) the informal caregiver must be untrained and unpaid for her services but will not be excluded if she provides formal acts of care for others in her professional life (i.e., nurse, personal support worker etc.); (4) the informal caregiver must be in a close relationship (i.e., family member, close friend, significant other) with the individual with YOD; and (5) and must be in some form of contact with the individual with YOD weekly. Further, each participant will be an informal caregiver for an individual that meets the following criteria (1) formally diagnosed with dementia before age 65 or within the diagnosis process; and (2) dementia must be the primary condition of concern.

As a participant you will be asked to complete the following:

- A background questionnaire
- A one-on-one semi structured interview conducted in person OR via Zoom concerning your role as an informal caregiver and the effects of caregiving on your overall health and quality of life. This interview will be conducted within two weeks of the background questionnaire.
- A second interview will be completed in person OR through an email interview. This interview will focus changes to CGs roles and advice for others.

The in-person interview will be dependent on the answers provided; however, it is anticipated, the interview will last 45 to 90 minutes, and the email interview will take 30 to 60 minutes to complete. As part of this study, you will be audio recorded and the interview will subsequently be transcribed verbatim. Only the researcher Hailey O'Neil, and her supervisor, Dr. Fletcher, will have access to these recordings. All information will be kept confidential. You will be able to review your interview in the form of a member check. You will be able to add, omit, or clarify any information provided. Information from the interviews may be used in presentations resulting from data collection, or my final paper which will be published as an academic journal or two. You will receive the transcript in the form of a member check and given two weeks to review the information. Should you not review the transcript, the analysis will occur with the transcript in its original form. It is important to note you will not be identified in any publications or presentations resulting from this work.

Risks

Given the sensitive and personal nature of this topic, you may feel a loss of privacy, boredom, and/or regret revealing certain information, as a direct result of your participation in this study. Do note should you have any discomfort; you may stop the interview process or refrain from answering any questions with which you feel uncomfortable. You may also use the member check to vet any information you have provided. In the event you wish to stop the interview, the recorder will be turned off and the interview will be discontinued if requested.

Benefits

Although there may not be a direct benefit to your participation, it is anticipated this research will help to fill the gap in research regarding informal caregivers for individuals with Young-onset Dementia and its effects on the overall health and well-being of informal carers. The information from this study could also help to further educate the general public and front-line health workers on the needs of informal caregivers to help with the development of specific resources for these beings.

Compensation

All participants will be entered in a draw to win a $25 dollar gift card following completion of the study (April 2022). Odds of winning depend on the number of eligible participants (approximately 1 in 15). The winner will be notified by email.

Confidentiality

Your name will not appear in any publications or presentations resulting from this research. Further your name will be replaced with a pseudonym in order to ensure confidentiality. Papers and presentations resulting from this research may contain direct quotations from your interviews; however, there will be no information revealing your identity or the identity of your family members in any of the quotations used. In addition, participants will have the opportunity to omit, clarify, and/or remove quotations prior to any report.

Contact

If you have any questions at any time about the study or the procedures, or you experience adverse negative effects as a result of participating in this study, you may contact the researcher, Hailey O’Neil at onei5330@mylaurier.ca OR her advisor Dr. Paula C. Fletcher at pfltecher@wlu.ca.

This project has been reviewed and approved by the University Research Ethics Board. If you feel you have not been treated according to the descriptions in this form, or your rights as a research participant have been violated during the course of this project, you may contact Jayne Kalmar, PhD, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 3131 or REBChair@wlu.ca.

Participation

Your participation in this study is voluntary, you may decline to participant without penalty. If you decide to participate you may remove yourself from the study at any point in time without penalty. You have the right to refuse to answer any interview question, and omit, clarify or remove any information your family states about you.

Feedback & Publication

The results of this research will be presented in a thesis defense presentation. The researcher will also submit the results to a journal to be published. Further, the results may also be presented in a class or conference presentation. Participants will be given the opportunity to receive an executive summary of the findings from this study when available in the Summer 2022. You can request the executive summary by emailing onei5330@mylaurier.ca

CONSENT

I agree I have read and understand the information above. I have received a copy of this form. I agree to participate in this study.

- YES
- NO

I agree to the personal interview being audio recorded.

- YES
- NO

I agree that anonymous quotations from my personal interview may be used in the final project.

- YES
- NO

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant’s signature ________________________________ Date ____________

Investigator’s signature _________________________________ Date ____________

I agree to be audiotaped during the face-to-face interview conducted in person or via Zoom.

Participant’s signature ________________________________ Date ____________

Investigator’s signature _________________________________ Date ____________

I agree consent to the use of direct quotations in presentations/papers resulting from this study.

Participant’s signature ________________________________ Date ____________

Investigator’s signature _________________________________ Date _____________

Appendix E

Background Questionnaire: Effects on Overall Health and Well-Being of Female Informal Caregivers for Individuals with Young-onset Dementia

Female Informal Caregivers Background Questionnaire

Thank you for taking the time to participate in this study. The purpose of this questionnaire is to obtain background information regarding you and your life as a female informal caregiver for an individual with young-onset dementia. Please complete the information to the best of your ability.

Background Information

This section will ask for some of your basic information.

1. What is your date of birth (MM/YYYY)? ______________________________

2. With which group do you identify most:
   - ☐ White
   - ☐ Black
   - ☐ Indigenous
   - ☐ Asian
   - ☐ East Asian
   - ☐ Mixed race: please specify ______________________
   - ☐ Other: please specify ______________________________

3. Are you:
   - ☐ Employed
     - Full time (please specify occupation): ___________________________
     - Part time (please specify occupation): ___________________________
   - ☐ Stay at home parent
   - ☐ Stay at home caregiver
   - ☐ Sick leave
   - ☐ Retired
   - ☐ Student (please specify grade/level): ______________________________
   - ☐ Other: please specify ______________________________

4. What is the highest level of education you have achieved? Check one.
   - ☐ Elementary school
   - ☐ High school
   - ☐ College diploma
   - ☐ Undergraduate degree
   - ☐ Masters or Doctoral degree
   - ☐ Other: please specify __________________________

5. What is your current relationship status? Check one.

   ☐ Now married
   ☐ Common-law
   ☐ Living with a partner
   ☐ Single (never married)
   ☐ Divorced
   ☐ Separated
   ☐ Widowed

6. Do you have any children? If yes, specify how many.

   ☐ Yes: ___________________
   ☐ No

7. How would you describe your current overall health (i.e., physical, and mental health)? Check one.

   ☐ Excellent
   ☐ Good
   ☐ Fair
   ☐ Poor

8. Do you currently have any illnesses/conditions/impairments (physical and mental)?

   ☐ No
   ☐ Yes (please specify):

   ____

   ____

Now a question about your total household income

9. What is your best estimate of your total household income received by all household members, from all sources, before taxes and deductions, during the year ending December 31, [Past year]?
   Income can come from various sources such as from work, investments, pensions, or government. Examples include Employment Insurance, Social Assistance, Child Tax Benefit, and other income such as child support, spousal support (alimony) and rental income
   ☐ Less than $5,000
   ☐ $5,000-$9,999
   ☐ $10,000-$19,999
   ☐ $20,000-$29,999
   ☐ $30,000-$39,999
   ☐ $40,000-$49,000
   ☐ $50,000-$59,000
   ☐ $60,000-$69,000
   ☐ $70,000-$79,999
   ☐ $80,000 or more
   ☐ I’d rather not say

   This information helps to establish the link between income and health. Please note all information is kept anonymous and individual data will never be shared.

Young-onset Dementia Experience

This section addresses basic information pertaining to the individual with young-onset dementia. Please provide the information for the individual you provide care for.

10. What is the individual's date of birth (MM/YYYY)?
    ____

11. How does the individual self-identify in terms of gender?
    ☐ Male
    ☐ Female
    ☐ Other (please specify): __________________

12. What form of young-onset dementia does the individual have?
    ☐ Alzheimer's disease
    ☐ Frontotemporal dementia
    ☐ Vascular dementia
    ☐ Lewy body dementia
    ☐ Other: please specify _____________________
    ☐ Not sure____

13. When and by whom was the individual officially diagnosed (MM/YYYY)? OR who is the individual currently seeing regarding there signs and symptoms?
    ____

14. Approximately how long (months/years) did it take for the individual to receive an official diagnosis? OR how long has the individual been seeking medical attention for their signs/symptoms?
    ____
    ____

15. Does the individual currently have any other chronic conditions?
    ☐ Yes (please specify any other chronic conditions)
    ____
    ____
    ____
    ☐ No

Informal Caregiving Demographics

This section asks for information pertaining to your role as an informal caregiver.

16. What is your relationship with the individual with young-onset dementia?
    - ☐ Spouse
    - ☐ Significant other
    - ☐ Sibling of person with dementia
    - ☐ Child of person with dementia
    - ☐ Friend of person with dementia
    - ☐ Other: please specify

    ____

17. How long (months/ years) have you been providing care to the individual with young-onset dementia?

    ____

18. How many hours per week on average do you spend providing care to the individual with young-onset dementia?

    ____

19. List any acts of care you provide on a weekly basis?

    ____
    ____
    ____
    ____
    ____

20. List any factors that might limit your ability to provide care.

    ____
    ____
    ____

21. Do you have any form of social support (e.g., Do you attend any support groups? Do you have any form of emotional support from family members or close friends)?

    - ☐ No
    - ☐ Yes (Please specify)

    ____
    ____
    ____
    ____

***Thank you for taking the time to fill out this questionnaire.**
Your responses are appreciated*

Appendix F

Interview Guide #1

Interview Guideline

- The purpose of this study is to provide in-depth information about the lived experiences of female caregivers caring for individuals with young-onset dementia, by specifically examining the effects of caregiving on caregivers, and the barriers to the provision of care.
- This interview will specifically focus on your story as a caregiver and any major effects or challenges you have experienced as result of your caregiving role.
- The interview will last for approximately 45-90 minutes. You are free to ask for a break, discontinue the interview, or choose not to respond to any question. In the event you do wish to stop the interview the recorder will be turned off and the interview will be stopped all together.
- Before we get started, I would like to take the time to introduce myself. I am a Masters of Kinesiology student at Wilfrid Laurier University, who is interested in adding to the limited current literature on young-onset dementia. Your responses will be a great contribute to my master's thesis.

1. Before we get started discussing your role as a caregiver, I would like to get to know you. Can you tell me about yourself?
    - Education
    - Work life
    - Lifestyle
    - Activities inside/outside of the home

2. Now let's talk about your family
    - Children (age, relationship, health)
    - Parents (relationship, health)

3. Prior to the diagnosis, can you tell me what you knew about young-onset dementia? Or dementia in general?
    - Have you had any formal education about the disease?
    - Have you cared for anyone with dementia in the past?

4. Now that you are providing care what have you learned about young-onset dementia, if at all?
    - From personal experience?
    - From education?

5. Describe to me the person with Young-onset dementia
    - Prior to diagnosis
    - After diagnosis

6. Tell me about diagnosis
    - Initial signs and symptoms
    - Path to diagnosis
    - Challenges experienced

Now let's talk about your relationship with the individual with young-onset dementia

7. Describe your relationship with the individual with young-onset dementia before the diagnosis?
    - Lifestyle
    - Living situation
    - Dynamics

8. If at all, how has their diagnosis effected your relationship? Or the dynamics of your family?
    - Effects of dementia on the children (if applicable)

Now let's talk about your caregiving role

9. Please describe to me what you believe it means to be a caregiver. (*Please elaborate on your response)*
    - Are there any factors that influence your definition? Personal experience?

10. What type of care do you provide for the individual with young-onset dementia?
    - Physical, social, psychological, financial, emotional?
    - Do you provide this care every day?
    - Describe a typical day? Week? Weekend/ week caring for the individual with young-onset dementia?
    - From diagnosis to now?
    - Do you share these responsibilities with anyone?

11. If at all, do you experience any barriers to providing care? (e.g., money or lack thereof) Or is there anything that helps you provide care? (e.g., social support groups)
    - Support network
    - Geographical location

12. Can you tell me about a significant event that has recently occurred?
    - Both positive and or negative

13. If at all, how has your caregiving role effected your own personal life?
    - Describe your health prior to becoming a caregiver? Improved, declined, stayed the same?
    - Physical health? Mental health? Selfcare? Personal health?
        - Do you feel you put the health of others over your own?
    - Positive? Negative?

  - Social, financial, physical, psychological?

14. What effect does young-onset dementia have on others, if at all?
    - Individual with young-onset dementia, children, other family members, social relationships
        - Physical health? Mental health? Selfcare?
        - Positive? Negative?
        - Social, financial, physical, psychological?

Now let's talk about coping

15. Can you define coping for me?
    - Personal experience that influences your opinion?

16. If at all, describe to me any coping mechanisms you have used to deal with your caregiving role?
    - Physically? Mentally? Socially?
    - Programs you attend.
        - YOD specific?

Final thoughts…

17. Describe to me in one word your feelings about being a caregiver?

Thank you for participating in this study and for taking the time to be interviewed. Once the interview is transcribed, I will send the transcription to you for a member check. Before we end off:

18. Do you have anything you would like to say or add that I may not have asked about?

19. Is there anything you would like to ask me?

Interview Guide #2

Interview guide for interviews conducted via Zoom

- The purpose of this study is to provide in-depth information about the lived experiences of female caregivers caring for individuals with early-onset dementia (EOD), by specifically examining the effects of caregiving on caregivers, and the barriers to the provision of care.
- This 2nd interview will specifically focus on your story as a caregiver, any changes to your caregiving journey since interview 1, caregiving wish list in terms of support/ services available, and advice for others who fulfill caregiving roles for individuals with EOD.
- The interview will last for approximately 30-60 minutes but will be dependent on your responses provided. You are free to ask for a break, discontinue the interview, or choose not to respond to any question. In the event you do wish to stop the interview the recorder will be turned off and the interview will be stopped all together.

For starters…

1. Please describe your health today compared to when we started this study (insert month of initial interview independent for each participant)
    - Has there been any significant changes to your role as a caregiver?
        - Physical health? Mental health? Selfcare? Personal health?
            - Do you feel you put the health of others over your own?
        - Positive? Negative?
        - Social, financial, physical, psychological effects of caregiving?

The following questions will address your journey as a caregiver

2. If at all, have you experienced any new barriers to providing care compared to when we started this study? (e.g., money or lack thereof) Or is there anything that you have recently discovered that helps you provide care? (e.g., social support groups)
    - Support network
    - Geographical location

3. Please describe a memorable event that has recently occurred and is associated with your role as a caregiver or the individual with early-onset dementia?
    - Both positive and/or negative
    - Why this memory? Importance?

The following questions will address the support you receive as a caregiver …

4. Please describe any current supports you may have with respect to your caregiving role.

5. In an ideal world, please describe the support you wished you had as a caregiver for an (or your current) individual with early-onset dementia.

  - Formal education
  - Increased healthcare worker knowledge
  - Physical, social, financial

These next set of questions involve any advice you have for others faced with a similar situation.

6. Prior to the care recipient's diagnosis of early-onset dementia, what is one thing you wish you knew, that you know now?

7. If you were to start this journey over, would you do anything differently? *Please elaborate.*

8. What advice would you give to someone who is just starting her journey as a caregiver for an individual with early-onset dementia?

9. Please describe any lessons you have learned through being a caregiver for an individual with early-onset dementia.
    - Is there anything that makes the journey easier?
    - Silver linings?

Final thoughts

10. What is the one piece of information you want people to know about your experience being a caregiver for an individual with early-onset dementia?

11. Do you have any questions for me?

12. Is there anything else you would like to add?

**** Thank you for taking the time to answer these questions****

Interview Guide #2

Interview Guideline for interviews conducted via email

- The purpose of this study is to provide in-depth information about the lived experiences of female caregivers caring for individuals with early-onset dementia (EOD), by specifically examining the effects of caregiving on caregivers, and the barriers to the provision of care.
- This 2nd interview will specifically focus on your story as a caregiver, any changes to your caregiving journey since interview 1, caregiving wish list in terms of support/ services available, and advice for others who fulfill caregiving roles for individuals with EOD.
- The interview will take approximately 45-90 minutes to complete but will be dependent on your responses provided. You are free to take breaks or choose not to respond to any question.
- All responses can be recorded directly within this document. If you have any questions, please do not hesitate to contact me, Hailey O'Neil the primary researcher at onei5330@mylaurier.ca

For starters…

1. Please describe your health today compared to when we started this study. Please answer the questions below.
    A. Please describe any significant changes to your role as a caregiver.

    B. Have there been any changes to your physical or mental health?

    C. Do you feel you put the health of others over your own? Please discuss.

    D. If at all, have these changes been positive or negative? Please elaborate.

    E. If at all, have you experienced any changes ***socially*** as a result of your caregiving role?

    F. If at all, have you experienced any changes ***financially*** as a result of your caregiving role?

    G. If at all have you experienced any changes ***physically*** as a result of your caregiving role?

    H. If at all have you experienced any changes ***psychologically*** as a result of your caregiving role?

The following questions address your journey as a caregiver…

2. If at all, have you experienced any new barriers to providing care compared to when we started this study? (e.g., money or lack thereof) Or is there anything you have recently discovered that helps you provide care? (e.g., social support groups) Please discuss.

3. Please describe a memorable event that has recently occurred and is associated with your role as a caregiver or the individual with early-onset dementia.
   A. If at all, how did this event positively affect you as a caregiver?

   B. If at all, how did this event negatively affect you as a caregiver?

The following questions will address the support you receive as a caregiver:

4.Please describe you any current supports you may have with respect to your caregiving role.

5. In an ideal world, please describe the support you wished you received as a caregiver for an (or your current) care recipient with early-onset dementia. Please answer the questions below:
   A. If at all, please discuss any formal education you wished you received as a caregiver for an individual with early-onset dementia.

   B. If at all, please discuss any information you wished health care providers received regarding early-onset dementia.

   C. If at all, please discuss any physical support you wished you received as a caregiver for an individual with early-onset dementia.

   D. If at all, please discuss any social support you wished you received as a caregiver for an individual with early-onset dementia.

   E. If at all, please discuss any financial support you wished you received as a caregiver for an individual with early-onset dementia.

These next set of questions involve any advice you have for others faced with a similar situation.

6. Prior to the care recipient’s diagnosis of early-onset dementia, what is one thing you wish you knew, that you know now?

7. If you were to start this journey over, would you do anything differently? *Please elaborate.*

8. What advice would you give to someone who is just starting her journey as a caregiver for an individual with early-onset dementia?

9. Please describe any lessons you have learned through being a caregiver for an individual with early-onset dementia.
    A. If at all, is there anything that makes the journey easier?

    B. If at all, have any silver linings emerged from your experience as a caregiver for individual with early-onset dementia? Please describe if yes.

Final thoughts

10. What is the one piece of information you want people to know about your experience being a caregiver for an individual with young-onset dementia?

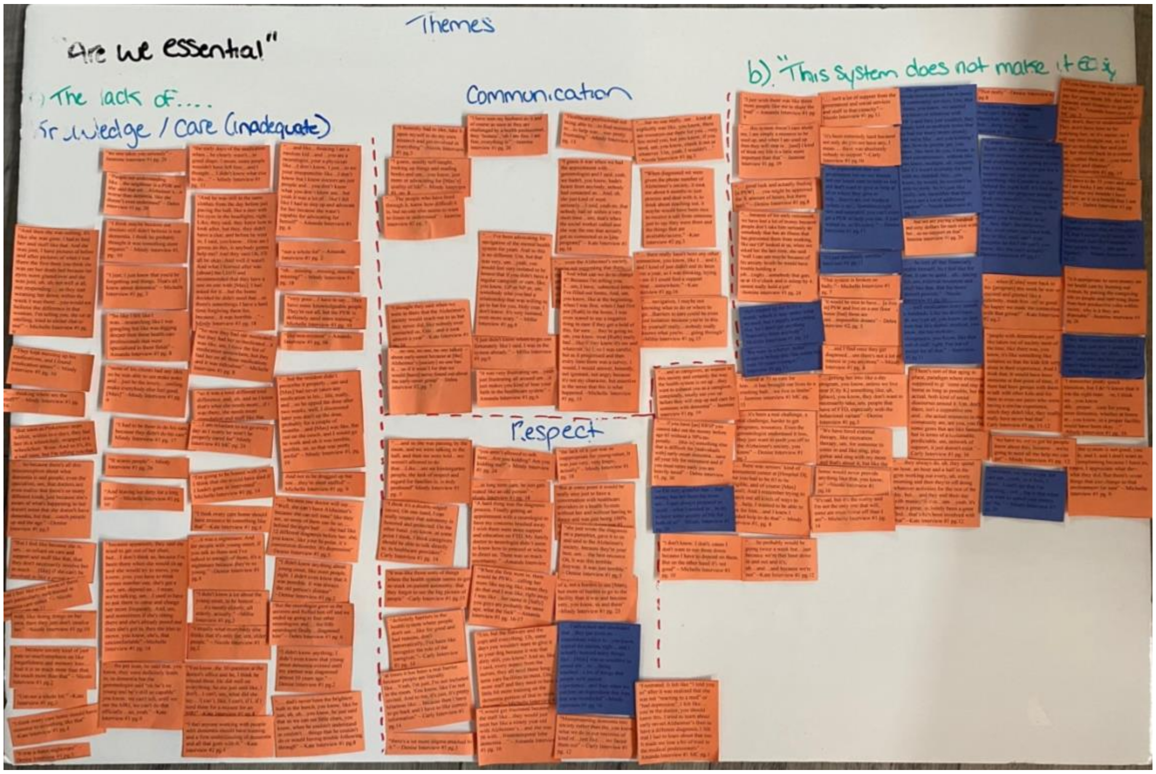
11. Do you have anything else that you would like to add?

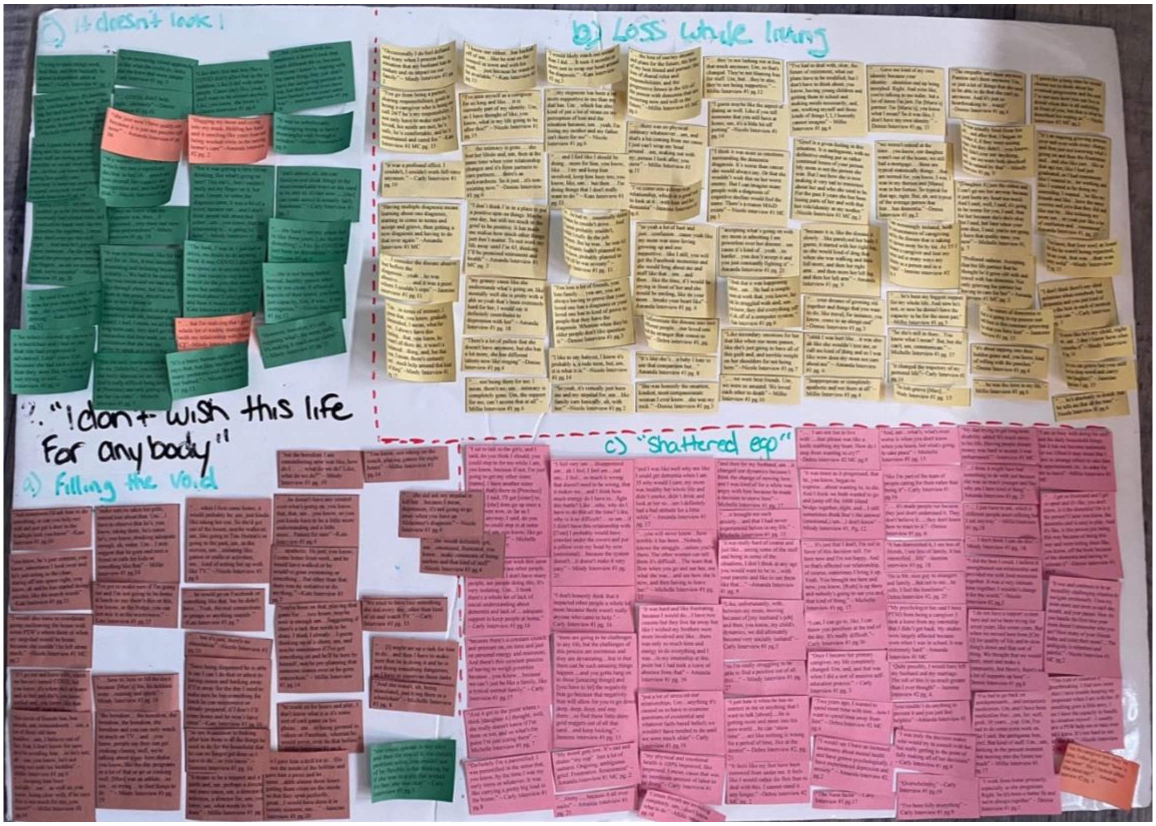
12. Do you have any remaining questions for me as the researcher?

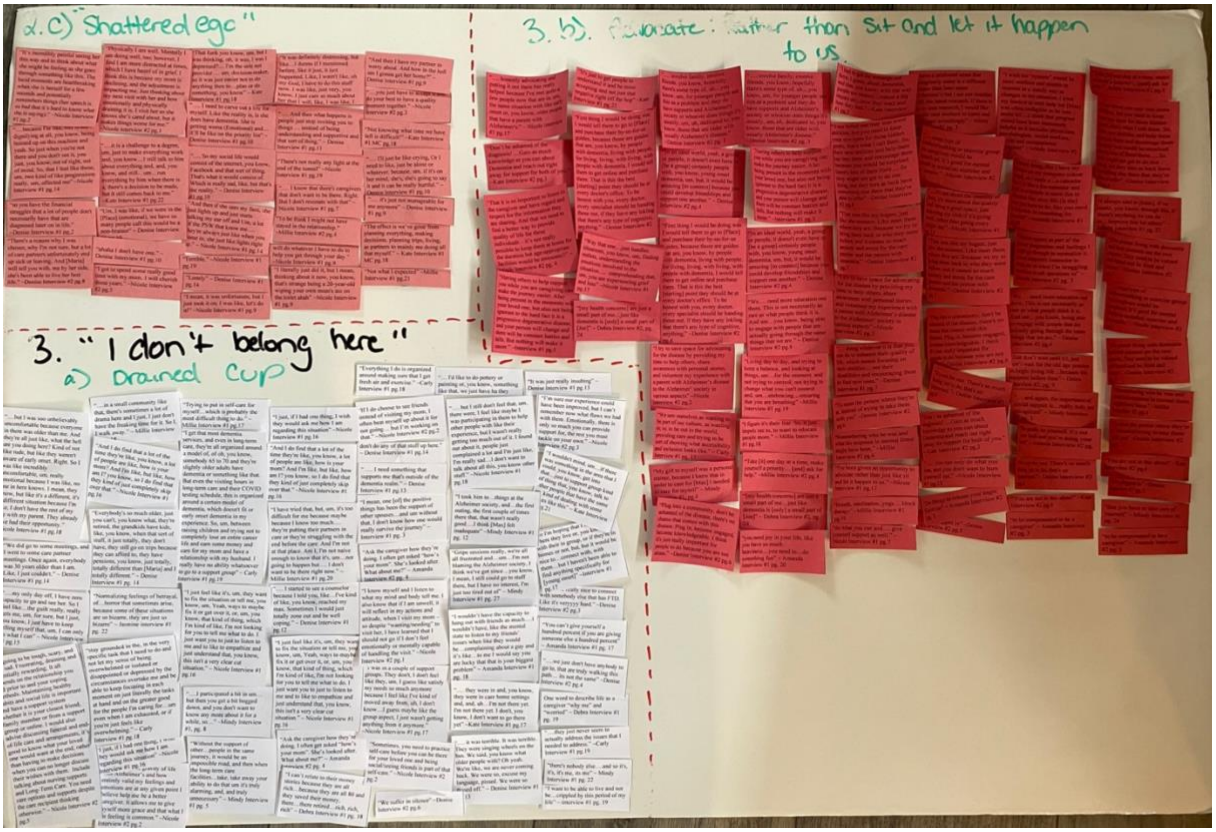
**** Thank you for taking the time to answer these questions****

Appendix G

Data Analysis






2.c) "Shattered ego"
3. b). Advocate: Rather than sit and let it happen to us.
3. "I don't belong here"
a) Drained cup

Appendix H

Addressing Research Questions by Interview Questions: Female Informal CGS-YOD Interview #1

		Research Questions		
Interview Guides and Question Numbers	Female Informal CGs-YOD Interview Guide 1	What effects does caregiving have on women CGs overall health and quality of life?	What are the challenges associated with being female CGs for individuals with YOD?	What effects do programs/resources or lack of programs/resources have on CGs?
		7. Describe your relationship with the individual with early onset dementia before the diagnosis? 8. If at all, how has their diagnosis effected your relationship? Or the dynamics of your family? 13. If at all, how has your caregiving role effected your own personal life? 14. What effect does young onset dementia have on others, if at all? 17.Describe to me in one word your feelings about being a caregiver?	11. If at all, do you experience any barriers to providing care? (e.g., money or lack thereof) Or is there anything that helps you provide care? (e.g., social support groups) 12. Can you tell me about a significant event that has recently occurred?	11. If at all, do you experience any barriers to providing care? (e.g., money or lack thereof) Or is there anything that helps you provide care? (e.g., social support groups) 16. If at all, describe to me any coping mechanisms you have used to deal with your caregiving role?

Addressing Research Questions by Interview Questions: Female Informal CGS-YOD Interview #2

		Research Questions		
Interview Guides and Question Numbers	Female Informal CGs-YOD Interview Guide 2	What effects does caregiving have on women CGs overall health and quality of life?	What are the challenges associated with being female CGs for individuals with YOD?	What effects do programs/resources or lack of programs/resources have on CGs?
		1. Please describe your health today compared to when we started this study. 3. Please describe a memorable event that has recently occurred and is associated with your role as a caregiver or the individual with early-onset dementia. 10.What is the one piece of information you want people to know about your experience being a caregiver for an individual with early onset dementia?	2. If at all, have you experienced any new barriers to providing care compared to when we started this study? (e.g., money or lack thereof) Or is there anything you have recently discovered that helps you provide care? (e.g., social support groups) Please discuss. 6.Prior to the care recipient's diagnosis of early-onset dementia, what is one thing you wish you knew, that you know now? 7. If you were to start this journey over, would you do anything differently? *Please elaborate.* 8.What advice would you give to someone who is just starting her journey as a caregiver for an individual with young-onset dementia? 9.Please describe any lessons you have learned through being a caregiver for an individual with early-onset dementia.	4. Please describe you any current supports you may have with respect to your caregiving role. 5. In an ideal world, please describe the support you wished you received as a caregiver for an (or your current) care recipient with early-onset dementia.

Addressing Research Questions and Interview Questions by Theme: Female Informal CGS-YOD Interview #1

		Research Questions		
Interview Guides and Question Numbers	Female Informal CGs-YOD Interview Guide 1	What effects does caregiving have on women CGs overall health and quality of life?	What are the challenges associated with being female CGs for individuals with YOD?	What effects do programs/resources or lack of programs/resources have on CGs?
		7. Describe your relationship with the individual with early onset dementia before the diagnosis? **Theme #2** 8. If at all, how has their diagnosis effected your relationship? Or the dynamics of your family? **Theme #1 & #2** 13. If at all, how has your caregiving role effected your own personal life? **Theme #2** 14. What effect does early onset dementia have on others, if at all? **Theme #1 & #2** 17.Describe to me in one word your feelings about being a caregiver? **Theme #2**	11. If at all, do you experience any barriers to providing care? (e.g., money or lack thereof) Or is there anything that helps you provide care? (e.g., social support groups) **Theme #1 & #2** 12. Can you tell me about a significant event that has recently occurred? **Theme #1 & #2**	11. If at all, do you experience any barriers to providing care? (e.g., money or lack thereof) Or is there anything that helps you provide care? (e.g., social support groups) **Theme #1 &#3** 16. If at all, describe to me any coping mechanisms you have used to deal with your caregiving role? **Theme #3**

Addressing Research Questions and Interview Questions by Theme: Female Informal CGS-YOD Interview #2

		Research Questions		
Interview Guides and Question Numbers	Female Informal CGs-YOD Interview Guide 2	What effects does caregiving have on women CGs overall health and quality of life?	What are the challenges associated with being female CGs for individuals with YOD?	What effects do programs/resources or lack of programs/resources have on CGs?
		1. Please describe your health today compared to when we started this study. **Theme #2** 3. Please describe a memorable event that has recently occurred and is associated with your role as a caregiver or the individual with young-onset dementia. **Theme #1** 10.What is the one piece of information you want people to know about your experience being a caregiver for an individual with young onset dementia? **Theme #3**	2. If at all, have you experienced any new barriers to providing care compared to when we started this study? (e.g., money or lack thereof) Or is there anything you have recently discovered that helps you provide care? (e.g., social support groups) Please discuss. **Theme #1 & #2** 6.Prior to the care recipient's diagnosis of early-onset dementia, what is one thing you wish you knew, that you know now? **Theme #3** 7. If you were to start this journey over, would you do anything differently? *Please elaborate.* **Theme #3** 8.What advice would you give to someone who is just starting her journey as a caregiver for an individual with young-onset dementia? **Theme #3** 9.Please describe any lessons you have learned through being a caregiver for an individual with early-onset dementia. **Theme #3**	4. Please describe you any current supports you may have with respect to your caregiving role. **Theme #3** 5. In an ideal world, please describe the support you wished you received as a caregiver for an (or your current) care recipient with early-onset dementia. **Theme #3**