

**Perceptions of the Caregiving Role Among Young-Onset Dementia Adult Child Caregivers**

by

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## **Author's Declaration**

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any final required revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

## **Abstract**

**Background:** Persons who receive a dementia diagnosis before the age of 65, are considered to have young-onset dementia. For many persons living with young-onset dementia, adult children take on caregiving roles. Evidence shows that there are many challenges for adult child young-onset dementia caregivers, such as issues with balancing relationships, maintaining a career, overcoming stigma, and their inability to cope. However, despite these difficulties, many adult child caregivers of persons living with young-onset dementia report that they do not receive adequate age-appropriate services and supports. Currently, a limited amount of research has explored perceptions of adult child caregivers of persons with young-onset dementia, although it has been recommended for further inquiry.

**Objective:** The objective for this research was to describe the perceptions of the caregiving role from the perspective of adult child caregivers of persons living with young-onset dementia.

**Methods:** A qualitative descriptive design was used to describe the perceptions of adult child young-onset dementia caregivers. Recruitment was through various organizations and support groups across Canada. Purposive sampling was utilized, including both snowball and convenience sampling. Individual semi-structured interviews were conducted with 15 adult child caregivers with a parent with young-onset dementia. The interviews were audio-recorded, transcribed verbatim, and analyzed using conventional content analysis.

**Findings/Discussion:** Four themes emerged from the data: 1) caregiving impacts are all-encompassing, 2) coping with the impacts of caregiving, 3) finding supports that fit my needs, and 4) managing changes during the COVID-19 pandemic. These themes suggest that there are many ways that the adult child caregivers are impacted by young-onset dementia. Participants expressed that caregiving had required them to take on many different responsibilities and roles.

Various coping techniques were identified regarding how to manage the impacts of their caregiving role. The participants spoke of both formal and informal supports they had accessed, as well as suggestions for future services. Finally, there were varying degrees in which the COVID-19 pandemic had shifted the caregiving roles for all participants.

Conclusion: The findings of this study provide a better understanding of the perceptions of adult child caregivers for persons living with young-onset dementia in Canada. These findings can assist with the development of age-appropriate resources, services, and supports for this population. This study also highlights the need for the expansion of future research to learn more about the perceptions of adult child caregivers for persons with young-onset dementia.

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## **Chapter 1: Introduction**

### **1.1 Introduction of YOD Caregiver Role**

Recent estimates indicate that there are approximately 402,000 Canadians diagnosed with dementia (Public Health Agency of Canada, 2017), and roughly 16,000 Canadians living with young-onset dementia (YOD) (Alzheimer's Society Canada, n.d.). Late-onset dementia (LOD) is when the diagnosis is made after the age of 65 (Freyne et al., 1999) and is what most dementia research focuses on as it is much more common (Cabote et al., 2015). YOD is defined as dementia that is diagnosed before the age of 65 (Alzheimer's Society Canada, n.d.). There have been inconsistencies surrounding the terminology for YOD in research, with many researchers using the terms 'young-onset' and 'early-onset' interchangeably (Johannessen & Möller, 2011). Most recently, 'young-onset' has been the desired choice of term to be utilized (Koopmans & Rosness, 2014).

YOD brings its own unique set of challenges to both the person with dementia and their family (Canadian Institute for Health Information, n.d.). Dementia symptoms appearing at a younger age, such as behavioural issues or changes in personality, are often what influence impacted families to obtain a diagnosis and further medical assistance (Arai et al., 2007). It has also been suggested that it is more common for people with YOD than LOD to have other neurological symptoms such as aggression, depression, agitation, hallucinations, or delusions than those with LOD (Mendez, 2006). Due to this, it can be challenging to diagnose YOD, as doctors can misdiagnose their symptoms to be psychiatric instead of being caused by dementia. After a diagnosis has been determined, many unmet needs have been identified for both persons with YOD and their caregivers (Cabote et al., 2015).

YOD caregivers are most often spouses and/or children of the person with YOD (Svanberg et al., 2011). Evidence shows that both persons with YOD and their caregivers have varying needs in comparison to those with LOD and their caregivers (Mayrhofer et al., 2018; Wawrziczny et al., 2017). These needs may differ, as YOD caregivers are often younger in age than LOD caregivers (Alzheimer's Society Canada, n.d.). For example, a YOD caregiver may have additional responsibilities, such as managing a career or taking care of other relatives, that an older caregiver may not need to worry about (Allen et al., 2009). Alongside this, research also suggests that YOD child caregivers have unique perspectives when compared to YOD spousal caregivers (Aslett et al., 2019). Being a child instead of a spouse, adult child caregivers will inherently have a different type of caregiving relationship with their parent. One reason for this difference may be due to a shift in family dynamics that requires a child to take on additional family roles (Allen et al., 2009; Gelman & Rhames, 2018; Millenaar et al., 2014). Little research has investigated adult children of people with YOD (Aslett et al., 2019; Sikes & Hall, 2018a; Barca et al., 2014; Svanberg et al., 2011; Hutchinson et al., 2016). Consequently, it has been recommended that research be conducted to further explore the perceptions of adult children with parents that have YOD in order to develop a more thorough understanding of what their caregiving role entails. With this information, more appropriate services and supports can be developed (Barca et al., 2014; Hutchinson et al., 2016), literature on this population within Canada can become more detailed, and avenues for future research can be identified.

There are many different definitions and interpretations of the word perception, as it is a concept that has been analyzed by many (McDonald, 2012). From a psychology point of view, perception can be identified through the five basic senses: touch, sight, hearing, smell, and taste (McDonald, 2012). Another aspect to consider is how one's social environment can impact their

perceptions, some examples being their gender and socioeconomic status (McDonald, 2012). The type of environment one grows up in, along with the gender they identify as, will inherently impact how they perceive the world throughout their life (McDonald, 2012).

How one interprets their perceptions is much more difficult to define. Two people can go through the same life event, such as having a parent diagnosed with dementia, and yet can come out with entirely different perspectives. Merriam-Webster (n.d.) defines perception as “*the ability to understand inner qualities or relationships,*” and “*the knowledge gained from the process of coming to know or understand something*”, while the Collins English Dictionary (n.d.) describes perception as the “*way that you think*” about something. While these definitions are similar, a common understanding of perception is that its meaning will always be unique to each individual (McDonald, 2012). Therefore, for the purposes of this thesis, the perceptions of each participant were understood as a unique description of their own personal experiences. While there may be similarities between the events the participants articulated in their interviews, this study acknowledges that there will always be some variability in how each participant comprehended both the questions asked in the interviews, and their perception of their own experiences.

The purpose of this study is to describe the perceptions of the caregiving role from the perspective of adult child caregivers of persons living with YOD. The hope is for this knowledge is to assist with gaining a range of perspectives of how caregiving impacts different aspects of their lives, such as their relationships, education, and career. This, in turn, can help inform the development of future age-appropriate supports intended for this population and obtain a more thorough understanding of the varying experiences of adult child caregivers for people with YOD. Using semi-structured interviews, adult child caregivers of persons with YOD were asked

about their perceptions of their caregiving role, and the potential impact that this had on other areas of their lives.

## **Chapter 2: Background and Literature Review**

This chapter will begin with an examination of the unmet needs identified for caregivers of persons with YOD, overall. Following this, literature will be reviewed concerning the specific unmet needs of adult child caregivers for persons with YOD. Further emphasis will be placed upon the various impacts of their caregiving role, stigma, as well as management and coping techniques. To conclude, gaps found within the literature will be identified.

### **2.1 Overview of YOD Caregiver Unmet Needs**

The diagnostic experiences for both persons with YOD and their caregivers have been identified as a challenging process (van Vliet et al., 2011; Bakker et al., 2010; van Vliet et al., 2010; Kilty et al., 2019; Pang & Lee, 2019; O'Malley et al., 2019; Hoppe, 2019; Johannessen et al., 2017; Millenaar et al., 2016; Harris & Keady, 2009). This is often a result of having a delayed diagnosis and not being offered proper supports from healthcare providers (Roach et al., 2008; Werner et al., 2009). A YOD diagnosis is often delayed due to the perception of healthcare professionals that dementia is most likely only to occur as an older adult (O'Malley et al., 2019). Therefore, the delay of an official diagnosis has the potential to be quite a stressful process for both the person with YOD and their caregiver, as they may go a long period of time not understanding what is happening and therefore, not having assistance or support.

Upon receiving a diagnosis, many caregivers of individuals with YOD have described the emotional impact associated with this experience (Cartwright et al., 2021), including feelings of grief, loss, social isolation, as well as feeling stigmatized (Spreadbury & Kipps, 2019; Hutchinson et al., 2016; Roach et al., 2008; Dourado et al., 2018; Johannessen et al., 2017; Roach et al., 2016; Cabote et al., 2015; Kilty et al., 2019; Pang & Lee, 2019; Kobiske et al.,

2019; Roach et al., 2008; Bakker et al., 2010). These challenges can be similar to what LOD caregivers experience, but it is important to understand that there may also be differences. YOD caregivers may experience stigma, as family members and friends might not believe a diagnosis of dementia is possible due to the person with dementia's relatively young age and, thus, refuse to accept the diagnosis. This reaction may then result in family or friends not wanting to visit or spend time with the person with dementia (Allen et al., 2009).

Many YOD caregivers report how family structures and roles shifted after the diagnosis of YOD in their family (Cartwright et al., 2021; Kilty et al., 2019; Pang & Lee, 2019; Roach et al., 2008; Johannessen et al., 2017; Roach et al., 2016; Cabote et al., 2015; Bakker et al., 2010; Harris & Keady, 2009; Allen et al., 2009; Svanberg et al., 2011; Aslett et al., 2019; Gelman & Rhames, 2018; Barca et al., 2014; Nichols et al., 2013; Lövenmark, 2020). For example, spousal caregivers can feel as if the persistent decline of their partner's health has led to their relationship no longer being an equal partnership due to their caregiving role (Kobiske et al., 2019). For children, the diagnosis may significantly shift the relationship they have with both their parent with YOD and their parent without dementia (Lövenmark, 2020). For example, the child may be thrust into larger roles of responsibility, such as helping provide for the family financially, parenting younger siblings, or altering their career path in order to remain at home to provide care (Allen et al., 2009). Therefore, this can have a significant impact on family dynamics as typically parents are supposed to take care of children, and not the other way around.

Evidence confirms there are many unmet needs for YOD caregivers. The literature suggests that YOD caregivers have different needs than LOD caregivers (Freyne et al., 1999; Beattie et al., 2004; van Vliet et al., 2010; Arai et al., 2007; Werner et al., 2009). For example, many YOD caregivers acknowledge issues regarding employment, caring for other family

members such as children, and increased financial responsibility (Cartwright et al., 2021; Harris & Keady, 2004; Harris & Keady, 2009; Chaston, 2010; Brodaty & Donkin, 2009; Gibson et al., 2014; Bakker et al., 2010; van Vliet et al., 2010; Svanberg et al., 2011; Wawrziczny et al., 2017; Roach et al., 2008, Dourado et al., 2018; Roach et al., 2016; Ducharme et al., 2014; Gelman & Rhames, 2018). Being a caregiver to a person with YOD may involve taking the person with YOD to appointments and providing assistance with activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs). ADLs can include basic functional activities, such as feeding, dressing, bathing, and walking, while IADLs are activities that enhance one's ability to live independently, for example doing laundry, cooking, and managing finances (Desai et al., 2004). For a caregiver who is working, these additional responsibilities may lead to increased unplanned absences from work (Brodaty & Donkin, 2009); employers may not be very understanding of such circumstances.

Another common issue is the lack of adequate age-appropriate services for both themselves and the person with YOD they are caring for, as most services are designed to address the needs of persons with LOD and their caregivers (Cartwright et al., 2021; Freyne et al., 1999; Hutchinson et al., 2020; Millenaar et al., 2016; Gelman & Rhames, 2018; Hutchinson et al., 2016; Millenaar et al., 2014; Gibson et al., 2014; Nichols et al., 2013; Bakker et al., 2010; Kilty et al., 2019; Kobiske et al., 2019; Werner et al., 2010; Dourado et al., 2018; Johannessen et al., 2017; Lövenmark, 2020). The absence of age-appropriate services can have a significant impact on both the physical and emotional health of the YOD caregivers, as they may not have access to supports that can help them fulfill their caregiving role (Hutchinson et al., 2020). For example, services could assist YOD caregivers with financial obligations, education, and relationship issues (Hutchinson et al., 2020). In addition, age-appropriate services could also help

with building connections to others in similar positions, which could greatly benefit one's health (Hutchinson et al., 2020).

## **2.2 Unmet Needs of Adult Child Caregivers of Persons with YOD**

One limitation in the current literature is that for the majority of research with YOD caregivers, children and spouses have been placed into the same category, when in fact they have differing perspectives worth investigating (Barca et al., 2014). Studies that have looked at these groups separately indicate that while adult children of persons with YOD have some experiences that are similar to LOD spousal caregivers (Allen et al., 2009), there are important aspects of these experiences that are unique only to children (Barca et al., 2014). Similar to spouses, adult children of persons with YOD frequently identify an emotional impact from caregiving, often resulting in feelings of loss, grief, guilt, annoyance, frustration, resentment, anger, and embarrassment (Cartwright et al., 2021; Allen et al., 2009; Aslett et al., 2019; Barca et al., 2014; Gelman & Rhames, 2018; Hutchinson et al., 2020; Sikes & Hall, 2018a; Sikes & Hall, 2018b). However, adult child caregivers of persons with YOD have reflected upon how their increased responsibilities make them feel as if they are the parent, instead of the child (Allen et al., 2009; Aslett et al., 2019; Barca et al., 2014; Gelman & Rhames, 2018). In fact, some adult children have reported that their parent without dementia can have a poor reaction to their spouse having dementia (Barca et al., 2014; Allen et al., 2009). Consequently, some adult child caregivers feel an obligation to also take care of their parent without dementia and/or siblings (Aslett et al., 2019). In cases where the persistent strain of a YOD diagnosis has resulted in divorce, adult child caregivers have had to take on an even more significant caregiving role (Hutchinson et al., 2016; Millenaar et al., 2016).

### **2.2.1 Impact of Caregiving Role**

A common concern for adult child caregivers of persons with YOD is the impact their caregiving role can have on their social relationships (Barca et al., 2014; Aslett et al., 2019; Gelman & Rhames, 2018; Hutchinson et al., 2016; Millenaar et al., 2014; Sikes & Hall, 2018b). Several adult child caregivers of persons living with YOD reported that they matured too quickly, resulting in a significant loss of many youthful experiences (Hutchinson et al., 2016; Allen et al., 2009; Gelman & Rhames, 2018). For example, similarly aged peers often possess an inability to relate to what adult child caregivers of persons with YOD have gone through, thus making it difficult to maintain close friendships (Aslett et al., 2019; Allen et al., 2009; Gelman & Rhames, 2018). Consequently, it is perhaps unsurprising that social isolation is commonly experienced by adult child YOD caregivers (Gelman & Rhames, 2018; Aslett et al., 2019; Allen et al., 2009; Hutchinson et al., 2016; Sikes & Hall, 2018b).

Adult child caregivers of persons with YOD also report having issues with learning how to balance their time between advancing their education or career, and maintaining their caregiving role (Aslett et al., 2019; Hutchinson et al., 2016; Barca et al., 2014; Millenaar et al., 2014). Some adult child YOD caregivers have stated that their own life must go ‘*on hold*’ to continue caring for their parent (Aslett et al., 2019). For instance, there are adult child caregivers of persons with YOD who have rejected opportunities to advance their career internationally, opting instead to remain closer to home to assist their parent (Hutchinson et al., 2016). Some consequences of these choices have been briefly explored within the literature, one example being the development of feeling loss, grief, and anger towards their parent with dementia (Barca et al., 2014). However, it has been recommended that further research is needed to explore the

consequences of the caregiving role on adult child caregivers of persons with YOD (Millenaar et al., 2014).

### **2.2.2 Stigma**

The scarce amount of research that has been conducted in this field suggests that adult children of persons with YOD potentially face both stigmatization and discrimination (Hutchinson et al., 2016). Stigma by association is a concept that occurs when caregivers experience stigma as a consequence of being associated with a stigmatized population (Goffman, 1963). For instance, while adult child YOD caregivers may not personally possess the same ‘*stigmatizing*’ characteristics as those with dementia, they can still experience their own form of stigma (Werner & Heinik, 2008). Some of the impacts of stigma by association can be shame, embarrassment, anger, isolation, and the inability to cope (Werner & Heinik, 2008). One example of this for adult child caregivers of persons with YOD is that some have spoken of poor experiences with healthcare providers, as adult children feel they do not receive the same amount of medical information or respect as an older caregiver would in the same position (Aslett et al., 2019; Barca et al., 2014).

Interestingly, there is also growing literature suggesting healthcare professionals do not receive adequate training on how to properly support YOD families (Johannessen & Möller, 2011; Roach et al., 2016; Lockeridge & Simpson, 2013; Werner et al., 2019). For instance, in Roach et al. (2016), some families described feeling frustrated when they received a lack of information from their healthcare providers following a diagnosis. Alongside this, of the limited research that does exist, one perspective from adult child YOD caregivers is the impact that stigma can have when deciding to place a parent into a residential care setting (Hutchinson et al.,

2016). For example, in Hutchinson et al. (2016), an adult child caregiver expressed experiencing stigma from the public as a result of choosing to place someone so young into what is typically considered a place for older people (Hutchinson et al., 2016). Similarly, other adult children have reported feelings of shame, guilt, and frequently chose to hide their own difficulties from others (Cartwright et al., 2021). Within Hutchinson et al.'s (2016) study, an adult child caregiver of a person with YOD described concealing their caregiving role from others to avoid bringing attention to their complicated situation and the possible consequences of stigma. However, this study failed to describe the details surrounding what those consequences may have entailed.

There is a paucity of research examining stigma in adult child caregivers of persons living with YOD (Ashworth, 2020; Hutchinson et al., 2016). Some of the literature that does exist has not been specific to adult child YOD caregivers and has included YOD spousal caregivers or LOD caregivers instead. Stigma has been briefly mentioned in other studies, such as in Hutchinson et al. (2016), but discussion of this issue remained minimal. Therefore, there is a gap within the literature where the perspectives of adult child caregivers of persons with YOD is needed, and it has been recommended that further research be completed to ensure that a greater understanding is obtained (Ashworth et al., 2020; Hutchinson et al., 2016).

### ***2.2.3 Coping***

In order to endure these challenging circumstances, many adult child caregivers of persons with YOD will use a variety of management or coping techniques. A systematic review conducted by Cartwright et al. (2021) identified that coping can be difficult for adult children who have a parent with YOD due to a combination of factors, including: financial concerns, moving to a new location, lack of support from both family and professionals, and moving their

parent into residential care. In the literature, some of the more positive coping techniques used included: finding and connecting with others in similar situations (Barca et al., 2019; Gelman & Rhames, 2018; Millenaar et al., 2014); living in the moment (Aslett et al., 2019); gaining support from siblings (Allen et al., 2009); confiding in close friends (Allen et al., 2009; Millenaar et al., 2014); using other activities - such as school - as outlets (Allen et al., 2009; Gelman & Rhames, 2018); seeking assistance through therapy (Gelman & Rhames, 2018; Millenaar et al., 2014); and normalizing their situation (Cartwright et al., 2021; Allen et al., 2009; Millenaar et al., 2014; Gelman & Rhames, 2018). Other, more negatively situated coping techniques included: drinking and smoking (Allen et al., 2009), self-harm and attempted suicide (Cartwright et al., 2021; Gelman & Rhames, 2018), denial and avoidance (Cartwright et al., 2021; Allen et al., 2009; Millenaar et al., 2016), and emotional detachment (Hutchinson et al., 2016). Hutchinson et al. (2016) reported that currently no services seem to exist that address the complex situations and potential mental health problems of adult child caregivers of persons living with YOD.

One of the common coping techniques mentioned by adult child caregivers for their parent with YOD was having the ability to access support services, such as professional support (Cartwright et al., 2021). These supports could be through memory clinics, social services, social workers, or other out-of-pocket support services (e.g., registered psychologist). The problem with these supports is that many adult children expressed they did not know where to find them, or if they even existed (Cartwright et al., 2021). Many found that the services that do exist were often created for older adults, deeming this to be unhelpful for their own particular needs (Cartwright et al., 2021). The lack of information, guidelines, and supports for the adult children of people with YOD has been suggested to partially contribute to the inability for some to develop healthy coping techniques (Cartwright et al., 2021).

### **2.3 Research Gaps**

Relatively little research has been conducted concerning the unique and challenging perceptions of adult child caregivers of persons with YOD (Barca et al., 2014; Hutchinson et al., 2016). Of the research that exists, significant gaps in knowledge have been identified. First, more research is required to determine the perceptions of adult child YOD caregivers regarding the impact of their caregiving role (Millenaar et al., 2014). Second, stigma is a potential concern for adult child caregivers of persons with YOD, but limited attention has been given to this issue (Hutchinson et al., 2016; Ashworth, 2020). Gaining a clearer understanding of stigma would be extremely beneficial when it comes to learning how and if stigma impacts adult child YOD caregivers. Finally, more information is needed regarding how adult child YOD caregivers cope with their caregiving role (Spreadbury & Kipps, 2019; Werner et al., 2019; Lockeridge & Simpson, 2013; Millenaar et al., 2018).

## **Chapter 3: Study Aims**

### **3.1 Study Rationale**

This research aims to provide a greater understanding of adult children's perceptions of their caregiving role for a parent with YOD. The following will be explored about adult child caregivers of persons with YOD: the impact their caregiving role has had on their lives; if and how stigma is experienced; and what coping techniques have been used to help mitigate their caregiving role. It is hoped that findings from this research will help to inform future supports and services for this population. This is the first known study to research this topic with adult child caregivers across Canada, thus, making this research extremely valuable within the context of Canada.

### **3.2 Research Question**

This research aimed to explore the following question:

*What are adult children's perceptions of their caregiving role for a parent with young-onset dementia?*

## Chapter 4: Methods

### **4.1 Research Design and Approach**

The perceptions of adult child caregivers of persons with YOD were explored using qualitative research methods. Qualitative research allows for more in-depth observations to be made to help gain a better understanding about a phenomenon (Green & Thorogood, 2018). Qualitative methods are appropriate when researching a topic such as this one, as it allows for information to be presented in a descriptive, and yet comprehensive manner.

A qualitative descriptive approach was utilized for this research. Qualitative description was an appropriate design as it allowed for “*a rich description of the experience/event/process depicted in easily understood language*” (Sullivan-Bolyai et al., 2005, pp. 128). Qualitative description is best used when a rich description is needed to understand perspectives or perceptions of a certain phenomenon (Sandelowski, 2000; Bradshaw et al., 2017). For this study, the phenomena explored was the perceptions of adult child caregivers of persons with YOD regarding their caregiving role. Qualitative descriptive research is rooted within the belief of naturalistic inquiry, meaning that the experiences of participants should be depicted in the most natural and non-disruptive of ways (Sandelowski, 2000; Willis et al., 2016). Therefore, a main goal of qualitative descriptive studies is to capture an ‘*accurate accounting*’ (Sandelowski, 2000, pp. 336) of both events, and the meanings that participants hold to those events. This approach helped ensure that truthful information was gathered and presented in easily understood language (Sandelowski, 2000). As research in this specific field is relatively new, obtaining simplified, but accurate descriptions will be extremely useful for other researchers or healthcare providers who may not have much knowledge surrounding this population. Qualitative descriptive research is

an excellent choice of methods when the intent is to help inform the future development of practical interventions or programs (Willis et al., 2016) thus, making this approach a good fit for this study.

Qualitative descriptive research is often referred to as the least theory-based qualitative method available (Sandelowski, 2000). Therefore, this research study did not include a theoretical framework. This decision was made due to this field of research being new and exploratory, as not many theories have been applied to this research population in the literature. Instead, this thesis focused on providing accurate descriptions of the perceptions of each participant. This research could potentially be used to assist with generating future theories concerning this population.

## **4.2 Participants, Recruitment and Data Collection**

### ***4.2.1 Setting and Sampling Strategies***

The goal of recruitment was to find as diverse of a sample as possible, reaching out to many different organizations to find adult children with different levels of experiences and life circumstances to share. This study was open to caregivers across Canada.

Purposive sampling was used to recruit for this study, as this is often the recommended sampling strategy for qualitative descriptive designs (Sandelowski, 2000). The overall objective of purposive sampling is to obtain participants with information-rich experiences or perspectives to share pertaining to the aim of the study (Sandelowski, 2000). Within purposive sampling, both convenience sampling and snowball sampling were used (Patton, 1990). Convenience sampling strives to identify participants who meet the criteria and are easily accessible (Palinkas et al., 2015). Utilizing snowball sampling helped identify information-rich cases by sampling people

who knew others with similar experiences and characteristics who, in turn, were asked to participate in the study (Palinkas et al., 2015; Patton, 1990). The intention behind this was that the participants are the experts, so they had the best suggestions for who else may have been interested in participating. As locating adult child caregivers of persons with YOD may be challenging due to the rarity of their situations, convenience and snowball sampling assisted greatly during the recruitment process.

Individuals were eligible to participate in the study if they:

- 1) are/have been a child (aged 18 or older) of a parent with YOD and have had a care experience with their parent with YOD in the past 2 years;
- 2) are able to speak and understand English; and
- 3) are able to provide informed consent.

#### ***4.2.2 Recruitment and Data Collection***

Multiple approaches were used to recruit study participants. Recruitment took place through contacts within local and provincial organizations including Alzheimer's Societies, Dementia Society of Ottawa and Renfrew, The Change Foundation, Ontario Caregiver Organization, SE Health, Canadian university counsellors, and various experts and YOD support groups/programs across Canada. Directors, managers, and staff were provided an emailed summary of the study (Appendix A) and asked to share information about the study directly with adult child caregivers of persons with YOD who may be interested in participating. In addition, information about this study was disseminated by these organizations via social media, in newsletters (Appendix B), and through posters (Appendix C). Moreover, to make use of snowball sampling, each participant was asked at the end of their interview if they knew of other

potential participants who met the inclusion criteria, and if so, they were asked to share information about the study with these individuals.

Adult child YOD caregivers who expressed interest in participating in the study were invited to schedule either a phone-call or video-call to conduct a semi-structured interview. Prior to the interview, participants were sent a copy of the consent form (Appendix D) and interview questions (Appendix E). Before completing the interview, the student researcher reviewed the consent form with them and answered any questions. Participants were made aware that participation in the study was voluntary and were provided a choice to withdraw at any point. Participants were then asked to provide verbal consent (Appendix F). Once verbal consent was provided, the interview began. Finally, all participants were sent a follow-up email thanking them for participating in the study (Appendix G). A summary of the research findings will be shared with the study participants.

A semi-structured interview guide was developed based on themes and gaps identified in the literature. To begin the interviews, participants were provided with a small background of the student researcher, and then were asked a few questions to help understand more about the unique situations of each participant. Within these questions, the interviewer asked about what services and supports that they, or their family members, had potentially used, and if they had any suggestions or improvements for future supports. The next section of the interview asked the adult child caregivers of persons with YOD about the impacts that their caregiving role had on other areas in their lives, as this had been suggested for further inquiry from the literature (Millenaar et al., 2014). These areas included their education, job, physical/mental health, and relationships. Participants were then asked if there were other areas of their life that they felt were impacted before moving on. Next, the caregivers were asked to recall potential experiences

with stigma that their parent had endured, as well as their own, and any impacts this had resulted in. The adult child YOD caregivers were asked throughout their interview how they managed/coped with the various impacts of their caregiving role. During each interview, the researcher clarified any uncertainties participants had with the questions being asked (Willis et al., 2016). This helped ensure that during the data analysis, the transcripts presented the most accurate information in relation to each participant's perceptions (Willis et al., 2016).

Throughout the interview process, field notes were recorded in an online reflection journal following each interview. Field notes included comments and reflections about non-verbal observations such as becoming emotional or frustrated, questions each participant asked, along with any topics that participants seemed very interested in or passionate about.

#### ***4.2.3 Participants***

Participants in this study included 15 adult child caregivers of persons with YOD residing in Canada. Participants were comprised of 10 females and 5 males, ranging from 19 to 46 years of age (average age was 33 years). Within the sample there were two sets of siblings, and all participants were Caucasian with the exception of one, who identified as being mixed-race. Of the 15 participants, 4 had been caregiving for 2-3 years, while 11 had been caregiving for 5-10 years. Four participants were still living with their parent at the time of the interview. Of the 11 who did not live with their parent, 7 had parents living in either long-term care or a long-stay unit within a hospital. The interviews lasted between 32 and 55 minutes, with the average interview being approximately 45 minutes long.

### **4.3 Analysis**

The semi-structured interviews were audio-recorded and transcribed verbatim after each interview was completed. To capture as much detail from each interview as possible, field notes taken at the end of each interview helped provide additional comments, questions and/or thoughts that were then referred to throughout the analysis phase. All transcripts were uploaded to the qualitative analysis software, NVivo 12 Pro (QSR International Pty Ltd., 2018).

Qualitative content analysis was chosen for this study, as it is the recommended analysis choice when completing qualitative descriptive research (Sandelowski, 2000). More specifically, conventional content analysis aims to describe a phenomenon without using preconceived categories (Hsieh & Shannon, 2005). Conventional content analysis allowed for an iterative coding scheme to be developed as the interviews were analyzed (Hsieh & Shannon, 2005). This method ensured that the analysis stayed close to the data, while it also allowed for some flexibility when ideas emerged (Willis et al., 2016). In line with qualitative descriptive research guidelines, the analysis aim was to identify the themes that most accurately represented what each participant was stating and meaning (Sandelowski, 2000). Thus, the researcher clarified any outstanding questions regarding ideas and meanings during each interview.

Using inductive coding, a coding framework was generated from the data (Sandelowski, 2000). Data analysis did not begin until after the data was collected. The coding process began with multiple readings of the interview transcripts as a way for the student researcher to achieve full immersion within the data (Hsieh & Shannon, 2005). Following this, the data was read word-by-word in order to determine key thoughts that emerged (Hsieh & Shannon, 2005). The researcher then utilized information from the field notes to combine first impressions and/or thoughts with the data collected (Hsieh & Shannon, 2005). From this, larger ideas were placed

into categories and sub-categories, used to develop the initial coding scheme (Hsieh & Shannon, 2005). Allowing the data to guide where the themes would emerge provided the student researcher with a more accurate description of the participants' perceptions.

Throughout the development of the initial coding scheme, discussions were held with the student researcher's thesis supervisor. To achieve this, three transcribed interviews were coded independently, and then reviewed by the thesis supervisor to help develop the initial coding framework. After a consensus was found, the coding framework was reviewed by the rest of the thesis committee before proceeding with the analysis of the remaining interviews. These discussions with the research team also allowed for the results of this thesis study to have more rigour, through the consultation with experts in this field.

#### ***4.3.1 Enhancing Rigour***

It is essential for qualitative research to demonstrate that the methods chosen will ensure high quality information will be collected and presented (Bradshaw et al., 2017). Therefore, this study utilized specific approaches to instill trustworthiness within the findings (Bradshaw et al., 2017). Transferability relates to the ability to transfer the findings to other settings and situations (Morse, 2015). This thesis supported this by using purposive sampling and taking field notes (Bradshaw et al., 2017). Snowball sampling allowed for participants with similar experiences to be identified (Patton, 1990), while maintaining field notes enhanced the quality of the data analysis (Hsieh & Shannon, 2005). By using both strategies, the intent was to create rich descriptions depicting the range of perspectives which were used to help describe the experiences of others in similar settings or circumstances. Credibility is another important way to demonstrate rigour in qualitative research (Bradshaw et al., 2017) by ensuring that the findings

were an accurate reflection of each participant's experiences (Morse, 2015). This study achieved this by establishing a rapport with participants at the start of each interview using introductory questions (Bradshaw et al., 2017). Alongside this, participants were reassured that the interview would be completed within a safe, compassionate, and empathetic environment free of judgement (Bradshaw et al., 2017). Finally, dependability refers to being able to demonstrate that your findings are reliable (Morse, 2015). Therefore, to establish an audit trail and defend decisions made, the initial coding framework was co-developed between the student researcher and their supervisor (Bradshaw et al., 2017; Morse, 2015). By obtaining the perspective of a second coder, as well as the opinions from the committee, this helped increase the reliability of the study results (Morse, 2015).

## **4.4 Considerations**

### ***4.4.1 Reflexivity***

It is extremely important within qualitative research to address how the background of the researcher may impact the study (Green & Thorogood, 2018). I acknowledged to each participant that I was a white woman who had a history of being a caregiver for my own parent with a different illness. This '*insider*' perspective proved to be a strength when I was conducting this research. An '*insider*' researcher is one who is a part of the population that is being studied (Dwyer & Buckle, 2009). This was a significant detail to consider, as those experiences played a large role in what drove me to pursue this research topic. While my caregiving experience was not the same as what the participants in this study had gone through, there were some important parallels that allowed for somewhat of a shared understanding. When I briefly discussed my background at the beginning of each interview, a result of this disclosure was that many of the

participants stated that they felt much more comfortable sharing stories and experiences. They believed I could identify to what they were going through, to some extent. This is a potential strength, as literature suggests being an '*insider*' can result in gathering data with greater depth, as participants can be more open during interviews (Dwyer & Buckle, 2009). Had I not shared this information, it is likely that some stories may not have been discussed due to the expectation that I would not properly understand. I was also able to empathize with the participants' experiences, and therefore determine follow-up questions during each interview that other researchers may not have been able to do.

With this in mind, it was important for me to lessen the potential impact my personal experiences could have had on my interpretation of the findings. This is a potential downfall of being an '*insider*,' as this type of researcher must be conscious to not impede the data collected with their own biases or experiences (Dwyer & Buckle, 2009). Therefore, strategies were used, such as note-taking during the entire research process, to mitigate those issues. This assisted with documenting all my decisions, thoughts, and feelings. Note-taking also provided me with some time to critically self-reflect on my thoughts and think about how my own background and assumptions may be influencing my consumption of the data. I acknowledged that while this would always be a potential bias, it was important to recognize this connection to the data and accept that biases and impressions are a part of the research process (Green & Thorogood, 2018). Having this critical self-reflection allowed for me to bring myself back to the data in front of me if I found my mind wandering. Another mitigation technique was to co-develop the coding scheme with my supervisor and the rest of the committee to ensure that the findings were being accurately represented, as mentioned earlier. In addition, I maintained consistent open dialogue

with my supervisor and committee throughout the whole research process. This was another way to ensure that I remained close to the data and reported accurate findings.

#### ***4.4.2 Ethical Considerations***

Ethics clearance for this study was through the University of Waterloo's Office of Research Ethics. Guidelines were followed in line with the Office of Research Ethics, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2), and the University of Waterloo Statement on Human Research. Obtaining ethics clearance helped in addressing issues relating but not limited to: data storage, maintaining confidentiality, disposal of data after 7 years, and the ability for participants to withdraw. Due to the COVID-19 pandemic, all UW guidelines were followed concerning off-campus research protocols.

## **Chapter 5: Findings**

Analysis of the individual interviews identified four larger themes concerning the perception of the caregiving role among adult child YOD caregivers. These themes were, 1) *Caregiving Impacts are All-Encompassing*, 2) *Coping with the Impacts of Caregiving*, 3) *Finding Supports That Fit My Needs*, and 4) *Managing Changes During the COVID-19 Pandemic*. In this chapter, the themes will be described using quotes and excerpts directly from the data collected in the interviews.

### **5.1 Caregiving Impacts are All-Encompassing**

Within the interviews, a dominant theme which emerged was the significant ways in which the adult child's parent's YOD dementia had impacted their life. Sub-themes identified were: a) *Increasingly Expanding Responsibilities*, b) *Feeling the Emotional Impacts of Caregiving*, c) *Recognizing Impacts on Relationships*, and d) *Experiencing Stigma*.

#### **5.1.1 Increasingly Expanding Responsibilities**

Many participants expressed that they took on several different roles throughout their time as a caregiver, often due to the progressive nature of the disease. These responsibilities included helping their parent with dementia with day-to-day tasks, providing care for their parent without dementia, becoming involved in managing finances, and taking on an advocacy role.

The main responsibility that many participants addressed was their ability to “*fill in the gaps*” for their other parent, who often was the primary caregiver, and assist with daily tasks for their parent with dementia. These tasks consisted of, cooking, taking their parent to appointments, maintaining the house, bathing/showering their parent, toileting, and taking their parent on walks. Examples of this are highlighted below:

*Now I'm cooking a meal or now I'm you know, making sure [...] he showered or whatever, like the TV's off and you know, he's in bed or he has a show on or [...] he can't work TVs, any technology at all, so anything like that he needs I'm \*snaps fingers\* I'm there. Um, or I try to be. (P07)*

*And when you're a teenager [...] it was definitely a bit weird to kind of come to terms with that but obviously I would never really second guess helping her with anything but yeah, like, helping her change, [...] go to the bathroom. Like, helping her put your clothes on like whatever. (P15)*

One of the most commonly identified responsibilities from the participants was that their caregiving role did not stop at just taking care of their parent with dementia, as many were increasingly involved in providing care for their parent without dementia. A few participants discussed the need to provide respite to their parent without dementia, for example:

*I would go over in the morning, bathe her help her dress, help with her breakfast, and then I would drop her off at the day program. And that was eight hours in the day. So that was such a huge respite for my dad. (P08)*

To this participant, she would purposely give up her days off to give her father a break. This caregiver had also mentioned that she chose to leave her full-time job in a big city that she was “loving,” for a part-time job in a small city to be closer to her parents. Participants also emphasized the need to take care of their parent without dementia, as sometimes they would be the only ones looking out for them:

*It's less about me but more about my dad [...] and me and my brother kind of made a pact being like, we can't let dad quit his job because we thought that he needed it as an outlet just for himself. So he doesn't become a full time, caregiver. (P05)*

Another participant demonstrated their longing to help their parent without dementia:

*It's surprisingly difficult to get my mom to take care of herself. And she knows that she's supposed to, right? Yeah, she knows better than anybody, right? Because she was nurse and a nurse that worked in home care. It's still surprisingly difficult to get her, to get her to access her own self-care. As she's a caregiver. (P09)*

This participant consistently emphasized the need to take care of their mother with the best of their ability throughout their interview. When the participant was asked what their caregiving

role was to them, they even stated that their first priority was their father, then mother, and then they placed themselves last.

Some participants expressed that their role also consisted of thinking about financial matters for either their parent with dementia or both parents. For some, this role was extremely overwhelming:

*Yeah, for me, it wasn't just dealing with dementia. But when I got here, I was in a really big shock. To see how bad the finances were. So, you know, just kind of borrowed everything against the house. And so I had a mortgage back home and then trying to keep up with her. That...it was, I was so over, overwhelmed with that. (P02)*

For others, they were not overly stressed but still thought about their family's financial situation as their parent without dementia got older:

*My parents are pretty [...] tight lipped about finances. I really don't know what their picture is. I'm not super worried about it. But I am a little bit worried about it as they get older. (P13)*

One participant, who considered themselves a remote caregiver, attested to calling their parent without dementia every day, and assisting them with every financial decision:

*So she runs by all of her financial decisions with me, she runs everything by me. Just to have a sounding board. (P09)*

While the extent to which the participants helped with financial matters was different among several adult child caregivers, many commented on the stress they themselves felt, or witnessed their parent without dementia feeling. Therefore, thinking about finances was a role that many caregivers either assisted with now, or would in the future.

Several participants described another role as often pushing or advocating to receive better care for their parents, or to have their voice be heard. One participant described attending a doctor's appointment with their parents and learned that their mother, who was taking care of their father with dementia, was unable to explain the truth of her situation to the doctor without

upsetting her husband. Therefore, the doctor was unaware of the immense needs the participant's father with dementia required, so the participant took it upon themselves to enlighten them:

*'...mom can't be honest in front of you. Because it'll just piss him off. And you're not getting the situation [...] they need to be seeing you more than once a year, my mother needs support of her own, he needs to be retested because he hasn't been tested in 18 months.' They retested him and he had lost another six points on his score... (P09)*

Another caregiver mentioned how one of the best parts about being a caregiver was learning how to advocate and navigate the healthcare system:

*... At least in my experience, I've learned how to like push for things and how to advocate and how to voice, right? Because you have to. You have to push the things that you think are important. And I think that's a really important life skill. And something really positive that comes out of this is that you're so young, but you have this ability to advocate hopefully for yourself, but also for this person, because I always found it was much easier to advocate for my mom than it was to advocate for myself... (P03)*

Interestingly, this participant recognized the idea that they are often a better caregiver for their parent with dementia, than for themselves. This sentiment was echoed by another caregiver, who attributed that they “try and [...] use their anger to fuel [...] their advocacy for [their] mom,” but that they did not know how to cope themselves.

### **5.1.2 Feeling the Emotional Impacts of Caregiving**

Participants discussed that their parents' dementia had left quite an emotional impact. Many participants expressed that at some point during their caregiving journeys their mental health had been impacted significantly. This had resulted in many caregivers struggling with the impacts of their emotions, and mentioned having trouble with feeling frustrated, angry, having guilt, and the grieving process. Below are a few examples of participants who expressed feeling anger and frustration due to their parents' dementia:

*I honestly didn't know that there was a way out of this. Yeah, I was depressed. I was scared. I wasn't going out. I was scared to leave my mom at home alone for the longest time. When I would leave the house she would call me like 10 times a day and you know,*

*10 times, like, where are you? What are you doing? [...] Yeah, so I had to learn how to just, you know, there's only so much you can do. Anger, I was angry. (P02)*

*I also am not the most patient person I will absolutely admit that, and I found it very frustrating at times because being a caregiver you have to be very, very patient and it tests you in ways that you never imagined. (P03)*

These quotes demonstrate that while the participants acknowledged feeling upset about their situations, they both found a way to learn something from those feelings. However, not all participants were able to find a silver lining to their situations, and instead attributed that anger towards their parent with dementia:

*It's kind of weird. She's dependent on me. And, I don't know...I was never really that close with her growing up. So, I feel there's a lot of resentment and anger towards her. (P06)*

The majority of the participants described feelings of guilt. For some, they felt guilty that they did not appreciate the earlier stages with their parent as much as they should have:

*I think there was, there's always been a lot of guilt for me like guilt that I didn't enjoy the early stages more when there was like more, \*more of her\* true to who she was prior to Alzheimer's. And I never [...] really got angry about it. I know some people get angry, but that was not really me. (P03)*

Others attached feeling guilty to their inability to do more for both of their parents:

*So I had all these kind of pressures and new things happening in my life, while at the same time, you know, spending as much time as I could with my mom and helping out my dad, and then also being very guilty about all the time I couldn't be spending doing that. [...] (P12)*

Similarly, Participant 15 shared feeling guilty for not visiting her parent with dementia as much as she would like to, and how at times visiting her mom was “a priority above school,” and therefore had fallen behind on her work. Another participant attempted to visit their parent less for their own wellbeing and mentioned having a difficult time not feeling guilty. Participant 8 also expressed that their feelings of guilt had held them back from pursuing job opportunities or travelling, as they did not want to leave their parents without support:

*But on the other hand, there's nowhere I'd rather be than take care of my mom. I mean, I could go traveling, but the guilt and the worry of being far away and not being there for my mom isn't worth it. So yeah, [...] I don't know how to accept it. My life is...I just need to continue with counseling and yeah, take breaks when I can. (P08)*

Participant 11, who also shared the same sentiments, stated she would not travel for her job as she did not want to leave her mother without dementia and would feel guilty if she left.

The majority of participants also brought up either feeling depressed or having depression as an emotional impact of their parents' dementia:

*But I think, overwhelmingly, in my undergrad, I was dealing with a lot of depression that I didn't realize that was depression. Probably also, because we lost my grandfather in the same year that my mom got diagnosed. Yeah. So I think I think that was part of the problem, too, is that I was dealing with this big thing that I didn't realize was such a big thing. And I didn't get any help. (P3)*

In addition, one participant connected how her parent with dementia's condition was connected to her own mental health, at times resulting in periods of depression:

*And so it just affected like, just when it's always there kind of like on your mind, or if she would have like a decline, a quick decline, it would always really affect me because I would go kind of into a bit of like a depression myself. So yeah, it definitely does affect like, every area of your life for sure. (P14)*

Several participants articulated that their caregiving role had created more stressful situations and increased their anxiety levels. For example, Participant 10 stated they could “*feel there was some anxiety in [themselves],*” which instigated them to reach out for help, as it was “*getting too much for [them].*” Another mentioned, “*So, I mean, it's definitely been more stressful, but I'm managing*” (P05).

One of the reasons for worry or anxiety was due to the adult child caregivers worrying about the future of both themselves, and their parents' condition. For instance, Participant 7 recalled that after his parent was initially diagnosed, he spent the next two years “*terrified*” that he would also develop YOD. Another participant explained they were worried about

“*anticipating the day*” that their parent with dementia would not be able to understand things in the future, or even remember who they are.

A few participants described feelings of grief for the loss of the person they knew. Participants described this as “*grieving someone who is still with you,*” and feeling that their parent was, “*still there, but they’re not here in the same sense.*” Many caregivers also described struggling with learning how to grieve:

*And I've talked a lot [...] about how that's such a confusing process. And [...] who's teaching you how to do that? [...] Grief is such a challenging emotion at the best of times that no one really helps you counsel through, never mind when you're living it every single day. (P03)*

### **5.1.3 Recognizing Impacts on Relationships**

Participants discussed many different ways in which their relationships had been impacted by their parents’ dementia. While some participants acknowledged they had experienced positive impacts on their relationships due to their parents’ dementia, others had found more negatively situated relationship outcomes.

Some participants noted that they became closer with their family as a result of their parent’s dementia:

*[...] so with my family, I think it's definitely brought us closer in some regards. It [...] allows us to kind of be more like, open and [...] talk about things. I think it's [...] still hard at times, but I think it's brought us closer. (P05)*

Other participants found that their caregiving experiences had “*brought [them] closer to [their] friends*” due to an increase in open communication. Participant 3 suggested that while her siblings had become closer, their relationship was largely “*centered around [their mother with dementia]*” but now that her mother lives in long-term care, she “*thinks [they’re] entering more of a [...] truer sibling relationship...*” When asked if participants felt closer to their parent without dementia, many of the participants agreed that they had experienced this:

*When one goes down, I guess the rest get stronger? I don't know. Something like that. (P07)*

For other participants, they spoke about their other parent with high praise: “... my dad's a champ. I have no idea how he's doing it. Like, he's such a hero.” (P05)

Furthermore, different participants acknowledged hurtful or difficult things they had heard their parent with dementia say, but still loved them unconditionally. For these participants, they cherished the small moments:

*I really do think that [...] this different kind of love for your parent in that it's like a very unconditional love of, you know, they can act in certain ways and it can be hurtful because of the disease, because of the illness. But [...] it doesn't impact you, in the way that you care about them it obviously impacts you, it hurts, it's terrible. But you know, you have this love for them that will prevail, and you want to take care of them and give the care and just have them be comfortable and happy and celebrate [...] those small moments. (P01)*

More participants shared these same feelings. Participant 14 felt her caregiving role was “rewarding” when she was able to “take care of [her] mom who took care of [her] for so many years,” and “know that it makes [her] happy.” Another participant talked about the importance of being able to appreciate those small moments but also knew that there was always going to be a sense of sadness when thinking about not having things happen the way they wanted it to in their life.

On the contrary, other participants addressed that their parents’ dementia diagnosis resulted in complications within their families:

*[Family] have seemed to [...] disappear and not want to be involved or help. (P06)*

*[...] I found myself [...] having resentment towards my siblings, which was such a weird feeling because we're also close. Like, we're really good friends. But [...] because I'm in healthcare it just became my responsibility to care for our mom. And she's not my patient. She's my mom. So yeah, it is hard. (P08)*

A few participants shared stories of their extended families causing problems. One example of this occurred when Participant 13 explained that his mother's side of the family "*[had] a very different opinion of how her husband and children should have been taking care of [his mother].*" For instance, the mother's family had strong views on "*what hospital [his mother] should have been to [and] what level of care [his mother] should have had.*" Having issues with the placement of parents into long-term care was another issue identified by participants, as extended families did not always share the same beliefs and desires.

For some participants, their parents' dementia diagnosis significantly impacted the relationship that the adult child had with their parent without dementia. One participant experienced conflict with their parent without dementia when they became absent as a parent after the diagnosis:

*My dad was, obviously took it pretty hard and then he [...] kind of kind of pressed pause on being a dad [...] When he found out about my mom and all that and he kind of turned into a whole like, frontal temporal dementia like FTD advocate, like went around doing press conferences and interviews and sharing his story and stuff and kind of left me and my brothers to fend for ourselves for the past like, I don't know, prime years growing up. So yeah, that was pretty tough. (P15)*

As mentioned before, some participants experienced becoming a caregiver for their other parent. One participant expressed that this caregiving role resulted in their parent without dementia "*putting too much on [them],*" even though this was generally not their intention. Another participant mentioned that his dad needed "*a lot of support from us*" and assistance with "*[figuring] out his own life*". This resulted in some participants taking on more of a parental role for their parent without dementia.

Some participants recognized their relationship with their parent with dementia had also changed, as "*the roles were kind of flipped,*" and they were now acting as the parent:

*Yeah, like, it felt kind of weird at first because, like we it would be pretty normal. And then over the years, it like, I started kind of being a mom to her, which was kind of different because [...] not many people have to do that. (P15)*

This idea of moving into a parental role for their parent was associated with the adult children feeling as if the parent they once knew was “gone”: *With my dad, it's just a deterioration of a relationship because they're forgetting you (P10).*

Within each interview, participants also addressed if their caregiving role had impacted their friendships or relationships. For many caregivers, they felt as though they had some difficulties talking to their friends about their situations:

*And I also never wanted to burden my friends with anything so if they would ask, I would just always say yep things are okay, things are fine, right? So, [...] it was hard for me to connect with them, and it was hard for them to connect with me because I put up such a wall about what was actually happening. (P03)*

Often participants would express concerns that their friends “[did] not really have any idea what [it was] like,” which made it challenging at times to maintain close friendships. One participant shared that they sometimes felt they were unable to relate to the life stages that their friends were going through, as they were “stuck in their life,” and felt “like a broken record,” as their life seemed to revolve around caregiving for their mom.

Participant 13 spoke about their caregiving role creating a strain on their marriage due to difficulties balancing their commitments. He would visit his parent “every night” and “all that parenting was left to [his] wife at home...” This eventually caused some problems, as “[his wife] had [lost] [...] a good chunk of her husband who was trying to take care of his mom.”

Participant 3 also spoke of the difficulty they had balancing their romantic relationship with their commitment to helping their parent and found it difficult to “pick and choose what things are the most important to you at that time.”

#### 5.1.4 Experiencing Stigma

Participants were given the opportunity to speak about whether they felt they had experienced stigma. It was commonly identified that several participants did not feel they had experienced stigma, and instead had found people to be supportive of their situation. However, other participants did express feeling stigma from various groups of people and environments. A few participants also acknowledged how they had placed stigma on their own parent in the past.

The majority of the adult child caregivers initially did not feel that they had experienced any form of stigma due to being associated with their parent with dementia: “*I personally haven't experienced anything that I can think of*” (P05). In fact, a few participants took it upon themselves to express that their family had experienced an abundance of inclusion from their communities.

Some participants suggested that instead of there being stigma from the public, they attributed those instances to be “*misunderstandings.*” For example:

*I don't think there's been stigma. I think there's been some confusion sometimes, if we're at a restaurant, [...] I'm gonna sometimes walk my dad and show him where the bathroom is. And maybe wait for him to make sure he can come back to the table. And people might be [...] what is she doing? But I wouldn't say there's a stigma around it. (P11)*

However, other participants expressed discontentment as they found that stigma was present when strangers “*judged*” them without knowing anything about their situation. One participant remembered feeling stigma when she was holding her mother’s hand in public, as this was not usual for a “*fully grown woman.*” Participant 6 also recalled a time when she felt judgement from a cashier in a grocery store when the cashier told the participant that she “*was being really bossy and rude to [her] mom,*” when in reality she was simply providing firm, but necessary, instructions for her mother to follow.

A few participants expressed feeling stigma back when they were in high school. Participant 1 recounted an incident where she was sick at school and was forced to call her mother with dementia, as the office would not accept a text message from her father. The participant then had to “*divulge*” her mother’s condition, even though she did not wish to, as she had to explain why it was hard to talk to her mother on the phone. The response back was extremely difficult for the participant, as the woman in the office exclaimed, ““*Your mom has dementia? But she’s so young,*”” which then prompted the participant to “*console*” the woman. She thought, “*you cannot do this, [...] I am the one who has to get upset right now, you cannot be upset.*” Participant 15 also described experiencing “*pretty rude*” comments from students at her school when they learned about her mother’s condition.

One participant shared an experience where she felt stigma from another caregiver who was older. She discussed talking to an older colleague at work who was preparing for a trip, and when the participant asked if she was excited, the colleague said she was not because it was “*hard to get excited about going away when you [have] a mom at home with Alzheimer’s.*” When the participant revealed that she too had a mother at home with Alzheimer’s, the response she received was quite negative. The colleague said that what she does for her own mother was “*so different than what you do.*” This made the participant extremely angry, as she felt that due to her young age, the colleague was assuming that she was not taking on as much of a caregiving role as she was. Therefore, the participant felt that “*younger caregivers are not [...] seen as valuable*” compared to older caregivers.

Another form of stigma noticed was from the adult child themselves and their family, as they did not always try to involve their parent with dementia in conversations:

*[...] I probably exclude him from more things than I should because it is such an exhausting process to get him involved. (P10)*

A different participant reminisced of one Christmas when their family did not allow their mother with dementia to help with any part of the dinner, even though cooking the dinner used to be their mother's job before her diagnosis. The caregiver recalled that perhaps "*it would have been better for us to find a way for her to help,*" as a way for make their mother feel like "*more of a participant.*"

As each interview would continue, some of the participants who had said they did not experience stigma would eventually change their mind and share a story once they had more time to think about it. One participant stated experiencing stigma from a healthcare professional when they were not taken seriously at an appointment due to their own young age:

*I found it more frustrating than anything [...] frustrating, because [my parents] were getting the wrong answers. It was frustrating, because I thought I had the right one. But I wasn't educated enough, or taken seriously enough, [...] because it was just like, you're an undergrad psych student. (P10)*

For this participant, due to the healthcare professional refusing to listen to them, it took their parent much longer to receive a concrete diagnosis. A few other participants addressed there being a lack of understanding among healthcare providers when helping people with YOD dementia and their families.

## **5.2 Coping with the Impacts of Caregiving**

Participants discussed in their interviews how they coped with the stressors of caregiving. Many of the coping techniques described were considered to be positive or healthy by the participants. On the other hand, some participants described that their coping techniques were unhealthy.

Many participants found that the best way for them to cope was to accept what was happening in their life and make the best out of their situation:

*But overall, I would say that my general, mental health from the situation is still pretty good. Because I guess, although I'm not happy it's happening...well, it's devastating it's happening. I've accepted that it's happening. [...] I'm okay that with the fact that I've accepted it. Like, because there's nothing else you can do. Like you have to make the best of it. And so [...] I just don't think that I would have a full life if I didn't think about it that way. (P10)*

Another emphasized the importance of “normalizing” their parents’ dementia in their own life:

*It's not my burden to bear. It's not his burden to bear. It's just a thing that happens kind of deal. Just normalize it within my own life and that's kind of what helps me the most. (P07)*

Participants also articulated that it is important for everyone to find the help they need in their own way. A few caregivers mentioned that accessing therapy or counselling assisted them, stating, “I do have a counselor that I speak with regularly who helps me a lot” (P14). Another participant spoke of using “anti-anxiety medication,” on an “as needed,” basis as what worked for them. Others identified that “being in touch” with their “own self” is how they processed their experiences. Participant 3 recalled that their best advice to give any caregiver is that “the decision that you [made] at that time was the right one,” and they had used this as a way to move forward with their life. A different participant found that letting out their emotions through crying was helpful:

*Sometimes I feel [...] if I spend a week up here with my parents, and then it's just like, oh God, you guys are a lot. But then I'll just be [...] driving back to the city, and sometimes you just got to [...] cry it out in the car for 10 minutes and just cry it out and be like, okay, I just needed to process a little and then [...] keep going. Yeah, I think just giving yourself some moments to process the emotion is good. (P11)*

Determining what you need for your own self-care was also considered beneficial to some, as self-care would look different for each individual:

*And finding something like ‘self-care’, as lame as it sounds, but really for me it's like creative projects. So like I love to do paint by numbers and things like that and that's been what's really helpful for me. (P03)*

Finding specific hobbies, such as gardening, or maintaining their fitness, was another common way of coping:

*I also make it a goal every day to work out. I find that even before my mom's diagnosis, like, like getting a workout in each day helps me mental health wise, I don't think I would be sane if I didn't. (P08)*

Finally, some caregivers found choosing hobbies that their parent with dementia used to do helped them best:

*Yeah, I think running, my sister and I really like crafting. We are big crafters. And my mom was very crafty. So it's [...] kind of nice to bring that in. [...] I've been trying in 2021 to [...] get better at sewing and my mom was really into sewing, she would make so many things. So it's nice to have [...] those interests that are similar to my mom's and [...] feel that connection. My mom also used to walk like power walk, marathons and half marathons. So [...] the running fits in. \*Laughing\* [...] So it just is like these things that also make me feel closer to her. And I think that also helps in my coping. (P01)*

The participants also demonstrated in their interviews the need for caregivers to take breaks and acknowledge when they had reached their limit. Participant 9 expressed a time when it “took quite a bit of convincing” to get his father with dementia to let him go on walks. Eventually he learned to “pre-plan” periods of time to walk as a break no matter what. Some other participants found that they had to set boundaries and give themselves breaks to maintain their wellbeing:

*I think it's also I'm like a very empathic and giving person to the point where I will run until my tank is on empty and then I'll give a little bit more, do you know what I mean? [...] I think it was also for me learning how to set boundaries, which is an ongoing process, I'm not perfect at it. (P02)*

*Yeah, and I did say that to her when I first moved in. I said, I'm here to help and I love you guys, but if it's gonna affect my relationship with [fiancé name], then I'm moving out. Because like, I had to set some healthy boundaries for myself as well, in order for me to take on that kind of roll of support for him. (P10)*

Similarly, Participant 1 found that communicating her needs with her family was beneficial:

*I've been really lucky to have really good family support and have an understanding within my family that, even within one moment of, I need to, [...] switch off, I can't do this*

*anymore. And taking those breaks. And I think that we've, over time, of course, this is not [...] ingrained at the very beginning. But over time, we've realized [...] how to let each other know that we needed the break, or that we needed to leave the house or whatever it was. And I think that that was very helpful. (P01)*

Talking about their parents' dementia diagnosis more with family, friends, and the general public was highlighted by many participants as helpful:

*I'm very open with my friends about it. And I find that allows me to kind of own it a lot more. (P07)*

*So I think just be more open and, and talking about it with people and just be, 'Oh, yeah, this is what's going on in my life,' [That] type of thing...has, I don't know, [...] it's more freeing, you know, [...] you just say it as opposed to kind of keeping it to yourself. (P05)*

Some participants emphasized how opening up to others in similar situations had also helped with their coping. Participant 1 mentioned how it was nice to have an “*understanding*” with her friend who had a mother with a similar disease where you “*don't have to explain how you feel.*” Another participant mentioned that she coped through meeting others in similar situations on social media, as it made her feel “*less alone.*”

Additionally, a few participants brought up the idea of needing physical separation from their parents as a way to cope. This physical separation could take different forms. For a few participants, they used their work as an escape:

*It's kind of nice, like working, I do [job name], so my days are super long. So, you know [...] if I don't really want to go home and [...] kind of [...] face like, seeing my mom, [...] I can still work, which is nice. (P04)*

Another participant had recently decided to try and “*take one day off a week from seeing [her] mom,*” in long-term care, as it was a way to prioritize her own mental health. For Participant 1, she had expressed that when living away from home for university “*it was helpful to get away,*” as it allowed her to understand her own grief and emotions once she was further from the situation, stating she “*couldn't see what was around [her] until [she] left.*”

However, several participants stated in their interviews that they did not cope well with their parents' diagnosis or their role as a caregiver:

*Yeah. I think for a long time, I didn't really cope with it because I would just sort of like push it down and not really, like I was thinking about it, but I wasn't dealing with my emotions. (P14)*

Due to this lack of coping, Participant 8 had found that she had “*put her life on hold,*” and could not move forward with her life due to feeling responsible for her mother with dementia.

A few participants also indicated that at times they turned to using substances as a coping technique:

*I drank more than I should have. Like, I drank a lot. And that, you know, that's part of [...] my general kind of mental health and depression as well. But [...] I know that was [...] caregiving for my mom and all the stresses that came with [...] her illness was definitely like a trigger for that. That kind of behavior. For me, it was anxiety inducing and stressful, and I would drink to fall asleep, to get my mind to stop thinking, [...] so I had I had sort of destructive coping mechanisms that way. [...] Not a lot of healthy coping. (P12)*

All the participants who mentioned using substances as a way of coping recognized it was an unhealthy habit for them, and all expressed that they did not rely on that technique anymore, replacing it with more healthy alternatives such as exercise.

#### **5.4 Finding Supports That Fit My Needs**

Many participants reached out to find a variety of services and supports to help themselves, as well as their parent with YOD. This included informal supports from friends and other family members, as well as more formal, professional resources. Participants also had suggestions for improving services to better support adult child caregivers of persons with YOD.

The majority of the participants discussed that a large source of support was found within their family and friends. Confiding in those who they were closest with, who could also understand their situation was seen as very valuable:

*But no, my support was sort of limited to informal. You know, chatting through things with my, my family, like my brothers, my dad and my wife, people who were sort of on the inside and knew what was going on. (P12)*

While some found support through their neighbours and family friends, a different participant found support through making connections at her mother's long-term care home:

*Okay, well, kind of like getting to know a whole new community was kind of nice. Like, you always drive by long term care buildings, and [...] never really think about it. But then you go there, and you're there alone and get to know people and kind of make some people's day, you know? [...] some people don't really get visited often. You just saying 'Hi' can make someone's day. [...] I would volunteer there [...] so it was really nice to like, get to know some of this staff as well. And I know that my mom likes seeing me, so I can look forward to doing that. And not just for her, for everyone else there. (P15)*

This “community,” as she called it, was very important to her, and resulted in her volunteering at the long-term care home during high school. Interestingly, this participant also mentioned confiding in the staff at the long-term care home and found this to be quite comforting. For others, they did not find they had any informal supports to confide in:

*Friends and family? Not really, I found it difficult to talk to people because unless they're in this...living in it. To me, I just felt like they didn't understand [...] (P02)*

Another participant felt the same way, and discussed their friends making them feel bad about their decisions at times, so she chose not to confide in them.

Only a few participants expressed accessing a support group designed for people their age caring for a person with dementia. For both of those participants, they exclaimed that it was “*extremely helpful.*” Participant 4 had only been able to attend one session at the time of the interview, and when asked if it was beneficial, stated:

*I'd say so [...], once I start going to more, I think I'll appreciate it and it'll be really helpful. Because right now [...] all my friends, [...] they can be sorry, but they can't really relate. (P04)*

For this participant, they mentioned that while the support group was small, most of the people were close to his own age, and that one of them had a situation that was almost exactly the same as his own.

Many of the participants had also found it beneficial to access therapy or counselling services as a way to manage their anxiety:

*Yeah, I think...access to counseling was very helpful, because it helped me manage the ongoing stress and anxiety. And that feeling of being lonely and being so, isolated from my peers. (P03)*

A few participants strived to find therapy that was more specialized to exactly what they were going through. For example, Participant 10 found that locating a psychologist with “*a lot of experience,*” helping others grieving in similar situations was beneficial to her. Similarly, Participant 8 discussed that she had recently accessed a “*grief counsellor*” which was quite helpful.

A few participants recognized that the Alzheimer Society had been an initial first point of contact for them to receive services for themselves. They had been provided some basic resources through the form of “*pamphlets,*” “*seminars,*” and “*courses.*” While this was considered helpful to some, others expressed that although the resources were informative, they did not meet all of their needs. One participant recalled that many of the resources were directed at helping them understand what dementia was, which they felt they already knew through “*dealing with [their] grandmother and on reading up on it.*”

Some participants expressed that they had not accessed any services, and “*in retrospect, [they] should have*” or will in the future: “*No, I haven't. And I should.*” When asked why the participants did not access supports when they thought they should have, they either did not know why, did not feel it was necessary at the time, or did not realize the need until much later in

their caregiving journey. There were also a few participants who did not access many supports, as they “*had a really hard time finding support groups.*”

Many participants suggested that there needs to be more guidance for adult child caregivers on how to navigate the healthcare system as well as finding resources. Participants recalled feeling overwhelmed with the number of resources thrown at them after their parents’ diagnosis, and thus thought it would be helpful to bring clarity to navigating these situations:

*... once you get officially diagnosed [...] they kind of throw everything at you at once. And they don't guide you per se, [...] they let you figure out everything on your own [...] Yeah, I think the overall system, they should [...] show you “Okay, this is what's probably going to happen, [here's] what you should do, here is resources for this if this happens, this if this happens, this if this happens. These things that [...] are going to happen at a different stage for your loved one. (P04)*

*I was [talking with] one of my friends who, [...] her dad's having some health issues now. But we were talking [...] how do you know what to do? Like when your parents [...], you know, start to deteriorate? No one teaches you. There's no, there's no lesson plan to follow. Like, where do you go? (P05)*

Another common sentiment from the participants was wanting more education surrounding dementia within the general public:

*I feel there just needs to be a little bit more education to everybody, that this is happening. (P14)*

This participant wanted there to be more information in the public specifically regarding YOD, as they found that there was still “*stigma out there that that [Alzheimer's] is an old timer's disease,*” and that the public needed to know more about the younger population with dementia.

Another participant’s parent was undiagnosed for many years and believed that it was largely due to the lack of education among healthcare workers. They thought that it would be beneficial for all healthcare workers to receive more education on “*how to deal with someone with Alzheimer's.*”

The majority of participants indicated that there needs to be more supports for adult child YOD caregivers to connect with others who are living in similar circumstances. Many found that having the ability to talk, either in a support group or even in an “*informal setting*,” would be helpful to them:

*... the first thing would be a support group or a network to talk to other people about their experiences, but also someone who's more my age [...] I think that would be a great resource. (P05)*

*Yeah, the things that you're experiencing are just so different from everyone else because of how young you are. Right? So yeah, I think what I wanted was the ability to connect with other people in the same situation as me, but know that we could go to brunch. But if I had to cancel at the last second, because, I had to watch my mom all of a sudden, no one would care. Everyone would be, 'Oh, yeah, that's totally fine. No problem.' (P03)*

For Participant 11, she spoke of how nice it was to be able to connect with other children “*around [her] age*.” She even acknowledged that she was a form of support for the children of family friends, who also had a parent with YOD:

*[...] I'm the oldest of that group, and my dad's definitely farther along. So they're more like, 'Hey [participant name], what about this?' But I think it is nice to just have that community of people who are dealing with similar shit, and being able to talk about it and the pressures of getting married or having kids earlier, or just all those kind of other things that come up and surface through dealing with all of it [...] (P11)*

Some participants did not know of any supports designed for people in their positions. In those cases, they suggested that more resources be created for younger caregivers:

*I feel like there's not a ton of resources out there for younger adult children. Like the Alzheimer Society, the support group they have for young-onset dementia is more for the partners, as opposed to, say, the kids. (P05)*

As a result, some adult child caregivers accessed support groups through the Alzheimer Society that were not age specific. One of these caregivers did not find this support to be beneficial, felt “*out of place*” given their age, and chose to “*not continue with [it]*.”

Another suggestion was to have more supports for families with a parent in long-term care, as Participant 8 stated “*there really aren’t any supports*” for them as of now. Participants also emphasized the need for more resources to be available to their own parents with YOD. One participant suggested that a place that had activities listed for their parent with YOD would be helpful, as she found it challenging to come up with them on her own.

### **5.3 Managing Changes During the COVID-19 Pandemic**

Overall, there were a range of experiences described from the participants concerning how the COVID-19 pandemic had impacted them. All participants expressed that COVID-19 had changed their caregiving role in one way or another, whether it was through spending more time at home, or having to adapt to only having socially distanced visits with their parent with dementia.

A challenge expressed by many participants was wanting to do more for their parents, as COVID-19 prohibited them from doing so. For example, visiting parents during the pandemic became problematic either due to their parent living in long-term care, or if the adult child lived in a different city or province, and travelling was not allowed. One participant exclaimed that this inability to visit essentially “*took [their caregiving role] away*”. Others shared the same sentiment:

*Yeah, [...] it's changed everything. Um, because I was going down to the long-term care home a couple times a week to be there and now I can't go at all. I only get to see her on Facetime calls which isn't really a great way of connecting with her. It's also hard because now you're not there so I can't peek into the things that I would like to, in the way that I would when I'm there [...]* (P03)

*So that was devastating. That was crushing. There [were] window visits. I mean, my mom isn't cognitive. She doesn't know who we are. She doesn't know where she is. So window visits, not being able to touch my mom not being able to make sure that her brief was clean, that she was clean, that she didn't have any cuts, bruises. I wasn't able to do like that assessment on my mom. That killed me.* (P08)

A few participants described that one of the major changes of their role was that they were not able to check in on their parents' wellbeing. For Participant 3, her parent had entered long-term care only a few months before the pandemic began. Thus, the inability of her family to visit further complicated her feelings about the move, and she believed the transition was harder on her mother:

*[...] my dad [...] is now able to go in and [...] feeds her at lunch but she's in a wheelchair and so he can't really move her and so [...] it's hard and the isolation has also been really hard on her which we could have controlled before, right? We could have been there we have been hanging out and even if we weren't talking to her if we were just playing a game at the table, she would have been there and around family and like taking in that interaction. (P03)*

Another issue highlighted was the impact that the pandemic had on the availability of activities and resources for their both of their parents. For instance:

*I'm also aware from afar of how their opportunities have shrunk. How their means of escape or relief or self-care have narrowed. (P09)*

*COVID has resulted in a lack of resources. I know a lot of [...] the organizations are trying to pivot and [...] do things online. But I don't think it's the same as [...] in person human connection. (P05)*

For Participant 9, they were a long-distance caregiver for their parents, and found it extremely challenging to find ways to help. Not only was their own role reduced through their inability to travel, but they witnessed both of their parents being unable to go anywhere or participate in many of the services they had been attending. One participant found that due to the loss of services, this had placed “*more pressure*” on themselves to provide extra care for their parents.

A few participants shared that prior to the pandemic, their parent with dementia was not receiving assistance from an outside source, such as PSWs. Therefore, the caregiver's transition to working at home due to the pandemic was a “*blessing in disguise.*” Participant 5 was able to move home to assist with her mother's care. Participant 7 explained that working from home had

allowed their family to face, “*the realities of [...] the services we are going to need,*” and was, “*thankful for the setup time.*” The ability to work from home had allowed them to monitor the condition of their parent with dementia more attentively and then plan accordingly for the future.

All participants with parents living in long-term care mentioned that while it was difficult not being able to know exactly how their parent was doing, the staff was “*very good about providing information*” about their parents’ care as well the reintegration of visits. Another participant stated:

*[...] they do the best they can and overall, like, I think the home she's in is pretty good. [...] the staff are all very nice. They do keep us updated about her condition and things like that, which is great [...]* (P14)

Many participants understood that the pandemic had been an extremely challenging time for the staff that worked there and felt grateful that their parent was still receiving good care during this time.

## **Chapter 6: Discussion**

### **6.1 Key Findings**

The aim of this study was to describe the perceptions of the caregiving role of adult children who have a parent with YOD. This study was helpful in yielding a greater understanding of both the roles taken on by the participants, as well as the ways in which these roles impacted them. The findings reaffirm much of what the limited research on this population has described but it has also identified new knowledge that will contribute to and expand the literature in this under-studied area. In addition, this study is the first to explore the perceptions of adult child caregivers of persons with YOD in Canada.

#### ***Caregiving Roles and Responsibilities***

The notion of advocating for the health and wellbeing of both parents, is a novel finding identified within this study. Advocating has not been a caregiving role that has been recognized in other research focused on adult child caregivers of persons with YOD. However, advocacy has been previously identified as an important role for some caregivers of older adults who have dementia (Fetherstonhaugh et al., 2021; Legault & Ducharme, 2009). The participants in this thesis described that advocating was typically a protective response, as they were looking out for their parents' best interests. For example, when one participant attended a doctor's appointment with their parents, they brought to the doctor's attention many issues that had been overlooked at past appointments. This participant described that there was no question that they would advocate for their parents' wellbeing and believed that if they did not stand up for them, no one else would. Thus, this is an area that may benefit from further research, as advocacy was described as an important part of the caregiving role of adult child YOD caregivers, and it is still largely unknown what advocacy means to this population. Additionally, future educational

programs for caregivers of people with YOD, including adult child caregivers, could include information and strategies on how to advocate on behalf of others.

There were many parallels identified between past research including adult child YOD caregivers and the study findings regarding their increasing caregiving responsibilities. Some of the responsibilities participants discussed being involved in were assisting their parent with YOD with daily tasks (e.g., bathing, dressing), helping with finances, and being a caregiver for their other parent. Hutchinson et al. (2016) described similar situations for adult child caregivers of persons with YOD in their study, expressing that many were overwhelmed by their “*increased responsibilities.*” Further, in Cartwright et al.’s (2021) systematic review regarding the findings from 15 studies with children who had a parent with YOD, these same findings were also acknowledged. For instance, many assisted their parent without dementia, resulting in an increase of their caregiving responsibilities (Cartwright et al., 2021).

### ***Coping Techniques***

Participants in this study identified a number of strategies to cope with the challenges of caregiving. A few participants found that choosing activities that their parent with dementia did in the past was a helpful coping technique for them. Other research that has explored the coping techniques of adult child caregivers of persons with YOD has not identified this strategy (e.g., Johannessen et al., 2016; Allen et al., 2009; Hutchinson et al., 2016). Undertaking these activities allowed participants to feel closer to their parents, thus they were more at peace with their current situations. This is important, as it suggests that further research may be beneficial to learn what other techniques may help other adult child YOD caregivers.

The coping techniques identified by participants in this study are quite similar to what has been discussed by other adult child caregivers of persons living with YOD. For instance,

congruent to this study, research has shown that adult child YOD caregivers can experience a lack of coping, resort to drinking or using substances, and/or use distance to cope (Allen et al., 2009; Cartwright et al., 2021). This study also identified that participants chose to be more open to talking about their experiences and normalizing their situation, which was also reiterated within Cartwright et al.'s (2021) systematic review.

### ***Supports & Resources***

The findings within this study contribute to the existing literature which suggests that more resources need to be developed that connect adult child caregivers of persons with YOD to others in similar situations (Cartwright et al., 2021). The majority of participants in this study discussed how obtaining access to support groups that were age-specific would be beneficial, similar to the findings of Cartwright et al.'s (2021) systematic review. However, a novel finding was that the participants in this study also suggested that future supports offered do not need to be formal in nature, but instead would prefer to have informal meetings, such as going on hikes or meeting for coffee. Participants discussed that connecting informally would reduce the pressure they may feel if they were to miss a meeting due to their caregiving responsibilities. Therefore, perhaps future resources should investigate identifying opportunities for these caregivers to connect in an informal way that provides more flexibility than regularly scheduled support groups.

Another novel finding from this study was that participants discussed a lack of support services provided to families who had a loved one living in long-term care. For example, one participant mentioned she would have appreciated being offered resources from long-term care staff for her own mental health during the pandemic. This suggests that for families who have a parent with YOD in long-term care, perhaps there should be future supports provided to them to

assist with their coping. Future research surrounding long-term care supports for families may be required to gain a better understanding regarding what would be considered helpful.

Formal and informal supports identified within this study were well aligned to what has been reported in the literature surrounding adult child caregivers who have a parent with YOD. In Millenaar et al. (2014), the supports discussed were very similar to what was acknowledged in this study. YOD child caregivers aged 14 and older shared that they too accessed therapy, wanted more guidance with practical issues, and wished to talk to others who were in similar situations (Millenaar et al., 2014). In Hutchinson et al. (2016), adult child caregivers of persons with YOD mentioned their inability to access supports, along with being unable to find supports that fit their needs. This was also echoed in the findings of this thesis, as some participants could not find age-appropriate supports for themselves. Therefore, this study reaffirms the need for the development of more age-appropriate supports for this population.

### *Stigma*

Within the limited research on adult child YOD caregivers, many have reported that they have felt stigmatization (Cartwright et al., 2021). However, in the current study, several participants indicated they had not experienced stigma. The participants who did not experience stigma all mentioned within their interviews the immense amount of support they had received from their friends, families, and/or communities. The absence of stigma is a significant finding to add to the literature on adult child caregivers of persons with YOD, as future research could explore the differences between those who experience stigma and those who do not. In addition, further exploration of stigma could assist in learning how to alleviate stigma for those that do experience it within this population.

A new finding within this study was the potential for older dementia caregivers to place stigma upon younger dementia caregivers. This is a novel finding that should be explored in future research, as a participant stated an older caregiver perceived themselves to be providing more care than the participant, who was younger. Knowing now that this can occur within the population of dementia caregivers, it would be interesting to see if other young carers, whose parents have different illnesses, have also experienced this. Perhaps this is an indication for more education to be provided to the general public regarding what YOD is, and the impact this can have on family caregivers.

Across all interviews, participants in this study expressed they did not feel any shame or embarrassment when spending time with their parent with YOD, and were instead quite protective of them, which varies from findings within the literature. In several past studies, it was frequently stated that some adult child caregivers feel shame and embarrassment when spending time with their parent with YOD, resulting in the choice to conceal their parents' diagnosis from others (Allen et al., 2009; Cartwright et al., 2021). This suggests that while it is possible for caregivers to feel shame and embarrassment, not all adult child caregivers of persons with YOD experience this. This indicates that it might be interesting for future research to investigate why some adult child caregivers of persons with YOD feel this shame and embarrassment, and others do not.

In the scarce literature that has explored the impacts of stigma on adult child caregivers who have a parent with YOD, some of the findings from this study are similar to what has previously been identified. For example, participants in this study discussed feeling stigma from healthcare professionals as they felt like they were not being taken seriously enough. This same idea was also reported within Cartwright et al., (2021) indicating that perhaps doctors should

receive more education in how to properly work with and support the families of persons with YOD. Participants in this thesis also expressed experiences of stigma through interactions with their peers, when one caregiver spoke of students at her high school making hurtful comments towards her situation. This sentiment was also reported within Nichols et al., (2013) when a child who had a parent with YOD discussed students at school creating rumours surrounding their parent's health and wellbeing. Thus, this indicates that more resources need to be put into place to educate the public regarding what YOD is, and how it can impact families.

### ***Impacts of Caregiving***

In accordance with other studies, the adult child caregivers of persons living with YOD experienced various emotional impacts due to their caregiving role (Cartwright et al., 2021; Allen et al., 2009; Hutchinson et al., 2016; Aslett et al., 2019). Participants in this study discussed feeling loss, frustration, and guilt regarding their relationship with their parent with dementia. This was similar to other research in this field. For example, Aslett et al., (2019) identified those same feelings were present among adult child YOD caregivers in their study and concluded that those feelings could have a negative impact on the caregivers' emotional wellbeing.

The adult child YOD caregivers also expressed in their interviews the large impact that their caregiving role had on their relationships with family, friends, and partners. For example, some participants discussed experiencing role reversal, taking on a parental role for their parent with dementia. This is a common sentiment that has been expressed by other adult child caregivers of persons with YOD in different studies (Cartwright et al., 2021; Aslett et al., 2019). As a result of this reversal, many adult child YOD caregivers have also identified that their caregiving role has prevented them from being able to relate to others their own age (Cartwright

et al., 2021). The same can be said for the participants in this study, as they acknowledged that at times it was quite difficult to find friends who understood their situation. Due to this, many participants expressed how helpful it was to find friends who were going through similar experiences. This is another similarity that has also been stated within the past literature (Cartwright et al., 2021).

### ***Young Carers***

It is important to be able to situate this research within the broader scope of literature regarding ‘*young carers*’ (i.e., beyond those caring for persons with dementia). Young carers are often identified as being under the age of 25, who typically provide care to a parent (Chadi & Stamatopoulos, 2017). A number of the findings mentioned above have also been identified within young carers literature. For example, participants in this thesis stated that they found it helpful to connect with others going through similar circumstances. Within research regarding young carers, they also reported that talking with others going through similar situations was “*meaningful*” for them (Chikhradze et al., 2017, pp. 13). Another similarity was within the coping techniques identified. For instance, participants in this thesis often tried to normalize their situations but could also struggle with a lack of coping. Both of these techniques have been discussed within the literature surrounding young carers (Chikhradze et al., 2017). Finally, the emotional responses discussed by the participants within this study, such as experiencing feelings of loss and guilt, have also been expressed by young carers in previous studies (Rose & Cohen, 2010). Therefore, this reaffirms the notion that there are many similarities between the experiences of young carers and adult child caregivers of persons living with YOD.

However, there are some significant differences to be acknowledged between the situations of adult child YOD caregivers and young carers. For the participants in this study, the

majority did not live with their parents. This is important to recognize, as a few caregivers in this thesis spoke of providing caregiving remotely. For one remote caregiver, their role largely consisted of calling their parent without dementia to check in and help problem solve. In previous research on young carers, most young carer participants lived with their parent with an illness, thus the caregiving roles discussed in the literature largely involve assisting with daily tasks (Chikhradze et al., 2017). This is one indication that there can be some significant differences between the caregiving roles of adult child caregivers of persons with YOD and young carers. Furthermore, a few participants in this thesis spoke of their struggles to find a balance between caring for their parent and having a healthy marriage. This is important to acknowledge, as adult child caregivers of persons with YOD may have other roles and responsibilities such as marriage or taking care of their own children. Thus, it is important to recognize that young carers are not one homogenous group.

### ***COVID-19***

There is an extremely limited amount of knowledge that exists regarding the impact that the COVID-19 pandemic has had on dementia caregivers overall (Greenberg et al., 2020), with even less being known about YOD caregivers. So far, it has been identified that dementia caregivers have had varying experiences during the pandemic, with some having everything in their life changing, and others feeling no impact at all (Savla et al., 2021). Within this thesis, varying perspectives were found as well.

This is perhaps the first study in Canada to identify some of the impacts on YOD caregivers when having a loved one living in long-term care during the pandemic. The results demonstrate that there is not much known about the short- and long-term impacts of the pandemic on the relationships between adult children and their parent with YOD living in long-

term care. For example, the inability to visit their parents during the pandemic was a great source of stress and sadness for the participants. Many expressed feeling helpless and accepted the fact that there was not much they could do. Interestingly, some participants described their experiences during COVID-19 as a loss of their caregiving role entirely. Others perceived they still were providing care, even if it was just through visiting or calling their parents. This suggests that for adult child caregivers of persons with YOD, while their caregiving role may shift over time, the importance of what they were doing did not. For them, calling their parent to provide emotional support during the pandemic may be as significant as when they were living at home with them, assisting with their ADLs.

There has only been one article thus far published which describes some experiences of YOD caregivers during the pandemic (Giebel et al., 2021). Within Giebel et al. (2021), experiences during the pandemic of people with YOD and LOD, along with their caregivers, were compared. The results indicate that the pandemic has brought to light that people with YOD and their caregivers may experience more inequalities than those with LOD and their caregivers (Giebel et al., 2021). For example, prior to the pandemic, there were less programs and services tailored to the needs of people with YOD and their caregivers, thus when programs were taken away, this became even more apparent. This is a similar finding to what was identified within this study, as participants shared that it was extremely difficult to find dementia services created for younger populations before the pandemic, and during the pandemic any supports that did exist were cancelled or modified to be online. This provides further confirmation that more services, such as day programs, support groups, and educational resources, need to not only be created for people with YOD and their caregivers, but advertised widely.

Both within the literature and within this study, dementia caregivers discussed one benefit from the pandemic – that they were able to spend more time with the person with dementia (Savla et al., 2021). However, this thesis found that a silver lining of the pandemic for some participants was the ability for them to work from home, maintaining their employment while also being able to provide care for their parent.

## **6.2 Strengths and Limitations**

As a way to add diversity of experiences, a strength of this study was to include the perceptions of adult child caregivers of persons living with YOD that did not consider themselves the primary caregiver at the time of the interview. It was important to include a variety of perspectives of the adult children as some participants were the sole person providing care, others were remote caregivers, and several had their siblings to rely on. This resulted in a diverse range of experiences that were able to be explored within this study. Had the study only included primary caregivers, many valuable perspectives may have been lost.

By utilizing a qualitative descriptive design, this allowed for rich, in-depth descriptions of the perceptions of the adult child caregivers to be identified. This is a strength for this study, as it has provided useful, straightforward descriptions that can provide insights into future practices and resources to be developed for this population (Green & Thorogood, 2018; Sullivan-Bolyai et al., 2005). Additionally, as research focused on adult child caregivers of persons with YOD is still relatively new, using this approach has provided a great starting point that gathered a variety of detailed viewpoints from this population which will only benefit future research on this topic. Furthermore, having multiple researchers, specifically the thesis supervisor and committee members, involved in the data analysis process also assisted in increasing the rigour of this study. Due to this, there is more credibility within the findings.

A limitation identified regarding sampling was the lack of diversity within the sample. While the student researcher was pleased with recruiting 5 men, given that much of the literature on dementia caregivers has predominantly been conducted with females, there is a need for better representation of male voices in this area of research (Xiong et al., 2020). Similarly, the study sample was predominantly Caucasian, with only one participant identifying as mixed-race. While this limitation does not diminish the value of the study findings, it is important to consider that the perceptions within this study are largely from a white, middle-class, perspective. Literature has suggested that younger caregivers in lower-class socioeconomic statuses may have more challenges within their caregiving roles (Robison et al., 2020). This limitation suggests the need for more research that highlights the perspectives of diverse populations, considering race, ethnicity, gender, and socio-economic status.

Another limitation of the study was that the type of dementia each participant's parent was diagnosed with was not considered. Research has shown that YOD caregiving experiences will likely differ depending on the type of dementia diagnosis (Millenaar et al., 2016). However, within most research regarding YOD caregiving experiences, many studies have failed to account for the type of dementia diagnosis (Millenaar et al., 2016). Therefore, future studies within this field should consider how the type of dementia one's parent has impacts their caregiving role and experiences.

The researcher also faced a challenge within interviews, when the concept of '*stigma*' was at times difficult for the participants to understand. As the researcher had thought that this may occur, a definition of stigma was provided to participants during each interview. However, not all participants understood stigma the same way. For example, a few participants considered '*misunderstandings*' within the public to be stigma, as some may have had less knowledge about

people of a younger age having dementia or other cognitive issues. In contrast, other participants thought that it was not the responsibility of the public to understand their parents' condition. The latter chose to view public '*misunderstandings*' as something that was an honest mistake, instead of stigma. Therefore, future research might want to explore the concept of stigma through a broader lens in order to capture the various understandings and experiences of adult child YOD caregivers.

### **6.3 Conclusions**

This thesis described the perceptions of the caregiving role of adult child YOD caregivers. Rich and in-depth descriptions of the perceptions were identified through semi-structured interviews, asking participants what their role was and how it impacted them. The findings from this study revealed that there are many similarities and differences among the experiences within this population. The impact of their parents' dementia resulted in increased responsibilities, complex changes of relationships between family and friends, as well as invoking strong emotional responses. Some participants expressed feeling stigma, while others did not. Many coping techniques were identified, with the most common being to find what works best for themselves as individuals. Both informal and formal supports were deemed to be valuable, with participants expressing the need for more age-appropriate services to be developed in the future for both themselves and their parent with YOD. As this study followed a qualitative descriptive design, the findings from this thesis can be used to inform the development of future supports for adult child caregivers of persons with YOD. This study contributes to the growing field of both research on adult child YOD caregivers and young carers, but it also is very valuable to future research within Canada. It is the hope that the

findings from this study will go on to inspire both further research within this field, as well as the development of supports for adult child caregivers of persons living with YOD.

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## Appendices

### Appendix A

#### Recruitment Email Script (Gatekeepers)

Dear [**Gatekeeper Name**],

My name is Camryn Berry, and I am a MSc graduate student working under the supervision of Dr. Carrie McAiney at the University of Waterloo.

We are contacting you to ask for your assistance with a research study titled **Perceptions of the Caregiving Role Among Young-Onset Dementia Adult Child Caregivers**. The purpose of this study is to describe the perceptions of the caregiving role from the perspective of adult child young-onset dementia caregivers. By gaining a better understanding of the experiences of caregiving among adult children of persons with young-onset dementia, we hope this knowledge can inform the development future age-appropriate assists/supports intended for this population. We are hoping you can assist us with identifying individuals who may be interested in participating in this study.

We would like to identify adult children who are caregivers for their parent with young-onset dementia. Specifically, we are looking for individuals who:

- 1) Are over the age of 18
- 2) Able to speak and understand English
- 3) Able to provide informed consent

Individuals who are interested in taking part will be asked to complete an interview to learn more about their perceptions of caregiving. Interviews will be approximately 45-60 minutes long and will be conducted either over the phone or online (e.g., Zoom).

To help us identify individuals who may be interested in taking part in this study, we are asking for permission to post or distribute a recruitment poster within your organization and/or share information about the study in a newsletter or through social media.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE # 42823).

If you have any questions about this study, or would like additional information, please feel free to contact myself at [c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca) or (519) 503-2234 or my supervisor Dr. Carrie McAiney at [carrie.mcainey@uwaterloo.ca](mailto:carrie.mcainey@uwaterloo.ca) or (519) 888-4567 ext. 45642.

Please let us know, at your earliest convenience, if you would be willing to help distribute our recruitment information.

Thank you for your consideration of this request.

Sincerely,

Camryn Berry, MSc Graduate Student, University of Waterloo  
[c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca) or (519) 503-2245

## **Appendix B**

### Recruitment Social Media & Newsletter Script

#### Perceptions of the Caregiving Role Among Young-Onset Dementia Adult Child Caregivers

Researchers at the University of Waterloo are conducting a study to better understand the perceptions of adult children who have a parent with young-onset dementia.

**Do you have a parent with young-onset dementia?**

**Are you aged 18 or older?**

**Have you had a caregiving experience within the past 2 years?**

If you meet these criteria and are interested in participating, we are asking individuals to share their caregiving experiences by participating in an online/telephone interview that will be 45-60 minutes in length. If you would like to learn more about the study and/or share your experience, please contact Camryn Berry at the University of Waterloo ([c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca) / 519-503-2245).

By sharing your experiences, we hope this knowledge can inform the development of future age-appropriate supports for this population.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42823).

Statement for Twitter:

\*Study Recruitment\* Do you have a parent with young-onset dementia? Are you aged 18+? Have you had a caregiving experience w/in the past 2 years? If you answered YES to these Qs, researchers at @UWSPHHS are interested in hearing from you. See attached & pls retweet!  
[insert poster]

## Appendix C

### Recruitment Poster

# We are conducting a study to learn about adult children who have a parent with young-onset dementia



## Who can participate?

- Adult children (18+) who have a parent with young-onset dementia and have had a caregiving experience within the past 2 years

## If I participate, what will I be asked to do?

- Take part in an individual phone or online interview that will be 45-60 minutes
- Talk about your experiences and the impact that this has had on your life to help inform future supports

To find out more about this study, please contact: **Camryn Berry**

[c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca) / 519-503-2245

This study has been reviewed by, and received ethics clearance through, a University of Waterloo Ethics Committee (ORE #42823)



## **Appendix D**

### Information Sheet and Verbal Consent Form

#### **Information Sheet**

**Title of Study:** Perceptions of the Caregiving Role Among Young-Onset Dementia Adult Child Caregivers

**Local Principal Investigator(s), Department, Institution:**

Carrie McAiney, School of Public Health and Health Systems, University of Waterloo

**Student Researcher(s):**

Camryn Berry, School of Public Health and Health Systems, University of Waterloo

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You are being invited to participate in a research study because you are/were an adult child caregiver of a person living with young-onset dementia. This study is being conducted for Camryn Berry's masters thesis.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study. Once you understand the study, you will be asked if you agree to participate in the study. Please take your time to make your decision. Feel free to discuss it with others.

#### **What is the purpose of the study?**

The purpose of this study is to describe the perceptions of the caregiving role from the perspective of adult child young-onset dementia caregivers. By gaining a better understanding of the experiences of caregiving among adult children of persons with young-onset dementia, we hope this knowledge can inform the development future age-appropriate assists/supports intended for this population.

#### **I. Your responsibilities as a participant**

#### **What will you be asked of you if you agree to participate in this study?**

Participation in this study is voluntary. If you agree to participate, you will be asked to:

- Participate in an interview about your experiences related to your caregiving role (e.g., impact on relationships, education, career) and identify ways that you have managed these potential impacts. Interviews will be conducted on-line (e.g., Zoom) or the telephone, depending on your preference. Interviews will be approximately 45-60 minutes in length.

With your permission, the interviews will be audio-recorded so that we are able to capture all of the information you share with us.

## **II. Your rights as a participant**

### **Is participation in the study voluntary?**

Participation in this research is entirely voluntary. You can decide to end your participation in the research at any time, without penalty. If you decide to end your participation, simply tell a member of the research team that you no longer want to participate. You do not need to provide a reason. If you decide to end your participation in the study, your data can be destroyed if requested but this cannot be guaranteed if data analysis has already begun. Data analysis will start once all interviews have been completed. If you decide to withdraw from the study, the research team will aim to permanently delete any audio files and transcribed electronic files within 2 weeks of your withdrawal.

### **Will you receive remuneration for participating in the study?**

You will not receive remuneration for participating in the study.

### **What are the potential benefits of your involvement?**

We cannot promise any personal benefits to you from your participation in this study. However, the information you share with us will be used to understand your perspectives regarding your caregiving role for your parent with dementia. This information will hopefully help gain a better understanding of the experiences of caregiving among adult children of persons with young-onset dementia. We hope this knowledge can inform the development future age-appropriate assists/supports intended for this population.

### **What are the possible risks and discomforts associated with this project?**

There is the potential for risks or discomfort associated with participation since the questions may ask you to recall a time that was stressful or distressing. If you experience any feelings of discomfort, please let the researcher know. You may also skip any questions you do not want to answer. As well, you may end your participation in the study at any time by advising the researcher of this decision.

### **Confidentiality and management of data**

Any identifying information will be removed from the data collection sheets and audio- and video- recordings that are collected. Audio- and video- recordings will be transcribed, confirmed for accuracy, and destroyed as soon as possible, and no later than two years after being recorded. Paper copies of study materials and data collected will be shredded once they have been transcribed electronically, as soon as possible, and no later than two years of being collected.

All electronic copies of study materials and data collected from you will be kept on a secure, encrypted server in the Faculty of Applied Health Sciences at the University of Waterloo. Transcriptions of the audio- and video- recordings will be kept for a minimum of 7 years. Your

name will not be included in any presentations or publications resulting from this study; however, with your permission, anonymous quotations from your interview may be used.

If you participate online, when information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

If you wish to withdraw consent to participate at any time, contact Camryn Berry at [c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca) / 519-503-2245. Only researchers associated with this study will have access to study records. All records will be destroyed according to University of Waterloo policy.

### **III. Questions, comments or concerns**

#### **Who is funding this study?**

This study is not receiving any funding.

#### **What are the potential costs of participation?**

There are no costs to participate.

#### **How will I find out about the findings from this study?**

If you are interested in receiving a summary of the study findings, we will ask for your email or mailing address and will send a copy of the summary when the results are available in mid-to-late 2021.

#### **Whom do I contact if I have questions or concerns?**

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42823). If you have questions for the Committee contact the University of Waterloo Office of Research Ethics at 1-519-888-4567 ext. 36005 or [ore-ceo@uwaterloo.ca](mailto:ore-ceo@uwaterloo.ca).

If you have questions about the study, please feel free to contact either Camryn Berry at [c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca) or Carrie McAiney at [carrie.mcainey@uwaterloo.ca](mailto:carrie.mcainey@uwaterloo.ca)

## Consent Statement: Verbal/Implied Consent

**Title of Study:** Perceptions of the Caregiving Role Among Young-Onset Dementia Adult Child Caregivers

**Local Principal Investigators, Department, Institution:**

Carrie McAiney, School of Public Health and Health Systems, University of Waterloo

**Student Researcher(s):**

Camryn Berry, School of Public Health and Health Systems, University of Waterloo

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By continuing with the interview, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

### **Participant**

I have read, and the researcher has explained verbally, the information presented in the information letter about a study for Camryn Berry's masters thesis being conducted by Camryn Berry and Carrie McAiney at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted. I am aware that I may withdraw from the study without penalty at any time by advising the researchers of this decision.

I consent to the following:

- To participate in an interview
- To having the interview audio-recorded to ensure accurate transcription
- To use anonymous quotations in any presentation or publication that comes from this research

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

- Please e-mail/mail me a summary of the results.

Contact information \_\_\_\_\_

- I do not wish to receive a summary of results.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42823) If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or [ore-ceo@uwaterloo.ca](mailto:ore-ceo@uwaterloo.ca)

## Appendix E

### Interview Guide

Can you tell me about your mom/dad?

How long ago was he/she diagnosed with dementia? What was that like for you?

When your mom/dad was diagnosed, what was happening in your life (in school or working? married? children?)

When your mom/dad was first diagnosed, did he/she need much assistance or support?

What is it/was like to be a caregiver for your mom/dad?

What do you find rewarding?

What do you find challenging?

Since your mom/dad was first diagnosed, have you used assistance/supports (e.g. support groups)?

Has being a caregiver for your mom/dad had an impact on your [education, job]?

Has being a caregiver for your mom/dad had an impact on your physical or mental health?

Has being a caregiver for your mom/dad had an impact on your relationships with family members or friends?

How has/did being a caregiver for your mom/dad affected your relationship with them?

When you have faced challenges or difficult times, what things have you done to cope with these experiences?

Do you know if your mom/dad experienced stigma because of their dementia?

Sometimes family members of people who are stigmatized can also experience stigma. Have you experienced stigma because your mom/dad had dementia?

Earlier in the interview you told me about what it has been like caring for your mom/dad. Has the COVID-19 pandemic impacted your caregiving role?

Is there anything else that you would like to add your role as a caregiver for your mom/dad that we haven't touched on?

What year were you born in?

What gender do you identify as?

What ethnicity are you?

How long have you been providing care to your mother/father?

Do you still live with your mother/father?

It can be difficult to find adult children of parents with YOD who are interested in participating in this study. Is there anyone else you know that is a YOD adult child caregiver who might be interested in participating in this study? If yes, would you be willing to share information about the study with them?

Do you have any questions before we wrap up?

## Appendix F

### Oral Consent Script

#### **Introduction:**

Hello. My name is Camryn Berry. I am conducting research about adult children who have a parent with young-onset dementia. This study is being conducted for my masters thesis at the University of Waterloo's School of Public Health and Health Systems in Waterloo, Ontario. I'm working under the supervision of Dr. Carrie McAiney of the University of Waterloo's department of Public Health and Health Systems.

Thank you for your interest in participating in my research.

*[If the LOI was provided in advance]*

Have you had time to read the Letter of Information I sent you?

*[If the LOI was provided in advance and the participant responds that they have read the LOI]*

Great, then I would like to take a moment to review some main points from the Letter of Information before we continue. *[Proceed to review the highlights of the LOI, be sure to include risks and what will happen with their data, and confirm the important points about voluntary participation and withdrawal listed below.]*

*[If it is not possible to give an LOI to the participant, or if the LOI was not sent in advance, or the participant responds that they did not read the LOI in advance, then proceed to go through the full LOI in detail with the participant and confirm the important points about voluntary participation and withdrawal listed below.]*

#### **Confirm the following to the participant:**

- Your participation in this study is voluntary.
- If you do not want to answer some of the questions you do not have to, but you can still be in the study.
- You can decide to stop at any time, even part-way through the interview. You do not need to provide a reason.
- If you do decide to end your participation in the study, your data can be destroyed if requested but this cannot be guaranteed if data analysis has already begun. Data analysis will start once all interviews have been completed.

- If you decide to withdraw from the study, the research team will aim to permanently delete any audio and video files and transcribed electronic files within 2 weeks of your withdrawal.
- Any identifying information will be removed from the data collection sheets and audio- and video- recordings that are collected. Audio- and video- recordings will be transcribed, confirmed for accuracy, and destroyed as soon as possible, and no later than two years after being recorded. Paper copies of study materials and data collected will be shredded once they have been transcribed electronically, as soon as possible, and no later than two years of being collected.
- All electronic copies of study materials and data collected from you will be kept on a secure, encrypted server in the Faculty of Applied Health Sciences at the University of Waterloo. Transcriptions of the audio- and video- recordings will be kept for a minimum of 7 years. Your name will not be included in any presentations or publications resulting from this study; however, with your permission, anonymous quotations from your interview may be used.
- If you participate online, when information is transmitted over the internet privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies, hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.
- This study has been reviewed and cleared by the University of Waterloo Research Ethics Board (ORE #42823).

Do you have any questions or want me to go over any study details again?

**Consent questions:**

Do you agree to participate in this study?

If yes,

- Would you like a summary of the study results? If yes, where should we send them (email, mailing address)?
- Do you agree to audio and video recording?
- Do you agree to allow your anonymous quotations from your interview to be used in the study?

If no, “Thank you for your time.”

## Appendix G

### Letter of Appreciation

Dear (Name of Participant),

I would like to thank you for your participation in this study, **Perceptions of the Caregiving Role Among Young-Onset Dementia Adult Child Caregivers**. As a reminder, the purpose of this study is to describe the perceptions of the caregiving role from the perspective of adult child young-onset dementia caregivers. By gaining a better understanding of the experiences of caregiving among adult children of persons with young-onset dementia, we hope this knowledge can inform the development future age-appropriate assists/supports intended for this population. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE #42823). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or [ore-ceo@uwaterloo.ca](mailto:ore-ceo@uwaterloo.ca).

For all other questions contact Camryn Berry at 519-503-2245 or by email at [c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca) or Dr. Carrie McAiney at [carrie.mcainey@uwaterloo.ca](mailto:carrie.mcainey@uwaterloo.ca) or (519) 888-4567 ext. 45642

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving a summary of the findings from this study, please provide your email address to Camryn Berry ([c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca)), and when the study is completed, anticipated by mid-to-late 2021, I will send you a summary. In the meantime, if you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below.

Sincerely,  
Camryn Berry

School of Public Health and Health Systems  
University of Waterloo  
519-503-2245  
[c3berry@uwaterloo.ca](mailto:c3berry@uwaterloo.ca)

### Helpful Resources

If you want to learn more about what services may be available, please see these resources below.

- ❖ Family doctor
- ❖ Alzheimer's Society

- ❖ Dementia Advocacy Canada
- ❖ <https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself/resources-young-carers>
- ❖ <https://the-ria.ca/resources/young-carers-project/>