A CRITICAL EXAMINATION OF ACCESS TO YOUNG ONSET DEMENTIA DIAGNOSTIC AND SUPPORT SERVICES

by

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Abstract

People living with young onset dementia and their families have high needs for support, but experience difficulties accessing services. This dissertation critically examines access to diagnostic and support services for people with young onset dementia drawing on in-depth interviews with those living with the condition, family members and providers. In addition, this research aims to advance understanding of inclusive approaches to dementia research through a review of the literature on safe research practices and reflections on the research process.

To develop a framework for including participants with young onset dementia, the first study in this dissertation critically reviewed approaches to promote the participation of people with dementia in qualitative research. This review identified a range of issues that impact safety such as: language, gatekeepers, the research relationship, communication, dealing with distress, knowledge dissemination, and researcher skills. In addition to contributing to the literature on inclusive methods, findings from this review informed the design of the ensuing qualitative study involving participants with young onset dementia.

Next, I conducted an empirical, qualitative inquiry into access to diagnostic and support services for people with young onset dementia in Winnipeg, Manitoba. In-depth, semi-structured interviews were conducted with six people living with young onset dementia, 14 family members and 16 health and service providers. Findings were analyzed using inductive thematic analysis and using the candidacy framework as a conceptual lens. Participants' accounts revealed complex barriers that constrained access to services and generated ongoing challenges for families. Age restrictions and eligibility criteria geared towards older adults systematically excluded younger individuals with dementia, creating barriers to care. Developing dementia at an early age also affected how participants identified with services and how they, in turn, were perceived by providers. Access was further constrained by contextual factors such as fragmentation, resource limitations and the underrepresentation of young onset and rare dementias. Together, these findings highlight the need for coordinated, family-centred services alongside the broader representation of young onset and rare dementias in research, policy and practice.

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For my mother, my inspiration.

And for Jacob, my everything.

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Preface

My Starting Point

My mother developed the first signs of dementia at the age of 50. I was 15 at the time. She was initially diagnosed with multiple sclerosis, but as her cognitive symptoms progressed in the absence of physical problems, that diagnosis was called into question. For five years my mother saw specialist after specialist, but her condition remained a mystery. After exhausting all options in Winnipeg, my family took her to the Montreal Neurological Institute, where she was diagnosed with dementia.

When I think about the impact of a dementia diagnosis, I often return to the moment, the transformative moment, when my mother's diagnosis was made clear. Over the previous years, doctors had mentioned the possibility of dementia, Alzheimer's disease, and even rarer conditions like Creuzfeldt-Jakob disease. But this was the first time the diagnosis was delivered with certainty. My family and I were crammed into a small examination room at the Montreal Neurological Institute. After completing his assessment, the neurologist looked at my 55-year-old mother and said: "You have a progressive dementia that will continue to progress until you die." The finality of the statement shocked us. Until then, doctors had spoken of her "cognitive impairment". Though disquieting, the concept did not carry the same progressive and terminal quality.

I remember the overwhelming force of her physician's statement, and the stress and sadness it brought. Yet, there was also a sense of relief. For the first time, dementia was not presented as a question, a possibility, another referral. We had travelled from Winnipeg to Montreal to seek diagnostic clarity, and after five years of seeing specialist after specialist, the question of my mother's illness – what it was and where it would ultimately take her – was finally put to rest.

In the months and years that followed, I often reflected on the meaning and impact of a dementia diagnosis. From my perspective, it provided a (limited) framework for understanding the changes that my mother experienced, and a broad sketch of the changes to come. It altered how we viewed our roles and relationships within our family. My father came to see himself as a caregiver, and eventually I did too. It also changed my mother's prospects for care and support.

Suddenly, things like home care, adult day programs and nursing homes were on the horizon. At the same time, it seemed like my mother's diagnosis closed more doors than it opened.

After she was diagnosed with dementia, my mother lost her status as a patient of a multiple sclerosis clinic. She no longer had a specialist who saw her on a regular basis, and no one followed up to determine her dementia subtype. Our family no longer benefitted from meetings with the clinic social worker or occupational therapists. There were other losses too. Eventually, my mother stopped participating in the therapeutic and recreational programs for people living with multiple sclerosis that she had previously enjoyed. As her symptoms of dementia worsened, the programs were no longer able (or willing) to accommodate her.

In contrast to her experience following her diagnosis of multiple sclerosis, my mother and our family did not identify with the dementia community in the same way. In fact, for years, I viewed my mother's condition as a mysterious anomaly; as far as we were concerned, she might be the only person in the world to develop dementia at age 50. That perception was challenged a few years later, in 2007, when my father sent me an article from *The Globe and Mail* about frontotemporal dementia. Titled, "A disappearing dad" (Hartley, 2007), the article profiled a man in his forties who had developed frontotemporal dementia and reported on Canadian research on the disease. It struck me: there are others out there, with similar symptoms, and specific diagnoses. Over the following years, I saw more and more examples of younger people with dementia in the news, books, film, and social media. I realized that my family was not alone, and that many others had also encountered difficulties accessing a diagnosis and supports.

While I was considering potential research projects for my PhD, I encountered a small but burgeoning literature on young onset dementia. At the time, there were only a handful of studies, primarily from Europe. Still, I was moved by the power of research to document and make visible a seemingly hidden population and illness experience. This discovery inspired me to focus my doctoral research on young onset dementia, and to contribute to this growing field of research. In addition to furthering understanding of access issues, my hope is that this project raises the visibility of people with young onset dementia in Manitoba, and serves as a tool for future advocacy and service development.

Publication Information and Author Contributions

Two of the chapters contained in this dissertation have been published in academic journals. Publication information and author contributions are listed below:

1. An adapted version of Chapter Four was published in the journal *Dementia*. I conceptualized the study, conducted the analysis, and wrote the manuscript. My co-author, Professor Heather Wilkinson, provided feedback and revisions on the manuscript. My supervisor, Dr. Verena Menec, provided guidance on the conceptualization of the study. I also received constructive feedback on the manuscript from journal reviewers.

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2. An adapted version of Chapter Six has been published in the journal *Qualitative Health Research*. I was solely responsible for conceptualizing this work, conducting data collection, data analyses, and writing the original manuscript. My supervisor, Dr. Verena Menec, provided feedback on the study design, analyses, and the manuscript. I also received constructive feedback on the manuscript from journal reviewers.

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Chapter 1. Introduction

At the South West German Psychiatrists meeting in 1906, the psychiatrist and neuropathologist, Alois Alzheimer, presented the case of an unusual brain disease observed in a 51 year old female (Alzheimer, Förstl, & Levy, 1991). The patient, who would later be identified as Auguste Deter, had developed severe and rapidly progressive cognitive impairment and neuropsychiatric symptoms (Alzheimer, 1987). After her death in 1906, pathological examination of her brain revealed atrophy, senile plaques and neurofibrillary tangles (Alzheimer, 1987). This was not the first time these pathological changes had been identified in a patient with dementia; Alzheimer himself had observed plaques in the brains of patients with senile dementia (Alzheimer et al., 1991). What was remarkable about Auguste Deter's case, was her age (Ballenger, 2006).

Although dementia is widely considered a disease of old age, younger people with dementia played a seminal role in the modern understanding of dementia. Alzheimer's discovery of dementia and neuropathological changes in a woman in her 50s challenged the dominant view of dementia as an outcome of senility, and sparked an ongoing debate about the relationship between dementia and aging (Ballenger, 2006; Holstein, 1997). Though scientists at the time recognized the clinical and pathological similarities between Deter's case and those of older adults with senile dementia, the association between dementia and aging was so entrenched that they were deemed to be two distinct entities. So, on the basis of age, Alzheimer's disease became an obscure and rarely diagnosed form of presenile dementia and the much broader concept of senile dementia persisted (Ballenger, 2006).

More than half a century later, in the 1970s, an expert consensus removed the age criteria for Alzheimer's disease and the previously obscure condition was transformed into a leading cause of death and disability associated with aging (Ballenger, 2006; Katzman, 1976). Over the next few decades, the concept of "senile dementia" was replaced with a biomedical model of dementia as specific disease processes (Ballenger, 2006). Age was no longer conceived of as a cause of dementia, or a criterion for diagnosis. Instead, age came to be understood as the primary risk factor for the major subtypes of dementia. The incidence of dementia increases exponentially with age; it is estimated to double with every 5-year increment in age in adults over 65 (Prince et al., 2015). Thus, while age is no longer understood as the underlying cause of dementia, dementia is still viewed as a disease of old age.

In recent years, dementia has begun to receive global attention comparable to other major diseases (Joanette, Hirsch, & Goldman, 2014; World Health Organization, 2012; Wu et al., 2016). The emergence of dementia as a major global health issue has been driven by concerns that population aging will lead to dramatic increases in the global prevalence of dementia resulting in significant health, social and economic consequences (World Health Organization, 2012; Wu et al., 2016).

In contrast to the growing global spotlight on dementia and aging populations, young onset dementia has received relatively little attention. The predominant view of dementia as a disease of old age, coupled with concerns about population aging, has overshadowed the presence of dementia in younger age groups and the needs and experiences of this population. Epidemiological data on young onset dementia is scarce and knowledge of the experiences and care needs of people with young onset dementia remains limited. Despite the paucity of empirical research, there is a growing recognition that people with young onset dementia constitute a significant subpopulation with distinct needs and barriers to services (World Health Organization, 2012).

Though limited, the literature on young onset dementia is growing (Bakker, de Vugt, van Vliet, Verhey, Pijnenburg, Vernooij-Dassen, & Koopmans, 2014; Beattie, Daker-White, Gilliard, & Means, 2004; Keady, Williams, & Hughes-Roberts, 2007; Kurz et al., 2016; van Vliet et al., 2011; Withall et al., 2014). The available research points to profound social, psychological and financial impacts on the entire family, high levels of unmet need, and barriers to care. Since young onset dementia strikes at midlife, affected individuals are often forced to give up employment, and they may not be prepared for early retirement, or eligible for the same benefits as older adults. Many people with young onset dementia have dependent children living at home, raising concern about the impact of the disease on the wellbeing of children and young adults, and the absence of support services to meet their needs (Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey, & de Vugt, 2014).

Compared to older adults with dementia, younger people appear to encounter additional barriers to care, including receiving an accurate diagnosis, obtaining information about the disease, and accessing health and support services (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013; Millenaar, Bakker, et al., 2016; Novek, Shooshtari, & Menec, 2016; van Vliet et al., 2011;

van Vliet et al., 2013; Williams, Dearden, & Cameron, 2001). Diagnostic delays, the lack of specialized services, and the stigma associated with dementia are thought to contribute to the stress and isolation experienced by people with young onset dementia and their families, and impede informed care planning (Ducharme et al., 2013; van Vliet et al., 2011).

These findings underline the need for improved diagnostic services, specialized supports, and family-centred approaches to care. Meeting this challenge requires a better understanding of the access issues, care experiences and support requirements of affected individuals and families. To date, much of the literature on health and support services has focused on family carers (Ducharme et al., 2014; Gibson, Anderson, & Acocks, 2014; van Vliet et al., 2011); comparatively few studies explore the views of people living with young onset dementia (Cations et al., 2017; Stamou et al., 2020). Broadening the inclusion of people living with young onset dementia in research is therefore critical to advance understanding of the lived experience of dementia and to ensure that affected individuals have opportunities to contribute to research, policy and practice (Hutchinson, Roberts, Roach, & Kurrle, 2020; Mayrhofer, Mathie, et al., 2020). Developing effective services also requires knowledge of the perspectives of health care and service providers, and the factors that impact the delivery of quality care to people with young onset dementia and their families.

1.1 Research Objectives

The principal aim of this dissertation is to critically examine access to diagnostic and support services for people with young onset dementia using in-depth interviews with individuals affected by young onset dementia, family members and providers. Applying the theoretical lens of the candidacy framework (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005), this research aims to contribute to a more comprehensive understanding of the complex processes that influence dementia care access, and to inform the development of more inclusive young onset dementia services. In addition, this dissertation aims to advance discussion of methods to promote the inclusion of individuals with dementia in qualitative research through a review of the literature and a reflection on the ethical and methodological aspects of my dissertation research.

Specifically, this dissertation is guided by the following three objectives:

Objective 1. To synthesize and critically appraise different approaches to support the inclusion and safe participation of people living with dementia in qualitative research.

Objective 1a. To use this literature review to guide the methods, research practices, and reflections on the research process undertaken for this dissertation.

Objective 2. To critically examine the process of accessing and delivering a diagnosis of young onset dementia using the candidacy framework as a conceptual lens.

Objective 3. To critically examine the processes that shape access to support services among individuals affected by young onset dementia using the candidacy framework as a conceptual lens.

Objective 1 was addressed through a literature review of strategies to support the safe participation of people with dementia in qualitative research (presented in Chapter 4). Objectives 2 and 3 were addressed through an exploratory, qualitative study that involved in-depth interviews with people living with young onset dementia, family members and providers (presented in Chapters 6 and 7).

1.2 Dissertation Overview

Chapter Two reviews the broad literature on young onset dementia, including its epidemiology, diagnostic challenges, support needs and service use, the experiences of people living with young onset dementia, and impacts on the family. The chapter ends with a discussion of emerging knowledge and critical gaps within the extant literature.

Chapter Three describes the conceptual framework guiding my analytic approach.

Chapter Four addresses Objective 1 and presents a review of the literature on strategies to promote the inclusion and safe participation of people with dementia in qualitative research. Findings from this review informed the methods and research practices undertaken throughout the qualitative study on access to young onset dementia diagnostic and support services presented in subsequent chapters.

Chapter Five describes the research design and methods used to address Objectives 2 and 3, including participant recruitment, data collection, and my approach to data analysis. This chapter

also includes a discussion of the ethical issues involved in including participants with dementia, and the methods and practices undertaken to support ongoing informed consent and well-being.

Chapter Six presents a critical examination of the process of accessing and delivering a diagnosis of young onset dementia from the perspectives of people living with young onset dementia, family members and health care providers.

Chapter Seven explores the processes that affect access to range of community-based supports from the perspectives of people living with young onset dementia, family members and health care providers.

Chapter Eight offers a reflection on the ethical and methodological dimensions of involving participants with dementia in this dissertation research. Addressing Objective 1a., I draw on the issues and strategies identified in Chapter Four to examine my observations and decisions throughout the research process.

Chapter Nine provides an overall discussion of the three studies presented in this dissertation, highlighting key findings and empirical and theoretical contributions. I also discuss research limitations, future directions for research and recommendations to improve young onset dementia services.

1.3 Language and Terminology

Throughout this dissertation, I use the term young onset dementia to refer to individuals who develop dementia before the age of 65. Other terms commonly used to refer to this population include early onset dementia and younger onset dementia. The terminology, construct and definition of young onset dementia remains a subject of debate (Carter et al., 2018; Koopmans & Rosness, 2014). To promote the use of consistent terminology, the International Psychogeriatric Association (IPA) task force on young onset dementia recommends using the term "young onset dementia" (Koopmans & Rosness, 2014). I chose to follow their recommendation, while also acknowledging the arbitrary nature of age cut-offs (See section 9.4 Research Limitations for a discussion of the construct of young onset dementia).

When referring to people with dementia, I use the terms: "people/person with dementia", "people/person living with dementia", "participant with dementia" and "participant living with

dementia." This language follows guidelines published by the Dementia Engagement and Empowerment Project (2015), the Canadian Alzheimer Society (2017), and the Alzheimer's Society UK (2018). Following the guidelines set forth by the Alzheimer's Society (2018) in the United Kingdom, I used varied phrasing to avoid contributing to the labelling of people with dementia (Alzheimer's Society, 2018).

Chapter 2. Review of the Literature

2.1 Dementia

Dementia refers to a neurodegenerative syndrome characterized by progressive impairment in cognitive function, including language, memory, behavior, visual spatial function, motor function, and the ability to perform activities of daily living (World Health Organization, 2012). Dementia does not refer to a specific disease; it is an umbrella term for a collection of symptoms caused by many different brain diseases (e.g. Lewy body dementia, Alzheimer's disease and vascular dementia).

2.2 Young Onset Dementia

Young onset dementia, also referred to as early onset dementia, or younger onset dementia, refers to cases where the onset of symptoms of dementia occurs at younger ages, typically defined as before the age of 65 years (Lambert et al., 2014; Withall et al., 2014). Compared to dementia in older adults, the causes of young onset dementia are more heterogeneous (Kuruppu & Matthews, 2013; Maiovis, Ioannidis, Konstantinopoulou, & Karacostas, 2015; Withall et al., 2014), and may include Alzheimer's disease, vascular dementia, frontotemporal dementia, dementia with Lewy bodies, alcohol-related dementia, prion diseases, traumatic brain injury, HIV infection, multiple sclerosis, Huntington's disease, Parkinson's disease and Down syndrome (Withall et al., 2014). Some studies identify Alzheimer's disease as the most common subtype of young onset dementia (Harvey, Skelton-Robinson, & Rossor, 2003), while others report higher rates of vascular dementia (Ikejima et al., 2009), frontotemporal dementia (Maiovis et al., 2015), and alcohol-related dementia (Withall et al., 2014).

2.3 Epidemiology of Young Onset Dementia

In 2019, the number of people living with dementia around the world reached an estimated 50 million people (Alzheimer's Disease International, 2019). This number is expected to double every twenty years, reaching 100 million by 2030, and 152 million by 2050 (Alzheimer's Disease International, 2019). Compared to late-onset dementia, epidemiological research on young onset dementia and its major subtypes is extremely limited. Individuals under 60 or 65 years of age are routinely excluded from epidemiological and population-based studies of dementia (Withall et al., 2014; World Health Organization, 2012). In 2007, an expert consensus in the United

Kingdom estimated that 2.2 percent of all cases of dementia occur before the age of 65 (Knapp & Prince, 2007), though a more recent report updated this figure to 5.2 percent of all dementia cases in the United Kingdom (Prince et al., 2014). Similarly, in 2012, the World Health Organization estimated that young onset dementia represents between 6 and 9 percent of all dementia cases (WHO, 2012). There are no available estimates of young onset dementia in Canada, and most international studies of young onset dementia rates are based on small registry studies, or extrapolated from research on older adults (Harvey et al., 2003; Withall et al., 2014; World Health Organization, 2012). The risk factors for young onset dementia are not well understood (Cations, Withall, Low, & Draper, 2016), and estimates of survival rates are sparse and inconsistent (Devineni & Onyike, 2015).

Studies of the prevalence and clinical profile of young onset dementia have produced variable results. A prevalence study conducted in London, England, reported prevalence rates of 51 per 100,000 in people aged 30 to 64, and 98 per 100,000 in those aged 45 to 64 (Harvey et al., 2003). In Japan, a study of young onset dementia prevalence in the Ibaraki prefecture found a similar rate of 54 per 100,000 in people aged 30 to 64 (Ikejima et al., 2009). More recent epidemiological studies of young onset dementia (Kvello-Alme, Bråthen, White, & Sando, 2019; Withall et al., 2014) report higher prevalence rates compared to past studies. A study by Withall et al. (2014) conducted in Eastern Sydney, Australia, reported prevalence rates of 68.2 per 100,000 among those aged 30 to 64, and 132.9 per 100,000 among people aged 45 to 64. Similarly, a population-based study of young onset dementia in central Norway estimated prevalence rates of 76.3 per 100,000 in people aged 30 to 64, and 163.1 per 100,000 in those aged 45 to 64 (Kvello-Alme, Bråthen, White, & Sando, 2019).

The subtypes of young onset dementia also vary across studies. While there is some consensus that Alzheimer's disease is the most common subtype of young onset dementia (Harvey et al., 2003; Kvello-Alme et al., 2019; Spreadbury & Kipps, 2019), Ikejima et al. (2009) reported higher rates of vascular dementia, and Withall et al. (2014) identified alcohol-related dementia as the most common subtype.

In each of the studies described above, prevalence rates were determined by the number of people diagnosed with young onset dementia, identified through local service providers, divided by the total census population within those age groups (Prince et al., 2014). This methodology

relies on diagnoses made and recorded by local care providers and assumes that all individuals with young onset dementia seek help early in the course of the illness and receive a timely diagnosis (World Health Organization, 2012). Given that diagnostic delays and misdiagnosis are common among people with young onset dementia (Draper et al., 2016; Novek et al., 2016; van Vliet et al., 2013), registry based studies are thought to systematically underestimate the true prevalence of young onset dementia (Prince et al., 2014; World Health Organization, 2012).

In fact, several population based studies of late-onset dementia that include individuals ages 60 to 64 have found significantly higher rates of dementia in this age bracket compared to registry-based studies of young onset dementia (Ott et al., 1995; Prince et al., 2014). Given this discrepancy, the World Health Organization (2012) surmised that the true prevalence of young onset dementia may be up to four times higher than the available epidemiological research reveals (World Health Organization, 2012). In short, the true proportion of the population living with young onset dementia is likely higher than previously thought. However, the current evidence base is insufficient to produce reliable estimates of young onset dementia prevalence.

2.4 Diagnosing Dementia

Access to a timely diagnosis is widely recognized as a critical component of dementia care policy and practice (World Health Organization, 2012). People with dementia themselves have called for improved diagnostic practices (Wilkinson & Milne, 2003), and evidence suggests that most people want to know their diagnosis and would prefer disclosure as early as possible (Prince, Bryce, & Ferri, 2011; Wilkinson & Milne, 2003). Although receiving a diagnosis is extremely difficult and often distressing for patients, it also marks "the first step in engaging coping strategies for living with, and managing, dementia effectively." (Wilkinson & Milne, 2003: 303).

Early diagnosis enables people to plan for the future while they still have the capacity to make decisions about their care, financial and legal matters, and other considerations such as participation in research (Connell, Boise, Stuckey, Holmes, & Hudson, 2004; World Health Organization, 2012). Diagnosis also facilitates access to symptom management and post-diagnostic services for patients and family members, including information, peer support groups, counselling, and community-based services such as home care or respite care (Prince et al.,

2011; World Health Organization, 2012). In settings with comprehensive dementia care services, a diagnosis should also lead to ongoing coordination and management of patient care from diagnosis to end of life (Prince et al., 2011).

Despite the push to improve diagnostic services, dementia diagnosis rates remain low and variable (Prince et al., 2011). According to a report by Alzheimer's Disease International, in high income countries, only 20 to 50 percent of dementia cases are identified and documented in primary care records (Prince et al., 2011). Using data from the Canadian Health and Aging Study, Sternberg, Wolfson, and Baumgarten (2000) found that dementia was undetected in almost two thirds of community dwelling older adults living with the condition in Canada (Sternberg, Wolfson, & Baumgarten, 2000). A more recent Canadian study focused on institutional environments found that 11.6 percent of long-term care residents in Ontario with no documented dementia diagnosis had severe cognitive and functional impairments suggestive of advanced dementia (Bartfay, Bartfay, & Gorey, 2013).

Studies investigating the barriers to dementia diagnosis have identified several contributing factors, including: the complexities and uncertainties of dementia diagnoses; the time required for assessment and disclosure; insufficient training for primary care practitioners; lack of knowledge about available services and resources; and therapeutic nihilism (i.e. the belief that nothing can be done for people with dementia) (Cahill et al., 2008; Prince et al., 2011; Wilkinson & Milne, 2003; World Health Organization, 2012). There is growing evidence that the stigma associated with dementia is a major barrier to diagnosis, as it delays people from seeking help and prevents diagnosis disclosure and honest communication on the part of physicians (Cahill et al., 2008; Prince et al., 2011; Vernooij-Dassen et al., 2005; Wilkinson & Milne, 2003). Research conducted in Canada has identified similar barriers to care within primary care settings (Aminzadeh et al., 2012; Pimlot et al., 2009). In rural settings, the availability of specialists and support services, as well as the time and costs required to travel to services, create additional barriers to diagnosis (Morgan et al., 2002).

2.5 Diagnosing Young Onset Dementia

People living with young onset dementia appear to encounter additional barriers to diagnosis, resulting in diagnostic delays, misdiagnosis, and treatment gaps. Using data from a national

survey of people living with neurological conditions, Novek et al. (2016) found that Canadians with young onset dementia waited three times longer than older adults to obtain a diagnosis of dementia. The period from symptom onset to diagnosis took an average of 4.4 years for individuals with young onset dementia, compared with 1.3 years among people with late-onset dementia. Similarly, a prospective cohort study of young onset dementia in the Netherlands found that patients under 65 years of age waited 4.4 years between the onset of symptoms and diagnosis, compared to 2.8 years among older adults with dementia (van Vliet et al., 2013). The INSPIRED study in Australia distinguished between initial diagnoses of dementia and the final diagnosis of a dementia subtype (Draper et al., 2016). Notably, the authors found that the median time for people with young onset dementia from symptom onset to initial dementia diagnosis was 3.2 years, while the time from symptom onset to final diagnosis of dementia subtype was 4.7 years (Draper et al., 2016). The authors also found that the median time from symptom onset to the first clinical consultation was 2.3 years, suggesting a long delay before individuals seek medical attention (Draper et al., 2016).

Several factors are thought to contribute to the diagnostic delays experienced by younger people with dementia, including the lack of awareness of young onset dementia among the public and health professionals, the broader differential diagnosis, differences in presenting signs and symptoms among younger people with dementia (e.g. higher rates of neuropsychiatric symptoms) (Koedam et al., 2010), and the absence specialist services for people with young onset dementia (Carter, Oyebode, & Koopmans, 2018; Ducharme et al., 2013; Luscombe, Brodaty, & Freeth, 1998; O'Malley et al., 2019; Rabanal, Chatwin, Walker, O'Sullivan, & Williamson, 2018; van Vliet et al., 2011; Williams et al., 2001).

As part of the NEEDYD cohort study of young onset dementia in the Netherlands, Van Vliet et al. (2011), analyzed interviews with 92 family carers about their experience of the diagnostic process**.** In the early stages of the illness, patients and their families often attributed the signs and symptoms of dementia to psychological issues, stress, or burnout at work. In most cases, the lack of awareness of dementia in mid-life, and misinterpretation of symptoms delayed help seeking. When patients did seek medical attention, they encountered multiple barriers from health care practitioners who commonly discounted their concerns, failed to refer them to a specialist, or misdiagnosed their condition as depression or stress (Van Vliet et al., 2011). A third of family

carers in the study reported that their family member received an erroneous diagnosis before they were diagnosed with dementia (Van Vliet et al., 2011).

Without services designed for younger people with dementia, there is no clear pathway to diagnosis for patients seeking an explanation of their symptoms. People with young onset dementia and their carers commonly describe being passed from specialist to specialist, including psychiatrists, geriatric psychiatrists, geriatricians and neurologists (Luscombe et al., 1998; Millenaar, Bakker, et al., 2016; Williams et al., 2001). Williams et al. (2001) identified 38 different referral pathways for people with young onset dementia in Leeds, England, out of a sample of 119 patients. The authors found that people with young onset dementia were commonly referred back and forth between and within psychiatry and neurology (Williams et al., 2001).

Certain populations may face additional barriers to diagnosis. For example, a qualitative study exploring supports for people with an intellectual disability and dementia by Herron et al. (2020) identified "diagnostic overshadowing" as a key impediment to timely diagnosis. The concept refers to the tendency to misattribute signs and symptoms of dementia to a person's intellectual disability. In addition, the authors found that the diagnostic process was constrained by the lack of baseline information about patients' cognitive functioning (Herron et al., 2020).

Research into the perspectives of people with young onset dementia and their carers have identified the diagnostic process as a significant source of stress and a key area for improvement (Allen & Oyebode, 2009; Ducharme et al., 2013; Johannessen & Möller, 2013; Millenaar, Bakker, et al., 2016; Rabanal et al., 2018; Roach, Drummond, & Keady, 2016; Sakamoto et al., 2017). The long and uncertain road to diagnosis is thought to contribute to distress and family conflict, and hinder access to care, information, services, and support (Chaston, 2011; Ducharme et al., 2013; Millenaar, Bakker, et al., 2016).

In light of the inadequacies of diagnostic services, researchers have recommended several strategies to facilitate timely diagnosis, such as increasing public awareness of the disease (Devineni & Onyike, 2015; van Vliet et al., 2011), improving knowledge of young onset dementia among clinicians (Devineni & Onyike, 2015; Novek et al., 2016; Withall et al., 2014) and developing multidisciplinary diagnostic services and specialized care teams for people with

young onset dementia (Chaston, 2011; O'Malley et al., 2019; Williams et al., 2001). Williams et al. (2001) argued that coordinated, multidisciplinary services for young onset dementia have the potential to streamline the diagnostic process, and provide continuity of care post-diagnosis. Although models of specialist young onset dementia care are emerging in places such as the United Kingdom and Australia (Cations & Day, 2020; Rodda & Carter, 2016; Spreadbury & Kipps, 2018), they remain rare, particularly in Canada.

2.6 The Perspectives of People with Young Onset Dementia

Much of the research on young onset dementia relies on the experiences and responses of family carers (Cabote, Bramble, & McCann, 2015; Ducharme et al., 2013; Ducharme et al., 2016; Gibson et al., 2014; Svanberg, Spector, & Stott, 2011; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010). Fewer studies have explored the experiences of people living with young onset dementia (Clemerson, Walsh, & Isaac, 2014; Harris & Keady, 2009; Johannessen & Möller, 2013; Sakamoto et al., 2017), their views of diagnostic and support services (Beattie et al., 2004; Cations et al., 2017; Rabanal et al., 2018; Stamou et al., 2020), or included their perspectives in program evaluations (Evans, Robertson, & Candy, 2016; Kinney, Kart, & Reddecliff, 2011). The paucity of research involving people with young onset dementia reflects the lack of attention to dementia in younger age groups, as well as the wider exclusion of people with dementia from research. Researchers and people living with dementia have challenged this practice, arguing that efforts to expand and improve services for people with young onset dementia require an understanding of the experiences, needs, and perspectives of people living with the condition (Beattie et al., 2004; Roach et al., 2016; Wilkinson, 2002).

Emerging research into the experiences of people living with young onset dementia highlights the emotional and psychological impact of the disease, the experience of stigma and social isolation, and the multifaceted barriers to care faced by people with young onset dementia and their families. Receiving a diagnosis of dementia, particularly at an unexpected age, can be devastating (Clemerson et al., 2014; Harris & Keady, 2009). Johannessen and Moller's (2011) qualitative study explored the everyday life of people living with young onset dementia in Norway. Study participants emphasized the psychological and emotional toll of obtaining a diagnosis for an incurable disease, and reported experiencing anxiety, embarrassment and even suicidal thoughts following diagnosis (Johannessen & Möller, 2013).

Dementia carries a powerful stigma that shapes the way people living with it perceive themselves, and how they are viewed and treated by others. Fear and stigma associated with dementia contributes to delayed help seeking on the part of patients and families, and often prevents diagnostic disclosure from health care practitioners (Cahill et al., 2008; Prince et al., 2011; Vernooij-Dassen et al., 2005; Wilkinson & Milne, 2003). Receiving a diagnosis of young onset dementia can injure a person's self-esteem and identity, and lead to social isolation and social exclusion (Clemerson et al., 2014; Greenwood & Smith, 2016; Harris & Keady, 2009; Spreadbury & Kipps, 2019; Sakamoto et al., 2017). Some people with young onset dementia report keeping their diagnosis a secret from friends and family out of shame and fear (Roach et al., 2016). Others have described avoiding social situations because of their impairments or difficulties communicating (Johannessen & Möller, 2013). People living with young onset dementia report that friends and family withdraw from them, leading to a sense of abandonment (Harris & Keady, 2009) and isolation (Beattie et al., 2004; Clemerson et al., 2014).

As the disease progresses, individuals affected by young onset dementia are faced with changes in their roles and relationships and encounter multiple losses including the loss of previous employment, the loss of the ability to drive, and the loss of the ability to carry out activities of daily living (Greenwood & Smith, 2016; Spreadbury & Kipps, 2019). Several studies have observed that these changes can have a profound impact on a person's self-image (Clemerson et al., 2014; Greenwood & Smith, 2016; Harris & Keady, 2009). For example, Harris and Keady (2009) found that young onset dementia posed a threat to participants' sense of self and disrupted multiple facets of their identity, including their identity as spouses, parents, and workers. Clemerson, Walsh and Isaac (2014) point out that these losses may be particularly pertinent when dementia occurs during mid-life, as it impairs the ability to fulfil age-related goals and social norms. These findings suggest that the experience of dementia should be interpreted within the broader context of an individual's life course, and highlight the need for psychosocial supports to assist people with young onset dementia cope with changing abilities and social roles.

2.7 Support Services for People with Young Onset Dementia

Research suggests that people with young onset dementia and their families have high needs for support, but face barriers to service use (Bakker, de Vugt, van Vliet, Verhey, Pijnenburg,

Vernooij-Dassen, & Koopmans, 2014; Bakker et al., 2013; Greenwood & Smith, 2016; Millenaar, Bakker, et al., 2016; Svanberg et al., 2011). Emerging research on service use suggests low uptake among people affected by young onset dementia and their families (Bakker et al., 2013; Cations et al., 2017; Gibson et al., 2014). Based on a survey of young onset dementia carers in Ohio, Gibson et al. (2014) found that over two thirds of respondents were not using any type of formal service. The study, however, did not examine the reasons for low uptake. Bakker et al. (2013) examined the relationship between patient and carer characteristics and patterns of informal and formal service use in the Netherlands. The authors identified a pattern of postponing service use until advanced stages of the illness. Based on this finding, Bakker et al. (2013) inferred that families were waiting to access formal services until care needs could not be met within the family. As part of the INSPIRED study in Sydney, Australia, Cations et al. (2017) analyzed the use of community services among individuals with young onset dementia and their supporters using survey and focus group data. Two thirds of survey respondents chose not to use one or more recommended services. The authors identified several barriers to service uptake such as a lack of perceived need, limited availability, age-restrictions, affordability, and a lack of childcare (Cations et al., 2017).

At the same time, there is growing evidence that people with young onset dementia value and benefit from participating in specialized programs. Beattie et al. (2004) explored the views of people living with young onset dementia on services in southwest England. Participants in the study valued services designed for younger people with dementia and expressed negative views of care and services for older adults. For example, participants who took part in day programs specifically for people with young onset dementia valued the program and the opportunity to socialize with other people living with the same condition.

Similarly, van Vliet et al. (2017) conducted focus groups among people attending specialized day programs for young onset dementia in the Netherlands, as well as their carers. The authors found that the programs helped members feel useful, socially engaged, and develop positive coping strategies. Notably, they found that the benefits of day programs changed over the course of the illness. Initially, participants emphasized the need for purposeful activities that helped them feel useful. In the later stages of dementia, however, participants' preferences shifted towards staying socially engaged through recreational opportunities (van Vliet et al., 2017).

Phinney et al. (2016) conducted an ethnographic study in Vancouver, Canada to examine the impact of a recreational program for people with young onset dementia on social citizenship. Drawing on the theoretical work of Bartlett and O'Conner (2010), the authors used a social citizenship lens to explore how community-based programs provide opportunities for people living with dementia to exercise agency and participate in public life. The authors found that the practice of walking in community spaces facilitated a sense of community-belonging and engagement, which ultimately positioned members as social citizens (Phinney et al., 2016).

A recent study by Stamou et al (2020) examined positive post-diagnostic support experiences using data from a national survey of people living with young onset dementia and their carers in the United Kingdom. In total, 233 respondents reported on their experiences of supports. The authors identified a range of positive experiences and benefits associated with post-diagnostic supports, such as maintaining physical and mental health, social participation, access to economic resources, and opportunities to engage in research and activism. Based on these findings, the authors concluded that access to a wide range of effective support creates a safety-net that enables people with young onset dementia to maintain important aspects of selfhood and identity.

A small number of evaluation studies have included the perspectives of people with young onset dementia (Kinney, Kart and Reddecliff, 2011; Evans, Robertson, and Candy, 2016). Kinney, Kart and Reddecliff (2011) evaluated a program for people with young onset dementia in Ohio that involved weekly supervised volunteer work at a local zoo. Analysis of interviews with six participants suggested that they identified with the program and valued the opportunity to socialize and participate in meaningful activities. The spouses of participants also felt that their partners derived benefits from the program and valued the respite it provided. Evans, Robertson, and Candy (2016) evaluated a workplace program for people with young onset dementia at a hardware store in Australia. Participants described feeling useful and productive, and commented on the friendships they formed through participating in the program. These studies point to the potential benefits of programs that provide opportunities to meet other people with young onset dementia and to participate in meaningful activities. While these results are promising, research into community-based programs and their impact on people with young onset dementia remains limited.

2.8 The Impact on Families

The available research on young onset dementia points to profound social, psychological and financial impacts on the entire family, as well as unique needs and barriers to care. The difficulties encountered by families usually begin long before a diagnosis of dementia is conferred, and in most cases, the challenges that families must navigate continue for years. Over time, families must cope with employment and financial losses, changing roles and relationships within the family, and the provision of increasing levels of care to accommodate a progressive and disabling condition. Family members of individuals with young onset dementia frequently report chronic stress (Ducharme et al., 2016; Kaiser & Panegyres, 2006); psychological and emotional distress (Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey, & de Vugt, 2014; van Vliet et al., 2010); feelings of guilt, anger and frustration (Roach et al., 2016); family conflict (Flynn & Mulcahy, 2013; Hutchinson et al., 2016; van Vliet et al., 2010); mental health problems (Bakker, de Vugt, van Vliet, Verhey, Pijnenburg, Vernooij-Dassen, & Koopmans, 2014; Ducharme et al., 2013; Svanberg, Stott, & Spector, 2010); and social isolation (Ducharme et al., 2013; Kaiser & Panegyres, 2006; Roach, Keady, Bee, & Williams, 2014). Diagnostic delays, the lack of specialized services, and the stigma associated with dementia are thought to exacerbate the stress and isolation experienced by family members and impede informed care planning and effective coping strategies (Ducharme et al., 2013; van Vliet et al., 2011).

A substantial body of evidence indicates that the stress experienced by family members caring for a person with dementia is associated with negative psychological and physical health outcomes (Schulz & Martire, 2004; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Vitaliano, Zhang, & Scanlan, 2003). Family carers have a heightened risk of social isolation (Shulz et al., 1995), psychological distress and psychiatric morbidity (Pinquart & Sorensen, 2007; Schulz et al., 1995), unhealthy behaviours (Vitaliano, Zhang, and Scanlan, 2003), and overall health deterioration (Pinquart and Sorensen, 2003; Shulz et al., 1995; Vitaliano, Zhang, and Scanlan, 2003).

Compared to the vast body of research on carers for people with dementia, the literature on caregiving for individuals with young onset dementia is limited. The available evidence, however, suggests that caregiving for someone affected by young onset dementia is associated

with high levels of stress (Ducharme et al., 2016; Kaiser & Panegyres, 2006), depressive symptoms (Arai, Matsumoto, Ikeda, & Arai, 2007; Freyne, Kidd, Coen, & Lawlor, 1999; Millenaar, de Vugt, et al., 2016), carer burden (Arai et al., 2007; Freyne et al., 1999; Uflacker, Edmondson, Onyike, & Appleby, 2016), and low health related quality of life (Millenaar, de Vugt, et al., 2016).

Although there is some evidence to suggest that family carers for individuals with young onset dementia experience more caregiver burden or health-related impacts compared to those caring for older adults with dementia (Freyne et al., 1999), the empirical evidence is mixed (Millenaar, de Vugt, et al., 2016) (Arai et al., 2007; Ducharme et al., 2016; Freyne et al., 1999; Millenaar, de Vugt, et al., 2016). Freyne et al. (1999) conducted the first published study comparing caregiver burden among carers for individuals with young onset dementia and late-onset dementia in Ireland, showed significantly higher caregiver burden among young onset dementia carers. However, the study has several important limitations. Young and late-onset dementia carers differed significantly in terms of care duration, which may have confounded the results (Freyne et al., 1999). The small sample size included 22 people with young onset dementia and their carers, and an undisclosed number of participants with late-onset dementia and their carers. Despite its limitations, this study is often cited as evidence of the greater burden experienced by young onset dementia carers.

Similarly, using data from the longitudinal NEEDYD study in the Netherlands, Millenaar et al. (2016) found that caregiving for individuals with young onset dementia, versus later onset dementia, was associated with lower health-related quality of life (both the physical and mental health components). No differences between the two groups were found for depressive symptoms, sense of competence, and physical health symptoms (Millenaar, de Vugt, et al., 2016).

Arai et al.'s (2007) cross-sectional study compared patients and carers with young and late-onset dementia recruited through an outpatient clinic at Ehime University Hospital in Japan. In contrast to Freyne et al. (1999), the authors did not find a significant difference in caregiver burden between the two groups. However, carers for patients with young onset dementia were more likely to report difficulties dealing with behavioural issues (Arai et al. 2007). On the other hand,

the study found no clinical differences between patients with young and late-onset dementia in terms of illness severity or behavioural symptoms.

Ducharme et al. (2016) conducted a cross-sectional study of carers for patients with young onset dementia (n=48) and late-onset dementia (n=48) who attended cognitive clinics throughout Quebec. Compared to the older adult group, young onset carers were caring for individuals with more heterogeneous types of dementia, and more severe cognitive and functional impairments. However, they found no significant differences in terms of psychological distress, informal supports, role confidence and self-efficacy (Ducharme et al., 2016).

2.9 The Experiences of Children

Emerging research on the experiences of children of parents affected with young onset dementia points to significant impacts on children. When a parent develops dementia, his or her children are "confronted with a parent who has a progressive disease that causes changes in personality, behavior and cognition." (Millenaar et al., 2014: 2001). For many children affected by young onset dementia, their adolescence and young adulthood is marked by grief, loss, stress, family conflict, and increasing responsibility for their parent (Hutchinson et al., 2016; Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey, & de Vugt, 2014; Svanberg et al., 2010). Some children, even at very young ages, take on significant caregiving roles (Allen & Oyebode, 2009; Hutchinson et al., 2016). This can impact their performance in school, relationships with family and friends, and their mental health. It can also disrupt their education or career plans if they have significant caregiving responsibilities, or need to work to support their families (Hutchinson et al., 2016).

Several scholars have raised concerns about the potential impact of young onset dementia on development and mental health outcomes (Hutchinson et al., 2016; Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey, & de Vugt, 2014; Svanberg et al., 2010), but the long-term effects of young onset dementia on children remain unknown. A growing number of qualitative studies have explored the experiences of children of individuals affected by young onset dementia (Hutchinson et al., 2016; Millenaar et al., 2010; Svanberg et al., 2010). These studies point to the profound psychosocial impacts of living with a parent with dementia, and highlight the need for family-centered dementia services.

Svanberg, Stott and Spector (2010) studied the experiences of children ages 11 to 18 living with a parent with young onset dementia (n=12) in the United Kingdom. Participants in the study experienced ongoing grief and loss, and many took on caregiving and adult responsibilities. Several participants reported social isolation, problems in school, and fatigue. Over half of the participants in the study scored above the cut-off for high levels of caregiver burden, and four out of 12 scored above the cut-off for a mood disorder. Although these findings are based on a very small sample, they raise important questions about the potential impact of young onset dementia on the mental health of children and young adults.

Millenaar et al. (2014) conducted a qualitative study (n= 14) with children of participants with young onset dementia enrolled in the prospective NEEDYD study in the Netherlands. The experience of dementia impacted participants' relationships with other family members, led to chronic stress, and placed significant demands on children. The authors expressed concern over the potential negative psychological effects associated with caregiving and taking on adult responsibilities. These findings highlight the need to develop family-centred services that support children affected by young onset dementia and provide age-appropriate information and counselling.

Hutchinson, Roberts, Kurrle and Daly (2016) explored the lived experiences of 12 young people in Australia (ages 10 to 33) who had a parent with young onset dementia. Interviews with participants revealed that the majority performed caring work, and several provided high levels of care to their affected parent. All participants in the study reported some degree of psychological distress, and many described difficulty coping with grief, family conflict and problems at school. The stigma associated with dementia extended to children who described experiences of embarrassment, discrimination, and social isolation. Certain forms of young onset dementia such as Alzheimer's disease and frontotemporal dementia can be caused by a genetic mutation that can be passed on to children. For some children, the genetic risks associated with young onset dementia added to their anxiety and experience of stigma (Hutchinson et al., 2016).

Although limited in scope, the available literature highlights the vulnerability of children and young adults affected by young onset dementia, and the absence of support services to meet their needs. Children are profoundly affected by dementia, and many make significant contributions to the care of their parent. Yet, they remain underrepresented in research and within health and

support services. Further research into the experiences and support requirements of children is needed to inform the development of family-centred approaches to dementia care. In addition, longitudinal research is required to investigate the long-term impacts of young onset dementia on children and families.

2.10 Financial Impacts

Dementia is a costly disease, with significant financial ramifications for affected individuals and families (Roach, Keady, Bee and Hope, 2009; Wheeler, Allen and Bentham, 2015; Luscombe; Kaiser and Panegyres, 2007; Van vliet et al. 2010). For people with young onset dementia, the economic costs appear to be higher, with one study reporting a doubling of economic losses compared to older adults with dementia (Kandiah et al., 2016). In addition to the costs of long-term care and other out of pocket expenses, younger individuals are far more likely to incur lost income due to the illness or caregiving responsibilities (Allen & Oyebode, 2009). Given their age, people with young onset dementia are often forced to give up employment earlier in life than expected, and they may not be financially prepared for early retirement, or eligible for the same benefits as older adults. For many people with young onset dementia, their earliest symptoms manifest as problems in the workplace (Ducharme et al., 2013, Van Vliet 2011). Without a diagnosis or explanation for their behavior, some people with young onset dementia are fired from their jobs, which may render them ineligible for employment insurance (Wheeler, Allen and Bentham, 2015). If the person with dementia is the primary income earner, the economic consequences for themselves and their families may be severe.

As the disease progresses, family carers may also have to reduce their hours or give up employment in order to provide care for the person living with dementia (Allen & Oyebode, 2009). Alternatively, spouses may have to take on additional employment, which can be particularly stressful if their partner has high care needs (Allen & Oyebode, 2009). In some cases, children may become financially responsible for their families (Allen & Oyebode, 2009).

With few exceptions (Kandiah et al., 2016), the financial consequences of young onset have not been examined in depth. However, the economic impact on the family is consistently identified as a key theme in qualitative studies of young onset dementia (Allen & Oyebode, 2009; Roach, Keady, Bee and Hope, 2009; Wheeler, Allen and Bentham, 2015; Ducharme, 2013; Van Vliet et

al. 2010) and has been identified as a priority issue for carers surveyed in the United States (Gibson, Anderson and Acocks, 2014) and Australia (Luscombe et al., 1998). These findings suggest that assistance with employment, financial planning and accessing benefits should be offered by services for people with young onset dementia and their families.

2.11 Discussion

The developing literature on young onset dementia suggests that younger people with dementia and their families encounter multiple barriers to care, including receiving an accurate and timely diagnosis, obtaining information about the disease, and accessing support services. Several factors are thought to contribute to these access challenges including the predominant view that dementia is a disease of old age, the lack of awareness of young onset dementia among health professionals, the stigma associated with dementia, and the absence of specialized young onset dementia services. In addition to the impairments brought on by the disease, people with young onset dementia must cope with the stigma of their illness, the loss of employment and other meaningful activities, changes in their familial roles and relationships, and increasing social isolation. Despite the profound psychosocial impacts reported by people living with young onset dementia, specialist care and post-diagnostic supports are rare. Instead, most people with young onset dementia seek care and support from services that are not designed to meet their needs, and from providers who do not have specialized knowledge of their health condition.

The stigma and marginalization experienced by people with young onset dementia extends throughout their families and support networks. Family members have expressed frustration with the health care system, the lack of resources for people with dementia, and the lack of awareness of dementia in younger age groups (Hutchinson et al., 2016). Research into the experiences of children and spouses suggests that they have significant unmet needs for care such as access to information about dementia and genetic counselling, assistance with financial and legal matters, and access to support services for people their age. These findings underline the need for improved diagnostic and support services, along with family-centred approaches to care. Meeting this challenge requires a better understanding of the experiences, needs and preferences of people living with young onset dementia and their family members.

Overall, research on young onset dementia is expanding, but critical gaps in the literature remain. The lack of epidemiological data reinforces the view that young onset dementia is rare and impedes evidence-based policy and service development. Though limited, there is growing evidence of diagnostic barriers (O'Malley et al., 2019; Rabanal et al., 2018; van Vliet et al., 2011; van Vliet et al., 2013), as well as difficulties accessing dementia supports (Cations et al., 2017; Greenwood & Smith, 2016; Mayrhofer, Mathie, McKeown, Bunn, & Goodman, 2018; Millenaar, Bakker, et al., 2016). Few studies, however, have focused specifically on access issues, or included the perspectives of people living with young onset dementia (Beattie et al., 2004; Cations et al., 2017). This dissertation aims to address these gaps in the literature by critically examining the access experiences of people affected by young onset dementia, family members and providers.

Chapter 3. Conceptualizing Access to Health Services: The Candidacy Framework

Analysis of access to health care services within the extant literature on young onset dementia remains largely undertheorized. Research to date has been limited to either measures of service utilization (e.g. the number of formal services used, or the length of time between symptom onset and receipt of diagnosis); or a description of barriers and facilitators to health and support services. Dixon-Woods et al. (2006), critique utilization studies, arguing that they rely on untested normative assumptions about the correct level of utilization and estimates of need. For example, measures of formal service use among people with young onset dementia are difficult to interpret without knowledge of appropriate service use levels. Descriptive analyses of barriers and facilitators also employ narrow conceptualizations of access (Chase, Cleveland, Beatson, & Rousseau, 2017), overlooking the complex social and contextual factors that influence access over time. Based on a review of models of dementia care access, Pratt, Clare and Kirchner (2006) recommend researchers develop dynamic conceptualizations of dementia care access that incorporate individual, social-interactional and wider contextual dimensions of access and utilization.

To advance understanding of access to young onset dementia care, my analysis was guided by a theoretical framework that attempts to integrate these dimensions of health care access. Developed by Dixon-Woods et al. (2006), the candidacy framework conceptualizes access to health care as a multifaceted and iterative process of negotiation among individuals, care providers and health services. A person's candidacy, or eligibility, for care, is co-constructed over time through interactions with providers and health services. These social interactions are shaped by the operating conditions of local health services including the organization of services and allocation of resources, as well as the wider social and policy contexts (Dixon-Woods et al., 2006). Access, therefore, represents a dynamic interplay between health services which "are continually constituting and seeking to define the appropriate objects of medical attention and intervention" and individuals seeking care who are also "engaged in constituting and defining what they understand to be the appropriate objects of medical attention and intervention" (Dixon-Woods, 2006: 7).

The candidacy framework identifies seven dimensions of candidacy that broadly correspond to stages within health care trajectories (see Table 6.1). The first dimension, *identification* of

candidacy, refers to the process of identifying a health problem that requires medical attention or intervention. The way people come to recognize their candidacy influences how they present their claim to candidacy. The next dimension, *navigation*, concerns the work and resources required to find, gain entry, and access services. *Permeability*, the third dimension, denotes the degree to which services are inclusive or restrictive. Permeable services have few restrictions on entry (e.g. walk in clinics), while less permeable services demand more qualifications (e.g. referrals, eligibility criteria). The fourth and fifth dimensions of candidacy draw attention to the ways in which candidacy is constructed through social interactions between patients and health professionals. *Appearances* refers to how patients present their health concern and assert a claim for candidacy. For example, Dixon-Woods et al. (2006) point out that asserting candidacy involves various competencies such as the ability to articulate a health concern, to present credibly, and to advocate for services. *Adjudication* refers to health professionals' judgements regarding an individual's candidacy for medical care. This category encompasses the range of clinical assessments and decisions such as testing, diagnosis, referrals, prescriptions, and other interventions. The sixth dimension, *offers and resistance*, points to the services offered and not offered following adjudications, as well as patients' decisions to accept or refuse offers of care. Finally, the category, *operating conditions*, focuses on the organizational features and distribution of resources that influence candidacy negotiations in a given location. Although this representation of candidacy suggests a linear progression (Mackenzie, Conway, Hastings, Munro, & O' Donnell, 2013), Dixon-Woods et al. (2006) and others (Chase et al., 2017; Mackenzie et al., 2013) emphasize the iterative and cyclical nature of individuals' pathways through the various dimensions.

By conceptualizing health care access as a series of interactions among users, providers and services, the candidacy framework reflects an interactionist orientation. Broadly speaking, interactionist theory examines the relationship between individuals and society with a focus on social meanings, symbols and social interactions (Handberg et al., 2015; Oliver, 2012). Originating from symbolic interactionism, this perspective is concerned with micro-social processes of interpreting and negotiating shared meanings through social interaction. In contrast to social theories that emphasize macro-structures, interactionism is less deterministic, focusing instead on "individually constructed meaning within co-constructed social experience" (Handberg et al., 2015, p. 1025). Similarly, the candidacy framework conceptualizes health care

access as a negotiated process, situated within human social encounters. This perspective emphasizes human agency, subjectivity, interpersonal processes and organizational conditions. Although less emphasis is placed on broader structural factors (Chase et al., 2017), social and political contexts are incorporated in the model in terms of their influence on health care interactions.

The framework was produced as part of a commissioned review of the literature on access to health care among vulnerable groups, with a focus on the United Kingdom. The authors used an approach they termed critical interpretative synthesis, to select, integrate and critique the literature on health care access, and to develop a mid-range theory that captures the complexity and scope of health care access (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005). The framework has since been used to examine the health care experiences of diverse groups including people with intellectual disabilities (Chinn & Abraham, 2016), refugees (Chase et al., 2017), older adults from ethnic minorities (Koehn, 2009; Koehn, Habib, & Bukhari, 2016), people living with multiple sclerosis (Methley, Chew- Graham, Cheraghi- Sohi, & Campbell, 2017), a comparative analysis of access for patients with cancer and heart failure (Macdonald et al., 2016), and older adults with dementia (Koehn et al., 2016). The framework has also been applied to a range of health and social service settings including primary care (Kovandžić et al., 2011; Llanwarne, Newbould, Burt, Campbell, & Roland, 2017), specialist and acute care (Chinn & Abraham, 2016; Macdonald et al., 2016); and community services and supports (Mackenzie et al., 2013; Koehn et al, 2016).

The dimensions of candidacy outlined above draw attention to points of transition and vulnerability during which candidacy must be negotiated, as well as the broader organizational features that influence these negotiations (Koehn, 2009). Applied to the study of young onset dementia, this conceptual framework highlights multi-level factors that influence access to diagnostic and support services, such as: individual and family circumstances; provider practices; service models and organizational conditions; health and dementia care policies; and broader social and economic contexts. As such, it offers a comprehensive analytic tool for examining access experiences from the perspective of people living with young onset dementia, family members and providers.

Preface to Chapter 4

To support the inclusion and well-being of participants living with young onset dementia in my dissertation research, I conducted a literature review of strategies to promote the safe participation of people with dementia in qualitative research. Increasingly, researchers and people with dementia have written about their experiences of the research process, and reflected on the methodological and ethical aspects of qualitative research involving people with dementia. The extant literature, therefore, contains practical guidance to help minimize discomfort and maximize the engagement of participants. However, these strategies have not been compiled or critically examined.

To address the first Objective of this dissertation, Chapter 4 presents a synthesis and critical appraisal of different approaches to support the inclusion and safe participation of people living with dementia in qualitative research. I searched two databases and identified 22 articles that discuss the methodological or ethical dimensions of qualitative research involving people with dementia. These articles were examined for discussion related to participant safety and analyzed thematically. By summarizing various approaches to promote participant safety along with challenges and ethical dilemmas, the findings from this review offer a framework for planning qualitative research involving people with dementia. As such, Chapter 4 laid the foundation for the methods and research practices undertaken throughout my empirical study on young onset dementia diagnostic and support services presented in Chapters 6 and 7. This work also informed how I navigated practical and ethical issues that arose during the research process, which I discuss in Chapter 8.

Citation details

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Chapter 4. Safe and Inclusive Research Practices for Qualitative Research Involving People with Dementia: A Review of Key Issues and Strategies

Abstract

Developing strategies to ensure the safe participation of people with dementia in research is critical to support their wider inclusion in research and to advance knowledge in the areas of dementia policy and practice. This literature review synthesizes and critically appraises different approaches to promote the safe participation of people with dementia in qualitative research. Two databases were searched for articles that discuss the methodological or ethical aspects of qualitative research involving people with dementia. The review did not focus on informed consent or ethical review processes as these have been reviewed elsewhere. Key issues that impact participant safety include: language, negotiating access, the research relationship, communication, dealing with distress, knowledge dissemination, and researcher skills. By synthesizing different approaches to safety and highlighting areas of debate, this paper aims to advance discussion and to contribute to the development of inclusive research methods.

4.1 Introduction

In the absence of effective treatments, research into the care, quality of life, and social inclusion of persons with dementia has been identified as a global public health priority (World Health Organization, 2012). There is growing recognition that the development of effective policies and services requires an understanding of the perspectives of persons with dementia, yet they remain widely excluded from research (Beattie et al., 2004; Hellstrom, Nolan, Nordenfelt, & Lundh, 2007; Whitfield & Wismer, 2006; Wilkinson, 2002). Since the 1990s, researchers, advocacy organizations and people with dementia have challenged this, arguing that it reinforces negative stereotypes and contributes to social exclusion (Cotrell & Schulz, 1993; Downs, 1997; Hellstrom et al., 2007; Robinson, 2002; Wilkinson, 2002). In response, the body of qualitative research involving people with dementia has grown, and the methods used to engage with people with dementia have expanded from observation and interviews to include a wider range of methods and techniques (Bartlett, 2012; Tanner, 2012; Wiersma, 2011). This work provides compelling evidence that many people with dementia can actively participate in qualitative research and provide rich data on their experiences (Beuscher & Grando, 2009; Digby, Lee, & Williams, 2016; Hellstrom et al., 2007; Hubbard, Downs, & Tester, 2003; McKeown, Clarke, Ingleton, & Repper, 2010; Murphy, Jordan, Hunter, Cooney, & Casey, 2015; Pratt & Wilkinson, 2001; Wilkinson, 2002; Wilkinson & Milne, 2003). The effective inclusion of people with dementia in qualitative research, however, presents complex ethical and methodological issues that require critical examination and innovative solutions.

All research involving human subjects poses risks. In dementia research, these risks are heightened due to the profound stigma associated with the illness (Garand, Lingler, Conner, & Dew, 2009), the impaired cognition of participants, and the sensitive nature of discussing the illness experience (Hellstrom et al., 2007; Pesonen, Remes, & Isola, 2011). The ethical principles of non-maleficence and beneficence require researchers to protect the welfare of participants from any foreseeable harm and to weigh the benefits of participation against the potential risks. Developing strategies to ensure the safe participation of people with dementia is therefore critical to support their wider inclusion in research and to advance knowledge in the areas of dementia policy and practice (Hellstrom et al., 2007; Pratt, 2002; Wilkinson, 2002).

In her paper, 'Nobody's ever asked how I felt', Pratt (2002) applies the concept of safe practice to research involving people with dementia and argues that researchers should strive to create a safe research context. Other dementia scholars have also stressed the need to ensure safe research practices (Digby et al., 2016; Hellstrom et al., 2007; Wilkinson, 2002) and many have published work that reflects on their approaches to promoting safety and well-being, the challenges they have encountered, and possible solutions to these issues (Bartlett & Martin, 2002; Beuscher & Grando, 2009; Clarke & Keady, 2002; Dewing, 2002, 2007; Digby et al., 2016; Hellstrom et al., 2007; Holland & Kydd, 2015; Hubbard et al., 2003; McKeown et al., 2010; Murphy et al., 2015; Pesonen et al., 2011; Pratt, 2002; Wiersma, 2011). People with dementia have also written about their experiences of the research process (McKillop, 2002; McKillop & Wilkinson, 2004; Robinson, 2002) and developed guidelines for research involving people with dementia (Scottish Dementia Working Group, 2014).

As a result, the current literature offers a range of strategies to promote safe and inclusive practices for research involving persons with dementia. The approaches described in the literature provide practical guidance to help minimize discomfort and maximize the potential benefits of participation. These strategies, however, have not been synthesized or critically reviewed.

Drawing on the concept of safe research practice advanced by Pratt (2002) and Hellstrom et al. (2007), this literature review synthesizes and critically appraises different approaches to promote the safe participation of people with dementia in qualitative research. Based on the ethical principles of beneficence and non-maleficence, I defined safe research practices as the methods, strategies and techniques that minimize the potential harms of participating in research, support participant well-being and promote the benefits associated with participation (Ellsberg & Heise, 2002; McCosker, Barnard & Gerber, 2001). Informed consent processes and ethical review procedures are critical to participant safety. However, I chose not to include these issues in this review because of their scope and because they have been reviewed elsewhere (Beattie, 2009; Cubit, 2010; Sherratt, Soteriou, & Evans, 2007; Slaughter, Cole, & Jennings, 2007).

4.2 Methods

This review was conducted following a narrative approach to literature synthesis and interpretation. Narrative reviews, also called traditional literature reviews, summarize and critique a topic of research by drawing on relevant studies and data sources (Cronin et al., 2008; Popay and Mallinson, 2010). This method offers a more flexible approach to data selection compared to systematic reviews which emphasize systematic and comprehensive approaches to searching, selecting and appraising studies (Dixon-Woods et al., 2006; Popay and Mallinson, 2010). Given that the topic of this review (safe research practices involving participants with dementia) has been discussed within previous literature, but is not the focus of previous studies, a flexible review strategy helped to identify literature that did not focus specifically on safety issues, but contained information that was relevant to the aim of this review.

Two electronic databases (CINHAL and MEDLINE) were searched for discussion and research papers that reflect on the methodological and ethical aspects of qualitative research involving people with dementia. These databases were selected for their coverage of qualitative health related research spanning medicine; nursing and allied health; and social sciences and humanities (Flemming & Briggs, 2006; Wright, Golder, & Lewis-Light, 2015). The search term 'dementia' was paired with combinations of the following search terms: 'research subjects', 'research ethics', 'ethics', 'consent', 'qualitative studies', 'qualitative research', and 'research methodology'. This was supplemented by reviewing the reference lists of retrieved publications. All searches were restricted to English language texts and there were no restrictions on publication dates. I reviewed the abstracts to identify articles containing a discussion of practical, methodological or ethical issues.

In order to capture the views of people with dementia, I also conducted a Web search to retrieve research and language guidelines published by organizations led by people with dementia. Two such sets of guidelines prepared by people with dementia were identified and included in the review (DEEP The Dementia Engagement and Empowerment Project, 2014; Scottish Dementia Working Group, 2014). The Dementia Engagement and Empowerment Project (DEEP) (2014) published guidelines on the use of language about dementia. The research subgroup of the Scottish Dementia Working Group developed core principles to guide research involving people with dementia (DEEP The Dementia Engagement and Empowerment Project, 2014; Scottish Dementia Working Group, 2014).

None of the retrieved articles focused specifically on participant safety, but many contained discussion of safety issues. Each article was read and examined for discussion related to the benefits and harms of participation, and strategies to promote safety and well-being. Notes were recorded for each article and then examined to identify themes. Articles that focused exclusively on informed consent processes or issues unrelated to safety were excluded. In total, 22 articles were included in the review. After compiling a preliminary list of themes, I re-read each article to capture discussion related to each theme. Those notes were then analyzed to refine themes, compare approaches and to search for contradictions and debates. Additional literature on qualitative methods and research ethics was consulted in order to further examine and contextualize the themes that emerged from this review process (Corbin & Morse, 2003; Dickson-Swift, James, Kippen, & Liamputtong, 2007; Hewitt, 2007; Manderson, Bennett, & Andajani-Sutjahjo, 2006; Richards & Schwartz, 2002).

4.3 Findings

The sections below explore each theme identified in the review process, followed by a discussion of debates, gaps in the literature and directions for future research. Figure 1 presents a summary of the safe research practices that emerged from this literature review.

4.3.1 Language and Dementia Disclosure

Avoiding Stigmatizing Language. The question of how best to describe people with dementia who are subjects of qualitative research remains an important consideration for researchers. Commonly used terms and phrases such as ‘demented’ and ‘dementia victim’ reduce the person to his or her disease and reinforce the stigma associated with dementia. Several organizations have issued calls to end the use of stigmatizing language and identified appropriate and respectful terminology as well as terms to avoid (DEEP The Dementia Engagement and Empowerment Project, 2014; Scottish Dementia Working Group, 2014). Guidelines prepared by the Dementia Engagement and Empowerment Project (DEEP) (2015) recommend using the phrases person/people with dementia or person/people living with dementia. Terms to avoid include dementia sufferer, victim, senile, and demented (for a full list see: http://dementiavoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf).

Figure 1.

Safe Research Practices Identified in The Literature

- Use respectful terminology and avoid stigmatizing language
- Develop a plan to communicate sensitively with participants who may be unaware of their dementia diagnosis
- Consult with participants (and/or carers where appropriate) to identify sources of support
- When possible, allow participants to choose the time, location and duration of the research encounter
- Take time to foster rapport and develop a strategy to withdraw from the research relationship
- Consider the problem of role ambiguity, and take steps to ensure that participants understand the role of the researcher
- Tailor interview questions and communication styles to participants' communication abilities
- Develop a strategy to deal with participant distress, and pay attention to verbal and non-verbal signs of distress
- Consider researcher safety, and identify strategies and resources to deal with ethical issues and emotional challenges
- Consult with participants about their preferences and expectations for communicating results, and ensure that findings are shared with participants and relevant stakeholders
- Novice researchers may consider seeking guidance from more experienced researchers, clinicians or people living with dementia

Dementia: A Contested Term. In fact, the use of the word dementia is a contentious issue, and several scholars have voiced concern that it has the potential to cause harm if participants are unaware of having a dementia diagnosis (Bartlett & Martin, 2002; Heggestad, Nortvedt, & Slettebø, 2012; Pesonen et al., 2011; Pratt, 2002; Wiersma, 2011). Bartlett and Martin (2002) point out that even when participants have been diagnosed, health professionals may have used

terms such as memory problems. Given the stigma associated with dementia, some people may not identify with the disease label (Garand et al., 2009). As a consequence of dementia, some participants may be unaware of their diagnosis at the time of the research encounter (Pratt, 2002).

This issue has sparked debate among dementia scholars about the ethical implications of using or avoiding the term dementia. If a person does not identify as having dementia, confronting them with a label of dementia in recruitment materials or during the course of an interview may cause considerable distress (Bartlett & Martin, 2002; Pesonen et al., 2011; Pratt, 2002). On the other hand, the principle of informed consent requires researchers to explain the purpose of the study and topics to be covered. Avoiding the term dementia can be seen as deceptive or paternalistic (Bartlett & Martin, 2002).

The literature offers several strategies to address this issue, though researchers acknowledge there are no simple solutions (Bartlett & Martin, 2002). Some researchers have chosen to avoid the term dementia, opting instead to use terms such as 'memory problems' or 'memory loss' (Bartlett & Martin, 2002; Hellstrom et al., 2007; Pesonen et al., 2011; Wiersma, 2011). Proponents of this approach have argued that these terms are more sensitive and carry less stigma (Hellstrom et al., 2007; Pesonen et al., 2011; Pratt, 2002).

Pratt (2002) and Heggestad et al. (2013) also suggest consulting with gatekeepers or family carers to determine whether participants are aware of their diagnosis and receptive to talking about it. Heggestad et al. (2013) describe employing 'situational sensitivity', rather than a universal approach, when deciding whether to disclose the dementia focus of the research. To approach the topic in a sensitive and careful manner, Pratt (2002) further suggests talking about the symptoms of dementia before bringing up the diagnosis.

Issues to Consider. Concealing the dementia focus of a project and avoiding the term 'dementia' may protect participants from distress but it also raises several issues that warrant consideration. First, it can be argued that this approach constitutes deception and violates the principle of fully informed consent (Bartlett & Martin, 2002). Researchers who use terms like 'memory problems' during the course of research should consider how they plan to report their

findings. Avoiding the term dementia during the research process, but then using it in presentations or publications could be viewed as deceptive and potentially harmful.

Second, it may not be possible to avoid talking about disease categories. For example, research examining the experiences of people with specific types of dementia such as frontotemporal dementia may require explicit eligibility criteria as well as clear information about the purpose of the study. Using the term dementia may be necessary for research into dementia related policies, programs or initiatives such as the dementia friendly communities movement. In participatory projects where people with dementia are involved as stakeholders, using euphemisms may be inappropriate. In addition, terms such as 'memory problems' do not reflect the full range of symptoms of dementia, and may not be a suitable term for all research projects (Sachdev et al., 2014).

4.3.2 Negotiating Access and Identifying Sources of Support

Negotiating Access. The issue of gatekeeping has received considerable attention among dementia researchers, and the literature on this topic suggests ambivalence towards the role of gatekeepers. On the one hand, gatekeepers can restrict access to participants and compromise participant autonomy (Bartlett & Martin, 2002). On the other hand, gatekeepers can provide valuable information about participants' abilities and needs, support participants' decision making processes, and provide support to participants who experience distress (Bartlett & Martin, 2002; Digby et al., 2016; Pratt, 2002).

Debates on the role of gatekeepers reflect the tension between protection from harm and respecting autonomy, and striking a balance can be challenging. Complicating the issue, the concept is used in the literature to refer to many different roles including ethical review boards, managers, health professionals, service providers and family members. These positions have different interests and relationships to participants, and are not necessarily advocates or trusted supporters. While there can be considerable overlap, there are also important differences between gatekeepers who influence access to participants, and the people who support their participation in research.

While recognizing some of the pitfalls, Pratt (2002) remarks that enlisting the help of family carers can promote safety and good research practice. Carers often provide relevant information,

such as a participant's awareness of a dementia diagnosis (Pratt, 2002), signs of well-being or ill-being (Dewing, 2002), capacity to consent (Bartlett & Martin, 2002), and any sensitive topics to avoid (McKillop & Wilkinson, 2004). When family carers are informed and involved, they may also assist with communicating the study aims and ensuring participants understand the research process (Bartlett & Martin, 2002; Hellstrom et al., 2007; Pratt, 2002), and supporting participants who experience distress (Digby et al., 2016; Hellstrom et al., 2007; Pratt, 2002).

Identifying Sources of Support. The Scottish Dementia Working Group (2014) recommends asking participants if they want someone to accompany them during the research process (Scottish Dementia Working Group Research Sub-Group, 2014). In addition to contributing their own perspectives, family members or friends can make participants feel more comfortable (Pesonen et al., 2011), and they may also offer emotional support and assistance with communication (Digby et al., 2016; Pratt, 2002). Enabling participants to decide what supports they require can promote safety and inclusivity, but it also raises some issues for consideration. For example, participants in Digby et al.'s (2016) study could nominate a trusted person to be present during interviews. During one interview, a participant's wife provided support and comforted the participant when he experienced distress. In another situation, a family member dominated the interview, and appeared to undermine the participant's responses (Digby et al., 2016).

These examples highlight some of the potential complexities that can arise when family members or friends are involved in the research process. From a methodological perspective, joint interviews can be difficult to facilitate and to interpret. Participants may feel uncomfortable discussing their concerns in front of family members, and joint interviews are often unbalanced, with one person directing the conversation (Pesonen et al., 2011). On the other hand, family members or friends may contribute to the research process and outcomes by supporting participants, offering prompts, and providing additional insights (Kendall et al., 2010).

4.3.3 The Research Relationship

Choosing the Time and Location of the Research. Allowing participants to choose the time, location and duration of interviews or other research meetings is recommended (Hubbard et al., 2003; McKillop & Wilkinson, 2004; Scottish Dementia Working Group, 2014). Research

involving people living in the community often takes place within participants' homes or other familiar environments to maximize comfort (Bartlett, 2012; Beuscher & Grando, 2009; Hellstrom et al., 2007; McKillop & Wilkinson, 2004; Pesonen et al., 2011). McKillop and Wilkinson (2004) and the Scottish Dementia Working Group (2014) suggest consulting with participants to determine what time they prefer to meet, and for how long. Nygård (2006) recommends adapting the duration of research meetings for each participant, and including the option of conducting multiple short interviews. Allowing choice and flexibility promotes inclusivity and it can also give participants some control over the research process (Hubbard et al., 2003; Nygård, 2009).

Developing Rapport. Developing rapport with research participants is considered essential in qualitative research (Corbin & Morse, 2003; Dickson-Swift et al., 2007; Nygård, 2009). Building trust and creating a comfortable atmosphere facilitates conversation and encourages participants to share personal information and experiences (Dickson-Swift et al., 2007). Developing trusting relationships can enhance participants' experiences of the research process, and can help to reduce the power inequalities between participants and researchers (Hellstrom et al., 2007).

In the literature reviewed here, building relationships and developing rapport is particularly emphasized. Researchers and people with dementia have identified several approaches to building rapport including meeting with participants before undertaking research (Hubbard et al., 2003), engaging in informal conversation before and after interviews (Beuscher & Grando, 2009; Hellstrom et al., 2007; McKillop & Wilkinson, 2004) and conducting research over several encounters (Hellstrom et al., 2007; Pesonen et al., 2011; Pratt, 2002). Tanner (2012) found that including people with dementia as co-researchers enhanced rapport and shared understanding, although the extent to which co-researchers and participants connected varied (Tanner, 2012). These strategies can ease participants' anxieties about the research process (Digby et al., 2016; McKillop & Wilkinson, 2004) and foster a supportive atmosphere where participants feel safe and not judged for any impairments they might have (Digby et al., 2016).

Spending time with participants also provides an opportunity for researchers to familiarize themselves with each person's cognitive and communication abilities, and to tailor their communication style and approach to each participant (Digby et al., 2016; Hubbard et al., 2003).

Pratt (2002) conducted multiple interviews with participants, and found that her comfort level and communication skills improved with each subsequent interview. Hubbard (2003) used preliminary conversations to determine whether to conduct interviews or observation with each study participant. The Scottish Dementia Working Group (2010) recommends asking participants how they are feeling at the start of each meeting, and finding out if they require any supports. This initial conversation can help researchers assess participant well-being, identify any issues or concerns, and adapt their approach to accommodate each participant (Dewing, 2002; Hellstrom et al., 2007).

Clarifying Roles. Pesonen et al. (2011) and Pratt (2002) discuss the problem of role ambiguity and highlight the importance of clarifying the researcher's role throughout the research process. Cognitive problems may contribute to confusion about the role of the researcher, and participants may forget who the researchers is or the purpose of the study. Ensuring that participants understand the role of the researcher is essential to maintaining informed consent, and Pesnonen et al. (2011) suggest paying close attention to participants' perception and expectations of the researcher. In some cases, researchers may need to explain their position and the purpose of the study throughout the research encounter (Nygård, 2009; Pratt, 2002).

From the perspective of participants, the boundaries between researcher and practioner may be blurred, particularly when the researcher is also a health practitioner, or when the research is conducted in a health or long-term care setting (Hewitt, 2007; Richards & Schwartz, 2002). Pratt (2002) and Pesonen et al. (2011) describe situations where participants sought advice about their condition, treatment options and available services. Navigating these types of questions can be particularly challenging, especially when participants appear to have unmet needs for support (Pesonen et al., 2011). Researchers with professional or clinical backgrounds may experience a role conflict, and struggle to balance their dual identities (Pesonen, 2011).

When participants ask questions that fall outside of the researcher's area of expertise, Pratt (2002) recommends re-establishing the position of the researcher and explaining the kinds of questions that he or she can and cannot answer. Pesonen et al. (2011) dealt with these situations by providing supportive feedback and referring participants to the appropriate services. Although limited, the available literature suggests that developing a plan to deal with role confusion, and

bringing information on available services and resources can help to maintain ongoing consent and appropriate boundaries.

Withdrawing from the Relationship. Given the time spent developing relationships, researchers should also consider how they plan to withdraw from the relationship (Hellstrom et al., 2007). This issue may be particularly salient in the context of dementia research as relationships are emphasized, and the risk of role confusion is heightened (McKeown et al., 2010; Pratt, 2002). Conducting research in participant's homes, engaging in informal conversation, and conveying empathy can further blur the boundaries between participants and researchers (Dickson Swift, 2007). In addition, some participants might experience a loss when a study terminates and the research relationship ends (Hewitt, 2007).

While this issue has been mentioned (Hellstrom et al., 2007; McKeown et al., 2010; Nygård, 2009), it has received little attention in the literature on dementia. Nygård (2006) advises clear communication about the parameters of the research relationship, and Hellstrom et al. (2007) suggest approaching the subject with "honesty and sincerity" (Hellstrom et al., 2007). Studies investigating sensitive topics might also consider following up with participants to debrief them and put them in touch with services that offer ongoing supports (Hewitt, 2007).

Research relationships vary and navigating the ending of relationships can be challenging (Dickson-Swift et al., 2007). Some research relationships end at the conclusion of a research project, while others may turn into friendships or research partnerships. In other cases, the researcher may decide to end a research encounter or withdraw a participant from the study if the participant is no longer able to provide informed consent or benefit from participation. Further examination of these issues from the perspectives of participants and researchers is required to develop sensitive and ethical approaches to relationship building and ending.

4.3.4 Communication and Data Collection

Communication Strategies. With the expansion of qualitative research to include participants with a wider range of communication abilities, researchers have reflected on the challenges that can arise, and the techniques that facilitate sensitive and effective communication (Beuscher & Grando, 2009; Digby et al., 2016; Hubbard et al., 2003; Murphy et al., 2015; Nygård, 2009; Pesonen et al., 2011; Pratt, 2002). Language and communication challenges

associated with dementia vary considerably depending on the type of dementia and the person's level of disability. Individuals experience different cognitive and communication symptoms that progress at different rates, and for some these can fluctuate from day to day. As a result, there is no single method or strategy to accommodate the diversity of participants' needs and symptoms (Hubbard et al., 2003). Instead, scholars emphasize sensitive, attuned and flexible communication approaches that enable researchers to adapt and respond to participants' needs and abilities (Beuscher & Grando, 2009; Digby et al., 2016; Heggestad et al., 2012; Nygård, 2009).

As mentioned previously, developing rapport allows researchers to identify any communication issues, and to adapt their approach to each participant. This can include the wording of questions, as well as the timing and pace of interviews (Digby et al., 2016; Nygård, 2009). Allowing participants to direct the conversation and discuss issues that matter to them can minimize the power imbalance of the research relationship (Dickson-Swift et al., 2007; Digby et al., 2016). Digby et al. (2016) point out that in some instances, tangential stories function as a protective strategy for participants to avoid discussing sensitive topics, or subjects they have difficulty remembering. At the same time, researchers need to be able to support participants who are struggling to find words or to direct the conversation (Beuscher & Grando, 2009; Hubbard et al., 2003). Finding a balance between allowing time and freedom while also supporting the flow of conversation can be challenging (Hubbard et al., 2003).

Preparing Research Questions. In qualitative research, the emphasis on communication can present challenges for some people with dementia, and there is a risk that research questions and techniques will call attention to a person's impairments (Bartlett, 2012; Hubbard et al., 2003). Several scholars recommend designing questions that focus on participants' strengths, and avoiding questions that require recalling detailed information such as dates or the sequencing of events (Digby et al., 2016; Pratt, 2002). Many people with dementia can talk about their experiences and perspectives, so researchers are encouraged to focus questions around participants' experiences (Hellstrom et al., 2007; Pratt, 2002; Tanner, 2012). Providing demographic information can be difficult for some participants, and Pratt (2002) recommends exercising caution when including any demographic questions. Unless it is essential to the study, the use of cognitive tests is discouraged, as they can be profoundly distressing for people with

cognitive impairment (Hellstrom et al., 2007). Methods that involve writing can also lead to distress if participants experience difficulties with written communication. Commenting on the diary interview method, Bartlett (2012) recommends informing participants of this possibility as part of the consent process.

Factors that Affect Communication. In a research context, a person's ability to understand and to communicate their perspective is influenced by several factors, and not simply their dementia (Digby et al., 2016; Hubbard et al., 2003). Digby et al. (2016) point out that all individuals possess unique communication styles and abilities that can impact the research process, and cautions against attributing communication issues to the dementia itself. Hubbard et al. (2003) argue that a participant's ability to communicate is affected by the skills of the researcher, including their ability to listen and to understand. The particular research methods and techniques employed can also affect a participant's ability to communicate. Dewing (2002) points out the need to develop methods that enable communication with individuals who have more pronounced cognitive and communication impairments.

4.3.5 Dealing with Distress

Investigating sensitive topics places participants at risk for emotional and psychological distress, and researchers have an obligation to think through how they will respond to signs of distress (Pratt, 2002). Confusion or difficulty communicating and recalling events can also lead to distress or agitation (Hellstrom et al., 2007; Hubbard et al., 2003; Pesonen et al., 2011). For example, after taking a Mini-Mental State Examination (Tombaugh & McIntyre, 1992), a participant in Hellstrom et al.'s (2007) study described feeling stupid. In some cases, misunderstanding the role of the researcher can cause anxiety (Hellstrom et al., 2007; Pesonen et al., 2011).

Researchers are advised to look for verbal and non-verbal signs of distress or discomfort (Digby et al., 2016; Heggestad et al., 2012; Pesonen et al., 2011). Paying attention to body language is particularly important when communication is impaired, and is considered essential to maintaining on-going consent (Digby et al., 2016). Strategies to deal with signs of distress include offering breaks, offering to stop the interview or research process, and changing to a neutral topic. It is important to allow participants to talk through difficult issues, and participants

often wish to continue even if the topic triggers difficult emotions (Moore & Hollett, 2003; Pesonen et al., 2011; Pratt, 2002). If a participant wishes to end the interview, Pratt (2002) suggests engaging in informal conversation until they no longer appear distressed. Ending interviews "on a positive note" by asking questions that focus on strengths and supports, and by engaging in informal interaction is widely recommended (Digby et al., 2016; Hellstrom et al., 2007; McKillop & Wilkinson, 2004; Murphy et al., 2015).

4.3.6 Feedback and Knowledge Dissemination

Contributions to the literature from people with dementia underline the responsibility to provide updates on the study's progress, and to disseminate findings to relevant stakeholders (McKillop & Wilkinson, 2004; Robinson, 2002; Scottish Dementia Working Group, 2014). The Scottish Dementia Working Group (2014) cautions that people with dementia can feel used and devalued by researchers who do not report back to participants. The report recommends consulting with participants about when and how they wish to be informed of the study's progress, and whether they want a trusted person to be kept informed too. When conducting longitudinal studies, researchers may also consider keeping in contact with participants between interviews or when there is a break in the research process (Hellstrom et al., 2007). The Scottish Dementia Working Group (2014) and McKillop and Wilkinson (2004) point out that individuals have different preferences and expectations around feedback, and highlight the importance of clarifying and negotiating the process of communicating results.

While there is a growing push to include people with dementia in all aspects of the research process, the issue of knowledge dissemination has received little attention. The Scottish Dementia Working Group (2014) recommends sharing findings with relevant stakeholders, and engaging people with dementia in all aspects of the research process. Wiersma (2011) reflects on the challenges of representing people with dementia in research reports and including participants in the dissemination process. Consistent with a participatory approach, she sought input from participants on knowledge dissemination strategies and invited them to take part in crafting and presenting findings (Wiersma, 2011). More work is required to develop strategies for engaging participants in knowledge dissemination, and to consider the ethical and practical issues that can arise.

4.3.7 Researcher Knowledge and Skills

In light of the complexities of the research process, McKeown et al. (2010) pose the question: "who should conduct research with people with dementia?" (p. 1940). According to the authors, the ethical complexity and sensitivity of dementia research demands particular knowledge and skills; skills which not all researchers possess (McKeown et al., 2010). Several scholars have commented on the importance of experience and skill (Beuscher & Grando, 2009; Digby et al., 2016; Heggestad et al., 2012; Hubbard et al., 2003), though the evidence in the area remains scant.

Knowledge of Dementia. Several papers make the case for attaining sufficient knowledge of dementia before partaking in research, including the causes and symptoms of dementia, and the range of impacts of dementia on affected individuals. According to Hubbard et al. (2003), researchers should understand the potential effects of dementia on memory, decision-making capacity and emotions in order to identify issues as they arise and to adapt the research process. The Scottish Dementia Working Group (2014) urges researchers to learn about the various types of dementia and to recognize the heterogeneity of symptoms and experiences. Beuscher and Grando (2009), Digby et al. (2016), and Hubbard et al. (2003) argue that researchers should be aware of the range of communication challenges associated with dementia and should be prepared to accommodate participants' communication abilities.

While knowledge of dementia is commonly described as essential (Digby et al., 2016; Hubbard et al., 2003), the issue of researcher training has not been considered in depth. For example, the literature reviewed here does mention knowledge of some symptoms associated with dementia that could influence research participation such as behaviour changes and perceptual and motor impairments. Further research is necessary to determine the scope of knowledge required for dementia researchers and to develop training materials for those entering the field.

Research and Interpersonal Skills. Other skills and researcher attributes highlighted in the literature are not specific to dementia research, but reflect the interpersonal skills required to conduct qualitative research. In their discussion of risk and qualitative interviews, Corbin and Morse (2003) commented, 'No one can predict what will be said in the course of an unstructured interview, the feelings it will provoke, or any long-lasting effects. Much depends on the ability of

the interviewer to judge and respond to the emotional state of the participant.' (p. 346-347). Researchers' skills may be particularly important in the context of dementia research given the sensitive nature of the subject matter, the potential for communication challenges, and the obligation to identify subtle signs of distress or lack of consent (Dewing, 2002; Digby et al., 2016; Hellstrom et al., 2007).

In addition to knowledge of qualitative methods and research ethics, pertinent researcher skills identified in the literature include verbal and non-verbal communication skills (Digby et al., 2016; Hubbard et al., 2003), active listening skills (Nygård, 2009), critical thinking skills, and reflexivity (Dewing, 2007; McKeown et al., 2010; Pesonen et al., 2011). Other researcher qualities thought to promote participant well-being and ethical practice include sensitivity (Digby et al., 2016), moral sensitivity (Heggestad et al., 2012), empathy (Digby et al., 2016; Hellstrom et al., 2007; Scottish Dementia Working Group, 2014), respect (Digby et al., 2016; Scottish Dementia Working Group, 2014) and authenticity (McKillop & Wilkinson, 2004).

Research and Practical Experience. While some attributes such as sensitivity may be personality traits, other skills can be acquired through experience (Corbin & Morse, 2003). Hellstrom et al. (2007) suggest that the lead author's experience as a nurse working with people with dementia helped to ensure the interviews were relaxed and comfortable. Several others highlighted their clinical and research experience with people with dementia, commenting that it prepared them to communicate with participants, to adapt to their needs and abilities, and to navigate ethical issues (Beuscher & Grando, 2009; Digby et al., 2016; Heggestad et al., 2012; Hubbard et al., 2003; Pesonen et al., 2011).

One possibility for novice researchers is to work with or seek mentorship from more experienced dementia researchers (Beuscher & Grando, 2009; Dewing, 2002; McKeown et al., 2010). McKeown et al. (2010) point out that researchers and students can learn from experienced clinicians and suggests developing working relationships between academics and clinicians working in the field of dementia. Engaging in reflexive practice may also help researchers develop their skills, navigate ethical issues, and process any emotional challenges they experience (Heggestad et al., 2012; Pratt, 2002). Another promising strategy is to promote cooperation between academics and organizations that actively involve, or are led by people with dementia. For example, the Scottish Dementia Working Group has established links with

researchers across the United Kingdom and collaborated with academic researchers to develop guidelines for research involving people with dementia (Scottish Dementia Working Group, 2014).

4.4 Discussion

This review identified a range of issues that impact participant safety as well as strategies to minimize discomfort and maximize the potential benefits of participation. People with dementia form a diverse group, so approaches to promote safe research practice should be tailored to the study design, setting, and to individual participants. As such, the findings from this review are not intended to be prescriptive. Rather, the aim of this paper is to advance discussion of the practical and ethical dimensions of inclusive dementia research, and to identify new lines of inquiry.

The issue of dementia disclosure has received considerable attention. While there are no simple solutions to this issue, the discussion in the literature highlights the need to exercise caution when using a term that carries significant stigma. As awareness and diagnostic practices improve, and the movement to end the stigma associated with dementia gains momentum, the potential for the word dementia to cause harm may diminish. Still, a participant's awareness of their diagnosis is subject to change, and researchers are advised to think through how they plan to deal sensitively with participants who may be unaware of their diagnosis, as well as those who may reject the disease label (Bartlett & Martin, 2002).

Qualitative research is a social endeavour, and efforts to ensure participant well-being occur in the context of relationships. The literature suggests that participant safety is enhanced when researchers develop relationships that convey respect and reciprocity with participants and the people who support them (Hellstrom et al., 2007). At the same time, ethical issues can arise in the process of relationship building. Time spent developing rapport, establishing trust and engaging in informal conversations can blur the boundaries between researchers and participants (Dickson-Swift et al., 2007). Conducting research in participants' homes and displaying empathy and concern can also shift the relationship and increase the risk of role ambiguity (Corbin & Morse, 2003; Dickson-Swift et al., 2007). In this context, it is important for researchers to consider how they will withdraw from the relationship. While this issue has been raised, it has

not been explored in depth. Further discussion of the practical and ethical aspects of relationship building and ending is required.

Strategies to uphold participant safety and ethical practice also have implications for researcher well-being and safety. Efforts to develop rapport and positive relationships can be emotionally taxing for researchers and may lead to attachments (Dickson-Swift et al., 2007; Pesonen et al., 2011). Hearing the stories of participants, witnessing suffering, and offering support can also affect researchers (Dickson-Swift et al., 2007). The task of resolving ethical issues and prioritizing participant safety can be challenging for researchers, and may have consequences for their well-being (Heggestad et al., 2012; Pesonen et al., 2011).

People with dementia have made important contributions to the literature on ethical practice. Papers written by people with dementia (McKillop & Wilkinson, 2004; Robinson, 2002) and the guidelines put forward by the Scottish Dementia Working Group (2014) emphasize the importance of feedback and knowledge dissemination. The Scottish Dementia Working Group (2014) also recommends consulting with participants to find out if they would like friends or family members involved in the research processes or updated about the study. Although researchers may already be employing this practice, it has so far received little attention in the literature.

The majority of literature reviewed here is based on the reflections of researchers; very few papers included the perspectives of participants living with dementia. The examples above highlight the importance of including the perspectives of people with dementia in discussions on research ethics and best practices. Their contributions to knowledge and ethical practice suggest that research safety is enhanced when people with dementia can influence the research process, and have a platform to express their views.

Qualitative research that includes people with dementia as participants has grown considerably over the last few decades, and now encompasses a wide range of methods and techniques. However, it should be noted that the majority of the research reviewed here focused on methods of interviewing and observation. Despite the push to include people with dementia in all aspects of the research process, only three studies in this review employed participatory approaches (Bartlett, 2012; Tanner, 2012; Wiersma, 2011).

Participatory and collaborative approaches to research expand the role of participants and seek to reduce the power inequalities that structure traditional research processes (Bartlett, 2012; Beresford, 2002; Kitchin, 2010). Compared to other areas of health and social research, however, the participation of people with dementia in research and knowledge production remains relatively narrow. The few participatory studies identified in this review indicate that people with dementia can make significant contributions as co-researchers and collaborators. For example, Tanner (2012) observed that involving co-researchers with dementia helped to establish rapport and enhanced the interpretation of research findings. In order to support the wider engagement of people with dementia in the research process, further exploration of the strengths and challenges of participatory and collaborative methods is required.

Another significant gap in the research reviewed here is the lack of attention to minority groups and other categories of social identity beyond dementia. Research relationships and processes are influenced by multiple factors including participants' and researchers' age, gender, ethnicity, sexual orientation, socio-economic status, and dementia status (Hewitt, 2007; Manderson et al., 2006; Wilson & Neville, 2009). These factors affect social interactions and relations of power between researchers and participants (Hewitt, 2007; Manderson et al., 2006). There is a growing call for research that includes the perspectives and voices of people with dementia from different populations and minority groups (McGovern, 2014; O'Connor, Phinney, & Hulko, 2010). Meeting this challenge requires the development of safe and inclusive research approaches that are sensitive to and respectful of the needs and concerns of different populations.

4.5 Conclusion

In the past, concerns about emotional harm and potential exploitation have been used to justify the exclusion of people with dementia from research and reliance on proxy accounts (Hellstrom et al., 2007). During the 1990s and early 2000s, researchers began to challenge the assumption that participation is inevitably harmful (Wilkinson, 2002). Since then, inclusive approaches to dementia research have expanded, and more and more researchers have reflected on the ethical dimensions of the research process. People with dementia have also entered the debate, writing about their experiences as research participants and developing guidelines for researchers.

The available evidence suggests that participation in qualitative research can contribute to well-being and social inclusion (Hellstrom et al., 2007; Wilkinson, 2002; Tanner, 2013), but it also carries risks. Participants' experiences of harm reflect the risks inherent to qualitative research on sensitive topics, and are not necessarily specific to dementia. At the same time, including people with dementia adds complexities to the research process, and research practices must meet high standards to ensure their welfare is protected. Attending to these issues is critical to support the wider inclusion of people with dementia in research.

This review identified key issues that emerge in the context of qualitative research involving people with dementia, as well as strategies and techniques proposed by researchers and people living with dementia to prevent harm and to promote well-being. However, the available evidence remains anecdotal, and largely confined to the perspectives and observations of researchers. Seeking the perspectives of people with dementia through further collaboration and research is required to advance understanding of safe research practices and to support the development of inclusive and participatory approaches to research.

Preface to Chapter 5

The literature review presented in Chapter 4 identified a range of approaches to promote the participation of people with dementia in qualitative research, as well as potential issues to consider. Building on these strategies and ethical considerations, Chapter 5 describes the methods used to examine access to diagnostic and support services for people with young onset dementia. Addressing Objectives 2 and 3 of this dissertation, this study aimed to critically examine the process of accessing and delivering a diagnosis of young onset dementia, and to explore the processes that shape access to support services from the perspectives of people with young onset dementia, family members and providers. The following chapter provides detailed information on the methods and procedures of this study including the methodological orientations of the research, the study sample and participant characteristics, recruitment procedures, data collection methods, and approaches to data analysis. The chapter concludes with a discussion of ethical considerations and stakeholder engagement. Results from this study are presented in Chapters 6 and 7.

Chapter 5. Research Design and Methods

This chapter describes the steps that were taken to explore access to young onset dementia services from the perspectives of individuals living with the condition, family members and providers. First, I situate the research approach in relation to the underlying methodological, ethical and philosophical positions that guided the research. Next, I describe the design, study setting, participant characteristics, recruitment procedures, data collection methods, and approaches to data analysis. Last, I discuss ethical considerations and the process of stakeholder engagement.

5.1 Methodological Orientations

In contrast to some qualitative methods (e.g. ethnography or phenomenology), the methods undertaken for this study – semi-structured interviews – are not associated with a particular methodology or philosophical framework (McIntosh and Morse, 2015). Interview research encompasses diverse methods that span quantitative and qualitative research and cross a broad range of disciplines. Semi-structured interviews are similarly versatile, compatible with a variety of research designs, methodological perspectives and philosophical assumptions (McIntosh and Morse, 2015). Rather than adhering to a singular methodological framework, this research was informed by multiple methodological and philosophical perspectives. In the following paragraphs, I describe the methodological approaches, ethical imperatives and philosophical assumptions that guided this research.

The research design and methods for this project followed an exploratory approach to qualitative inquiry, which emphasizes flexible and inductive research processes. Exploratory research is indicated when little is known about a topic or phenomenon, and theoretical development is limited (Rendle et al., 2019; Stebbins, 2001). Rather than selecting a fixed research design and theoretical framework prior to data collection, this inductive approach involves adapting research questions, objectives, and methods throughout data collection. According to Stebbins (2001), exploratory research strategies require two orientations: "*flexibility* in looking for data and *open-mindedness* about where to find them." (Stebbins, 2001, p. 48). As a research strategy, this approach begins with broad research questions and flexible methods which are refined throughout the process of data collection and analysis.

When I began this research project, the literature on young onset dementia was extremely limited, which posed challenges for planning and designing a study. Epidemiological evidence was scarce, and there were no available estimates of the number of people living with young onset dementia in Manitoba or across Canada. Without a clear picture of the study population, or specialized services that could facilitate access to participants, recruitment was uncertain. In addition, as noted by Spreadbury and Kipps (2019), the literature on young onset dementia remains at an "early stage theoretically and methodologically" (p.137). Given the barriers to recruitment and gaps in evidence and theory, undertaking an exploratory approach enabled me to adapt my research questions, methods, and theoretical perspectives based on who I was able to recruit, and the topics and concepts that emerged during data collection. Accordingly, I began this project with the broader objective to explore how people with young onset dementia and their families experience health and social services. Over the course of data collection and analysis, I refined my objectives to focus on access processes, and subsequently applied the theoretical lens of candidacy to guide data analysis.

This research was also guided by the expressed goal to maximize the inclusion of participants with dementia and to support their well-being throughout the research process. Accordingly, the study design and research process were informed by a review of the methods that promote the engagement and safe participation of people with dementia in qualitative research (Novek & Wilkinson, 2019). This literature review, presented in Chapter 4, influenced the methodological decisions discussed in the sections below. Reviewing and synthesizing this literature also helped to prepare me to navigate unexpected ethical and methodological issues that arose during the course of data collection (See Chapter 8 for a detailed discussion).

Finally, this qualitative inquiry is underpinned by an interpretivist, constructivist epistemology which differs from positivist research traditions that seek to uncover universal truths about an objective world. In contrast, constructivism frames knowledge as socially and culturally embedded and constructed through social interaction (Charmaz, 2006). Applied to interview methods, it emphasizes the subjectivity of participants and researchers, and situates data collection and analysis within the social relations of the research process (Charmaz, 2006; Hewitt, 2007). Through in-depth interviews, the researcher attempts to learn about participants' views and experiences, which are then interpreted and analyzed conceptually. Interviews are not

neutral recordings of participants' perspectives or lived experiences. Rather, a constructivist understanding of research production views data collection and interpretation as situational, and shaped by the interactions, perspectives and social identities of researchers and research participants. In line with an interpretivist, constructivist orientation, I sought to understand young onset dementia care from the perspectives of multiple groups (people living with young onset dementia, multiple family members, health care professionals and service providers). In addition, I adopted a reflexive practice throughout the research process, and have attempted to make visible my role in co-constructing interview data through a reflection on the research process presented in Chapter 8.

5.2 Study design and methods

The research design for this exploratory study involved a combination of sequential, semi-structured interviews with people living with young onset dementia and family members; and one-time, semi-structured interviews with health and service providers. The method of semi-structured interviews was used to explore the perspectives, knowledge and experiences of research participants (Kelly, 2011). Multiple stakeholders were included to situate individual and family experiences within the broader context of health and social care, while also ensuring that the voices of people living with young onset dementia were included. To date, the majority of research on young onset dementia has mainly focused on the perspectives of family caregivers or formal providers. This more inclusive approach was chosen to better understand the complex relationships among care experiences, provider practices, and the broader contexts of health services.

Qualitative interviews are well suited to conducting research on sensitive topics, exploring participants' lived experiences, and developing an in-depth understanding of care contexts (Kelly, 2010). They feature conversational, interactive encounters aimed at eliciting and interpreting the experiences, meanings and perspectives of research participants (Kelly, 2010; Warren, 2001). Semi-structured interviews involve a pre-determined set of topics or questions to be discussed, but also permit the exploration of new topics and lines of inquiry as they emerge (Kelly, 2010). This format was chosen to enable a flexible and in-depth exploration of participants' experiences of health and support services. Evidence suggests that interviews

provide reliable accounts of individuals' pathways through dementia care, producing more accurate data than questionnaires (Drebing et al., 2004).

Semi-structured interviews were conducted with three participant groups: 1) health care and service providers 2) people living with young onset dementia; and 3) family members of individuals living with young onset dementia. Health and service providers were interviewed at one point in time. People with dementia and family members were invited to participate in two sequential interviews (Charmaz, 2001). Given the sensitive nature of interviews with participants with dementia and family members, a sequential interview design was selected to foster rapport, to elicit contextualized accounts, and to enable exploration of emergent concepts and themes (Charmaz, 2001; Murray et al., 2009).

5.3 Context of the Study

The study was conducted in Winnipeg, Manitoba. Winnipeg is a midsized city and capital of the province of Manitoba. The city has a diverse population; in 2016, 28.0 percent of residents identified as a member of a visible minority, and 25.5 percent identified as immigrants (Statistics Canada, 2017). The city is also home to Canada's largest urban indigenous population, representing 12.2 percent of the total population of the city (Statistics Canada, 2017). In terms of health care services, Winnipeg has a substantial tertiary care sector that provides specialist services for people throughout the province. In Canada, provinces are responsible for the delivery of medical services, which are universally insured under the 1984 *Canada Health Act*. There is no centralized, multidisciplinary dementia clinic or referral process, so patients who require specialist assessment may be referred to a range of health care professionals from various sub-specialties (geriatrics, geriatric psychiatry, neurology and psychology).

In Canada, provinces are also responsible for the delivery of extended health services such as community supports, home care, and long-term care. These services, however, are not insured under the *Canada Health Act*. As a result, there is considerable regional variation in terms of cost, availability, accessibility, and the mix of public, non-profit, and private providers. Like most cities in Canada, Winnipeg does not have specialized services for young onset dementia, except for a support group for carers run by the local Alzheimer Society (see Table 7.1. for a description of local dementia services).

5.4 Participants

5.4.1 People Living with Young Onset Dementia and Family Members

Eligibility Criteria. Eligible participants with young onset dementia were required to have a diagnosis of dementia, or probable dementia, where the onset of symptoms began before the age of 65. Participants needed to be aware of their diagnosis, and willing to discuss their experiences of health and social care. For the purposes of the interview, they were required to have conversational familiarity with the English language.

Family members of individuals who had young onset dementia, or had passed away from young onset dementia within the past year, were recruited for this study. For the purposes of this study, family was defined broadly to include anyone who viewed their relationship as family-like. Eligible participants had to be at least 18 years of age.

Recruitment. Recruiting participants with dementia to research is a recognized challenge, hampered by the lack of available programs and services for people with dementia, the stigma associated with the disease, and the low rates of diagnosis (Withall, 2013). Recruiting participants with young onset dementia who make up a much smaller sub-population, is even more difficult. In order to overcome these challenges, I recruited participants through multiple avenues (support groups, clinicians, advertisements, and a study website)

Multiple recruitment materials were developed to convey information about the study and to facilitate recruitment. These included a study website, a recruitment brochure, and advertisements. The study website contained information about the study, eligibility criteria, study procedures, information about the researcher, and contact information. The recruitment brochure and advertisements contained basic information about the study such as procedures, eligibility criteria, risks and benefits, and contact information.

Participants were recruited through three support groups hosted by the Alzheimer Society of Manitoba, at various locations in Winnipeg. One support group was for carers of individuals living with young onset dementia; the other two support groups were for people of all ages in the early stages of dementia. With the permission of the Alzheimer Society and support group members, I met with each support group between March and June 2017 to discuss the study and

to distribute recruitment materials. Support group members were offered brochures with information about the study, contact details, and the study website.

During each meeting, I discussed the purpose and process of the study, and answered questions. Support group members were encouraged to invite their family members to participate, including their relative with dementia if they thought they would be able to participate in the study, and to discuss their experiences of health and support services. After the meeting with the carers support group, the facilitator emailed the recruitment brochure to all support group members on their mailing list. In total, 15 participants were recruited through support groups (See Table 5.1 for participant recruitment methods).

Table 5.1

Participant Recruitment Methods

Recruitment method	Number of participants
Support groups	15
Clinicians	2
Study advertisements	3

The support groups for individuals in the early stages of dementia had some members with young onset dementia. Typically, the family carers met for coffee at a nearby restaurant while their family members attend the support group. After meeting with the support group, I joined the family carers at the nearby restaurant in order to let them know about the study and to distribute the study brochures. At the second support group I attended, the facilitator had arranged for family carers to attend the start of the meeting. In this instance, I distributed the study brochures and discussed the project with individuals living with dementia and their carers.

The second recruitment strategy involved recruiting participants through specialist physicians or clinicians who work with patients with young onset dementia. Physicians or clinicians who participated in an interview were provided with information about the study and study brochures

to distribute to patients or family members. They were asked to offer the brochures to patients with young onset dementia who are aware of their diagnosis, and who, in their opinion, would be able to participate in the study and talk about their experiences. In total, two participants were successfully recruited through clinicians. In addition, one couple and one family member approached by their clinician expressed interest in the study, but ultimately chose not to participate.

In addition to the recruitment methods described above, the research study was also advertised in the Alzheimer Society of Manitoba newsletter and on their website; in the University of Manitoba Centre on Aging's newsletter and website; and through advertisements posted in local personal care homes. Three participants learned about the study through advertisements (see Table 5.1).

Brochures and recruitment advertisements contained contact information so that interested participants could contact me to ask questions or to indicate their interest in participating. These materials also referred potential participants to the study website where they could find additional information about the study and download a consent form. Potential participants who contacted me had the opportunity to ask questions about the study, and if interested in participating, were screened for eligibility over the phone or by email correspondence. Eligible participants were sent an informed consent form to review prior to scheduling an interview. This process was designed to give study participants the opportunity to share and discuss information about the study with their support network and to provide additional time to make a fully informed decision about participation (Hellstrom et al., 2007). One to two weeks after sending the consent form, I contacted potential participants and invited them to schedule an interview at a time and location convenient to them.

Involving Family and Ensuring Supports for Participants with Young Onset Dementia. Involving family carers in research involving people with dementia is widely recommended, although it can restrict access to participants and compromise participant autonomy (Bartlett & Martin, 2002). When family carers are informed and involved, they often assist with communicating the study aims and ensuring participants understand the research process (Bartlett & Martin, 2002; Hellstrom et al., 2007; Pratt, 2002).

Recruiting individuals with living with dementia together with their carers ensured that families were informed of the research aims and process. While I did not set out to exclusively recruit people with young onset dementia through their family members, family members were involved as much as possible. In the end, only family members contacted me about the study; none of the participants with dementia made the initial contact. In addition, all participants with young onset dementia had family members who took part in the study and who helped to arrange the interview.

When a family member indicated that their relative with dementia wished to participate, I used the opportunity to gather information about the person with dementia including: their ability to understand the research study and to talk about their experiences; their ability to read and fill out forms; their comfort level with the term dementia; any topics that might cause distress; and whether they were diagnosed with a dementia subtype. This conversation provided pertinent information about each participant's abilities and capacity to consent. As has been done in previous research involving people with dementia (Digby et al., 2016; Pratt, 2002), participants with young onset dementia had the option of having a family member or friend accompany them during the interview. Each participant with dementia opted to have their spouse join them for the interview.

Participant Characteristics. Participants included six individuals living with young onset dementia, and 14 family members of people affected by young onset dementia. Multiple members of the same family were invited to participate in the study, including the person affected by young onset dementia. This approach has been employed in previous research on young onset dementia to facilitate an in-depth examination of the family context (Roach et al., 2016; Roach et al., 2014).

The twenty participants represented 12 different families and included: six individuals living with young onset dementia, 11 spouses, two adult children and one niece. Six family members participated on their own, with no other family members participating in the study. The other 14 participants comprised six married couples and two adult children:

- Four couples (person with dementia and their spouse)
- Two families of three (person with dementia, spouse, and adult child)

Participants with dementia ranged in age from 57 to 66 years old at the time of their interviews (2 females and 4 males). Four participants were diagnosed with Alzheimer's disease, one had Lewy body dementia, and one had an unknown subtype. All participants with dementia were married at the time of the interview (see Table 5.2 for participants' characteristics). All participants with dementia lived in Winnipeg, Manitoba.

Family members ranged in age from 20 to 76 years old (seven male and seven female). Family member participants had relatives with the following subtypes of dementia: Alzheimer's disease (n=10), Lewy body dementia (n=1), frontotemporal dementia (n=1) and unknown dementia (n=2). In two cases, their relative with dementia had died within the past year. All of the family members and participants with dementia were White and born in Canada (see Table 5.3 for family members' characteristics). Two family members lived in rural communities outside of Winnipeg, and chose to conduct interviews over the phone. In both cases, their relative with dementia had accessed health and support services within Winnipeg, as well as local services within their communities.

Table 5.2

Characteristics of Participants with Dementia

		Frequency (percent)
Gender	Male	4 (67%)
	Female	2 (33%)
Age	Mean	61
	Range	57-66
Age at first symptoms	Mean	53.5
	Range	49-55
Age at diagnosis (MCI or dementia)	Mean	56.5
	Range	53-62
Dementia subtype	Alzheimer's disease	4 (67%)
	Lewis body dementia	1 (17%)
	Unknown	1 (17%)
Years since diagnosis	Mean	4.3
	Range	<1 - 10
Children living at home	Yes	2 (33%)
	No	4 (67%)
Education	Highschool or less	1 (17%)
	College diploma	1 (17%)
	University and/or post-graduate degree	4 (66%)
Annual household income	$39,000 and under	1 (17%)
	$40,000 - $79,000	4 (67%)
	$80,000 and up	1 (17%)

Table 5.3

Characteristics of Family Members

		Frequency (percent)
Gender	Male	7 (50%)
	Female	7 (50%)
Age	Mean	53.4
	Range	20-76
Relationship to person with dementia	Spouse	11 (79%)
	Child	2 (14%)
	Niece/Nephew	1 (7)
Living situation*	Lives with PWD	9 (75%)
	PWD in long-term care	2 (17%)
	PWD in separate household	1 (8%)
Age of family member with dementia*	Mean	60.5
	Range	54-66
Family member's subtype of dementia	Alzheimer's disease	10 (71%)
	Lewis body dementia	1 (7%)
	Frontotemporal dementia	1 (7%)
	Unknown	2 (14 %)
Years since diagnosis*	Mean	4.6
	Range	<1 - 10
Employment status	Full time	5 (36%)
	Part time	2 (14%)
	Retired	6 (43%)
	Other (unemployed, never participated)	1 (7%)
Education	Highschool or less	2 (14%)
	College diploma/some university	3 (21%)
	University and/or post graduate degree	9 (64%)
Annual household income	$39,000 and under	1 (7%)
	$40,000 - $79,000	8 (57%)
	$80,000 and up	3 (21%)
	missing	2 (14%)

Note: *Excludes bereaved family members

5.4.2 Health and Service Providers

Recruitment. With ethical approval from the Health Research Ethics Board of the University of Manitoba, recruitment took place over a five-month period from February 2017 to June 2017. A purposive sampling approach was used to recruit providers with experience working with people with young onset dementia. This strategy involved identifying potential participants and contacting them directly by phone, email or mail to request an interview. Providers were identified through websites for the University of Manitoba, the College of Physicians and Surgeons of Manitoba, regional health authorities, local hospitals, long-term care facilities, and the Alzheimer Society of Manitoba. Potential participants who specialize in dementia were contacted and invited to participate in the study. Employing a snowball sampling technique, participants were asked to provide contact information for other potential participants. In addition to participating in interviews, providers were also consulted regarding recruiting people with young onset dementia and family members. Those who worked with individuals living with young onset dementia or their families were provided with information about the study, and asked to distribute an information sheet to potential participants.

Participant Characteristics. In total, 16 providers participated in semi-structured interviews. This participant population included:

1. Eight physicians involved in the diagnosis, treatment and management of young onset dementia (neurologists, geriatric psychiatrists, geriatricians, and family physicians).
2. Four other health care providers involved in diagnosing, treating or supporting people with young onset dementia and/or family members (psychologists, long-term care managers, and social workers).
3. Four service providers who work with people with dementia (support group facilitators and recreation coordinators).

With one exception, all providers worked in Winnipeg. One health care provider worked in a rural Manitoba community and chose to participate over the phone. Though she worked outside of Winnipeg, she had previous experience working in Winnipeg and referred patients to services in Winnipeg.

Data Collection – Sequential, Semi Structured Interviews

In-depth, semi-structured interviews with people living with young onset dementia and family members at two points in time between March and October of 2017. Depending on the preference of participants, interviews were conducted in participants' homes (n=16), at an alternate location (n=3), or over the phone (n=1), and lasted between 23 and 133 minutes, with an average length of 65 minutes. These interviews explored multiple facets of the diagnostic process such as symptom onset and help seeking, interactions with health care providers, and diagnostic testing and communication. Interviews also examined participants experiences of post-diagnostic services and supports, areas of unmet need, and the impact on the family. Open-ended questions elicited participants' experiences of health and support services while also allowing the exploration of new topics. (see Appendices C and D for interview guides). Follow-up interviews after 3 to 6 months explored additional experiences with health or support services, and provided an opportunity to examine themes that emerged during initial interviews. The sequential interview process was selected to foster rapport, to add depth and to facilitate further exploration of concepts that emerged during initial interviews (Charmaz, 2001; Murray et al., 2009). With the permission of participants, all interviews were digitally audio-recorded and transcribed by a professional transcriptionist.

5.4.3 Interviews with People Living with Young Onset Dementia

Interview methods involve verbal communication, which can be challenging for individuals with cognitive impairment. The emphasis on communication and the interview style can call attention to a person's impairments (Bartlett, 2012; Hubbard et al., 2003). Several dementia researchers recommend developing questions that focus on participants' abilities, and avoiding questions that involve the recollection of detailed information such as dates or the sequence of events (Digby et al., 2016; Pratt, 2002). Many people with dementia can discuss their experiences, so researchers are encouraged to develop questions that focus on participants' views and experiences (Hellstrom et al., 2007; Pratt, 2002; Tanner, 2012). Providing demographic information can be challenging for some, and Pratt (2002) recommends avoiding any unnecessary demographic questions.

In order to minimize harm and maximize participation, interviews with people with dementia focused on their experiences of health care and support services. Participants were asked questions about their experience of receiving a diagnosis, and their experiences within community-based services such as peer support groups, day programs, or home care. They were also asked about information needs and preferences, and the kinds of activities or programs they would like to participate in (see Appendix C). All six participants with dementia chose to have their spouses present. While the questions focused on the experiences of the person with dementia, both spouses were invited to respond and contribute. Demographic information, and the timing and sequencing of health-related events was collected during interviews with family members.

5.4.4 Interviews with Family Members

In-depth semi-structured interviews with family members explored how they and their relative with dementia navigate and experience health and support services. Interviews began by asking participants about their relationship to their relative with dementia, and their roles and responsibilities within the family (see Appendix D). Participants were then asked to talk about the onset of dementia, the process of obtaining a diagnosis, their experiences of health services and supports, and the impact on the family. Other topics that were explored during interviews included unmet needs and preferences for information and service provision. At the end of the interview, participants were also asked a brief series of demographic questions; these data were collected for the purposes of describing the sample.

Family members who had a relative with dementia participating in the study were invited to participate in a separate, individual interview. Two married couples requested to conduct both interviews together. To accommodate them, I conducted joint interviews. The first set of questions focused on the experiences of the person with dementia, followed by questions focusing on the family member.

5.4.5 Sequential Interviews

Eligible family members and participants with dementia were invited to participate in a second interview. Since these interviews inquired about new experiences with health and support services, family members who were bereaved at the time of the first interview (n=2) were not

asked to participate in a second interview. After completing the initial round of interviews, all participants were sent an update on the study's progress in September 2017. The update included information about participants, some preliminary findings, and a reminder that eligible participants would be contacted to schedule a second interview.

In the research proposal, the plan was to re-interview participants after a period of six months. However, due to time constraints imposed by my personal circumstances (parental leave), as well as participants' schedules, follow-up interviews were conducted between 3.5 to 6.5 months after the initial interview (from September to October 2017). In total, 15 participants took part in follow-up interviews (four participants with dementia and 11 family members). Two participants with dementia did not participate in follow-up interviews as their carers felt that their cognitive abilities had worsened, and they would not be able to provide informed consent or meaningfully participate. One family member expressed interest in participating a second interview, but did not respond to requests to schedule an interview.

Follow-up interview guides were tailored to each participant based on a review of their initial interview as well as a preliminary analysis of interview data (see Appendix E for a sample follow-up interview). Participants were asked whether they had experienced any changes in symptoms, care needs or services. They were also asked follow-up questions regarding topics that arose during their first interview, as well as questions of clarification. In addition, these interviews sought feedback from participants regarding community-based programs for people living with young onset dementia. In the first round of interviews, many participants voiced their desire for community-based programs and activities for younger individuals with dementia. However, the data contained little information about the types of programs participants wanted, or the factors that might influence participation. In order to further explore this topic, follow-up interviews included questions about participants' preferences for program settings and activities as well as potential barriers and facilitators to participation. The length of follow-up interviews ranged from 14 to 105 minutes, with an average length of 51 minutes.

5.4.6 Interviews with Health and Service Providers

Semi-structured interviews were conducted in person (n=13) or over the phone (n =3), depending on the preference of the participant. Interviews with providers lasted between 22 and 103

minutes, with an average length of 54 minutes. Each interview was tailored to the participant, based on the nature of their work and their area of expertise (see Appendices A and B for interview guides). Interviews were audio-recorded and subsequently transcribed by a professional transcriptionist.

Interviews with providers examined the following topics:

- The context of dementia care in Manitoba, including the strengths and limitations of available services and supports.
- Approaches to diagnosis, and barriers and facilitators to diagnosis and support services.
- Age restrictions, service gaps, and areas of good practice.
- Recommendations for improving and expanding services for people with young onset dementia.

5.5 Reflexivity

In qualitative research, the researcher plays an active role in shaping and constructing the research process, interpretation and outcomes (Finlay, 2003). Broadly speaking, reflexivity involves analysis of the ways that the researcher and her research relationships influence the research process (Finlay, 2003; Hewitt, 2007). Adopting a reflexive approach, I documented and examined how my assumptions, social position, interpersonal dynamics, and chosen methodology influenced the research process. To do so, I wrote memos and took field notes throughout the research process to keep track of my decisions, any issues that arose, and reflections on each research encounter.

Following each interview, I wrote down my thoughts and reflections on the interview process, including any ethical dilemmas, the dynamics of the research encounter, my personal feelings and reactions to the interview, and any other observations or analytic insights. I used this process to critically reflect on how my own personal experiences and assumptions influenced the research interactions and outcomes. In addition to field notes and memos, I also met with my supervisor, Dr. Verena Menec, on a regular basis to discuss the research process. This provided me with an opportunity to review ethical or methodological issues as they arose and to debrief any emotionally difficult experiences (Heggestad et al., 2012; Pratt, 2002). For a more detailed description of my reflections on the research process, see Chapter 8.

5.6 Approaches to Data Analysis

The data set was studied using a combination of inductive, thematic analysis (Braun & Clarke, 2006) as well as a theoretical analysis of access using the candidacy framework as conceptual lens. Data analysis occurred throughout the data collection process, so that emergent concepts could be incorporated into subsequent interviews (Bradley, Curry, & Devers, 2007). Specifically, I took fieldnotes after each interview to document my observations, analytic ideas, and reflections on the research process. In addition, interviews were transcribed as they were completed, enabling me to read transcripts, identify emergent themes, and refine interview guides during data collection. The sequential interview design among family members and participants with dementia further facilitated an exploratory and iterative approach to data collection and analysis.

Once data collection was complete, I read all transcripts and fieldnotes repeatedly to familiarize myself with the data, and to identify themes and patterns. For participants who conducted sequential interviews, transcripts and fieldnotes from both interviews were analyzed together as a single unit (Murray et al., 2009). Next, I coded all transcripts and fieldnotes and developed a preliminary list of codes. These codes represented concepts, categories and themes identified within the data set (Bradley et al., 2007). Codes were compared within and between participant groups to identify commonalities, differences and negative cases. Codes were continuously reviewed, refined and organized into a coding scheme. The coding scheme defined each theme and organized them hierarchically (Braun & Clarke, 2006). After completing this phase of thematic analysis, I returned to the data set using the candidacy framework as a conceptual lens to further explore access processes and barriers. This generated new themes and interpretations of the data, which I incorporated into the coding scheme through a process of iterative comparison. The coding scheme was further refined using the dimensions of candidacy as an organizing framework. I met with my supervisor, Dr. Menec, throughout the analysis to discuss emerging patterns and themes. Once the coding scheme was finalized, I coded the data set using Nvivo 11 software. Thematic analysis continued throughout the writing process as I refined my analysis and further developed my themes conceptually.

5.7 Some Notes on Participant Recruitment, Data Collection and Data Analysis

In line with an exploratory research approach, participant recruitment and data collection procedures were designed to be flexible. As a result, recruitment strategies shifted over the course of data collection. In the following paragraphs, I outline my decisions and strategies, and consider their impacts on data analysis.

I chose to define family broadly so that various family members could take part in the study. In the end, most family member participants were spouses; only two adult children and one niece participated in the study. Data from these participants made important contributions to the analysis, and furthered my understanding of the family context. However, there were not enough adult children to facilitate an analysis of children's unique needs and experiences.

Another recruitment decision concerned the population with intellectual disabilities and dementia. Participants with co-existing intellectual disabilities were eligible to participate in this study; however, none of the participants in my sample (or their relatives) had dementia and an intellectual disability. This population has been underrepresented in previous research on young onset dementia (Withall et al., 2014). Given that individuals with dementia and intellectual disabilities face addition barriers to care, and use different services and providers (Herron et al., 2020), recruiting participants from this population would likely have required a targeted recruitment strategy.

Preliminary data analysis yielded several observations that were not well explained by the existing dataset. For example, findings from interviews with specialist physicians and family members pointed to the role of primary care providers in the diagnostic process. However, my initial recruitment strategy targeted specialist physicians and clinicians with expertise in dementia care. In order to further examine the perspectives of primary care providers, a study advertisement was distributed to primary care centres associated with the University of Manitoba Department of Family Medicine. This recruitment initiative only yielded one participant. Due to time constraints, I was not able to pursue any further recruitment for this group. With only one primary care provider, I was not able to explore their role within the diagnostic process or access to support services. Instead, her interview was included in my analysis and grouped together with other health care providers.

Another decision concerned the inclusion of people from outside of Winnipeg. My recruitment strategies focused on people who live in Winnipeg. However, two family members and one health care provider from outside of Winnipeg expressed an interest in participating. I decided to include these participants because that they had used services within Winnipeg or, in the case of the provider, referred patients to services there. The sample of participants from rural areas was too small to explore differences between urban and rural contexts. However, these interviews were included in my analysis and grouped together with other family members and health care providers.

Overall, the flexible and inclusive approach to data collection generated diverse perspectives on young onset dementia care, and added important contextual information. Although I did not have enough participants to conduct a focused analysis on the experiences of certain groups (e.g. children, people who live in rural settings, primary care providers), their accounts enriched and expanded the data set and analysis.

5.8 Ethical Considerations

5.8.1 Ethics Approvals

This study received ethical approval from the University of Manitoba's Health Research Ethics Board. Additional approval to interview employees of the Winnipeg Regional Health Authority (WRHA) was also obtained from the WRHA Research Access and Approval Committee. Permission to recruit participants through the Alzheimer Society support groups was also sought from the Alzheimer Society of Manitoba. All participants were required to provide informed consent prior to participation (see Appendices F to H). Steps were taken to minimize any potential risks such as emotional distress (see below). All appropriate measures were taken to protect participants' privacy and confidentiality.

5.8.2 Gaining and Maintaining Informed Consent

Due to the progressive nature of dementia, it is likely that the ability to understand and to make informed decisions will be increasingly impaired over time (World Health Organization, 2012). However, there is a growing consensus that researchers should presume that participants with dementia have the capacity to make informed choices (Sherratt et al., 2007; World Health Organization, 2012). Dementia is a diverse and highly variable syndrome caused by various

diseases and conditions. Individuals exhibit different cognitive symptoms that progress at different rates. As a result, people often retain decision-making capacity during the early stages of the disease, followed by intermittent or progressive impairment (Peisah, Sorinmade, Mitchell, & Hertogh, 2013).

In addition, decision-making capacity is situational; it depends on the complexity of the study, the context surrounding the decision-making process, and the potential capacity of the participant at a particular moment in time (Peisah et al., 2013; Sherratt et al., 2007). It may also depend on the supports available to the participant, such as the support of their social network or an advocate, and the communication skills of the person explaining the project (Peisah et al., 2013).

To support informed decision making, efforts were made to provide information about the study in clear and accessible language. As mentioned above, information about the study was shared with participants' family members. Participants with dementia also had the option of having someone accompany them to the interview. These supports were offered to maximize participants' understanding of the research project, its aims, and any possible benefits or risks.

The British Psychological Society published a practical guide to conducting research involving people not having the capacity to consent to their participation in research (Dobson, 2008). In the absence of a comparable Canadian document, I drew on the advice and examples of good practice contained in this guide to inform my approach to obtaining informed consent. According to the guide (Dobson, 2008), when a person agrees to participate in a research study, the researcher is responsible for assessing the quality of that decision and should consider whether the participant has agreed or refused to participate on the basis of: 1) freedom of choice and absence of coercion; 2) a general understanding of the research and its purpose; and 3) an understanding of possible risks and benefits (Dobson, 2008).

In order to enhance the decision-making abilities of participants with dementia, I read through the Participant Information and Consent Form, taking time to pause and to check with participants to make sure they understood the material. For each participant, I considered whether their decision to participate met the standards of informed consent put forth by the British Psychological Society (Dobson, 2008). If at any point I was unsure whether a participant had the capacity to make an informed decision, I used checking questions, based on the consent

form, to determine whether the participant understood the general purpose of the research study, and the benefits and risks of participating. While I did not seek proxy consent, I asked each participant's spouse, who was present for the interview, whether they had any questions, and whether they were OK with going forward before beginning the interview.

Participants with dementia were given the option of providing oral consent, rather than written consent. This option was intended to provide a more accessible method of providing informed consent, particularly for participants who had difficulty with reading or writing. All six participants with dementia chose to provide oral consent. After reading through the Participant Information and Consent Form, I read through the Consent Form and asked participants whether they agreed or disagreed for each of the six questions listed on the form (see Appendix G). With the permission of participants, their consent to participate was audio recorded. In addition, I kept a written record of all oral consent procedures including the time, date, and presence of a support person.

In addition to formal consent procedures, ongoing process consent was sought throughout the research process (Dewing, 2007). This approach to consent entails seeking ongoing verbal consent and looking for verbal and non-verbal signs of distress or discomfort (Digby et al., 2016; Heggestad et al., 2012; Pesonen et al., 2011). Paying attention to body language is particularly important when communication is impaired, and is considered essential to maintaining ongoing consent in the context of dementia research (Digby et al., 2016).

5.9 Stakeholder Engagement and Knowledge Dissemination

To enhance the relevancy of this research project for dementia care programming and advocacy efforts, I engaged with key stakeholders throughout the course of the research. Specifically, I met with stakeholders from the Alzheimer Society of Manitoba, the Winnipeg Regional Health Authority, and Manitoba Health. I also presented preliminary findings to Manitoba's Dementia Implementation Advisory Committee (DIAC), a committee of stakeholders established by Manitoba Health for planning and implementing the provincial dementia strategy. I also shared early results at the Alzheimer Society Care4U conference in October 2017, which is primarily attended by individuals affected by dementia and family carers. Results of the study were shared with participants, the Alzheimer Society, as well as key stakeholders within regional and

provincial health agencies. I also met with carers at an Alzheimer Society support group to discuss the report and to identify avenues for dissemination. Following their suggestions, I shared the report with several politicians and other stakeholders.

Preface to Chapter 6

Chapter 6 presents a qualitative inquiry into the process of accessing and delivering a diagnosis of young onset dementia using data from in-depth interviews with people living with young onset dementia, family members and health care providers. This chapter addresses the second objective of this dissertation to critically examine access to a diagnosis of young onset dementia using the candidacy framework as a conceptual lens. To support the recruitment, participation and well-being of participants living with young onset dementia, the research process was guided by the methods and practices of inclusive dementia research described in Chapter 4. Drawing on the theoretical construct of candidacy, multiple dimensions of access and vulnerability are presented and critically examined. Additionally, recommendations to develop more age-inclusive diagnostic services are considered.

Citation details

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Chapter 6. An Examination of Access to a Diagnosis of Young Onset Dementia using the Candidacy Framework

Abstract

People living with young onset dementia face significant barriers to diagnosis, resulting in delays, misdiagnoses and gaps in treatment. I examined the process of accessing and delivering a diagnosis of young onset dementia from the perspectives of people living with young onset dementia, family members and health care providers. Semi-structured interviews were conducted with a purposive sample of six people living with dementia, 14 family members and 16 providers in Winnipeg, Canada. Findings were analyzed using inductive thematic analysis, and using the candidacy framework as a conceptual lens. Participants' accounts revealed the diagnosis of young onset dementia as a multifaceted, negotiated process involving patients, family members, and health professionals. Assumptions about age and dementia affected how participants interpreted their symptoms, how they presented to health services, and how they, in turn, were perceived by health care providers. At the organizational level, age-restrictions, fragmentation, and unclear referral pathways further complicated the diagnostic process. My findings lend support to the growing call for specialist young onset dementia care and point towards several recommendations to develop more age-inclusive diagnostic services.

6.1 Introduction

Access to a timely diagnosis is widely considered an essential component of dementia care, and has been adopted as a principal goal of dementia care policies around the world (World Health Organization, 2012). Despite the movement to expand diagnostic services, the condition remains underdiagnosed worldwide (Prince, Bryce, & Ferri, 2011; World Health Organization, 2012). In high income countries alone, an estimated 50 to 80 percent of dementia cases go undetected (Prince et al., 2011). For people living with young onset dementia (dementia that develops before the age of 65), the barriers to diagnosis appear to be compounded, resulting in diagnostic delays, misdiagnosis, prolonged periods of uncertainty and gaps in treatment (Draper et al., 2016; Novek, Shooshtari, & Menec, 2016; van Vliet et al., 2013).

Although a diagnosis of dementia carries significant consequences, it also confers important benefits (Jutel, 2011). A timely diagnosis of dementia enables individuals to understand their condition, adapt to changes, and to participate in decisions about their current and future care. Diagnosis also facilitates access to treatments, services and resources such as financial benefits. Because individuals with young onset dementia are more likely to be working and supporting families, the financial impact is profound (Kandiah et al., 2016). Without a diagnosis to explain changes in behavior or productivity, working individuals affected by dementia risk losing their employment, and may be unable to access financial benefits. Given the significance of dementia diagnoses and evidence of diagnostic delays, this qualitative study aims to critically examine the process of accessing and delivering a diagnosis of young onset dementia from the perspectives of people living with young onset dementia, family members and health care providers.

6.1.1 An Overlooked Population

Dementia is an umbrella term for a range of conditions characterized by progressive impairment in cognitive function (World Health Organization, 2012). Symptoms vary and may involve impaired attention, planning, problem solving, memory, language, visual perception, motor skills, as well as behavior changes (The British Psychological Society, 2016). The term young onset dementia refers to individuals who develop dementia at younger ages, typically defined as under 65 years of age (Carter, Oyebode, & Koopmans, 2018; Draper & Withall, 2016). The category echoes the previous distinction between senile and pre-senile forms of dementia, which demarcated dementia diagnoses on the basis of age (Ballenger, 2006). Age is no longer used to discern dementia subtypes (Carter et al., 2018); the concept, however, is increasingly used to draw attention to a population that remains overlooked in dementia research, policy and practice.

The presence of dementia in younger age groups is often obscured by the predominant perception of dementia as a disease of old age. The paucity of research on young onset dementia also contributes to the limited visibility of this population (Carter et al., 2018; Withall et al., 2014). Individuals under 65 years of age are routinely excluded from epidemiological research on dementia (Withall et al., 2014; World Health Organization, 2012). More recent epidemiological studies of young onset dementia (Kvello-Alme, Bråthen, White, & Sando, 2019; Withall et al., 2014) report higher prevalence estimates compared to past studies, with estimates ranging from 132.9/100,000 (Withall et al., 2014) to 163.1/100,000 (Kvello-Alme et al., 2019) in

adults aged 45-64. Although young onset dementia is frequently described as “rare”, these rates are comparable to other well-known neurological diseases such as Parkinson’s disease (Marras et al., 2018; Moisan et al., 2016). Since these studies only capture individuals with a documented diagnosis of dementia, the true prevalence is thought to be considerably higher (World Health Organization, 2012).

6.1.2 Emerging Research on Young Onset Dementia

Though limited, research on young onset dementia has expanded over the past decade, reflecting a growing recognition that people with young onset dementia have distinct characteristics, experiences and needs. This emerging literature points to profound social, psychological and financial impacts on families (Svanberg, Spector, & Stott, 2011; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010); unmet needs (Bakker, de Vugt, van Vliet, Verhey, Pijnenburg, Vernooij-Dassen, & Koopmans, 2014; Bakker, de Vugt, van Vliet, Verhey, Pijnenburg, Vernooij-Dassen, Koopmans, et al., 2014; Millenaar, Bakker, et al., 2016); and barriers to health and social services (Cations et al., 2017; van Vliet et al., 2011). A common thread throughout this research is the idea that younger people face significant barriers to obtaining a diagnosis (Beattie, Daker-White, Gilliard, & Means, 2004; Carter et al., 2018; O’Malley et al., 2019; Rabanal, Chatwin, Walker, O'Sullivan, & Williamson, 2018; van Vliet et al., 2011)

Evidence suggests that younger individuals wait significantly longer compared to older adults to receive a diagnosis of dementia (Draper et al., 2016; Novek et al., 2016; van Vliet et al., 2013). Novek, Shooshtari and Menec (2016) found that Canadians under 65 waited three times longer than older adults to obtain a diagnosis of dementia. Similarly, a prospective cohort study in the Netherlands reported that patients with young onset dementia waited 4.4 years from the onset of symptoms and diagnosis, compared to 2.8 years among older adults (van Vliet et al., 2013). The INSPIRED study from Australia reported that the median time from symptom onset to initial dementia diagnosis was 3.2 years, while the time from symptom onset to the final diagnosis of a specific subtype of dementia was 4.7 years (Draper et al., 2016).

Qualitative studies exploring the lived experiences of people with young onset dementia and their families routinely identify the diagnostic process as a significant source of stress and a key area for improvement (Ducharme, Kergoat, Antoine, Pasquier, & Coulombe, 2013; Johannessen

& Möller, 2013; Millenaar et al., 2016; Rabanal et al., 2018). Few qualitative studies have focused specifically on the diagnostic process (Spreadbury & Kipps, 2018; van Vliet et al., 2011), so questions remain about how people with young onset dementia and their family members interact with health services, and how health care providers experience the diagnostic process.

The available literature on young onset dementia identifies several factors that may hinder access to a diagnosis such as delayed help seeking (Rabanal et al., 2018; van Vliet et al., 2011), clinical complexity and heterogeneity (Carter et al., 2018; Spreadbury & Kipps, 2018), lack of knowledge of young onset dementia among health care providers (van Vliet et al., 2013), and the absence of clear referral pathways (Williams, Dearden, & Cameron, 2001; World Health Organization, 2012). While these issues are often proposed as explanations for diagnostic delays, few studies have examined the diagnostic process in depth, or considered the perspectives of people living with young onset dementia. What's more, discussion of access remains largely atheoretical, limited to a description of barriers, or measurements of the time elapsed between symptom onset and diagnosis. Theoretically informed, in-depth qualitative research is therefore needed to better understand the social and structural factors that shape the diagnostic process. To address this gap in the literature, I used qualitative interviews to explore how people living with young onset dementia, family members and health care providers experience the diagnostic process. Applying the lens of the candidacy framework (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005), the present analysis examines multiple dimensions of access, and explores the complex relationships among care experiences, provider practices, and the wider context of health services.

6.2 Conceptualizing Access: The Candidacy Framework

Developed by Dixon-Woods et al. (2005), the candidacy framework conceptualizes access to health care as a multifaceted and iterative process of negotiation among individuals, care providers and institutions. Central to the conceptual model is the notion that a person's candidacy, or eligibility for care is interpreted, pursued, sustained or diminished through interactions with health care providers and services. These micro-level social interactions are influenced by organizational conditions such as the configuration of health services, as well as the wider social and policy context. Access, therefore, represents a dynamic interplay between

health services which "are continually constituting and seeking to define the appropriate objects of medical attention and intervention" and individuals seeking care who are also "engaged in constituting and defining what they understand to be the appropriate objects of medical attention and intervention" (Dixon-Woods et al., 2006: 7).

The framework delineates six constructs that represent distinct but overlapping dimensions of candidacy (see Table 6.1). The dimensions broadly correspond to key stages in a patient's health care trajectory, beginning with the recognition that symptoms require medical attention, through presentation at services and interactions with providers, and culminating in an offer of care. The latter construct refers to the broader organizational features of health services that influence these interactions. The framework has been used to examine the health care experiences of diverse populations (Chase, Cleveland, Beatson, & Rousseau, 2017; Chinn & Abraham, 2016; Koehn, 2009; Macdonald et al., 2016; Methley, Chew- Graham, Cheraghi- Sohi, & Campbell, 2017), including older adults with dementia (Koehn, 2009).

6.3 Methods

This study used the method of semi-structured interviews to examine young onset dementia health and support services in Winnipeg, Canada. This approach was selected to facilitate a flexible, in-depth exploration of participants' experiences, while also maintaining a focus on health and support services.

6.3.1 Study Context

Winnipeg is a midsized city and capital of the province of Manitoba. The city has a substantial tertiary care sector that provides specialist services for people throughout the province. In Canada, provinces are responsible for the delivery of medical services, which are universally insured under the 1984 *Canada Health Act*. Under the *Act*, hospital and physician services are universally insured and provided free of charge. Like most cities, Winnipeg does not have specialized services for young onset dementia, except for a support group for family carers run by the local Alzheimer Society. There is no centralized, multidisciplinary dementia clinic in the city. Instead, specialist dementia assessment is available through various services administered by different medical specialties (e.g., geriatric services, and geriatric mental health services), or

Table 6.1

Dimensions and Characteristics of Candidacy (Dixon-Woods et al., 2005)

Dimensions	**Characteristics**
Identification	The process of recognizing a health issue that requires medical attention. How people come to recognize their candidacy affects how they present their claim to health services.
Navigation	The process through which people find and gain access to services.
Permeability of services	The degree to which services are inclusive or restrictive. More permeable services have few requirements for entry, while less permeable services demand more qualifications (e.g. referrals, eligibility criteria).
Appearances and adjudications	Appearances refers to the ways in which patients present their health issue and assert a claim for medical attention. Adjudication refers to health professionals' judgements and decisions regarding an individual's candidacy for care.
Offers and resistance	The interventions or services offered (or not offered) following adjudications of candidacy, and patients' decisions to accept or decline such offers (Dixon-Woods, 2005).
Operating conditions	Organizational and contextual factors that influence provider-patient interactions and the process of asserting candidacy.

through referral to individual practitioners from a range of specialties (e.g., geriatrics, psychiatry, neurology and psychology).

6.3.2. Participant Recruitment

With ethical approval from the Health Research Ethics Board of the University of Manitoba, I recruited a purposive sample of people living with dementia, family members and providers between February 2017 and November 2017. People with dementia and family members were recruited through support groups, health care providers, advertisements, and snowball sampling. I attended three support groups hosted by the Alzheimer Society of Manitoba to discuss the study and distribute recruitment materials (two support group for people with early stage dementia, and one support group for carers of people with young onset dementia). Health care providers with expertise in young onset dementia were asked to offer recruitment materials to eligible patients and family members. The study was also advertised in newsletters, long-term care facilities, and on a study website.

Recruitment material contained contact information so interested participants could contact the principal investigator to indicate their interest in participating. Potential participants were screened for eligibility and sent an informed consent form prior to scheduling an interview. This process was intended to enable participants with dementia to discuss the study with their support network and to provide additional time to make an informed decision about participation (Hellstrom, Nolan, Nordenfelt, & Lundh, 2007). One to two weeks after sending the consent form, potential participants were contacted to schedule an interview.

To be eligible, participants with young onset dementia were required to have a diagnosis of dementia, or probable dementia, where the onset of symptoms began before the age of 65. Potential participants were also asked if they were comfortable discussing their diagnosis and care experiences. Family members of individuals who have young onset dementia, or who have passed away from young onset dementia within the past year were eligible to participate. Participants were encouraged to invite their family members to participate in the study. This approach has been employed in previous research on young onset dementia to facilitate an in-depth examination of the family context (Roach & Drummond, 2014; Roach, Drummond, & Keady, 2016). All participants were 18 years of age or older.

A purposive sampling approach was used to select health care and service providers with relevant expertise. Potential participants were identified through websites for universities, government agencies, health and social care organizations, and non-profit organizations. Health and service providers who specialize in dementia were contacted and invited to participate in the study. Employing a snowball sampling technique, participants were asked to suggest other contacts with relevant experience. To recruit primary care providers with experience treating people with young onset dementia, a study advertisement was distributed to family medicine centers affiliated with the University of Manitoba.

6.3.3. Participants

In total, 36 participants were interviewed for this study. Twenty participants from 12 families took part: six individuals living with young onset dementia, 11 spouses, two adult children and one niece. Participants included: six married couples; two adult children (each one connected to a participating couple); and six family members with no relation to other participants in the study.

Participants with dementia ranged in age from 57 to 66 years old (2 females and 4 males), and all were married at the time of the interview. Participants' dementia subtypes included Alzheimer's disease (n=4), Lewy body dementia (n=1), and unknown (n=1).

Family members ranged in age from 20 to 76 years old (seven male and seven female). Nine participants were living with their relative with dementia, three lived apart, and in two cases their relative with dementia had passed away within the past year. Participants' family members had diagnoses of Alzheimer's disease (n=10), Lewy body dementia (n=1), frontotemporal dementia (n=1) and unknown dementia (n=2). All 20 family members and participants with dementia were White, born in Canada, and spoke English.

I also interviewed 16 health and service providers who had experience working with people with young onset dementia or their family members. There were 11 participants from a range of health professions (neurology, psychiatry, psychology, family medicine, geriatrics, and nursing) and five allied health professionals and service providers from social work, recreation therapy, and non-profit organizations.

6.3.4 Interview Procedures

Sequential, semi-structured interviews were conducted with people with dementia and family members of individuals affected by young onset dementia at two points in time. Interviews were conducted in participants' homes (n=16), at an alternate location (n=3), or over the phone (n=1). Interviews ranged from 23 to 133 minutes, with an average length of 65 minutes. All participants provided informed consent prior to taking part in interviews. With the permission of participants, all interviews were digitally audio-recorded and transcribed by a professional transcriptionist.

People with Dementia.

Participants with dementia had the option of having someone accompany them during the interview, and all six chose to have their spouses present. Care was taken to ensure the consent process was inclusive, accessible and rigorous. Study information and consent forms used clear and accessible language. I read through the consent form, taking time to pause and to check with participants to make sure they understood the material. Spouses were not asked to provide proxy consent. However, before beginning the interview, each spouse was asked whether they were comfortable proceeding. In addition to formal consent procedures, ongoing process consent was practiced throughout the research process (Dewing, 2007). This involved seeking ongoing verbal consent, restating the study aims when necessary, and looking for verbal and non-verbal signs of distress or discomfort (Digby, Lee, & Williams, 2016; Heggestad, Nortvedt, & Slettebø, 2012).

Interview questions explored participants' experiences of the diagnostic process, their interactions with providers, and the experience of receiving a diagnosis of dementia. Participants were also asked about their experiences of community-based services. Interview questions focused on the experience of the person with dementia. However, both spouses were invited to respond to questions. Four participants with dementia took part in follow-up interviews.

Family Members.

Family members who had a relative participating in the study were invited to conduct a separate, individual interview. Two family members requested to conduct their interview along with their spouse with dementia. All other family members (n=12) were interviewed alone. Interviews with family members explored multiple facets of the diagnostic process such as symptom onset and

help seeking, encounters with health care providers, diagnostic testing and communication, post-diagnostic supports, and the impact on the family. Open-ended questions elicited participants' experiences of the diagnostic process while also facilitating the exploration of new topics. Family members were also asked a brief series of demographic questions. Follow-up interviews were conducted approximately three to six months later to explore additional experiences of health and support services, and to examine themes that emerged during initial interviews. Family members who were bereaved at the time of the first interview were not asked to participate in a follow up interview. Eleven family members took part in follow up interviews.

Health and Service Providers.

One-time, semi-structured interviews were conducted with health and service providers. Interviews with providers were tailored for each participant, depending on their work and expertise. Providers were asked about the strengths and limitations of services, their experiences of the diagnostic process, and the factors that affect diagnostic and post-diagnosis care. Interviews were conducted in participants' offices (n=13) or over the phone (n=3) and lasted between 22 and 103 minutes, with an average length of 54 minutes.

6.3.5 Data Analysis

The data set was studied using a combination of inductive, thematic analysis (Braun & Clarke, 2006), as well as a focused analysis of the diagnostic process using the candidacy framework. First, I read all transcripts and field notes to identify broad themes and patterns in the data. Transcripts from initial and follow-up interviews were analyzed together for each participant. Next, I coded all transcripts to generate a preliminary list of codes. These codes were reviewed, refined and organized into a coding scheme. After completing this phase of the analysis, I determined that the candidacy framework (Dixon-Woods et al., 2006) was well suited to analyzing the diagnostic issues described in the data set. I then returned to the data set using the candidacy framework as a conceptual lens to focus and refine the analysis of the diagnostic process. I compared new themes and interpretations to previous codes and integrated them into the coding scheme. The coding scheme was further refined using the dimensions of the candidacy framework (see Table 6.2). The sub-themes, presented under each dimension of candidacy, were developed through an iterative process of inductive thematic coding and

deductive, theoretical analysis (Braun & Clarke, 2006). I met with my supervisor, Verena Menec, throughout the analytic process to review themes and codes. Once the coding scheme was finalized, the I coded the data set using Nvivo 11 software.

6.4 Results

The following sections present our findings for each dimension of the candidacy framework and corresponding sub-themes (Table 6.2).

6.4.1 Identification

According to Dixon-Woods et al. (2006), the process of accessing health care begins with identifying a health issue that requires medical attention. In common with previous research on young onset dementia (Hoppe, 2019; van Vliet et al., 2011), participants described this period as a confusing and difficult time during which they struggled to cope with, and to make sense of the changes they observed in themselves or their family member. My analysis indicates that the process of identifying the symptoms of dementia was complicated by the diverse manifestations of the condition among young individuals. Assumptions about dementia as a disease of old age also affected how participants interpreted symptoms, and ultimately hindered help-seeking.

Table 6.2

Dimensions of Candidacy and Corresponding Sub-Themes

Dimensions	Sub-Themes
Identification	• Making sense of diverse symptoms • Interpreting signs of dementia at midlife
Navigation	• The diagnostic maze • Navigation as work
Permeability of services	• The age criterion • Atypical patients
Appearances and adjudications	• Presenting dementia at midlife • Adjudicating complex and atypical presentations • Diagnostic communication, discomfort and uncertainty
Offers and resistance	• Limited offers of care • The interpersonal dimensions of health interactions
Operating conditions	• A fragmented system

Making Sense of Diverse Symptoms. Participants described a wide range of early symptoms that manifested in different contexts, progressed at different rates, and led to health care trajectories. Early changes observed by participants included: stress, relationship problems, personality changes, communication and language changes, apathy, memory problems, anxiety, paranoia, hearing problems, disorientation, and balance issues. Two participants originally

sought help for persistent headaches, and one reported experiencing depression prior to the onset of dementia.

While some symptoms signaled a cognitive issue, such as memory or word finding problems, other changes were difficult to interpret. For example, some family members described the early symptoms as subtle and insidious, and referred to a vague sense that something was wrong:

> *"She just didn't seem right, but nobody really knew that she had dementia or what she had. So it was kind of confusing…because she had balance issues, she had a lot of things that were just not right; she couldn't - there were hearing issues, she had a lot of issues that just didn't - and she had some memory issues but like everybody has memory issues."* (Spouse, male).

> *"We just noticed things, I just noticed, just some peculiar things for her where, you know, maybe she wasn't as interesting in cooking as she used to be. [My wife] has always been a fantastic cook and a really active mother."* (Spouse, male).

Psychological symptoms such a depression, anxiety or apathy, are common in young onset dementia (Bakker, de Vugt, van Vliet, Verhey, Pijnenburg, Vernooij-Dassen, Koopmans, et al., 2014; Carter et al., 2018). When these symptoms are present early on, they may be misinterpreted as signs of psychiatric illness. In the following quote, a participant describes how she interpreted her husband's initial symptoms:

> *"We honestly thought he had a nervous breakdown. That's what we thought, he lost his job and that meant everything to him…It came across as a nervous breakdown and I would like people to understand that…I mean we thought that for at least a year plus, you know? It was quite a long while before we actually realized oh, there's something else wrong here."* (Spouse, female).

Another participant experienced depression prior to developing dementia. When he started getting lost, his wife attributed it to his mental health condition:

> *"I just said, no, [my husband]'s always been bad with directions and whatever. But those are probably some early signs. But we tied it into [husband]'s depression, because he never had really good meds for his depression."* (Spouse, female).

Interpreting Signs of Dementia at Midlife. Participants' accounts of how they came to recognize the early symptoms of dementia suggest an evolving process of interpretation and negotiation among the person experiencing symptoms, family members, and health care providers. Dementia at midlife is unexpected and most participants did not consider the possibility of dementia until it was mentioned by a health care provider. Whereas the symptoms of dementia in older adults are often attributed to aging (Koehn, Badger, Cohen, McCleary, & Drummond, 2016; Perry-Young, Owen, Kelly, & Owens, 2018; Rogers, Coleman, Brodtmann, Darby, & Anderson, 2017), participants in this study lacked a framework for understanding the changes they observed. Several family members stated that it did not occur to them that their spouse could have dementia:

> *"I noticed things but I kind of just shrugged them off thinking it was something else, just, you know, exhausted from work or he had too many drinks or, you know, just … it didn't cross my mind that he could have dementia."* (Spouse, female)

> *"So you have those things but you don't really key in that oh maybe I've got dementia or I've got Alzheimer's."* (Spouse, male).

> "*I could not believe it would be [dementia] because he was too young and because that just couldn't happen to us."* (Spouse, female).

In three families, the person affected by dementia raised concerns about their cognition to their spouse and health care provider. Other participants described a more muddled process: concerns were noticed, occasionally discussed, but not understood as signs of possible dementia. In common with previous research on young onset dementia (van Vliet et al., 2011), early symptoms were often misinterpreted, denied, or concealed:

> *"One night she was coming to bed and she was crying and I said, "What's the matter?" I can't remember what led up to that and she had said to me, "I think I'm losing my mind"; and I said, "No", I said, "You know-", it doesn't sound very sympathetic but I said, "Oh no you're not, you must be just having menopause"... that was one way to just say "Okay it must be that, don't worry about it."* (Spouse, male).

> *"I think she went through a phase that's pretty standard with a lot of people with dementia is that you first start to cover it up. And not everybody does that but she was just trying, you know, she still had her, enough cognitive faculties that she was able to do that for longer."* (Adult child, male).

The stigma associated with mental health and cognitive problems also affected how participants approached the issue. For example, one family member described how she and her husband struggled to discuss his cognitive changes:

> *"We didn't speak of it. It was almost again the whole stigma around it and he was very uncomfortable with it; and I could see that something was going on; but we didn't talk a lot about it."* (Spouse, female).

Problems encountered at work indicated that something serious was wrong and motivated participants to seek medical help. Some reached a diagnosis of mild cognitive impairment or dementia before leaving the workforce. Others were laid off, pressured to retire, or went on leave without determining the underlying cause of their problems at work. Without an understanding of their condition, some individuals continued to seek employment and ultimately lost multiple jobs.

In eight out of the 12 families interviewed, the person living with dementia was working when their first symptoms manifested. They all experienced issues in the workplace that eventually led them to stop working. Issues at work served as an early signal that something was wrong and as a motivator for seeking help:

> *"Well, I noticed it at home. It would take more and more time for her to prepare for the next day. Like she'd be up … till 11:30, 12 o'clock, through the night, and it would take her like 45 minutes to an hour where it used to take her 10, 15 minutes…. Then she started reporting to me too about … forgetting to send the kids for lunch or forgetting where she's taken them when she was going to the library. Marching down the hall, had no idea where she was going."* (Spouse, male).

> "*He was having difficulties at work, couldn't perform certain functions, couldn't follow through with things, he was working in sales. Sometimes he got confused with sending*

emails and kind of combined emails that weren't relevant to what he was answering, just things that they were starting to notice at the office. And then they talked to me about it and then we started…setting up doctors' appointments." (Spouse, female).

Recognizing and interpreting the signs of dementia was a complex and often prolonged process involving the person living with dementia, family members, and health care providers. Assumptions about dementia as a disease of old age, coupled with the lack of awareness of the range of symptoms associated with young onset dementia affected how participants interpreted changes, and ultimately constrained help seeking.

6.4.2 Navigation

Navigation refers to the process through which people find and gain access to services. Dixon-Woods et al. (2005; 2006) point out that accomplishing navigation work requires knowledge, skills and resources such as social support. The scope of navigation work required of patients and carers is also a reflection of the complexity of the health care environment. My findings show that participants' paths to a diagnosis of young onset dementia often resembled a maze, and required difficult and time-consuming navigation work.

The Diagnostic Maze. Peel and Harding (2014) used the metaphor of a maze to signify the complexity, confusion and dead ends that people encountered in their interactions with dementia services in Britain. Similarly, participants in the present study described meandering pathways towards diagnosis, complicated by misdiagnoses, long wait-times, and a lack of coordination. Young onset dementia is not the purview of a single medical specialty. The diagnosis of young onset dementia is complex and requires multidisciplinary assessment. Depending on their initial symptoms, patients may be referred to many different medical specialists, leading them down different paths towards a diagnosis. Without a multidisciplinary assessment process, participants were referred to one specialist after another, waiting for long periods of time between each consultation. As one health care provider put it:

"[Ideally] you'd probably start off with a neurologist to make sure you don't have sort of a treatable neurologic disease. Second is to be seen by a psychiatrist to make sure you don't have a treatable psychiatric illness… and then probably a neuropsychologist … So

probably right now you'd need to make three stops, three referrals, three different waiting lists, so it's really…cumbersome." (Health care provider).

Once a concern about cognitive impairment or dementia is established, health care providers indicated that there is no formalized referral pathway. I identified several specialists in Winnipeg from different medical specialties (Psychiatry, Neurology and Neuropsychology) who can assess and diagnose young onset dementia, but they were not widely known to the public or other health care providers. Family members and providers expressed concern that patients are referred to specialists without adequate expertise in young onset dementia. For example, one health provider commented:

I think that family [doctors] might recognize something's going on, but …don't know who they should refer to…Some family [doctors] just refer to their favourite neurologists who may or may not have any kind of specialty or expertise in dementia, or a psychiatrist, or to a geriatrician." (Health care provider).

Family members also commented on the level of expertise of their health care providers. For example, one participant described her relief when her husband was finally referred to an experienced specialist:

"She was wonderful and I said to her: 'It's been so hard dealing with the doctors and the neurologist…because they really don't know…. they really need to be educated because they're not.' … But yet it's sad that we waited all these months to see her so clearly she's really busy so there's a need to have more people trained or specialised in that area." (Spouse, female).

Family members and people with dementia described the referral process as disjointed, prolonged and profoundly stressful:

"They say we'd like you to go do this test and then you would go to that test and then you would go to another test, many tests unfortunately… it's a very arduous and slow process." (Person living with dementia, male).

> *"Yeah 2010 is when we started down this road … and it was the end of 2014 when we actually got the diagnosis. So it was a long four years, it was harsh ... I don't even know how we made it through."* (Spouse, female).

Navigation as Work. For families, navigating within such a fragmented health care environment posed multiple challenges. In line with previous research on dementia (Koehn et al., 2016), participants living with dementia relied on family members to navigate the diagnostic process. In some families, the person living with dementia accessed services on their own, but over time, navigation work shifted to their spouses and other family members. This work included researching available services and treatment options, attending appointments, maintaining health records and information, performing bureaucratic procedures, and advocating for tests, referrals and information.

Participants' efforts to navigate the diagnostic process were hampered by a lack of information about available services and specialists. For example, one family member discussed her frustration with the lack of information she received about services for her husband:

> *"I didn't know what was [out] there, it felt like nothing; like it just felt like this bad thing was happening to us…so more information at the outset when we were looking for a diagnosis would have been nice."* (Spouse, female).

The level of navigation work required to access a diagnosis placed a considerable burden on families. Participants were already coping with financial losses, changes in their roles and relationships, and some still had children living at home. In this context, the demands of navigating a fragmented system with limited services added to an already stressful family situation. For example, while discussing his wife's lengthy diagnostic process, one family member reflected on his decision not to pursue an alternative specialist:

> *"Maybe I should've gone to a different doctor or a different neurologist and tried to find some different support if you're unhappy with one source. But I didn't do that because all this takes . . . energy and stress and time and emotions."* (Spouse, male).

6.4.3 Permeability of Services

Dixon-Woods et al. (2005) introduced the concept of permeability to describe the degree to which services are inclusive or restrictive. More permeable services have few or no formal requirements for entry such as emergency departments or walk-in clinics, while less permeable services demand more qualifications such as referrals, eligibility criteria, and typically require more work to access. The services examined here were characterized by low permeability due to explicit age-restrictions as well as tacit perceptions of younger individuals as atypical patients with complex and unique needs.

The Age Criterion. Consistent with previous studies (Cations et al., 2017; World Health Organization, 2012), age restrictions for dementia services were common, generating systemic barriers for people with young onset dementia. Age restrictions were often used by services that were geared towards older adults, but were not dementia-specific. For example, Winnipeg has several geriatric clinics and assessment services for people over 65 that diagnose and treat people with dementia. Although these services are not specifically for dementia, they provide multidisciplinary dementia assessment and management for older adults. Some participants who were 65 or older at the time of the study, accessed these resources as soon as they were old enough. For example, one family member's wife was diagnosed with early-onset Alzheimer's disease after she turned 65 and was able to access a geriatric mental health service:

> "*We were told we could not access it until she's 65, but I didn't call until she was after 65 anyway... But if that kind of intervention and support had been there earlier it might've been more helpful*." (Spouse, male).

Atypical Patients. In addition to explicit criteria, such as age restrictions, services may also rely on tacit assumptions about the "ideal user", that is "someone who uses services precisely in the way they are intended, for precisely the problems providers have identified the services as serving." (Dixon-Woods et al., 2005: 287). Interviews with health care providers revealed that people with young onset dementia were often perceived as atypical users whose clinical presentation and care needs fall outside of their expertise and scope of practice.

Providers tended to describe people with young onset dementia as different than their typical patients, and some felt ill-equipped assessing and treating younger patients. They were generally described as clinically more complex, with different and often higher care needs. For example,

providers who primarily treat older adults pointed out the extra work involved in employment insurance applications:

> *"You have to have a diagnosis that will satisfy the insurance company and will keep the person safe from doing potentially injurious things at work. So if you just saw people over 65 you wouldn't have to deal with any of that. It is a lot more trouble with people under 65 if you're a geriatric focused person."* (Health care provider).

A few participants emphasized the rarity of young onset dementia, including among patients with cognitive complaints, and suggested it was problematic for dementia services to admit a patient population who are unlikely to have dementia. As one provider put it: "*Whatever it is they've got is not what you're good at helping people with*." (Health care provider). Another participant disagreed with that position, and saw no problem assessing younger people who don't have dementia:

> *"The majority of people that come to me in that age category with that concern do not have a primary neurodegenerative disease. It doesn't mean I don't investigate them anyway, I talk to them, I think about their problem and decide."* (Health care provider).

Providers who worked in geriatric services tended to emphasize the differences between patients with young onset dementia and geriatric populations:

> "*The population that we define ourselves as looking after in geriatrics is frail older people, usually with multi-morbidity and often with cognitive impairment. So there certainly are people under age 65 that have that, but they are … still not necessarily similar to our 85-year-old people*." (Health care provider).

Providers who worked in clinics with age restrictions indicated that they occasionally made exceptions for younger patients who resemble an "ideal" geriatric user. As one provider commented: "*If they're 64, especially if they had multiple other problems, which is the kind of patient we see when they're 85, we would just see them anyway*." (Health care provider).

6.4.4 Appearances and Adjudications

Viewed from the lens of the candidacy framework, obtaining a diagnosis of young onset dementia can be understood as a negotiated process, situated within the social context of clinical interactions. Dixon-Woods et al. (2006) delineate two dimensions of these encounters: appearances and adjudications. Appearances refers to the ways in which patients and carers present their health issue and assert a claim for medical attention. Adjudication refers to health professionals' judgements and decisions regarding an individual's candidacy for care. The present findings show that people with young onset dementia and family members often felt their symptoms were discounted by health care providers due to their age or appearance. Providers, on the other hand, attributed diagnostic delays to clinical complexity and atypical presentations. Moreover, diagnostic communication was complicated because some providers, particularly those who primarily treat older adults, were less comfortable disclosing a diagnosis of dementia to younger individuals.

Presenting Dementia at Midlife. Participants often described young onset dementia as an invisible illness, unseen and misunderstood by others. One participant with dementia described how he felt perceived by others: *"There are times where some people just say 'Well, no, you look fine and you're doing well.' But, um . . . it's not something that's consistent. You know, the next day might be just totally off."* (Person living with dementia, male). This sense of being invisible also applied to interactions with health care providers. Participants commonly felt that their (or their family member's) symptoms were discounted, or misinterpreted by health care providers. Several participants raised concerns about their cognition or memory to their family physician on multiple occasions before they were referred to a specialist:

> "*Over the course of the year she was speaking to her doctor about memory issues. I can remember her saying that her doctor had told her that it was probably just stress, that … it would be helpful if she had a glass of wine or a drink a night."* (Spouse, male)

Participants often felt that their (or their family member's) age and appearance affected how they were perceived and assessed by health care professionals. Participants identified dressing neatly or professionally, being employed, and the appearance of physical fitness and good health as factors that affected how they were perceived by providers. For example, one participant commented that his age affected the length of time it took for providers to consider he might have dementia:

> *"The time that it takes someone to get in their head that possibly this is an individual that has something, that was a very, very frustrating time in my life…The dementia, Alzheimer's, the usual diseases and things like that do not come to the forehead of doctors….Not when you're young.*" (Person living with dementia, male).

Another family member felt that her husband's neurologist failed to recognize his condition in part, due to her husband's age and how he dressed: "*[His neurologist] looked at [my husband] … 'He looks good. He looks like he's clean, he looks like he's neat, he does not present like Alzheimer's therefore he does not have Alzheimer's*.'" (Spouse, female).

Family members also commented on the performance of the person with dementia during clinical encounters, and the ways that they concealed or showcased their symptoms. Some family members felt that their relative with dementia attempted to hide or downplay their symptoms:

> *"I was really sure that something was wrong. He went to a doctor … I didn't go with him because I was working and I - I should've gone with him but anyway he told them there was nothing wrong and he could just carry on."* (Spouse, female).

Family members also pointed out that day to day symptom fluctuations affected how they presented to health care providers. For example, one son discussed how his mother presented during a mental health assessment:

> "*My mom was very much herself and slamming doors and yelling at the assessor which like I'm sure was upsetting to my dad. But I was also quietly, like, not that I was happy that this happened but also pleased that my mom presented the way she's functioning day to day."* (Adult child, male).

Both family members and providers highlighted the role that family members play during clinical interactions. Family members felt it was critical to be present during appointments to relay information, act as a support and advocate, and to interpret health information. For example, one family member, whose husband was living with Alzheimer's disease, described how she advocated for tests and referrals in response to what she perceived as inaction on the part of her husband's neurologist:

"*I said, 'There's got to be something more we could do here'... I wanted a diagnosis because financially I have to do something here, I have to - if we're gonna lose a job ... Like I think I need a diagnosis here, so that's what I pushed for."* (Spouse, female).

Providers also valued having access to knowledgeable family members who could provide information about their patients. In the following quote, a health care provider described the challenges of assessing a patient with young onset dementia who didn't have close family members to accompany her:

"She was single and so didn't have somebody that was with her all the time that could come and be the collateral for me ... and her parents ... I didn't find them always right on the ball and so they weren't as helpful as someone in another case might be, where you have that person that knows the person really well and says this is what I'm seeing, because a person with a memory impairment can't really report all those things." (Health care provider).

Adjudicating Complex and Atypical Presentations. When asked about the diagnostic process and its challenges, health care providers emphasized the clinical complexity of assessing young onset dementia. For example, providers referred to the broad differential diagnosis, the heterogeneity of clinical presentations and the limitations of diagnostic tools. Several specialists pointed out that patients with young onset dementia are more likely to present with conditions and symptoms that differ from the classic presentation of Alzheimer's disease, which may lead to misdiagnoses or diagnostic delays:

"*Younger people often have atypical dementias, so those things may come across as just the person being a bit strange or depressed more likely, because sometimes it's a more psychiatric manifestation to begin with, and that can last for a few years. So the person could be going through this kind of phase and they are treated for psychiatric stuff ... when they are actually having brain disease*." (Health care provider).

"*If it's a frontal-temporal dementia and it's a lot of the more behavioural variant symptoms, so they're very disinhibited, or being inappropriate, they'll either end up in the emergency room diagnosed as being manic or psychotic or something like that, or the*

family doc will kind of be trying medications. So, I think it's just. . . it's not high on anyone's radar…the index of suspicion isn't there." (Health care provider).

Providers also emphasized the clinical nature of the diagnostic process and the limitations of diagnostic tests:

"*One of [the problems] is just the nature of the disease and unfortunately [the] lack of sensitivity of our diagnostic tests… A lot of them are not quite sensitive [enough] to pick up the disease at earlier stages*." (Health care provider).

"There's no lab test where we can say, 'We'll order this test and if the number is five, you've got dementia'. There's nothing like that, it's a clinical diagnosis based on everything else… Like this patient that I'm sending for the PET scan, if her PET scan comes back as normal, which it might, I still think she's got dementia." (Health care provider).

Diagnostic Communication, Discomfort and Uncertainty. For many families, the uncertainty surrounding the dementia diagnosis was magnified by the way the diagnosis was communicated. In fact, most participants reported receiving unclear or insensitive communication about the diagnosis, prognosis, treatment options or supports. Several family members described their health care providers as vague, evasive or uncomfortable discussing the diagnosis:

"*I remember actually having to press [the neurologist] a little bit because, up until that point, it was more sort of around the diagnosis instead of actually naming it*." (Spouse, male).

"Nobody ever kind of said … this is what you have, this is the prognosis, there was none of that. It was sort of like we'll do these tests and the neurologist did say that the damage that is done is permanent and the best that we can hope for is that it won't get any worse." (Spouse, female).

"*He's a very good doctor, but … he's [non-committal]. I think it bothered her because she said 'Why don't you just say I've got Alzheimer's?'…Like, tell me what I've got and then I'll face it."* (Spouse, male).

Even when providers used explicit terminology, participants were often left with the sense that the diagnosis was provisional. For example, one family member, when describing his wife's diagnosis, noted her neurologist's stated lack of expertise in young onset dementia: "*He said that he doesn't specialize in this but from what he can see it looked like … early-onset Alzheimer's disease." (Spouse, male).* Participants who received diagnoses from one-off consultations often expressed uncertainty around the diagnosis, especially when it conflicted with the opinions of other health care providers. Without long-term follow-up and confirmation, the uncertainty remained unresolved.

By contrast, some participants felt that the diagnosis was delivered with clarity and a sense of certainty. For example, one family member described how her husband's specialist delivered the diagnosis of Alzheimer's disease: "*I could see that when he gave us the news he wasn't happy about giving us the news, but it was the reality and that's a hard thing to do*." (Spouse, female). A participant with dementia praised his doctor's direct communication style: "*I can actually have a conversation with [my doctor]. He will have blunt communications sometimes but basically speaking he doesn't fluff anything…And it's always in front of my face too*." (Person living with dementia, male).

Given the impact of the diagnosis, participants stressed the importance of establishing rapport, communicating sensitively, and conveying empathy:

> "*If he had just said, 'You know, I'm sorry I'm gonna have to give you some bad news here, it really looks from this test like you have either Alzheimer's or some sort of, some sort of dementia', but it wasn't like that it was just like, "Well you've got Alzheimer's", like as if we had wasted his time or something*." (Spouse, female).
>
> "*It was a very blunt and very clear message but there was not really any compassion or there was not really any hope there*." (Spouse, male).

Health care providers stressed it was important to communicate a diagnosis as soon as they reached a determination. However, some acknowledged that they were more cautious establishing and communicating a diagnosis to younger individuals:

"The process is similar, but you are a little more careful about saying - you might be a little slower to use the word dementia. You might kind of couch it and say well let's watch how this thing goes and bring you back three months or six months." (Health care provider).

"*There's a huge impact of saying, 'I think this might be dementia'. And so you have to kind of be careful not to dump something like that on someone prematurely… At the same time people have a right to know and they have a right to know as early as possible."* (Health care provider).

Providers emphasized the profound impact of a diagnosis of young onset dementia on the patients and families and described the process of diagnostic disclosure as emotionally challenging:

"*It's usually a little bit more of a shock…Emotionally it's harder for everybody and sometimes it can be a lot more of a challenge*." (Health care provider)

"*I find it much more emotionally difficult. You know, they have nine-year-old children and it's just altogether a different situation than, you know, an 85-year-old person."* (Health care provider).

Overall, health care providers attributed diagnostic delays and misdiagnoses to the clinical complexity and heterogeneity associated with young onset dementia. However, their comments also revealed that some health care providers, particularly those who primarily treat older adults, are less comfortable disclosing a diagnosis of dementia to younger individuals. Family members and participants with dementia also remarked on the challenges and inherent uncertainty underlying a diagnosis of dementia. They tended to attribute diagnostic problems, however, to inadequate knowledge and poor interpersonal skills among health care providers.

6.4.5 Offers and Resistance

The category "offers and resistance" (Dixon-Woods et al., 2006) refers to the interventions or services offered (or not offered) following adjudications of candidacy, as well as the decisions on the part of patients to accept or decline such offers. Conceptualized as a negotiated process, the concept draws attention to the alignment between the care that is offered and the needs and

interests of patients (Chinn & Abraham, 2016). The care that people require following a diagnosis of dementia expands over time and ranges across health and social care sectors. Here I focus specifically on the care that is offered, and not offered, in conjunction with a diagnosis of dementia. My findings indicate that offers of post-diagnostic support were limited, and that the patient-provider relationship influenced participants' decisions to accept or refuse offers of care.

Limited Offers of Care. Family members and participants with dementia reported receiving various offers of care such as: information provision, suggestions for living with dementia, medication prescriptions, follow-up appointments, discussions of safety, future planning, and referrals to support groups and the local Alzheimer Society. For most participants, however, offers of care were limited. Some were diagnosed without any offer of follow-up, and several felt that their health care provider did not take the time to explain the diagnosis, to help them cope with the news, or to connect them to local supports:

> *"It was terrible, I didn't like him from the get go and he's just - you know he may be very smart and he might know his scans and his stuff, but as far as dealing with any of the emotions and stuff when you're first talking about this stuff, it's highly emotional for the people going through it; and he didn't deal with that at all. Not at all."* (Spouse, female).

> "*There's no cure for any of this stuff, so I think for many [doctors] they've kind of washed their hands and go onto the next. The reality is people still need to live with dementia. As we walk out of their offices we're not dead… it doesn't mean that you can't still live your life to the best that you can, and there's supports that are out there can assist you, you know there still needs to be hope that's given."* (Spouse, male).

Participants diagnosed with dementia emphasized the emotional impact of their diagnosis, and the challenge of processing and accepting the news:

> *"[Receiving the diagnosis] was a little rough at first. It took a while for me to realize that, yeah I do have this… Now I'm more or less comfortable with it…a couple years ago I might not be. You know, especially when I first got the diagnosis…it was uncomfortable saying it…The best advice I think would be is just not trying to deny it…There's no use trying to hide it."* (Person living with dementia, male)

> *"I'm one of those guys who likes to win and I'm losing this battle and it's hard for me to accept it. And it's frustrating to accept it but somewhere down the line I'm going to have to accept it."* (Person living with dementia, male)

Providers emphasized the lack of effective treatments and some questioned their ability to offer meaningful care:

> *"Unfortunately the kind of downside of that is there isn't really much to do other than put a label on things and to plan for the future."* (Health care provider)

> *"I see them longer term, but unfortunately as you may know it is not a whole lot we have to offer anybody with dementia."* (Health care provider)

Most (though not all) providers indicated that they typically offer long-term follow up, and several discussed helping families prepare for the future (e.g. driving cessation and health care directives). While some providers emphasized the importance of connecting patients and families to supports, others appeared less knowledgeable about local services for people living with dementia:

> "*I honestly don't know too much about [community supports]. If someone asks questions about it I do tell them there's the Alzheimer Society, and they're kind of like a catch-all right, and so they'll help people in general, and if there's something more specific I'm sure they can point them in the right direction."* (Health care provider)

The Interpersonal Dimensions of Health Interactions. In line with Koehn (2016), I found that participants' decisions to accept or decline offers of care often related to their experiences with health care providers. Participants who felt a lack of rapport or empathy from their health care providers were likely to resist offers of care such as medication prescriptions or follow-up appointments:

> "[*The doctor] said 'I can be your neurologist', and I thought yeah [my wife's] not gonna come back to see you…what's the point? Like what is it that he could do for us that's gonna actually help us? And there's nothing… so he does more testing and says, 'You know what, she's progressed'*. (Spouse, male).

> *"[The neurologist] had said to us, "I have some Aricept here that drug manufacturers have given us lots of samples", he said, "I can send you home with them… So I said, "Well we don't want the medication because-" like it wasn't a prescription for medication it was just kind of samples of this Aricept. I said..."We'll see our family doctor when we get home."* (Spouse, male).

> *"When I would ask questions he would always say things like well, "Ask your family doctor" you know, like he didn't want to answer anything. And he was quite demeaning, you know, he was not good at all. So we … I said to our family doctor like we're not, there's no benefit in us seeing him anymore."* (Spouse, female).

In fact, some participants questioned or even rejected the diagnoses delivered by health care providers they perceived as insensitive or hurried. For example, one participant with dementia initially sought medical attention for headaches, and was not aware that the neurologist was assessing him for dementia. This participant and his wife rejected what seemed like an abrupt diagnosis, and later sought a second opinion: "*We didn't believe him…We just thought he was full of it*." (Person living with dementia, male).

Conversely, participants valued providers who took time to discuss their concerns and offered suggestions for living well with dementia. One participant with dementia, for example, recounted advice she received from her family doctor: *"I think the best thing was, maybe it was that doctor that said … 'Your job is to be happy.' And so I've kind of used that since then."* (Person living with dementia, female).

Although many participants felt that their health care providers had little to offer, their accounts underscored the importance of establishing positive relationships with health care providers. The level of confidence participants placed in their health care providers informed how they interpreted diagnostic communication and influenced their decisions to accept or resist offers of care.

6.4.6 Operating Conditions

This category refers to the organizational structures, availability of resources, and policies that affect the process of attaining candidacy in a locality. My analysis suggests that service

fragmentation, age-restrictions and resource limitations influenced the process of pursuing and delivering a diagnosis of young onset dementia.

A Fragmented System. Assessment and diagnostic services for young onset dementia were delivered by a patchwork of services that spanned multiple medical specialties and organizations. Although there are knowledgeable specialists, the absence of a designated clinic or clear referral pathway jeopardized access to these specialists. As one provider put it: "*In terms of there being … a clear pathway to getting help, that doesn't exist."* (Health care provider). For providers, working in silos constrained their ability to diagnosis complex cases and to provide meaningful supports. Age-restrictions created additional barriers as a significant portion of dementia services were not open to people under 65.

Providers also connected service gaps to the limited resources and systematic problems affecting dementia care overall. For example, providers often referred to the constraints of their practice, the scarcity of health care providers working in the field, and the limitations of the health and social care system:

> "*There is a big lack of dementia care in general, like quite a stunning lack of it. And one of the issues is that there are very few services there for younger people with dementia. That said it's not a huge population. But for them it's important obviously.*" (Health care provider)

> *"Geriatric psychiatry, in my opinion there's very few of us and everyone's spread very thinly under different programs."* (Health care provider)

In this context, some providers questioned whether services for a niche population could compete for attention and resources:

> *"Right now it is a big hole. I think all of us acknowledge it's a hole but it's a hole amongst a lot of issues in dementia care."* (Health care provider).

> *"It's not that the resources for geriatric care are so generous that we can just say, oh well, we'll look after all the young people [too]"* (Health care provider).

6.5 Discussion

There is growing concern that people living with young onset dementia face barriers to health and social care, beginning with accessing a diagnosis. To my knowledge, this is the first study to examine the process of obtaining a diagnosis of dementia from the perspectives of people living with young onset dementia, family members, and health care providers. This approach enabled us to situate the experiences of individuals and families within the broader context of health care provision and organization.

Seen through the lens of the candidacy framework, my analysis indicates that the diagnosis of young onset dementia is a shifting and negotiated process involving patients, family members and multiple health care providers. It emerges in the context of clinical interactions and is shaped by organizational contingencies that influence how care is structured and delivered. Health care interactions are also influenced by the broader social context including the predominant understanding of dementia as a disease of old age.

The diagnosis of young onset dementia unfolded over numerous clinical encounters with health care providers from different services and specialties. For most participants, the diagnosis evolved from an initial diagnosis of cognitive impairment, to dementia, and eventually a dementia subtype. The time it takes to obtain a diagnosis has been a focus of research on young onset dementia (Draper et al., 2016; van Vliet et al., 2013). The shifting nature of the diagnosis observed in this study raises questions about how the timing of diagnostic disclosure should be measured. These findings support the approach taken by Draper et al. (2016) to differentiate between initial and final diagnoses of young onset dementia, and to consider discrepancies between families' reports and medical records.

My analysis further suggests that participants living with dementia and family members played an active role in negotiating the diagnostic process, from identifying symptoms, to presenting (or concealing) symptoms, advocating for tests and referrals, and integrating information from multiple providers. The interpersonal dimensions of patient-provider relationships were also significant, impacting how participants interpreted diagnostic information, and their acceptance or rejection of offers of care.

In line with Peel and Harding's (2014) characterization of dementia services, we found that participants' diagnostic pathways were confusing and maze-like, imposing onerous navigation

work on patients and families. Reliance on family members to navigate the diagnostic process raises the possibility that people with fewer family supports and resources face additional barriers to care. This finding also suggests that for people who have dementia, the capacity to assert one's candidacy for care likely diminishes as the disease progresses. However, the ability to navigate services is contingent on the level and complexity of navigation work imposed on patients, as well as the resources available to support people through this process. In other words, the duration of the diagnostic process and the complexity of navigation work created barriers for people with dementia constraining their participation in this facet of their health care.

A key finding of this study is the critical role that age plays in how individuals with cognitive concerns are perceived and categorized. Dixon-Woods (2005) argues that clinicians rely on a repertoire of routine judgements that categorize people based on certain traits. How individuals are categorized affects how their claims to candidacy are perceived and adjudicated. Many participants, for example, felt that their age, appearance, and symptoms affected how they (or their family member) were assessed and judged by health care providers. Several family members and participants with dementia expressed frustration that symptoms they viewed as significant and distressing were not recognized as possible signs of dementia.

Health care providers expressed ambivalence towards age categorizations. On one hand, providers pointed to the arbitrary nature of age cut-offs. On the other hand, they characterized young onset dementia as distinct from dementia in later life, requiring a different diagnostic approach, tools and specialist expertise. Throughout interviews, providers commonly referred to the conditions and symptoms of young onset dementia as "atypical", positioning them in contrast to a classic presentation of Alzheimer's disease in later life. The traits ascribed to young onset dementia (rare, atypical, variable, complex) were juxtaposed with the prevalent, and comparatively discernable pattern of dementia among older adults.

While all providers affirmed the importance of diagnostic disclosure, some acknowledged they are less comfortable disclosing a diagnosis to younger individuals. Several family members also remarked on their providers' discomfort discussing the diagnosis. These findings suggest that for people with young onset dementia, candidacy may be compromised by providers' discomfort communicating a diagnosis of dementia to younger individuals. Improving access to a team of providers with expertise in young onset dementia may address this issue.

At the organizational level, age categorizations created structural barriers, excluding people with young onset dementia from services designated for older adults. This process occurred through explicit age restrictions as well as tacit perceptions of people with young onset dementia as atypical patients who are not well served by mainstream dementia services. These exclusionary practices reinforced the invisible status of young onset dementia, and suggest a structural disregard for this population at the organizational and policy levels. Removing age-restrictions for dementia services, particularly when alternative options are unavailable, is necessary to achieve equitable access to care.

The boundaries that transect health professions and services further complicated the configuration of diagnostic services. Young onset dementia is not the purview of a single health discipline or medical speciality. Without a multidisciplinary service to facilitate collaboration, the assessment process was fragmented, and diagnostic information was often delivered in a piecemeal fashion. The boundaries between medical and social care created further divisions, and many participants expressed frustration that their health care providers failed to connect them to local supports. The absence of psychosocial supports also weighed on providers, some of whom acknowledged taking extra time diagnosing young onset dementia given the limitations of available supports.

My analysis also indicates that the process of obtaining a diagnosis of young onset dementia was influenced by prevailing assumptions about dementia as a disease of old age. Misperceptions of dementia complicated the process of symptom recognition and help seeking and contributed to misdiagnoses and diagnostic delays. The lack of recognition of young onset dementia was also evident in the structure and organization of local health services, exemplified by the widespread use of age restrictions for dementia-related services. These findings underscore the need to promote awareness of young onset dementia among the public, providers and policy makers.

Our findings point towards several additional recommendations. The fragmented diagnostic experiences described by participants in the present study lend support to the growing call for specialist young onset dementia services (Carter et al., 2018; Draper et al., 2016; O'Malley et al., 2019). Coordinated, multidisciplinary services for young onset dementia have the potential to streamline the diagnostic process, and provide continuity of care post-diagnosis (Draper et al., 2016; Williams et al., 2001). Access to a dedicated team could reduce the level of navigation

work imposed on patients and families, and could also provide support to practitioners who are less comfortable diagnosing younger patients. Finally, the social, psychological and financial challenges participants experienced provide further evidence of the need for family-centred supports during the diagnostic process and after ((Masterson-Algar & Williams, 2020; Rabanal et al., 2018).

Applying the lens of the candidacy framework illuminated multiple and intersecting barriers encountered by participants, and facilitated a critical examination of the social-interactional, organizational, and wider contextual factors that affect how young onset dementia care is pursued, adjudicated and conferred. The framework, which conceptualizes heath care as a negotiated process, was particularly well suited to examining a diagnosis that shifted over time and was often delivered in uncertain terms.

My analysis also revealed some potential limitations of the candidacy framework. Chase et al. (2017) note that the framework overlooks the power dynamics that shape health care interactions. In the present study, comments from participants with dementia around feeling invisible and invalidated indicate a sense of powerlessness during clinical interactions. For people who have dementia, their power to assert candidacy may be additionally compromised by the symptoms they experience, the stigma associated with the condition, and the complexity of navigation work imposed on them. Candidacy constraints may also reflect the lack of power afforded to people with dementia to influence the services that affect them. Though limited, dementia activism is emerging, offering new avenues for people with dementia to influence health policy and practice (Bartlett, 2014; Weetch, O'Dwyer, & Clare, 2020).

Chase et al. (2017) and Mackenzie et al. (2013) further point out that the framework focuses on micro-social and organization level factors and does not explicitly incorporate the macro-structural factors that influence health interactions. Several researchers have argued that broader social factors influence candidacy, such as public discourses around deservingness (Chase et al., 2017; Mackenzie, Conway, Hastings, Munro, & O' Donnell, 2013); discourses about the function of health services (Chinn & Abraham, 2016); and the social status ascribed to specific diseases (Macdonald et al., 2016). Similarly, I found that sociocultural perceptions of dementia influenced the process of pursuing and adjudicating candidacy. The framework, therefore, would benefit

from further explicating the social-contextual factors that affect candidacy, and accounting for the power inequities underpinning health practice and policy.

6.6 Limitations

There are several limitations of this study that warrant consideration. First, the sample is not representative of the population of people living with young onset dementia in Winnipeg or their families. Bartlett and O'Conner (2010) point out the tendency among researchers to conceptualize people with dementia as a homogenous group, overlooking the diversity of dementia subtypes, as well as the social identities and inequalities that shape individual experiences. Future research with larger and more diverse samples is required to examine the unique diagnostic experiences associated with specific dementia subtypes, and to better understand the experiences of groups who face intersecting barriers to dementia care.

There is growing recognition that individuals with dementia can actively participate in qualitative research and contribute critical perspectives on the lived experience of dementia (Cridland et al., 2016; Dewing, 2007; Hellstrom et al., 2007). Moreover, broader inclusion supports access to the potential benefits of research participation such as the opportunity to contribute to research and service development, feeling valued and understood, and being perceived as a capable person (Cridland et al., 2016; Hellström et al., 2007). In the present study, people with dementia provided rich data on their experiences. However, their discussion of diagnostic issues was limited compared to other topics. Recruiting people with dementia during or soon after the diagnosis may provide a better opportunity for participants to speak about the diagnostic experience. Some participants with dementia became emotional during conversations about their diagnosis or frustrated when they had trouble communicating. Paying attention to signs of distress, responding empathically, and offering breaks helped to ensure participants' well-being.

Most health care providers interviewed were medical specialists. Primary care providers such as family physicians and nurse practitioners also play an integral role in the diagnostic process. Future research focused on the role of primary care is warranted.

6.7 Conclusion

My findings suggest that the diagnosis of young onset dementia is a multifaceted, negotiated process involving patients, family members, and health care providers. Applying the candidacy framework generated new insights into how a diagnosis of young onset dementia is pursued and delivered, and the factors that facilitate or hinder this process. In the absence of dedicated services, participants faced a complex array of barriers to diagnosis. Assumptions about age and dementia affected how participants interpreted their symptoms, how they presented to health services, and how they, in turn, were perceived by health care providers. At the organizational level, age-restrictions, fragmentation, and unclear referral pathways further complicated the diagnostic process. Participants' interactions with health care providers and health services ultimately influenced their interpretation of the diagnosis and willingness to accept post-diagnostic care.

Receiving a diagnosis of dementia is a profoundly difficult and impactful experience. For many participants, the diagnosis marked a turning point in their lives, shifting how they saw themselves, their relationships and their future. It also represented a necessary step towards understanding the condition, accessing care and benefits, and adapting to life with a progressive disease. Without a clear diagnostic pathway, the process was often prolonged, fragmented and fraught with uncertainty. For family members, navigating a lengthy diagnostic process was stressful and left them financially vulnerable. Their experiences highlight the importance of improving access to young onset dementia assessment services and ensuring that diagnostic information is delivered with clarity, compassion, and in tandem with ongoing supports.

Preface to Chapter 7

Chapter 7 shifts the focus from diagnostic services to consider the broad spectrum of community-based support services required following a diagnosis of dementia. Drawing on data from the qualitative study described in the previous two chapters, Chapter 7 addresses the third objective of this dissertation by exploring the process of accessing a range of supports from the perspectives of people living with young onset dementia, family members and providers. Using the candidacy framework as a conceptual lens, my analysis identifies multi-level factors that shape and constrain service use. This work aims to advance understanding of the complex processes that impact service access, and to inform the development of more inclusive and accessible service models.

I conceptualized the study in Chapter 7, conducted all data collection, data analysis, and wrote the first draft of the chapter.

Chapter 7. Access to community-based support services for people with young onset dementia and family members

Abstract

People living with young onset dementias and their families have high needs for support, but experience difficulties accessing services. This study explored the process of accessing a range of support services from the perspectives of people living with young onset dementia, family members and providers. In-depth, semi-structured interviews were conducted with six people living with dementia, 14 family members and 16 service providers in Winnipeg, Canada. Data analysis involved a combination of inductive coding, and theoretical analysis using the candidacy framework as a conceptual lens. Participants accounts revealed a pattern of fragmented access to critical resources and supports that generated continuous work and stress for families. Access was further constrained by services that did not accommodate working families, provide meaningful forms of support, or foster a sense of belonging. At the organizational level, fragmentation, inflexible service offerings and underrepresentation of young onset and rare dementias diminished access. My findings underscore the need for coordinated, family-centred services that provide sustained supports throughout the illness trajectory, alongside broader representation of young onset and rare dementias within research, policy and service development.

7.1 Introduction

A growing body of evidence suggests that individuals and families affected by young onset dementia have high needs for support, but experience difficulties accessing services (Bakker, de Vugt, van Vliet, Verhey, Pijnenburg, Vernooij-Dassen, & Koopmans, 2014; Bakker et al., 2013; Greenwood & Smith, 2016; Millenaar, Bakker, et al., 2016; Svanberg et al., 2011). Young onset dementia is associated with profound financial, social, and psychological impacts on the entire family, and complex care needs (Kandiah et al., 2016; Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey, & de Vugt, 2014; Spreadbury & Kipps, 2019; van Vliet, de Vugt, Bakker, Koopmans, & Verhey, 2010). These needs are thought to differ from those diagnosed in

later life due, in part, to differing financial and family contexts (Mayrhofer, Shora, et al., 2020). Because those affected are working age, the condition often leads to job loss and financial strain (Kandiah et al., 2016). The family circumstances associated with young onset dementia also differ from those of older adults, as affected individuals are more likely to have children living at home who have unique challenges and support requirements (Hutchinson et al., 2016; Millenaar, van Vliet, Bakker, Vernooij-Dassen, Koopmans, Verhey, de Vugt, et al., 2014; Svanberg, Stott, & Spector, 2010). Despite growing recognition of the need for young onset dementia supports, people with young onset dementia remain underrepresented in dementia policies and programming (Carter et al., 2018). As a result, those living with young onset dementia must navigate systems and services designed for older adults, and emerging research points to significant access barriers (Greenwood & Smith, 2016; Millenaar, Bakker, et al., 2016) and low levels of service use (Bakker et al., 2013; Cations et al., 2017; Gibson et al., 2014). In the present study, I examine the process of accessing support services from the perspectives of people with young onset dementia who live in the community, family members and providers, using the conceptual lens of the candidacy framework (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005).

7.2 Young Onset Dementia and Access to Support Services

Dementia refers to a group of life-limiting diseases that impair brain function resulting in progressive cognitive and functional limitations. People living with dementia experience a wide range of symptoms such as impaired attention, memory, language, visual perception, motor skills, as well as behavior changes (The British Psychological Society, 2016). The term young onset dementia, or early-onset dementia, refers to dementia that develops within younger age groups, typically defined as before the age of 65 (Carter et al., 2018; Draper & Withall, 2016). Compared to dementia in older adults, the causes of young onset dementia are more diverse (Kuruppu & Matthews, 2013; Withall et al., 2014). Several studies have identified Alzheimer's disease as the most common cause of young onset dementia (Harvey et al., 2003), however others have found higher rates of vascular dementia (Ikejima et al., 2009), frontotemporal dementia (Maiovis et al., 2015), and alcohol-related dementia (Withall et al., 2014). Given the heterogeneity of dementia subtypes and higher rates of rarer dementias, illness progression, symptoms, and support needs vary considerably (Mayrhofer, Shora, et al., 2020).

To alleviate the impacts of dementia on individuals and families, and to enable people to live as well as possible, a wide variety of support services are considered essential (World Health Organization, 2012). Community-based support services such as post-diagnostic counselling, case management, peer support groups, psycho-educational programming and recreational programming can help individuals and families cope with the diagnosis, navigate health and social care services and maintain social inclusion (Canadian Academy of Health Sciences, 2019; World Health Organization, 2012). Health and social care services such as respite and home care promote independence, reduce caregiver burden, and support quality of life (World Health Organization, 2012). Long-term residential care and end of life supports are also key components of dementia care; however, given my focus on people who still live in the community, they fall outside the scope of this paper.

Stamou et al. (2020) argue that collectively, sustained supports provide a critical safety net for individuals and families affected by young onset dementia. Previous studies have shown that effective support services help individuals affected by young onset dementia understand and accept their diagnosis (Millenaar et al., 2018; Stamou et al., 2020); secure financial benefits and legal advice (Mayrhofer et al., 2018; Wheeler et al., 2015); overcome stigma and social isolation (Beattie et al., 2004; Stamou et al., 2020); participate in meaningful activities (Beattie et al., 2004; Richardson et al., 2016; Roach & Drummond, 2014; van Vliet et al., 2017); engage in activism and social citizenship (Phinney et al., 2016; Stamou et al., 2020); and remain living at home for longer (Mayrhofer et al., 2018).

Despite the known benefits of support services, research to date indicates relatively low service use among younger people with dementia (Bakker et al., 2013; Cations et al., 2017; Gibson et al., 2014). A survey of family carers for people with young onset dementia in Ohio found low rates of service use, with over two thirds of respondents reporting that they did not use any type of formal service (Gibson et al., 2014). As part of the longitudinal NEEDYD study in the Netherlands, Bakker et al. (2013) examined the relationship between patient and carer characteristics and the use of formal services. The authors found that the relationship between disease severity and service use was stronger in more advanced stages of illness, suggesting a pattern of postponing service use until care needs could not be met within the family. Cations et al. (2017) assessed the use of community services among individuals with young onset dementia

and their supporters in Sydney, Australia using a combination of survey and focus group data. The authors found that two thirds of respondents chose not to use one or more recommended services and identified a range of barriers to service use (e.g., a lack of perceived need, limited availability, age-restrictions, affordability, and a lack of childcare).

Qualitative studies and research reviews examining the lived experiences of people living with young onset dementia and their families commonly report barriers to service use (Beattie et al., 2004; Cations et al., 2017; Greenwood & Smith, 2016; Mayrhofer et al., 2018; Millenaar, Bakker, et al., 2016; Rabanal et al., 2018). These studies have identified a variety of possible barriers such as diagnostic delays (Millenaar, Bakker, et al., 2016), the absence of specialized services (Mayrhofer et al., 2018); the lack of tailored information (Cations et al., 2017); and service fragmentation (Mayrhofer et al., 2018). Although access problems are frequently reported in the literature, few qualitative studies have focused specifically on access issues, or included the perspectives of people living with young onset dementia (Beattie et al., 2004; Cations et al., 2017).

In addition, the literature on young onset dementia routinely cites the lack of "age-appropriate services" as a key barrier to service use (Cations et al., 2017; Mayrhofer et al., 2018; Millenaar, Bakker, et al., 2016; Stamou et al., 2020). Although widely used, the concept "age-appropriate" remains undefined. Underlying the term is the assumption that services designed for older adults, or services primarily attended by older adults, are unsuitable for younger individuals with dementia. Reasons cited for this mismatch include differences in physical mobility, interests, and difficulty relating to peers from older age groups (Cations et al., 2017; Rabanal et al., 2018; Stamou et al., 2020). Although evidence supports a preference for young onset specific services (Cations et al., 2017; Rabanal et al., 2018; Stamou et al., 2020), the uncritical use of the concept "age-appropriate" may inadvertently reinforce ageist ideas, and neglects the complex intersections between age, dementia, service suitability, and other facets of social identity and experience.

Moreover, research to date has emphasized either utilization of services (Bakker et al., 2013; Cations et al., 2017; Gibson et al., 2014), or barriers to service use (Greenwood & Smith, 2016; Mayrhofer et al., 2018; Millenaar, Bakker, et al., 2016); both of which offer limited insights into

the complex processes that shape service access (Chase et al., 2017). Dixon-Woods et al. (2006) point out that utilization studies rely on "questionable assumptions" (p.7) about the correct level of utilization, making it difficult to interpret patterns of service use. Analyses of barriers and facilitators may also be reductionist (Chase et al., 2017), overlooking the dynamic processes that influence access. The factors known to impact access to dementia supports are multifaceted and complex, encompassing individual-level, service-level, and wider contextual factors (Pratt, Clare, & Kirchner, 2006). Following a review of models of service access, Pratt, Clare and Kirchner (2006) call for more dynamic conceptualizations of dementia care access that integrate individual, social-interactional and wider contextual dimensions of service access and utilization.

7.3 Conceptualizing Service Access: The Candidacy Framework

In the present analysis, I applied the lens of the candidacy framework (Dixon-Woods et al., 2006; Dixon-Woods et al., 2005) to examine these multifaceted dimensions of service access. Developed through a critical interpretive synthesis of the literature on health care access, the concept of candidacy, "describes the ways in which eligibility for medical attention and intervention is jointly negotiated between individuals and health services" (Dixon-Woods et al., 2006: 7). Access to care is conceptualized as a dynamic and contingent process of negotiation, constructed through interactions between individuals, providers and institutions. These social interactions are shaped by organizational conditions, as well as the wider social and policy contexts.

The framework defines six dimensions of candidacy that represent transition points in the process of candidacy negotiation (Mackenzie et al., 2013). The first dimension– *identification* – refers to the process through which individuals come to recognize a need that would benefit from an intervention or service. Once an individual has identified a need for services, they must gain entry to that service. The next dimension – *navigation* – refers to the work required to access and maintain service use. After finding an entry point, individuals must interact with providers to assert a claim for candidacy. The third and fourth dimensions – *appearances and adjudications* – refer to the ways that individuals present their candidacy, and the judgements made about that candidacy by professionals (Dixon-woods, et al., 2006). After qualifying for a service, an individual may decide to accept or decline the offer. Thus, the next dimension – *offers and*

resistance –refers to the services offered following adjudications of candidacy, as well as the decisions of services users to engage or refuse such services. Finally, the sixth construct – *operating conditions* – refers to the organizational and wider contextual factors that influence candidacy negotiations. Although the candidacy framework was originally intended to theorize health care access, it has since been applied to the study of social service use among diverse populations (Green et al., 2020; Koehn, 2009; Mackenzie et al., 2013).

7.4 Design and Methods

Given the complexity of access issues, and the paucity of in-depth, theoretically informed research on the subject, qualitative inquiry is indicated to better understand the complex processes that shape access to support services among individuals affected by young onset dementia. This exploratory study used a combination of sequential and one-time semi-structured interviews to facilitate a flexible, in-depth exploration of participants' access experiences.

7.4.1 Study Context

This study was conducted in Winnipeg, Manitoba, a midsized city in western Canada. In Canada, provinces and territories are responsible for the delivery of medical services, which are insured under the 1984 *Canada Health Act*. Under the Act, medically necessary hospital and physician services are universally insured in all provinces, but "extended health services" such as home care, social programming and long-term residential care are not. In the absence of universal coverage or minimum standards, the cost and availability of these services are, therefore, inconsistent across provinces and health regions (Canadian Academy of Health Sciences, 2019). In Manitoba, home care services are publicly administered and available free of charge, based on assessed need and service availability. Regional health authorities are responsible for the delivery of home care, and evidence suggests variation in service availability across health regions (Toews, 2016). Alternatively, eligible home care clients may apply for Self and Family Managed Care, whereby funds are transferred directly to the client/family based on assessed needs (see Table 7.1). In Winnipeg, adult day services are publicly administered and delivered for a fee. However, other community-based dementia supports such as educational sessions and peer support groups are delivered by non-profit organizations. Like most Canadian cities,

Winnipeg does not have specialized services for young onset dementia, except for a support group for family carers run by the local Alzheimer Society, a nonprofit organization. For a detailed description of service offerings in Winnipeg, see Table 7.1.

Table 7.1

An Overview of Key Dementia Services and Local Availability

Service type	Service description	Availability in Winnipeg
Information support and referral	Providers and services that offer information about dementia, managing the condition, and available resources and services.	The Alzheimer Society provides information resources on dementia to the public. The organization runs a program called First Link which aims to connect people diagnosed with dementia to their local Alzheimer Society for information and community resources.
Psycho-educational supports	This term incorporates a range of service models that offer education, psychological supports, social support, skill building and advice (Milne, Guss, & Russ, 2014)	A variety of dementia educational sessions are offered through the Alzheimer Society. Some sessions are tailored for individuals with young onset dementia. The organization also runs the Minds in Motion program which combines exercise, cognitive stimulation and dementia education. A neuropsychology clinic runs a program called the Memory Partners Group. The program provides dementia education, cognitive health strategies, and carer supports to eligible patients.
Peer supports	Peer support groups foster the exchange of social support among people with shared experiences or life circumstances.	Peer support groups for people with dementia and family carers are offered through non-profit organizations such as the Alzheimer Society. The organization runs a support group for carers of individuals affected by young onset dementia that meets once per month.

Case management	Delivered by an individual or a team to coordinate access to resources, health care and social services. Case managers perform assessments, develop care plans, provide education, facilitate access to resources and supports, and reassess as needs and circumstances change (Livingston et al., 2017).	Manitoba does not offer dementia-specific case management programs. Home care services provide limited case management for home care clients. Other health or social care services may provide case management.
Home care services	Home care refers to a range of health and personal care services provided in a client's home to meet the needs of individuals who require assistance with activities of daily living.	In Manitoba, home care services are publicly administered and available free of charge, based on assessed need and service availability. Available services include nursing, personal care, rehabilitation services, household maintenance, meal preparation and respite. Regional health authorities are responsible for the operation and delivery of home care, and research suggests significant variation in service availability across health regions (Toews, 2016). Eligible home care clients may choose the Self and Family Managed Care option, a direct-funding home care model. Funds are transferred directly to the client/family based on assessed needs. The client/family is responsible for employing care providers (Toews, 2016). For-profit home care agencies also provide home care services.
Adult day services	Adult day services provide social and recreational programming to adults who require assistance with activities of daily living. These programs are also intended to provide respite for family carers.	In Winnipeg, adult day services are funded by the regional health authority, and clients must be referred through the home care program. Clients pay a fee, and services are located throughout the city. With few

	Some localities offer specialized adult day programs for people with dementia. Specialized day programs for young onset dementia remain rare.	exceptions, services are not specifically designed for people with dementia. However, the program is intended for individuals with cognitive impairment and/or other health conditions.

7.4.2 Participant Recruitment

Following approval from the Health Research Ethics Board of the University of Manitoba, I recruited a purposive sample of individuals living with dementia (n=6), family members (n=14) and providers (n=16), between February 2017 and November 2017. Participants with dementia and family members were recruited through support groups, providers and advertisements. I attended three support groups at the Alzheimer Society of Manitoba to publicize the study and distribute recruitment materials. Specialist health care providers were asked to offer recruitment materials to eligible patients and family members. The study was also advertised in newsletters, long-term care facilities, and on a study website. Providers with relevant expertise were identified through websites, government agencies, health and social care organizations, and subsequent snowball sampling. Potential participants were contacted by phone or email and invited to participate in an interview.

7.4.3 Participants

Interviews were conducted with six individuals living with young onset dementia and 14 family members from 12 different families. Among participants with dementia, four were diagnosed with Alzheimer's disease, one had Lewy body dementia, and one had an unknown subtype. The sample included four male and two female participants ranging in age from 57 to 66 years old. Family members included 11 spouses, two adult children and one niece. Half of the family members were male, half were female and their ages ranged from 20 to 76 years. Their relatives had diagnoses of Alzheimer's disease (n=10), Lewy body dementia (n=1), frontotemporal dementia (n=1) and unknown dementia (n=2). In two cases, their relative with dementia had died within the past year.

I also interviewed 16 providers who had experience working with people with young onset dementia or their family members. Providers came from a variety of professions (medicine, psychology, nursing, social work, recreation therapy) and had experience working in a range of services (health care, mental health services, long-term care, adult day services, psycho-educational programs and peer support groups).

7.4.4 Interview Procedures

Participants with dementia were asked if they wanted to conduct the interviews by themselves, or with a support person present, and all six chose to have their spouses accompany them. All participants provided consent before participating in interviews, and steps were taken to ensure an inclusive and rigorous informed consent process. For individuals with dementia, I read through the consent form, checking with participants throughout to make sure they understood the material. Participants with dementia were given the option to provide verbal or written consent, and all six chose to provide verbal consent. All other participants were required to provide written informed consent. In addition to formal consent procedures, I practiced ongoing process consent throughout interviews by seeking ongoing verbal consent, restating the purpose of the research, answering questions, and responding to signs of discomfort (Dewing, 2007; Digby et al., 2016).

Sequential, semi-structured interviews with people living with young onset dementia and family members of individuals affected by young onset dementia were conducted at two points in time (approximately three to six months apart). Interviews explored participants' experiences of the diagnostic process and community-based supports, as well as the impact of life with dementia on the family. Open-ended questions elicited participants' experiences of support services while also allowing the exploration of new lines of inquiry (see Appendices C and D for Interview Guides). In addition, family members were asked to complete a brief demographic questionnaire. Follow-up interviews were conducted between three to six months after the initial interview. Sequential interviews with participants with dementia and family members were designed to add depth and detailed description, and to enable exploration of emergent themes and lines of inquiry (Charmaz, 2001). Participants were asked about any subsequent experiences with health and support services since the initial interview, as well as follow-up questions based on the topics

and themes that arose from the previous interview. Interviews took place in participants' homes (n=16), at an alternate location (n=3), or over the phone (n=1). Interviews averaged 65 minutes, with a range from 23 to 133 minutes.

Interviews with providers were tailored for each participant, depending on their profession and area of expertise. Providers were asked about the strengths and limitations of services, and the factors that affect access to dementia services and supports. Interviews took place in participants' offices (n=13) or over the phone (n=3), and ranged from 22 and 103 minutes, with an average length of 54 minutes. Interviews were audio-recorded, transcribed by a professional transcriptionist, and anonymized.

7.4.5 Data Analysis

Data analysis involved an iterative process of inductive, thematic analysis (Braun & Clarke, 2006), and deductive, theoretical analysis using the candidacy framework as a conceptual lens. First, I read all transcripts and field notes to familiarize myself with the data, and to identify emergent themes. Transcripts from initial and follow-up interviews were analyzed as a single unit for each participant. Next, I coded transcripts and fieldnotes to generate a preliminary list of codes. These codes were iteratively refined and organized into a coding scheme. Next, I returned to the data set applying the lens of candidacy to further develop my analysis of access to support services. This process generated new themes and interpretations, which were integrated into the coding scheme through iterative comparison. The coding scheme was further refined using the dimensions the candidacy as an organizing framework (see Table 7.2). The sub-themes, presented under each dimension of candidacy, were developed through a combination of inductive coding and deductive, theoretical analysis (Braun & Clarke, 2006). To support analytic rigor, I met with my supervisor, Dr. Verena Menec, throughout the analytic process to discuss emerging themes and to review the coding scheme. After finalizing the coding scheme, I coded the data set using Nvivo 11 software.

7.5 Results

Participants accessed, or attempted to access, a variety of support services over time such as information support and referral; psycho-educational services (e.g. dementia education sessions);

peer support groups; adult day services; day hospitals; home care services; recreational programs; volunteer programs; and mental health services. In the following sections, I present my analysis of access barriers and facilitators for each dimension of the candidacy framework and corresponding subthemes (Table 7.2).

Table 7.2

Dimensions of Candidacy and Corresponding Sub-Themes

Dimensions	Sub-themes
Identification	• Access to diagnostic and prognostic information: Making informed decisions • Finding relevant answers in an information sea • Perceptions of service suitability: Finding the right fit
Navigation	• Continuous and complex navigation work • Access to care coordination and management • The impacts of onerous navigation work
Appearances and Adjudications	• Age restrictions and candidacy • Not impaired enough or too impaired
Offers and Resistance	• Family-centred care: Responding to family needs and circumstances • Meaningful experiences, relationships and respite • Experiences of belonging and otherness within community supports
Operating Conditions	• A fragmented system • Task-based versus flexible service offerings • Representation and visibility

7.5.1 Identification

In order to initiate access to support services, individuals must first identify themselves as a legitimate candidate for a particular service (Mackenzie et al., 2013). In light of the progressive and unpredictable nature of dementia, participants were continuously tasked with assessing and

re-assessing needs, and matching those needs to existing services. My analysis shows that their ability to accomplish this work was contingent on their access to diagnostic and prognostic information, finding relevant information in a sea of information, as well as their perception of service suitability.

Access to Diagnostic and Prognostic Information: Making Informed Decisions. Diagnosis plays an important role in the process of identifying needs and determining eligibility for services (Jutel, 2011). As reported in the previous chapter, the diagnostic process was often prolonged, and many participants received unclear information about the diagnosis or prognosis. Without a clear understanding of their condition and prognosis, participants struggled to identify potential sources of support. One family member, for instance, described how diagnostic uncertainty left her unsure of her husband's eligibility for financial benefits:

> "*When the jobs changed and he was let go from one place and then let go from another and then...that became, "Well I have to figure something out here" ... Is there disability money? ... I didn't know anything about anything."* (Spouse, female)

Over time, family members relied on ongoing assessment and updated prognostic information to identify current and future care needs. However, many participants found it difficult to get updated health and prognostic information. For example, one family member recounted how she pressed her husband's neurologist for prognostic clarity in order to plan for an uncertain future:

> *"I was looking for answers and I said to him at one point ... "I need to plan for the future and you're not giving me any information as to what I should be planning for." ... The doctors, they don't want to label, you know, and they really don't know what the prognosis is even though I need to know, they don't, so that's been tough.…it's hard to know what exactly is needed and when it's going to be needed."* (Spouse, female)

Finding Relevant Answers in an Information Sea. Overall, participants were knowledgeable about local services and sought information from multiple sources (e.g. health care providers, community services, dementia education classes, peer support groups, friends and family, books, and the internet). Still, they found it difficult to access relevant information when they needed it. Many family members felt that information resources were geared towards older adults and not

representative of the issues that affect people with young onset dementia or their families. Family members commonly described information they received as overwhelming, but also lacking. For example, one participant did not realize his wife was eligible for a disability benefit, even though he had received information about the benefit as part of a larger information package:

> "*The thing that would have been really helpful to have sooner is the disability pension information. I actually did get it from Alzheimer Society, but I didn't realise I had received that information …[It's] so overwhelming, all the stuff that you get…it took a couple of years before I actually realised, oh my goodness, there's this funding available through disability pension. And fortunately it's retro-active, but it didn't go back far enough to cover the whole time…I do remember being encouraged to go to the different homes and start making a plan about where, you know which personal care home is right, but that's - that can be many years down the road, and it's in some ways too early for that. But the disability pension, that's right away*. (Spouse, male)

Participants commonly recounted experiences of being put off or distressed by information they felt was geared towards older adults in the later stages of the illness. For example, several family members reported feeling overwhelmed or out place at dementia education sessions that covered topics such as personal care homes or advanced care planning. If their relative with dementia had been recently diagnosed, confronting these topics was often distressing. In the quote below, a family member described how a phone call from the Alzheimer Society triggered an episode of depression:

> *"They don't ask for the person's age. So when [the Alzheimer Society] are getting [the referral], they have no idea what age the person is. … Also, they don't ask the onset, when did it happen….so whether in your early, middle, later. So I think that is very much a lack of awareness for the early-onset group…. So I get a phone call from a person … asking me questions about [my husband] and we haven't even gone for an interview yet and he's asked me very personal questions and pretty much telling me that [my husband] needs to go into personal care right away….So that sent me into a tailspin. I, um, developed depression from that part, had to take time off work. And I have a very strong*

support group, so it was just really . . . situational depression. So I got through that part." (Spouse, female).

Some family members, on the other hand, wanted information to help them plan for the future, including long-term care and end of life care. One participant, for instance, described how her aunt and uncle were turned off from a support group after attending a session that covered advance care planning. She felt the information was important, but also understood that her family members were not prepared to receive it:

"I think they were turned off a bit when the topic of advanced care planning came up … really showing that this is happening and this is real and these are some of the things that you should think about as time progresses and make decisions when you can, when you're in a semi-good frame of mind. I think that scared them from using that resource and from utilizing it more than it should." (Niece, female).

Perceptions of Service Suitability: Finding the Right Fit. Dixon-Woods et al. (2005) argue that the process of identification is influenced by perceptions of the quality and suitability of services. Without clearly demarcated young onset dementia services, participants were often skeptical of the appropriateness of available services. When considering the suitability of services, family members commented on the quality of the service, the willingness of their relative to engage with services, and the presumed characteristics of service users. Services that did not appear to be in line with a person's needs, interests or attributes (e.g. age), were often perceived as unsuitable. In the following quote, for example, a family member described why she felt adult day services would not be a good fit for her husband:

"*I don't think he would [be willing to attend] and I don't even know if there are any day programs that would cater to somebody his age. You know, most of them cater to older seniors. And I know cause my mom had done that a few times, you know, and they come, they pick you up on a bus and take you to this day program. I can't see him doing it."* (Spouse, female).

Similarly, when asked if his family had ever considered day programs for his father, an adult son commented:

> "*No, my mom was talking about that though and she was like, 'He wouldn't go for that at all, he would hate that.' He would be like, 'What are we going to daycare?' Or something like that. He's very old school in that way, 'I can take care of myself', you know."* (Adult child, male).

In the absence of specialist young onset dementia services, participants had to determine whether they belonged within services geared towards other groups. When considering the suitability of a service, they often compared their own (or their family members') attributes to an imagined typical service user. Those who felt they differed from typical service users in terms of age, health condition, abilities, or interests, were less like to identify themselves as a potential candidate for that service.

Identifying suitable services was also a challenge for family members looking for supports. Children, in particular, expressed a sense of non-belonging that precluded them from accessing services. For example, the two adult children in this study were familiar with a support group for carers of people with young onset dementia, but assumed they would feel out of place among older spouses:

> *"I suspect if I'd gone to that support group I would have noticed that everyone was a spouse, it wouldn't have surprised me and I would have gotten along well enough with them. But like would that be useful?*" (Adult child, male).

> "*It's mostly the caregiver right, the primary caregiver that goes. So, I'd feel a little bit out of place almost, but I am a part of it obviously where I see it every day, it's just as much on me as it is on my mother sometimes to help him out with things. Yeah, I'd feel a little bit weird.*" (Adult child, male).

The above quotes illustrate a key challenge for people with young onset dementia and their families. Without clearly marked, specialist young onset dementia services, how do individuals and families self-identify as candidates for services? Given the social component of many dementia supports, participants looked for services geared towards people with similar experiences, interests or attributes. Even though the services discussed above catered to

participants' needs such as respite, social activity, and social support, family members did not identify themselves or their relative with dementia as candidates.

7.5.2 Navigation

My analysis indicates that people with young onset dementia and their families were engaged in a continuous cycle of demanding navigation work. As needs changed over the course of the illness, families struggled to find, access and coordinate services. The level and complexity of this work placed a significant burden on family members and, in some cases, prevented them from accessing needed supports.

Continuous and Complex Navigation Work. Family members engaged in a wide range of navigation work such as researching local resources, negotiating with gatekeepers, filling out applications, performing bureaucratic procedures, care planning, care coordination, and advocacy. Without specialized young onset dementia services, participants struggled to find and access supports. As one spouse commented: "*We didn't really find any programs. We searched high and low and there was just nothing out there. There's tons of stuff for over 65 but nothing for under 65*." (Spouse, female).

Dealing with employment losses and accessing financial benefits was one of the first navigation challenges participants faced. One family member described the stress and anxiety she experienced as she tried to navigate her husband's disability benefit application. Eventually, she accessed a social worker through her workplace Employee Assistance Program. Her experience, described in the quote below, illustrates the complexity of bureaucratic procedures and the impact of receiving help:

> *"I was so afraid of getting the wording wrong or doing something wrong in the process that I would make everything not work … so for me to go to the social worker was a huge help because she helped me with the paperwork which I was just fussing over all the words, like "Describe in detail how this daily task can't be done", and I'm like I don't know what to say …but she helped me, we took an hour and filled out the forms. She goes, 'When you walk out of here this is going to be ready to go in the mail, for you to*

photocopy'. Oh that was so helpful to me so I'm glad that I called and asked for the help because that was what I needed." (Spouse, female)

As needs and circumstances changed, families were constantly tasked with finding new sources of support. Without access to ongoing care coordination, they struggled to manage change and piece together supports within a fragmented care environment:

"It just keeps changing and so your grief just continues to change along with it and it never seems to end; and you're continually coming up with new ways to manage different things, from her leaving, to getting dressed, to her medication, to having someone there when I'm at work, to every aspect of our life." (Spouse, male).

"You think you kind of get a handle on it and then it changed again, so it's ongoing." (Spouse, female).

At times, family members encountered particularly complex navigation work. For instance, during care transitions, family crises, or when dealing with health or behavioural changes, participants often felt responsible for care planning and coordination. This work involved assessing the needs and abilities of the person with dementia, as well as other family members, organizing informal family care, and identifying and accessing suitable formal supports. In the quote below, a family member recounted her struggle to navigate services and access care for her husband who had behavioural and psychological symptoms, and at times, was violent towards her:

"The violence is really hard because nobody really knows what to do. Basically, the Alzheimer's Society says have this plan in place, you know, how you're gonna run out, carry your phone with you at all times and your car keys at all times. Like, I'm sorry, who walks around in their house with the phone and car keys? I's not gonna happen ... You almost want someone to say to you that you don't have to take this and there are other things you can do with this person, but they don't; like no one ever tells you it's okay, it's okay to place somebody or to put them somewhere else if they're violent. Nobody ever says that. Nobody wants to say that and I think they do need to say that, I need to hear it you know. I mean you have no one to turn to here, that's how I feel." (Spouse, female).

Access to Care Coordination and Management. In light of changing and complex care needs, family members emphasized the importance of having a plan in place for managing current and future care needs. Most participants, however, felt unsupported in their effort to plan and coordinate care:

> *"I need to plan for the future … I need some answers and nobody's willing to give me any answers as to, you know, these are the steps that you need to take, you know, eventually you're going to need home care, which, I've now looked into. And from there, you know, at some point [nursing home] placement." (Spouse, female).*

Family members and providers highlighted the importance of having access to a key health or service provider who can assist with care coordination over time. For most family members, however, their access to this form of support was limited. Some received useful advice or referrals from their family physicians, while others found them less helpful:

> "*Talking with the doctor that's been really helpful, he's always taken time to listen and answer questions … The doctor, the family practitioner, suggested that we connect with someone at church, the pastor or something. And we did that and got that set up … For some people it would be a counsellor and in this case it's a spiritual caregiver who we can just talk about anything with.*" (Spouse, male)

> *"I would say our family physician has showed very little interest … I thought that the physician would actually be interested in it because it's somewhat rare and unique but he has shown no interest."* (Spouse, male).

When family members did receive valuable advice or referrals, it was often during a one-off consultation from medical specialists. These gestures of support often stood out as notable exceptions:

> "*Of all of the neurologists and specialists that we saw, she was the only person that actually followed up, looked into some stuff and said, "You know what, I've looked into this [support] group … you're more than welcome to join." … To me that's, I guess shocking and sad all at the same time.*" (Spouse, male).

Health care and service providers emphasized the importance of ongoing support and care coordination for people living with dementia and their carers:

> *"I think there's a need for more navigation and more support in primary care. Like, doctors unfortunately just don't have the time to -- you know, they can talk about dementia and they can do tests and screens, but that more psycho-social support? I think there's a need for that."* (Service provider).

> *"I really, really, think that there has to be case management with patients with dementia regardless of their age because … you just do. Because having them show up in the emergency room is never helpful. They don't have all the information, they don't know the whole background, the person's certainly not at their best … If someone knows them and knows the situation and what's worked, what hasn't worked, you know, what's their housing situation? Who's at home? How much home care do they have? Like, it's easy to problem solve if you know all that stuff."* (Health care provider)

The Impacts of Onerous Navigation Work. The amount and difficulty of navigation work that family members encountered posed a significant burden. Many were juggling caregiving, paid work and caring for their children. Some participants were dealing with mental health issues related to the impact of dementia and the stress of caregiving. The accumulative demands of navigating fragmented services added to an already difficult family situation. Family members frequently described their navigation efforts as time consuming, stressful, exhausting, overwhelming and frustrating. In the following quote, for example, a family member describes her frustration after her attempt to arrange a volunteer opportunity for her husband fell through:

> "*We went and had our meeting and then it turned out they had nothing for him to do and I'm like, oh my God do you know how much work it was for everybody involved to figure all this out and to get him… agreeable and excited about it? Like you have no idea how that crushes things because now if another day program comes up how am I ever gonna get him in there? It's frustrating*." (Spouse, female).

In some cases, family members avoided accessing services if the work required to access it was too onerous. As a result, those who are most in need of support may have a harder time accessing resources:

> "*Part of the reason why I didn't make it to the support group is that like if you're younger and working and have a young family of your own and you're that so-called sandwich generation, like how do you attend a group with any regularity? How do you take advantage of those kinds of supports? Because it's great to have the supports and I know there are supports out there like the day programs and … support groups that I can attend too and home care if you then qualify for it. But in some ways it's like all the steps you have to take just to get to the point where you're able to access it, or all the other things that have to take place in your own life in order to be able to take advantage of something. It's hard when you otherwise don't have time to do that*." (Adult child, male)

> *"[Family managed care] may be the route we have to go. The only thing is I know how it works because we had looked into it with my mom and it's basically you're running your own business. And I'm about here with, I mean, I've taken over everything and to add that to my plate is a little overwhelming. … I just don't know where I'm going to find the time to do it, you know, with everything else*." (Spouse, female).

7.5.3 Appearances and Adjudications

The constructs appearances and adjudications draw attention to the ways that candidacy is asserted, sustained or diminished through interactions between service users and providers (Dixon-Woods, et al., 2006). In their attempts to access services, participants were confronted with age-restrictions as well as eligibility criteria that disqualified the person living with dementia for being either not impaired enough, on the one hand, or too cognitively and behaviorally complex, on the other. The experience of being labelled ineligible affected how participants interpreted their candidacy and impacted their future decisions to seek care.

Age Restrictions and Candidacy. As reported in the previous chapter, participants encountered age-restrictions that prevented them from accessing community supports. For example, participants were turned away from some adult day services, day hospitals, and mental health

services on account of their age. As one family member commented: "*You don't know who to turn to because a lot of stuff is 65 plus and that really knocks you out of so many things*." (Spouse, female). One family member discussed her attempt to get her husband, who is living with Alzheimer's disease, into a day hospital program that was located at her workplace. The program only accepted individual over 65 and would not accept him. Without other options to provide him company during the day, she decided to retire early:

> *"It would've been wonderful if [my husband] could've gone to the day hospital … I could've continued working, you know … Those supports were not there… The occupational health care nurse went to the geriatrician and said: 'Can they make an exception?'. He would've done it, but the rules up above said no. So it's frustrating*." (Spouse, female).

Not Impaired Enough or Too Impaired. In addition to age-restrictions, participants encountered restrictive eligibility criteria that categorized the person with dementia according to their cognitive and functional status, behavioural support needs, and family circumstances. Family members recounted being denied access to supports because their relative with dementia was either not "impaired enough", or "too impaired".

Accessing home care proved particularly challenging. Family members commonly explained that relative's impairments did not meet the service's eligibility criteria geared towards functional limitations and safety considerations:

> "*I ended up just retiring because I didn't know what to do with him and when I talked to home care at the time it was like well they'll come in and do pills or they'll come in and give him a bath but there really was nothing there for - well for me to work and for him to stay home … I felt I had to quit, like I had to retire because I didn't know what to do with him, so I don't know. I was told by home care that they only provide services, they don't provide all day care if … his ADL's aren't bad enough."* (Spouse, female).

> *"[Day programs are] the only supports out there for us because no-one will come into the home and give respite unless you are totally dependent on me all the time."* (Spouse, female).

By contrast, another participant described how the seriousness of her husband's condition became apparent during their home care assessment, qualifying him for services:

> *"When the [home care] case coordinator came to interview she realized within minutes that he doesn't make any sense and he was quite – that day – he was quite anxious, looking for things and he couldn't find his runners and he was looking all over the house for his runners and kept on getting up, up and down, up and down and she saw that he was quite nervous and uncomfortable or agitated and so she said, 'Yes, you definitely qualify for home care.'"* (Spouse, female)

Family members also described instances when their relative with dementia was disqualified from services for being "too cognitively impaired" or behaviourally complex. For instance, one family member discussed his mother's disqualification from an adult day program:

> "*She was eventually told that she couldn't return because her attitude was too aggressive towards the staff which is really frustrating … so unless you're of the demure, placid, laid back type of person with dementia these programs aren't accessible to you … Why – aren't these trained professionals supposed to be trained in that? Just because my mom is making their job difficult that means my mom can't attend anymore? … Because my mom may be quote unquote 'acting out' or challenging a bit more all of a sudden that can't be accommodated, like where is the expertise, where's like the conflict management, where's the skill-set for that to manage that because that's what it's there for. It's there for the respite as well, for the people who are at home.*" (Adult son, male).

In addition to being judged inappropriate for adult day services, his mother was also denied eligibility for home care services. The experience of receiving unfavourable adjudications from multiple services left him with the impression of community supports as "inhospitable" to his mother, and skeptical that any future services would accommodate her:

> *"I'm not surprised it didn't work exactly but it doesn't make me feel terribly optimistic that she's going to be able to have other services while she's still living in the community." (*Adult child, male).

Similarly, a service provider who coordinated support groups for people living with dementia described the challenge of accommodating people with dementia as their condition progresses and behaviours change. Her comments highlight the limited and fragmented structure of community-based dementia services, which can result in the exclusion of people with dementia who are regarded as "inappropriate":

> *"There is kind of a gap … if somebody is not appropriate for a [support] group anymore because it's for early-onset, so once they no longer think they have the disease, they wouldn't qualify, if they need assistance in the bathroom, … if they start to become inappropriate or you know, they don't have an hour and a half attention span anymore, things like that ... But what I sometimes come across, because I would have to be the one to tell people they were no longer appropriate, was if they didn't want to go to an adult day program or in some cases they were no longer appropriate for an adult day program, they weren't appropriate for our program and maybe Minds and Motion they weren't as well and let's say they weren't going into a personal care home yet because the waiting list was too high, then family would say to me, 'Well what is there for them?'"* (Service provider).

7.5.4 Offers and Resistance

People living with dementia are often labeled "resistant" or "challenging" within care contexts (Doyle & Rubinstein, 2014; Dupuis et al., 2012; Götell et al., 2002). In many instances, this terminology reduces an individual's choices or actions to an outcome of their disease, overlooking their personhood (Doyle & Rubinstein, 2014; Dupuis et al., 2012). By contrast, the concept of resistance employed here emphasizes the agency of service users to judge the quality and appropriateness of services. My findings indicate that participants' decisions to utilize or reject services was influenced by the degree to which services accommodate working families; foster meaningful experiences, relationships and respite; and promote a sense of belonging and inclusion.

Family-Centred Care: Responding to Family Needs and Circumstances. Family members pointed out that many dementia services are designed to support retired couples, and do not

accommodate families with a working spouse or children at home. Their accounts revealed several barriers to service use such as: the timing of programs; transportation availability; and costs. For working carers, the timing of services had a significant impact on accessibility. Programs designed for family carers, or those that required carer attendance were inaccessible if they were offered exclusively during work hours. Several families were also unable to make use of services for people with dementia that did not provide transportation or that required a family member to provide transportation during work hours. For example, one family member commented on the difficulty of accessing dementia education sessions offered during work hours:

> *"When I was working, we couldn't do that… because it was on a work day and you can't, you know, you can't keep using up your vacation time when you really aren't vacationing together or getting the vacation part."* (Spouse, female).

Another family member who worked shift work expressed interest in a support group for carers of people with young onset dementia but was unable to attend because it ran during her work hours: *"I haven't been able to be part of that group because of my work hours*." (Spouse, female).

Service providers also commented on the challenges of accommodating the schedules of working families within mainstream dementia services. In the quote below, a service provider points out the low attendance among younger, working families at a popular support program for people living with dementia and carers:

> "*Yes there are some younger people with dementia that attend that but for family members who are employed they're saying it sounds really good but I can't get somebody to that unless I can find a neighbour or a friend or unless I have a paid companion or family managed care that will take them there, it's not accessible to me."* (Service provider).

Transportation and the costs of services were also identified as barriers. Many families required services that provided transportation, which limited the options available to them. In some cases, family members paid additional fees for transportation services, or had to pay a private care

provider to drive or accompany their relative with dementia. For some, the cost of paying for programs and transportation was unaffordable. In the quote below, a spouse commented on the challenges of arranging and paying for transportation to an adult day service:

> "*If you're not in that catchment area there's no transportation. So you're always running into this issue…it would cost us about … $18 for a ride there and back … For me it would end up costing $30 every time [my husband] wanted to go between the transport and day program costs, so getting a little steep*." (Spouse, female).

Meaningful Experiences, Relationships and Respite. The available literature on young onset dementia identifies the loss of meaningful activities as a key challenge facing younger people living with dementia (Greenwood & Smith, 2016; Roach & Drummond, 2014). Similarly, people with dementia in the present study recounted experiences of social isolation and boredom. Participants living with dementia were dealing with significant changes and losses such as the loss of employment, the ability to perform household tasks (e.g. cooking), the ability to drive, or to leave the house on their own. For example, one participant described his struggle with boredom and loneliness during the day:

> "*It's tough because everybody gets up and everybody goes to work or everybody goes to university, everybody whatever. And there's me and [the dog] and I love her to death but everybody's gone, everybody is gone to work. I can't do that anymore."* (Person living with dementia, male)

At the same time, participants living with dementia emphasized their desire to remain active, socially engaged and contributing members of their families and communities:

> "*We got a new snow-blower last year and I had a great – I was gone every day. I was, 'No! I'll take care of it, I'll do yours.' I had a riot, and I came back and I went, 'I did something today,' and I felt better about myself. But just to sit and then there's really not a lot to do, all my friends all still work so it's pretty tough, you know? You see them; I mean you still see your friends and stuff but it's different. If you were working and you were working with a bunch of people or whatever, like I said, in the winter it's fun because of the snow*." (Person living with dementia, male)

> "*I find that anxiety is managed well if you're actually doing things. And that's one of the things that I do a lot. I go out and I do things to make my life full instead of thinking oh, I'm on a negative path or whatever I'm thinking*." (Person living with dementia, male).

> "*There's no point in being miserable about it or not wanting to do certain things. You want to be figuring out what you want to be doing with your life."* (Person living with dementia, female).

In light of these changes, participants with dementia valued services that enabled them to maintain active lives and a sense of purpose. Overall, participants with dementia had mixed reactions to group programs. Some participants attended adult day services, peer supports groups, or psycho-educational programs for people living with dementia. Others had negative experiences at group programs and chose not to return. Participants were more inclined to utilize group programming if they offered activities in line with their interests and abilities. For example, one participant with dementia spoke of his positive experience at an adult day service that offered a range of activities tailored to each person's abilities:

> "*The types of games that we play are enjoyable, doable, I can actually do the games. There's nothing more frustrating than not having the ability to…Say if somebody comes and says here, look why don't you play that game? Well if your cognitive capability doesn't allow you to do that, that's frustrating….And everything can be tampered up or tampered down or whatever you want to call it but it's really a question of how adaptive are you going to be*?" (Person living with dementia, male)

When participants discussed the quality or impact of a service, they often spoke about the quality of relationships with service providers or other service users. Their accounts emphasized the relational aspects of care (Nolan, Davies, Brown, Keady, & Nolan, 2004), and the impact of these relationships on participants' sense of security, well-being, and willingness to accept service use. Both family members and participants living with dementia valued services that fostered meaningful relationships and tended to reject services that did not promote social connection.

The relational aspects of service provision were particularly evident in participants' discussions of home care services. Accepting help at home was difficult for families. Home care services that enabled families to develop relationships with care providers facilitated trust and ongoing service use. Conversely, participants tended to avoid or discontinue home care services that were not conducive to relationship building:

> "*She actually stayed home for quite a long time, she was receiving home care … She got close to one in particular, so that was actually a really great thing to see, not all of her homecare workers were necessarily engaged when talking to her but there was one that was fairly frequent in the schedule, so that was awesome*." (Niece, female).

> "*It makes a big difference on how much she enjoys the time. If I'm away and the caregiver has been you know, not engaged her, then … she feels like she's being babysat by somebody who doesn't really care. Whereas if it's somebody who is really interested in her, engages with her, just tries to spend a good few hours or whatever it is with her… she's happy at the end of the time*." (Spouse, male).

When reflecting on their decisions to utilize or discontinue services, family members commented on whether the service provided meaningful forms of respite. Respite refers to temporary relief from caregiving or caregiving duties (Vandepitte et al., 2016). Although respite is a widely regarded as a principal form of support for family carers and an area of unmet need, low uptake of respite services is a recognized problem (Vandepitte et al., 2016). Family members experienced meaningful respite when services allowed them significant periods of time to themselves; when the work required to attend a service or program was minimal; and when they felt secure that their family member was having a positive experience.

In the quote below, a family member commented on the respite she received from her husband's participation in an adult day service:

> *"[You need] something that's more than two hours you know, the day program is just perfect, it's a perfect model …from two o'clock to seven and you get snacks, they feed him supper, … so that gives me a nice long break and then I know I have this break so*

that I can make plans, I can do things, I can get out … I know I've got this chunk of time and it's like a guaranteed chunk of time." (Spouse, female).

The work required to make use of services also affected family members' experience of respite, and their decisions to accept or discontinue services. Even services designed to provide respite imposed considerable work on families. For example, some services required family members to provide transportation, attend programs, or remain present in the home. Preparing the person with dementia to attend a service was also challenging: some family members had to repeatedly convince their relative with dementia to attend a service. In the quote below, a husband describes the work required to help his wife attend an adult day service:

"*With the [adult day service], if I have to spend an hour and a half, say [it's] at 10 o'clock. I have to get up at 8, I have to have breakfast and some time I have to break the news that it's time for the [day program] and then she's all anxious about when the bus is coming, what she's going to wear. And I'm getting these questions every five minutes, it's stressful."* (Spouse, male).

The experience of respite was also affected by family members' perception of service quality and suitability. Respite was enhanced when family members felt that their relative with dementia was benefiting from the service and enjoying a positive experience. One participant with dementia, for example, received music therapy at home. His wife commented on the combined benefits of receiving a break and knowing that her husband is having a positive experience:

"[My husband] has taken music therapy, which is really good … it's here in the house. But that's really kind of neat, because when she comes, I don't have to be part of it. I can go do something else for an hour in the house… He is just himself when she is here…[he] really comes alive." (Spouse, female)

Conversely, several family members withdrew their relative from services that provided significant periods of respite because their family member expressed dissatisfaction with the program or exhibited signs of stress before or after attending. For example, the family member quoted above withdrew her husband from an adult day service after he expressed discontent with the program, even though she reported a significant need for respite.

Experiences of Belonging and Otherness within Community Supports. Many community-based dementia services involve social activities or the exchange of social support within group settings (e.g., peer support groups, psycho-educational programs, adult day services and other recreational services). My analysis found that participants' sense of belonging or otherness within group programs shaped their experiences and ultimately influenced their decisions to participate or withdraw. Those who had positive experiences at group programs emphasized a sense of belonging and social inclusion. Many participants, however, reported negative experiences defined by a sense of otherness.

Participating in social programs presented several challenges for individuals living with dementia. The stigma associated with dementia made it difficult for participants to share their diagnosis, and some avoided social situations out of fear of embarrassment. While some described themselves as social and talkative, others felt uncomfortable in social situations, group settings and unfamiliar environments. In the quote below, a participant living with dementia described his experience within group contexts:

> "*I got to be careful if I go into a big group of people that I don't know. I won't say…I just sit there, I won't say a word. And it's, 'what am I doing here?' So, I will walk out of that situation, I will just leave and I will come home 'cause there's no point in me being there when they're all talking and I can't understand it.*" (Person living with dementia, male).

Another participant with dementia commented on her preference for socializing with familiar people in familiar spaces. After her husband pointed out that they left two group programs because of the older ages of other participants, she compared her experience at dementia supports to a social group she attended at her church:

> Participant's spouse: "*The group that we participated in … we started and didn't finish because they were all a fair bit older and we didn't enjoy that, and same with the day program.*"
>
> Person living with dementia: "*It makes a difference if you don't have to get to know more people. I mean like church, church is a place where it's safe*."

Given these challenges, individuals with dementia identified the need for programs that foster a sense of inclusion, acceptance and belonging. Those who had positive experiences within group programs spoke of feeling accepted, understood, normal, comfortable and open with their diagnosis:

> "*I was reluctant to go, but once I finally got into it ... because those people that were there were exactly like me with the same issues. And you can relate to those people. You can sit there and you can laugh at yourself and they can laugh at you, and it's all good*." (Person living with dementia, male).

> "*When we go to [the day program] we're normal. And it's nice, you know? And I might be having a bad day but everybody still smiles ... we talk, we communicate amongst one another*." (Person living with dementia, male).

This participant went on to say:

> "*There's a group of people that are very much like me. We go and meet at the Alzheimer's Society …We sit and discuss amongst us things that we have done in the week … Most people unfortunately believe that there is a person who had zero value and the challenges behind that. And as I've said before there is a [stigma] that you are a challenge, a problem. Yeah, it's too bad … we are busy, we are active*." (Person living with dementia, male).

When the person with dementia had a negative experience at a group program, participants often focused on the older age of other service users. Several family members, for example, described experiences when their spouse attended an adult day service, and felt uncomfortable at a program primarily attended by older adults:

> "*I talked to the [day program] co-ordinator, most of them are a lot older. So it – it was really hard. We went to take a look at starting the program. The fact that here is [my husband] and there is people there that are 20 years older.*" (Spouse, female).

"My wife completely rejected the idea of the day programs. She just looked, and everybody was 25 years older than she. You know because they're waiting in the waiting room at [the hospital]… And these little old ladies mostly, are sitting in their wheelchairs waiting." (Spouse, male).

"*Speaking for my wife, and this is really still early-onset, I think she needs more [of a] mixture from 30 to 85. Not a bunch of 85-year-old people. Like any of us do, if you want to feel younger, you mix with younger people. You start hanging around 80-year olds all the time, you're going to become like them*." (Spouse, male).

In some of the above quotes, participants expressed ageist attitudes and a preference to socialize within their age group. However, concerns about age differences appeared to intersect with several other factors that influenced participants' sense of belonging. In some cases, comments about age differences reflected the stigma associated with institutional environments or hospital settings. Some comments around age differences related to a concern that a program was not suited to the interests or abilities of younger individuals with dementia. Conversely, when participants enjoyed programs and identified with other users, age differences did not appear to matter. In the quote below, for example, a husband and wife discussed his experience trying out an adult day program:

Spouse: *"We did try a day program [for my husband], though most of the people - it wasn't so much their age as their abilities and you really didn't like that at all and you were among the youngest person there but you were the most fit person there, so you didn't feel like you fit in there…I couldn't [convince] him into going back."*

Interviewer: "*Can you talk about that … that experience of going and trying it out*?"

Person with dementia: "*Yeah, yeah and I...it just - this is not for me. I just about went in and went 'Oh dear'*."

By contrast, this participant enjoyed a support group for people with dementia where he identified as the youngest person in the group:

Interviewer: "*How has that been for you, have you managed to connect with other people in the support group despite any age differences?*"

Person with dementia: "*I kinda look forward to it when it's getting time. I think, you know, like we can kinda goof around in there a little bit and [laughs].*"

Spouse: "*Yeah I don't think age has never been an issue for - like for us as far as having friends, some of our friends are younger and some are older.*"

Family members who had attended carer support groups also commented on the age of other members. Peer support groups are designed to foster the exchange of social support among people with shared experiences or life circumstances (Keyes et al., 2016). In this context, age-differences signified discrepant, rather than shared life circumstances. For example, one family member recounted his experience entering a support group for carers of individuals with dementia, and immediately leaving:

"*I went to one meeting and turned around and left… it was a pretty big group, but I would have been the youngest person there by a good way... It did not look like a context in which I would be able to talk about things or - you know connect with people who are going through the same kinds of things as I [am].”* (Spouse, male).

Several family members attended a local support group specifically for carers of people with young onset dementia. Those who attended support groups emphasized the importance of relating to other family carers who were still working or looking after children:

"*Well you're just talking to somebody who's in the same boat as you, you're not talking to someone who is already retired and … you know, no young kids at home. You're just dealing with a whole different set of circumstances I think when you're younger, you're still working, you're still raising kids, you're still, like it's just the circumstances are quite different*." (Spouse, female).

7.5.5 Operating Conditions

This category refers to the organizational and broader structural factors that impact the local

production of candidacy (Dixon-Woods et al., 2006). My analysis found that service fragmentation, inflexible service offerings and the invisible status young onset dementia created structural barriers that constrained access to services and supports.

A Fragmented System. Coordinated, continuous service delivery is widely considered a cornerstone of effective dementia care (Public Health Agency of Canada, 2019; World Health Organization, 2012). Integrated care models have the potential to help patients and families manage change as the disease progresses and care needs shift. In practice, however, coordinated dementia care services are uncommon. In the present study, support services were fragmented, time-limited, and delivered by a patchwork of health care providers, public sector services, non-profit organizations, and for-profit agencies. As a result, families were continuously tasked with finding and accessing supports across a range of services and sectors. Without access to case management or coordinated services, participants struggled to manage change within a fragmented system.

Providers also identified a need for coordinated, multidisciplinary services. The lack of integration constrained providers' ability to support patients and families:

> *"One of the challenges is what happens to these people after the diagnosis? Because I'm not seeing them for follow-up … But what I would like to see happen, and - my understanding is there's been some talk about this but it never went anywhere - is to have patient navigators, like what they have for cancer care. So if you get a diagnosis of dementia, then you get on this track and somebody will check in with you every six months or so and make sure that, you know, if you're needing home care, if your family member's wandering that you get on the wandering registry. You know, if they're having issues with driving, you know, just keep an eye on these people because they are at risk."* (Health care provider).

> *"[Specialists are often set up as] solo practices where it's just the neurologist and a receptionist, and, you know, maybe you'd be lucky if you were in an outpatient department of a hospital, but you still might not have a nurse anywhere to be seen and you absolutely do not have a social worker, so if anyone is going to phone home care it*

has to be you, the consultant. So, I mean I think it definitely is a problem that's best dealt with by multidisciplinary teams." (Health care provider).

At the organizational level, access to services was also affected by resource limitations within the social care sector. Providers connected age-restrictions and narrow eligibility criteria to the scarcity of resources and resulting strain on services. One provider, for example, commented on the shift within a geriatric outreach service to discontinue accepting clients under 65 with dementia:

"There was a time where they would– if a person had … a disease that is more typically associated with aging like a dementia… that was a bit of a loophole where people could be seen even though they were under 65…But I think now it's a pretty hard and fast rule that under 65, not being seen … I recognize that that comes from limited resources and they have to draw the line somewhere because they were feeling burdened by just too many people. The challenge is that I think the people who often times have the highest need are these families where someone has early-onset because there's more complexity and there's more need for support and resources." (Health care provider).

Providers commented that specialized supports for young onset dementia were unlikely to attain funding or priority status given the resource limitations and the growing demand for dementia and aging related services. For example, one provider commented:

"*Our health care system is struggling to keep its head above water on most days and I don't think that there is enough specific resources going into looking at that population [with young onset dementia]. And I don't think that will happen anytime soon, to be sadly honest with you*." (Service provider).

Task-Based versus Flexible Service Offerings. Another organizational condition that impacted candidacy was the level of flexibility of service offerings. The impact of service flexibility was particularly evident in participants' discussions of home care services. Home care services in Winnipeg are primarily delivered through a publicly administered program that provides free home care services based on assessed need and service availability. Eligible clients may also opt to use the Self and Family Managed Care program, a direct-funding home care model. In this

option, funds are transferred directly to the client or a designated family member, giving clients the flexibility to hire their own care providers.

As previously discussed, many participants were denied eligibility for home care services. Most of the families in this study initially sought home care services to provide companionship during the day, and to support participation in activities inside or outside of the home. Following cutbacks and restructuring, however, home care services are increasingly focused on task-based care such as bathing or medication administration. Several providers commented on the growing demand for home care services, and the subsequent shift towards more restrictive assessment criteria and task-oriented services:

> "*I think this task-based care for a cognitive impaired person is not good. Care needs fluctuate and they change and to have four or five different care workers go in for specific tasks and those tasks will vary over time, is quite rigid and inflexible and impersonal. So, although there's a lot of homecare now, I think it should perhaps be more flexible and more - it's not really as patient-centred as it was*." (Health care provider)

After initially applying to mainstream home care services, several participants switched to the self-managed home care program. Family members valued the program's flexibility, and the opportunity to hire care providers who could connect with the person with dementia. They often compared service models, pointing out how inconsistent care providers and inflexible, task-focused services undermined relation care:

> "*One of the most helpful things for us, it's a self-directed respite program where we hire our own worker … That's been a lifesaver for us and it really has been for [my wife] as well because we were able to … hire somebody [my wife]'s age that didn't want to work full-time, that's outgoing, that's got a great personality, that her and [wife] have become best friends... That's a relationship that they've built over time and they spend about four or five hours a day on those two days a week together. So they build that rather than someone coming in and boom, you know, going to be there for an hour. And that's not helpful for me, that would be more confusing for her.*" (Spouse, male)

Interviewer: "*There are a number of people now that have made that switch [to family managed care]. Is it nice to have caregivers that you know?"*

Person with dementia: "*Well, we didn't know them at the beginning but we've learned to know them. And instead of having ten people there's just two, it's so nice."* (Person living with dementia, female).

Another benefit of the self-managed model identified by participants is that care providers can take clients outside of the home to participate in social or recreational activities. This option enabled people living with dementia to engage in a wider range of activities that reflected their interests.

For example, one participant living with dementia discussed her experience attending a church group along with her care provider:

"*It's been nice. One of our caregivers has driven me there. She stays too so it's been nice to have somebody. There's always food and people to talk to and stories. They tell their stories, I like that.*" (Person living with dementia, female).

Similarly, a family member commented on his wife's activities with her care provider:

"*I have someone go over she just considers to be her girlfriend … They go out for lunch, they go for walks and they go skiing and they keep active, do different things, go volunteer*." (Spouse, male)

Although self-managed home care programs required family members to take on significant administrative work, many participants chose this option because it enabled their relative with dementia to participate in meaningful activities, and it allowed them to hire consistent care providers. Even though the service does not offer any specialized young onset dementia supports, the program's flexibility enabled families to access tailored supports. By contrast, mainstream home care services offered less flexible care arrangements that did not match participants support needs or preferences.

Representation and Visibility. Underpinning access barriers was a lack of recognition and representation of young onset and rare dementias at organizational and policy levels. Individuals living with young onset dementia and family members were forced to navigate systems and services that do not formally recognize their rights and needs. Age-restrictions and eligibility requirements geared towards older adults with functional limitations systematically exclude people with young onset dementia from critical services, undermining the right to equitable care. Information resources and service offerings were also geared towards older adults and not representative of the conditions, characteristics, and support requirements of younger individuals. In the following quote, a service provider commented on the limited representation of young onset dementia within dementia care resources and programming:

> "*What I hear from the families … the feeling is that they are not well represented in the dementia world. So whether it even be educational materials, seminars, workshops, things like that that are designed for families where there's a dementia or even preventing dementia, that they don't feel well represented by that. The pictures and you know all the examples are often of people who are much older and it's still sort of thought of as, you know, a disorder of aging which it is in a lot of ways*." (Health care provider)

Some participants also pointed out that certain forms of dementia receive less attention than others. For example, a participant with Lewy Body dementia and his spouse commented on the predominance of Alzheimer's disease and relatively invisible status of less common causes of dementia:

> Spouse: "*Not every person with dementia has a memory issue. They don't leave their keys in the fridge, you know? [My husband] has never put his keys in the fridge you know?"*
>
> Interviewer: "*So do you feel like you're not really represented*?"
>
> Spouse: "*Oh, yeah. Huge, huge, huge*."
>
> Person with dementia: "*Yeah, we're silent*."

Spouse: "*Oh, believe me I know*."

Person with dementia: "*'Cause no one knows we exist*."

7.6 Discussion

Despite growing recognition of the need to expand supports for people with young onset dementia, specialized services remain rare (Carter et al., 2018; Mayrhofer et al., 2018). Previous studies suggest that people with young onset dementia encounter barriers within mainstream dementia services (Cations et al., 2017; Greenwood & Smith, 2016); however, most studies rely on narrow conceptualizations of access that overlook the dynamic processes that impact service use (Bakker et al., 2013; Gibson et al., 2014; Greenwood & Smith, 2016; Millenaar, Bakker, et al., 2016). This study addressed this gap in understanding by critically examining the multifaceted influences on service access from the perspectives of people living with young onset dementia, family members and service providers. The combination of inductive thematic coding and theoretical analysis generated fourteen themes related to access vulnerabilities and candidacy negotiation. Given the large number of themes, the following discussion focuses on key findings for each dimension of candidacy.

My findings show that families affected by young onset dementia face multiple, intersecting barriers to support services across each dimension of candidacy. The data presented here also highlight the impacts of support services on individuals and families. Accessing meaningful supports helped participants accept their diagnosis, access economic resources, maintain employment, regain purposeful activity, and secure much needed respite. When participants were unable to access critical services, however, the impacts were profound. Several family members, for example, felt compelled to leave the workforce after being denied home care. The practice of excluding individuals with behavioural complexities meant that families caring for individuals with higher and more complex needs had less access to community supports and respite.

According to Dixon-Woods et al. (2006), the process of accessing services begins with identifying oneself as a candidate for a particular service. In line with previous studies (Cations et al., 2017; Ducharme et al., 2014; Millenaar, Bakker, et al., 2016), I found that problems finding relevant information constrained access to supports. In addition, my analysis indicated

that without clearly marked young onset dementia services, identifying candidacy posed a critical challenge. To identify suitable supports, family members and individuals with dementia looked for services geared towards people with similar attributes or experiences. Even when services catered to an identified need such as respite or social support, participants did not identify themselves as potential candidates if they felt they differed from other users in terms of their age, life circumstances, abilities or interests. These findings point to the need for relevant services to clearly communicate whether and how they are inclusive of people with young onset dementia and/or family members, as well as the ways they accommodate people with different needs, abilities and preferences.

Accessing services requires work and resources on the part of service users (Dixon-Woods et al., 2006). However, to the best of my knowledge, the concept of navigation has not been examined within the literature on young onset dementia. A key finding of this study is that the level and complexity of navigation work required to access services created significant barriers and contributed to family stress. With limited support from providers, families struggled to identity needs, and to find and access services. Providers also felt constrained in their ability to assist with navigation due to resource limitations, fragmentation, and the lack of care coordination. For family members, the time and effort required to navigate services compounded an already stressful family situation. In some cases, the level of work required to access services was prohibitive, causing participants to delay or avoid seeking services they considered valuable. Over time, encounters with unhelpful providers and fragmented services left many feeling alone and unsupported in their efforts to manage change and access supports. Ultimately, these experiences contributed to a perception of support services as inaccessible and incompatible with participants' needs and circumstances.

Age-restrictions have been previously identified as a key barrier to service use among people with young onset dementia (Cations et al., 2017). In addition to age-restrictions, my analysis found that people with dementia encountered gatekeeping and eligibility criteria that categorized them based on their age, cognitive and functional impairments, behaviour in social settings, support needs, and family circumstances. These adjudication processes often constructed individuals with young onset dementia as inappropriate users for being "not impaired enough" or "too impaired". Participants' candidacy appeared to be particularly constrained by restrictive

eligibility criteria geared towards individuals with functional limitations, as well as the practice of excluding individuals categorized as behaviourally challenging. To promote equitable access, services should examine eligibility criteria to determine whether it disproportionately excludes younger individuals with dementia.

My analysis further suggests that access experiences are dynamic and affect how individuals understand and assert their candidacy over time. Receiving unfavourable adjudications challenged participants' perceptions of candidacy and diminished their expectation of qualifying for services in the future. These experiences influenced participants' subsequent decisions regarding accessing supports, and in some cases contributed to deferred help-seeking.

Previous research shows relatively low levels of service use among the population with young onset dementia (Bakker et al., 2013; Cations et al., 2017; Gibson et al., 2014). However, the factors that contribute to service utilization are not well understood. My findings revealed that participants' decisions to accept or reject services depended on the degree to which services accommodate working families; foster meaningful experiences, relationships and respite; and promote a sense of belonging and inclusion. Like Cations et al. (2017), the challenges of balancing work, parenting and caregiving described by participants underscore the need for flexible service offerings that accommodate the schedules of younger, working families. These findings lend support to the growing call for family-centred services that recognize and respond to diverse family circumstances and support requirements (Hutchinson et al., 2020; Mayrhofer, Shora, et al., 2020; Rabanal et al., 2018).

The extant literature on young onset dementia emphasizes the impact of age differences on the experience of otherness or belonging in group programs (Carter et al., 2018; Mayrhofer et al., 2018; Millenaar, Bakker, et al., 2016; Rabanal et al., 2018). My findings suggest a more complicated picture, in which age differences intersect with a variety of factors to influence perceptions of belonging or otherness. Participating in group programs was challenging for participants with dementia and family members due to social anxiety, stigma and discomfort in unfamiliar environments or group settings. Moreover, without specialized services, it was difficult for participants to identify where they might fit in. To overcome these barriers, participants sought services that promoted a sense of belonging based on shared experiences, life

circumstances or interests. Although experiences of otherness were often attributed to age-differences, concerns about age diminished when participants identified with the program's content, setting, or other attributes of service users. Conversely, experiences of otherness were intensified when older age intersected with other forms of stigma, such as institutional environments, frailty and advanced dementia.

These findings raise questions about the widespread use of the term "age-appropriate" services, which offers a narrow window into the factors that shape experiences of belonging and inclusion, while also reinforcing ageist views. At the same time, participants identified a strong preference for specialized services tailored to the experiences, abilities and preferences of people with young onset dementia and their families. Based on these findings, I propose the term "inclusive services" to better capture the desire for social inclusion, and the complex individual, social and contextual factors that contribute to experiences of belonging and otherness.

My findings also show that organizational contexts throughout the dementia care sector constrained access in important ways. Fragmentation, resource scarcity, and services driven by task-based priorities depressed candidacy and compromised continuity of care. Despite growing calls for comprehensive, coordinated dementia supports (Carter et al., 2018; Mayrhofer, Shora, et al., 2020), the services examined here were primarily provisional supports delivered by a patchwork of public sector health and social services, non-profit organizations, and for-profit agencies. Without access to case management, families were tasked with identifying needs, finding and accessing new forms of support. Mayrhofer et al. (2020) argue that though needed, specialized young onset dementia services are insufficient without broader service integration. Similarly, my findings underscore the need for coordinated service delivery to ensure continuity of care and to reduce the level of navigation work imposed on families.

To my knowledge, this is the first study to apply the lens of the candidacy framework to examine access to services among people with young onset dementia and their families. The construct of candidacy facilitated a critical exploration of the multifaceted processes that impact service access. Accordingly, my analysis responds to the calls from Pratt, Clare and Kirchner (2006) for conceptualizations of dementia care access that integrate individual, relational and broader contextual factors.

On the other hand, my findings point to some potential limitations of the framework. The candidacy framework is underpinned by an interactionist orientation, which emphasizes the interactions between users, provider and institutions. Although this perspective recognizes the influence of social and political contexts on candidacy negotiations, the framework does not explicitly incorporate the structural conditions that influence access. In their influential work on dementia and social citizenship, Bartlett and O'Connor (2010) call for dementia research that accounts for the status of people with dementia, and the socio-political contexts that shape care experiences and interactions. My findings indicate that the social status and visibility of people with young onset dementia influenced the construction of candidacy. With one exception, none of the services examined here formally recognized young onset dementia as a user or patient group. This invisible status constrained candidacy, as participants were forced to navigate systems and services that do not formally recognize their rights or support requirements. For example, age-restrictions and eligibility requirements geared towards older adults systematically excluded people with young onset dementia, undermining the right to equitable care. These exclusionary practices reflect and reinforce the invisible status of young onset and rare dementias, suggesting a connection between candidacy constraints and the social and political status of patient groups.

7.7 Limitations

The results of this study should be considered in light of several limitations. First, the perspectives included in this study are not representative of the population living with young onset dementia and their families. Without specialized young onset dementia services, recruitment was challenging, and likely contributed to the lack of diversity in the sample. People with dementia are not a homogenous group, so further research with larger samples that capture the diversity of dementia subtypes, family structures, and other categories of social identity and experience is needed.

The inclusion of multiple members of the same family, including the person affected by dementia, facilitated an exploration of the family context of service use. In contrast to the conventional focus on a primary family carer, this approach recognizes that multiple family members engage in and are affected by care processes (Kemp, Ball, & Perkins, 2013). However,

only two adult children participated in the study, so findings related to children's access barriers are limited.

Second, all participants with dementia chose to conduct interviews in the presence of their spouse. Conducting joint interviews adds ethical and interpersonal complexities to the interview process. For example, some participants may have been reluctant to discuss certain topics in front of their partners. In some cases, participants with dementia looked to their spouses to confirm their responses. On the other hand, joint interviews facilitated the inclusion of participants with dementia who would have been uncomfortable taking part on their own. In addition, spouses supported participation by offering prompts and filling in memory and communication gaps.

Finally, while a few participants discussed end-of-life supports, this topic was not explored with all participants. Given that end-of-life care has been identified as a critical gap in research on young onset dementia (Carter et al., 2018), future examination of this topic is warranted.

7.8 Conclusion

Applying the lens of "candidacy" illuminated the complexity of intersecting barriers to service use among people with young onset dementia and their families. Without service coordination, participants were engaged in a continuous cycle of navigation work, diminishing candidacy and generating constant stress for families. Candidacy was further constrained by services that did not accommodate working families, provide meaningful forms of support, or foster a sense of belonging. At the organizational level, there was a tension between the progressive nature of dementia, and a system characterized by fragmented, time-limited supports and narrow eligibility criteria geared towards functional limitations. Overall, the access barriers families encountered reinforced a sense of non-belonging within health and social services and diminished expectations of securing suitable services in the future. These findings highlight the need for coordinated, inclusive, family-centred services that provide sustained supports throughout the illness trajectory. To achieve this aim, increased recognition and representation of people with young onset and rare dementias in research, public policy and service development is required.

Chapter 8. Reflections on involving participants with dementia

In following section, I discuss the ethical, methodological and practical issues that arose during the course of my dissertation research. Throughout the research process, I documented my experiences, observations and encounters with research participants. I also met with my supervisor, Dr. Verena Menec, on a regular basis to discuss any issues or concerns. As noted in Chapter 4, engaging in reflexive practice is considered particularly important for research involving individuals with dementia in light of the added risks and complexities of research interactions (Heggestad et al., 2012; Pratt, 2002). The following chapter is an attempt to make visible the ethical and methodological issues that I encountered during this project, and to reflect on my role navigating research processes and interactions. Addressing Objective 1.a. of my dissertation, I draw on the issues and strategies identified in Chapter 4 to situate my observations and decision-making processes within the existing literature.

8.1 Consent Processes

In line with Dewing (2007), I found that formal written consent procedures were incompatible with the abilities of many participants with dementia. One of the first issues I encountered was the length and complexity of the Participant Information and Consent Form. It was challenging to make a simplified and accessible document while still including the information required by the research ethics board. It was clear when I shared the document with participants who had dementia that the material was overwhelming. Participants with dementia were given the option to provide oral or written consent and all six chose to provide oral consent. Several commented that they found reading challenging, or were no longer able to record their signature. Their reluctance to provide written informed consent suggests that the six-page Participant Information and Consent Form was not accessible and posed a potential barrier to participants with cognitive challenges. In retrospect, making a stronger case for simplified consent forms with the research ethics board may have improved the document's accessibility. The barriers posed by written consent procedures were circumvented by allowing participants to provide oral consent, along with other strategies I adopted (e.g., taking time to read through the consent form, using checking questions to make sure participants understood the material, enabling participants to have a support person present). However, handing participants a complicated document at the

start of the interview process may have intimidated some participants and highlighted their impairments rather than their abilities.

I had another experience that called into question the utility of traditional consent procedures. Towards the end of data collection, I had an interview scheduled with a married couple at their home. The wife had recently been diagnosed with dementia. Unlike the other participants with dementia who struggled with the consent form, she read through the document, signed and dated it. As she read it, she asked questions, expressed her interest in participating, and appeared to have a full grasp of the project. Shortly after completing the consent form, but before beginning the interview, she suddenly became emotional and upset with her husband. Her agitation with her husband escalated quickly, and we decided to cancel the interview. Ultimately, the couple did not participate in the project. The experience served as a reminder of the limitations of formal consent in the context of a fluctuating condition. It was also an important reminder that dementia is a diverse condition, and though she was able to read, understand and sign the consent form, she had other symptoms that affected her participation.

Given the limitations of formal consent procedures, practicing ongoing process consent (Dewing, 2007) was essential. This approach involved seeking ongoing verbal consent, responding to questions, restating study aims when necessary, and looking for signs of discomfort (Digby et al., 2016; Heggestad et al., 2012; Pesonen et al., 2011). In one interview, a participant with dementia appeared to become distressed by the term dementia, and her responses suggested that her understanding of the interview questions and the nature of the study was fluctuating. While she would start to answer interview questions, her responses veered towards other topics of conversation and stories about her past. In the quote below, she initially responds to the question and then shifts towards a story that she repeated throughout the interview:

> Interviewer: "*What was like to get the diagnosis of mild cognitive impairment*?"
>
> Person with dementia: "*I don't really remember that much about it. That's the way it is, that's the way it is, so what. Deal with it the best you can and that's it, you know. … There's no point in being miserable about it or not wanting to do certain things. You want to be figuring out what you want to be doing with your life… 'cause where I slept upstairs where the window was, I slept up there a lot, I loved it up there, it was great*."

Digby et al. (2016) point out that tangential stories are common when interviewing individuals with dementia. In some cases, there may be connections between the research question and the participant's response that the researcher is unaware of. It is also possible for participants to feel more comfortable telling stories they know well, rather than answering questions they find difficult or confusing (Digby et al., 2016). After listening to the participant, and attempting to redirect her to the interview questions, the pattern continued. At that point, I decided to stop asking questions, and instead engaged in informal conversation. This helped to end the interview on a positive note.

8.2 Communication and Dealing with Distress

Overall, participants with dementia contributed pertinent information about the lived experience of accessing diagnostic and support services. However, participants varied in term of their ability to respond to interview questions, and what topics elicited the most responses. Specifically, discussion of the diagnostic experience was limited compared to other topics such as support services or day to day life. As a result, the chapter on support services contains considerably more direct quotes from participants with dementia. The amount of time that had passed since participants' diagnoses varied and may have contributed to difficulty recalling diagnostic events. Recruiting participants during or soon after the diagnosis may provide a better opportunity for participants with dementia to speak about the diagnostic experience.

In addition, the sensitive nature of some interview topics brought up difficult emotions for some participants. When I observed signs of stress, I offered to pause the interview, or change to a different topic. Paying attention to signs of distress, responding empathically, and offering breaks helped to support participants' well-being. In the following quote, for example, a participant became tearful when I asked about her experience living with dementia:

> Interviewer: "*What do you think is important for other people to know about living with dementia*?"
>
> Person with dementia: "*An understanding I guess. People are generally good like that*."
>
> Interviewer: "*Do you want to take a break maybe for a minute? How are the questions so far? Is it a bit much*?"

Person with dementia: "*It's hard to talk about it, yeah. We talk about other things. [laughs]"*

Interviewer: "*Okay*."

Person with dementia: "*If it can help other people it will be okay*."

Although the interview brought up difficult emotions, she chose to complete it, and indicated her motivation to help others. In fact, all participants completed their interviews, and several others commented on their motivation to benefit others.

Following the recommendation of several dementia scholars (Digby et al., 2016; Hellstrom et al., 2007; McKillop & Wilkinson, 2004; Murphy et al., 2015), the interview guide was designed end the interviews "on a positive note" by asking questions that focus on strengths and supports. I found that shifting to less sensitive topics, asking questions about their experience of the research process and engaging in informal conversation at the end of the interview helped to create an overall positive experience.

Confusion or difficulty communicating and recalling events can also lead to distress or agitation (Hellstrom et al., 2007; Hubbard et al., 2003; Pesonen et al., 2011). Some participants expressed frustration when they had trouble communicating or recalling events. When participants expressed upset or frustration, I tried to empathize with their frustration, offer reassurance and rephrase the question, as illustrated in the following exchanges:

Person with dementia: "*Yeah. It's . . . there was something I was going to say, now it's gone. That's something that's annoying when it does – when I do that.*"

Interviewer: "*Mm-hmm. It's tough*."

Person with dementia: "*Um . . . yeah it was . . . it took a while for me to, um, realize that, yeah I do have this.*"

He went on to say:

Person with dementia: "*And . . . I lost my thought. Happens quite a bit*."

Interviewer: *"Just wondering – you've already answered the question, but if there's anything else that's helpful for you day-to-day or…"*

Person with dementia: "*Um . . . Not really. Just [wife] and the kids that are . . . They're great with it, so…. And really sort of . . . They know when I'm having difficulty or not*."

8.3 Researcher Knowledge and Skills

As discussed in Chapter 4, some researchers have observed that clinical experience working with people with dementia helps to facilitate communication and create a comfortable atmosphere (Digby et al., 2016; Hellstrom et al., 2007). Although I don't have a clinical background, I have had relationships with individuals affected by dementia throughout my life. I got to know many of the residents of my mother's long-term care facilities over a five-year period. I also gained experience working with clients who had cognitive impairments as a volunteer at an adult day program during the first two years of my PhD. In addition, I had the opportunity to meet activists and researchers living with dementia at workshops and other events during a research exchange at the University of Edinburgh. As a result, I have experience interacting with people with diverse cognitive and communication challenges. In addition, conducting the literature review presented in Chapter 4 made me feel prepared to navigate any issues that arose. While I can not speak to participants' comfort level, I hoped that my interview skills and comfort level contributed to a positive and comfortable atmosphere.

8.4 Identifying Sources of Support

The literature review presented in Chapter 4 identified the importance asking participants with dementia if they want someone to accompany them during the research process (Scottish Dementia Working Group Research Sub-Group, 2014). Following this recommendation, participants with dementia were given the option of conducting the interview on their own or with a support person. All participants with dementia chose to conduct the interview in the presence of their spouse. Offering joint interviews facilitated the inclusion of participants with young onset dementia who would have been uncomfortable taking part on their own. Spouses also encouraged participation by providing support, offering prompts and filling in memory or communication gaps. While this method offered key advantages, it also added complexities to the research process. Some participants, for example, looked to their spouses to confirm their answers or repeated back their spouse's responses. In the following quote, a participant's spouse prompts him to make a specific comment:

Spouse: "*Tell her about [name of a day program]*."

Person with dementia: "*What's that?"*

Spouse: "*Just tell her about [day program]. You did not like [it]."*

Person with dementia: "*No, [day program] was—"*

Spouse: "*For old people."*

Person with dementia: "*It was old people."*

Managing the dynamics of joint interviews required paying attention to any imbalances, checking in with both participants, and ensuring that each partner had an opportunity to respond.

In Chapter 4, I examined the dual role that family carers play in research involving participants with dementia. On one hand, they can restrict access to participants (Bartlett & Martin, 2002). On the other hand, family carers support recruitment efforts by communicating information about the study, supporting participants' decision making processes, and providing valuable information about potential participants such as their capacity to consent (Bartlett & Martin, 2002; Digby et al., 2016; Pratt, 2002).

Although I did not plan to solely recruit participants with dementia through their spouses, all participants with dementia in this study had spouses who participated in the study and arranged their interview. Accordingly, spouses played an important role negotiating access to participants with dementia and supporting their participation. Because there are no services specifically for people with young onset dementia, I had no direct access to this population. Diagnostic delays may have also been a factor, as fewer people are diagnosed with young onset dementia in the earlier stages of the illness when they are more likely to be able to participate in research without assistance.

Although I was not able to capture the perspectives of individuals with dementia who are single or living alone, recruiting participants through their family members offered important benefits. Family members provided information about participants' diagnoses, their capacity to consent and their comfort level discussing diagnostic and service experiences. Family members also communicated information about the study to participants with dementia and supported their decision-making. Hellstrom et al. (2007) caution, however, that family members' role as the

study spokesperson may at times cross over into convincing. Similarly, while discussing their experience of the research process, I learned that two participants had trouble recalling the purpose of the interview, and were reluctant to participant prior to our interview. In each case, their spouse had reminded them of the study aims and encouraged them to go ahead with the interview. The following quote illustrates some of the ethical issues that can arise outside of research encounters:

> Interviewer: "*How do you feel about participating in this research study, did you have any concerns?"*
>
> Spouse: *"I'm pushy, right?"*
>
> Person with dementia: "*She is, she's very pushy. And I'm going what is this going to do for me now, like what is this going to do? Well, it's going to help the girl or the guy maybe she'll do something miraculous, I don't know."*
>
> Spouse: "*He asked me a hundred times and I saved that little card and every time he asked me I gave him the card. And I said this is what it is. I said you know what? It's just trying to put information out there so that we can make this better. That's all, it's just, you know, can we just try for the positive instead of the negative and that's basically all it is is you're sharing information."*

Hellstrom et al. (2007) note that these conversations, which commonly happen outside of the research context, on the one hand, raise questions about the voluntary nature of participation. On the other hand, this participant provided informed consent at the start of the interview, appeared to have an overall positive experience, and chose to conduct a second interview. Moreover, these conversations are not simply the result of cognitive impairments, they also reflect the interpersonal dynamics and decision-making processes within a relationship. Still, this complexity underscored the importance of obtaining ongoing consent throughout the interview process and paying attention to participants' engagement and well-being.

8.5 Feedback and Knowledge Dissemination

The literature review presented in Chapter 4 highlighted the importance of providing feedback to participants, and disseminating findings to relevant stakeholders (McKillop & Wilkinson, 2004; Robinson, 2002; Scottish Dementia Working Group, 2014). To enhance the relevancy of research questions and the application of research findings, consultation with stakeholders and

participants occurred throughout the research process. Additionally, I provided feedback to participants at two points in time. First, I sent out a study update in between initial and follow-up interviews. Next, after completing data collection, I prepared a research report for participants and stakeholders entitled, "*Heath and support services for people living with young onset dementia*." (see Appendix I). Before it was finalized, I shared a draft report with participants and invited them to provide feedback. I received comments and suggestions from providers and family members. Notably, no participants with dementia offered feedback. Sharing research findings and eliciting feedback in person may have provided a more accessible format for participants with dementia.

8.6 Conclusion

There is growing recognition that individuals with dementia can actively participate in qualitative research and contribute critical perspectives on the lived experience of dementia (Clark et al., 2018; Cridland et al., 2016; Hellstrom et al., 2007). In my dissertation research, participants with dementia provided critical commentary on adjusting to a diagnosis of dementia and the factors that enhanced or diminished their experiences of community-based supports. Although their inclusion brought some additional challenges to the research process, these issues were mitigated by thorough planning, reflexive practice, and paying attention to participants' well-being. In terms of my own experience, conducting interviews with people living with dementia and their partners helped me to hone my interview skills and develop a better understanding of, and sensitivity towards, the ethical and interpersonal dimensions of qualitative research.

Chapter 9. Discussion, Recommendations and Conclusions

In this final chapter, I summarize and discuss key findings and contributions from the three studies compiled in this dissertation. First, I discuss the results and contributions from the literature review on safe research practices presented in Chapter 4. Next, I provide an overall discussion of the exploratory qualitative inquiry into diagnostic and support services presented in Chapters 6 and 7. More specifically, I discuss common themes across both analyses, situate these findings within the broader literature, and consider the implications for research and service development. Subsequently, I outline key recommendations arising from this study. The chapter ends with a discussion of knowledge translation activities, research limitations and concluding remarks.

9.1 Key Findings, Implications and Contributions

To guide the inclusion of participants with young onset dementia in my dissertation research, I first reviewed the literature on methods to promote the safe participation of people with dementia in qualitative research. Historically, people with dementia have been excluded from research and knowledge production (Beattie et al., 2004; Hellstrom et al., 2007; Whitfield & Wismer, 2006; Wilkinson, 2002). Accounts of life with dementia were commonly derived from family carers or other proxies, a practice that continues today. In the 1990s, researchers and people with dementia began to critique exclusionary methods and practices, along with the negative stereotypes and assumptions that underpin them (Cotrell & Schulz, 1993; Downs, 1997; Hellstrom et al., 2007; Robinson, 2002; Wilkinson, 2002). Since then, the participation of people with dementia in qualitative research has expanded, along with the methods and tools of inclusive research (Bartlett, 2012; Tanner, 2012; Wiersma, 2011). Even so, including people with dementia adds complexities to the research process that require careful consideration.

Along with the expansion of research involving people with dementia, researchers and people living with dementia have increasingly commented on their experiences of research process and offered suggestions to minimize discomfort and maximize inclusion. Approaches to promote participant safety, however, have not been previously compiled or critically reviewed. My review of the literature, presented in Chapter 4, addressed this knowledge gap by examining a range of issues that impact participant safety such as language, negotiating access, the research relationship, communication, dealing with distress, knowledge dissemination, and researcher

skills. By identifying research practices that promote well-being, and key topics of debate, this chapter adds to the growing conversation about the methods, practices and challenges of inclusive dementia research. In addition to contributing to the literature on safe research practices, this review served as a framework for my research design, and better prepared me to respond to ethical, methodological and interpersonal issues that arose during the research process.

Chapters 6 and 7 explored access to young onset dementia diagnostic and support services drawing on data from in-depth qualitative interviews with people living with young onset dementia, family members and providers. In both studies, data were analyzed using a combination of inductive thematic analysis and theoretical analysis using the candidacy framework as a conceptual lens. To my knowledge, these chapters represent the first studies to examine the process of accessing diagnostic and support services from the perspectives of people living with young onset dementia, family members, and providers. Capturing multiple perspectives facilitated a critical exploration of the complex relationships among access experiences, provider practices, and the broader contexts of health and support services. In addition, they represent the first studies to use the candidacy framework to examine health and support service access among people with young onset dementia. As such, these chapters constitute an original contribution to the literature on young onset dementia care, and to the theoretical development of this area of research.

Taken together, these studies identified multiple, intersecting barriers to diagnostic and support services that constrained access over time and caused significant stress for individuals and families. Given the large number of themes and access barriers, this discussion focuses on overarching findings that emerged across both analyses, as well as implications for research and service development. Specifically, I examine: the lack of clearly demarcated services; challenging navigation work; the impact of age on access; organizational constraints and the underrepresentation of people with dementia.

In both analyses, the process of identifying and gaining access to services was hampered by the lack of clearly demarcated services for people with young onset dementia. In the absence of dedicated, coordinated diagnostic services, the path to diagnosis was confusing and maze-like. This complexity prolonged the diagnostic process and imposed considerable navigation work on

patients and families. The path to community-based support services was similarly constrained by the absence of clearly marked young onset dementia services. These findings lend support to the growing appeal for specialist young onset dementia services (Carter et al., 2018; Draper et al., 2016; O'Malley et al., 2019). My analyses also affirm the recommendation by the non-profit organization, Young Dementia UK, for all dementia services to clearly communicate whether and how they accommodate individuals with young onset dementia or their families (Young Dementia Network Steering Group, 2020).

Throughout the process of obtaining a diagnosis and post-diagnostic supports, participants encountered complex and demanding navigation work. The level of work required to navigate health and support services and the resulting consequences for family members can be understood as a form of structural burden (Taylor & Quesnel-Vallée, 2017). In contrast to traditional models of caregiver burden that focus on interpersonal care processes within the family sphere, the concept of structural burden draws attention to the strain that results from "managing complex interactions with the fragmented structures of formal health and social care systems" (Taylor and Quesnel-Vallee, 2017; p. 2). The impacts of navigation work constitute a distinct form of caregiver burden produced by structural conditions such as fragmentation (Funk, Dansereau, & Novek, 2019). While there has been considerable attention to the level of caregiver burden associated with young onset dementia (Arai et al., 2007; Freyne et al., 1999; Millenaar, de Vugt, et al., 2016), this literature has not examined the impact of system navigation on carer outcomes. Future research that differentiates this form of burden, along with strategies to alleviate it, is warranted.

One approach to reducing navigation burden and improving service coordination is the use of patient navigators. Initially developed to assist patients undergoing cancer treatment, similar models been implemented across various clinical settings to assist patients with navigating medical care and support services (Funk & Hounslow, 2019; Manderson et al., 2012; Renehan et al., 2017). Some countries, such as Scotland and Australia, have introduced system navigator roles to help people with dementia access services and to provide tailored information on available resources and supports (Cations & Day, 2020; Levin et al., 2016). In 2016, Australia implemented a national Younger Onset Dementia Key Worker Program to improve access to information and system navigation for people with young onset dementia (Cations & Day, 2020).

Such initiatives have the potential to reduce the burden associated with navigation work, and to improve care coordination. However, more research is required to evaluate the impacts of system navigation models among people with dementia, including those with young onset and rare dementias.

My analyses also found that age affected service access and utilization. In terms of the diagnostic process, assumptions about age and dementia influenced how individuals with dementia interpreted their symptoms, how they were perceived by providers, and how health providers approached diagnostic disclosure. While previous studies have reported that patients with young onset dementia and their family carers often feel dismissed by providers (Rabanal et al., 2018; van Vliet et al., 2011), the finding that some providers are less comfortable communicating a diagnosis to younger individuals constitutes a novel contribution to the literature. Age also affected participants' eligibility for services. Previous studies have identified age restrictions as barriers to young onset dementia care (Cations et al., 2017; World Health Organization, 2012). My findings show that even when age restrictions are not in place, access is still constrained by eligibility criteria geared towards older adults with functional limitations. Removing age-restrictions, and reviewing eligibility criteria to assess whether it disproportionately excludes younger individuals, is therefore necessary to achieve equitable access to care.

An important contribution of this study is the examination of organizational contexts and structural barriers. Coordinated, continuous care is widely regarded as the most effective model of dementia service delivery (Public Health Agency of Canada, 2019; World Health Organization, 2012). Given the progressive nature of dementia, ongoing, coordinated care can help individuals and families manage change and access services throughout the course of the illness. By contrast, I found that health and support services were patchy, fragmented and under-resourced. These organizational conditions prolonged the diagnostic process and complicated access to critical supports. In line with Mayrhofer et al. (2020), these findings highlight the importance of broader service integration to ensure continuity of care and to reduce the navigation work forced on families.

Underlying the access barriers described in Chapters 6 and 7 was a lack of recognition and representation of young onset and rare dementias at organizational and policy levels. With one

exception, the diagnostic and support services examined here did not formally recognize people with young onset dementia, or their family members, as a user group. Instead, individuals and family members were forced to navigate services that do not recognize their rights or needs. As a result, participants frequently encountered eligibility criteria and service offerings that were misaligned with their support requirements and preferences. Following the model of other chronic health conditions, there is an emerging push to include people living with young onset dementia in policy development and service design (Hutchinson et al., 2020; Mayrhofer, Mathie, et al., 2020). Such efforts have the potential to raise the status and visibility of young onset dementia and contribute to the development of more equitable and accessible services.

Applying the lens of the candidacy framework revealed access processes and vulnerabilities that had not been previously examined in the literature such as the level of work required to navigate services, the interpersonal dimensions of patient provider interactions, restrictive eligibility criteria and organizational contexts such as fragmentation and resource limitations. The study design, which included the perspectives of service users and providers, was well suited to the framework's emphasis on the interactions between service users and providers.

While all three participant groups in this study offered insight into each dimension of candidacy, there were differences in terms of which dimensions were emphasized by each participant group. For example, family members provided the bulk of data concerning the process of identifying candidacy, while interviews with providers elicited the organizational features and institutional contexts that affect candidacy negotiations. Participants with dementia, by contrast, tended to focus on their experiences using support services. In future research on dementia care access, I therefore suggest involving a broad range of stakeholders, including people with dementia, in order to capture the range of factors that influence access.

My analyses also identified some potential limitations of the candidacy framework. As discussed in Chapter 6, Chase et al. (2017) point out that the candidacy framework does not address the power inequities at play in health care interactions. Power dynamics are particularly relevant in the context of dementia care, given the stigma associated with the disease, as well as the potential for communication challenges. Additionally, the candidacy framework emphasizes interactional processes and organizational conditions, placing less emphasis on the social-

structural contexts that shape candidacy. My findings suggest that candidacy construction was influenced by sociocultural perceptions of dementia as well as the status and visibility of people with young onset dementia. Accordingly, the framework would benefit from further elucidating the broader social contexts and power inequities that structure candidacy negotiations.

9.2 Recommendations to Enhance Diagnostic and Support Services

In the following section, I outline key issues and recommendations to improve diagnostic and support services based on the findings from my dissertation research:

1. The lack of awareness and understanding of young onset dementia delayed symptom recognition and help seeking and contributed to diagnostic delays.

> **Recommendation:** Enhance the public's understanding of dementia by showing the diversity of the condition, its symptoms, and the impact on families. Promote education and awareness of young onset dementia among health care providers.

2. The absence of information on the prevalence of young onset dementia in Canada contributes to the low visibility of this population and impedes service development and advocacy efforts.

> **Recommendation**: Expand epidemiological research on young onset dementia in Canada. Develop reliable estimates of young onset and rare dementias in Canada.

3. There is currently no clear pathway for people under 65 with suspected dementia to get assessed and diagnosed. Participants were often unaware of available specialists, and many were referred to specialists who lacked experience treating young onset dementia.

> **Recommendation:** Clarify the pathway to assessment and diagnosis for people below 65 with cognitive impairment or suspected dementia.

4. Diagnosing and supporting people living with young onset dementia requires many different health and support providers but participants lacked access to multidisciplinary care teams.

> **Recommendation:** Develop multidisciplinary services for young onset dementia to streamline the diagnostic process and to provide ongoing care coordination.

5. Most participants reported receiving unclear or insensitive communication about the diagnosis, prognosis, treatment options and supports. Health care providers also found it challenging to deliver diagnoses without supports such as counselling.

> **Recommendation:** Promote sensitive and honest communication between health care providers and families. Families should be offered supports to help them cope with the diagnosis and connect to local services.

6. Age restrictions create barriers for people under 65. Many important services for people living with dementia are not open to individuals under 65.

> **Recommendation:** Review age restrictions for dementia-related services and ensure people of all ages have equitable access to resources and services.

7. Access to support services was also constrained by restrictive eligibility criteria geared towards older adults with functional limitations, as well as the practice of excluding individuals who are labelled behaviorally challenging.

> **Recommendation:** To promote equitable access, services that provide supports to people with dementia should examine eligibility criteria to determine whether it disproportionately excludes younger individuals with dementia.

8. Navigation work refers to the work that people do to find and access the care they need. The level and complexity of navigation work required to access services posed significant challenges for individuals and families.

> **Recommendation:** Develop dedicated young onset dementia services, and encourage all dementia services to clearly communicate whether and how they accommodate individuals with young onset dementia and/or their families. Consider developing system navigation programs to help people with young onset dementia and their family members navigate health and social care.

9. Participants had a hard time finding information about their illness, treatment options, income supports, and community services.

> **Recommendation:** Develop informational resources specifically for people living with young onset dementia and their families. Resources should include information about employment rights and financial benefits.

10. Participants described the profound impacts of young onset dementia on the entire family and highlighted the need for family-centred services and psycho-social supports.

> **Recommendation:** Identify providers and services with expertise in supporting families dealing with young onset dementia. Encourage care providers to address the needs of the entire family.

11. Participants identified the need for services that accommodate working families and families with children at home.

> **Recommendation:** Existing services should consider ways to accommodate working families' schedules and financial circumstances such as flexible start times, transportation options, and reduced fees.

12. Participants living with dementia highlighted the need for social programs that provide meaningful experiences and foster a sense of belonging.

> **Recommendation:** Develop a range of options including: 1) specialized group programming; 2) one-on-one supports; and 3) making existing recreational activities dementia-friendly. When specialist young onset dementia supports are not available, people with young onset dementia should have access to services that cater to their interests and abilities.

13. Underpinning access barriers was a lack of recognition and representation of young onset and rare dementias within health and support services and public policy.

> **Recommendation:** People with young onset and rare dementias and their family members should be included in policy development and service design. Broader recognition and inclusion can contribute to more equitable and accessible services.

9.3 Knowledge Translation

Knowledge translation refers to processes of engaging with knowledge users in order to promote the application of research findings (Straus, Tetroe, & Graham, 2009). As outlined in Chapter 5, I shared the research plan and findings with various stakeholders throughout the research process. In addition, I prepared a study report for participants entitled, "*Heath and support services for people living with young onset dementia*." (See Appendix I). The report summarized

key findings and recommendations from the research study. Before finalizing the report, I shared it with all participants and invited them to provide feedback. Their feedback was incorporated into the final version of the report which was shared with all participants, local and national Alzheimer Societies, young onset dementia services in other provinces, as well as key stakeholders within regional and provincial health agencies. In addition, I met with young onset dementia carers at an Alzheimer Society support group to discuss the report and to identify strategies for knowledge dissemination. This ongoing process of engaging stakeholders and soliciting participant feedback was intended to increase the utility of the research report as a tool to support advocacy efforts. However, as previously noted, participants with dementia did not provide feedback on the study report, which suggests the knowledge dissemination process was not accessible for them. Moreover, without local organizations or services dedicated to young onset dementia, the capacity to leverage the research was limited. Knowledge translation efforts may have benefited from more inclusive dissemination strategies and a formalized feedback mechanism such as an advisory council.

9.4 Research Limitations

The findings of this dissertation should be considered in the context of its limitations, which have been addressed within each chapter. In addition, Chapter 8 provides an extended discussion of the challenges related to conducting research involving participants with dementia. In this section, I provide an overview of the main limitations of the research compiled in this dissertation.

Broadly speaking, there are two key limitations to the review of the literature presented in Chapter 4. First, most of the literature included in the review relied on the reflections of researchers. Comparatively few studies incorporated the views of research participants with dementia. The articles and guidelines that did include input from people with dementia brought forward issues that were otherwise overlooked, such as the importance of feedback. The unique contributions of people with dementia and dementia advocacy groups underline the importance of involving people with dementia in discussions on research practices and ensuring they have opportunities to influence research processes.

The second limitation concerns the inattention to minority groups and other categories of social identity beyond dementia. Research relationships are influenced by the identities and social locations of researchers and participants, and their associated relations of power (Hewitt, 2007; Manderson et al., 2006; Wilson & Neville, 2009). Further inquiry into safe research practices among different populations and minority groups with dementia is therefore needed to promote diversity in dementia research (McGovern, 2014; O'Connor et al., 2010).

Turning to the qualitative study presented in Chapters 6 and 7, there are three principal limitations that warrant consideration. First, the sample was relatively small, lacked diversity, and is not representative of the population living with young onset dementia or their families. The lack of dedicated services for people with young onset dementia made recruitment challenging, and likely contributed to the lack of diversity in the sample. Specifically, all family members and participants with dementia were White and born in Canada. The lack of diversity within the study sample is particularly notable given the diversity of Winnipeg's population. In addition, all participants with dementia had spouses who were actively involved in their care. As a result, the study did not capture the experiences of people with different family structures or dynamics, such as those who are single. Only two adult children took part in this study, so analysis of children's experiences was limited. In addition, most of the participants were from Winnipeg, so I was not able to examine rural service settings.

The sample also lacked diversity in terms of dementia subtypes. Emerging evidence suggests that access to a diagnosis varies according to dementia subtype (Draper et al., 2016). Of note, the sample did not include individuals with intellectual disabilities and dementia. This population has unique diagnostic pathways and complex barriers to care (Herron et al., 2020). Research with larger and more diverse samples is therefore needed to capture access experiences associated with various dementia subtypes, and to further understanding of access issues among groups who face additional barriers to dementia care. Given that recruiting participants from diverse backgrounds is a widespread challenge in dementia research (Dilworth-Anderson & Cohen, 2010), researchers should consider a range of strategies to promote diversity and inclusion such as: creating a diverse and culturally competent research team; including community members in research design; collaborating with community organizations; reducing barriers to participation

(e.g. transportation, cost, language barriers); and developing tailored recruitment strategies for different populations (Dilworth-Anderson & Cohen, 2010; Waheed et al., 2019).

Second, participants with dementia made important contributions to this study and provided critical information about their experiences of health and support services. However, the research process presented challenges that may have affected their participation. Among participants with dementia, for example, discussion of diagnostic issues was limited compared to other topics such as social and recreational programs. Timing recruitment closer to the diagnostic process may better facilitate discussions of the diagnostic experience. Some participants had difficulty communicating at times, which limited their ability to respond to interview questions. Having a support person present who could provide prompts or assist with communication was helpful, as was offering breaks and restating interview questions. Some participants became emotional during conversations about their diagnosis or frustrated when they had trouble communicating. Watching for signs of stress, offering breaks, and shifting topics helped to promote an overall positive experience. Despite the sensitive nature of interview, all participants chose to complete it, and several noted they valued the opportunity to share their perspectives and contribute to research.

The third limitation concerns the category of young onset dementia itself. Young onset dementia is not a diagnostic category, and age is no longer used to determine dementia subtypes. Instead, the term is increasingly used by individuals affected by the condition, advocacy groups, policy makers and researchers to draw attention to an overlooked population with unique characteristics, needs and barriers to services. However, it is important to consider some of the limitations of this relatively recent construct. Like the outmoded categories of senile and pre-senile dementia, the concept of young onset dementia relies on an arbitrary cut-off of 65 years of age (Ballenger, 2006). This categorization lumps people together with significant age differences (e.g. those who develop dementia in their 40s versus 60s), and diverse dementia subtypes. Using an age cut-off also risks overstating the differences between those who are close in age but fall into different categories (e.g. someone who is 64 versus 67). Despite these limitations, there are important reasons to focus on this population. Dementia services are typically geared towards older adults, and often exclude people under 65. Given the enduring association between

dementia and old age, as well as the structural barriers to care for people under 65, young onset dementia offers a useful construct for examining access process and barriers.

9.5 Conclusion

Though research into health and support services for young onset dementias has expanded in recent years, the social and contextual factors that influence service access have received limited attention. Moreover, the current literature emphasizes the perspectives of family carers (Ducharme et al., 2014; Millenaar et al., 2018; van Vliet et al., 2011); comparatively few studies examine the views of people living with young onset dementia (Cations et al., 2017; Stamou et al., 2020), or service providers (Spreadbury & Kipps, 2018). This dissertation makes an original contribution to knowledge by combining theory with empirical work to develop a more comprehensive picture of the processes that impact access to young onset dementia diagnostic and support services. Including multiple perspectives (individuals affected by young onset dementia, family members and providers), facilitated a multifaceted exploration of service access and demonstrated that people with young onset dementia can provide critical information about their experiences of service use. Applying the lens of the candidacy framework further illuminated access processes and vulnerabilities, and identified new directions for research, policy and service development.

Without dedicated diagnostic and support services, participants encountered a complex array of barriers that constrained access and generated ongoing work and stress for families. Age-restrictions and eligibility criteria geared towards older adults systematically excluded younger individuals with dementia, jeopardizing the right to equitable care. Developing dementia at an early age also influenced how participants identified with services and how they, in turn, were perceived by providers. At the organizational level, fragmentation, resource limitations and the underrepresentation of young onset dementia prolonged the diagnostic process and complicated access to community supports. Taken together, these findings underscore the need for coordinated, continuous, family-centred services as well as broader representation of young onset and rare dementias in research, policy and practice.

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Appendix A. Sample Interview Guide for Health Providers

Note: Health provider interview guides were tailored to each participant's area of expertise. The following interview guide provides a sample of questions commonly posed to service providers.

To begin with, could you tell me a little bit about how you come to see patients with young onset dementia? Is it through a specific service or by referral?

Can you tell me about the process of assessing and diagnosing young onset dementia?

Does your approach to diagnosis with younger patients differ from late-onset dementia?

Do you usually refer to or consult with other specialists?

[*probe: scans? Does it take several sessions? Do you think people with young onset dementia are more likely to be given the broad diagnoses of dementia or a specific subtype?*]

I'm wondering if we could talk a little about age restrictions. I understand that several geriatric services have age restrictions. What's your perspective on age restrictions? What are some of the reasons for restricting these services?

The literature on young onset dementia suggests that younger people encounter long diagnostic delays and they're often misdiagnosed with other conditions.

What are some of the barriers to diagnosing and treating patients with young onset dementia?

What helps to facilitate diagnosis?

Can you tell me a little about managing young onset dementia over time? Can you comment on patients' care needs over time, and the kinds of issues that can arise?

In terms of dementia policy and services, what changes or additional services would you recommend to improve the diagnosis and care of people with young onset dementia in Manitoba?

Is there anything else you'd like to add?

Is there anyone else you'd recommend I speak to about this topic?

Appendix B. Sample Interview Guide for Service Providers

Note: Service provider interview guides were tailored to each participant's background and type of service provision. The following interview guide provides a sample of questions commonly posed to service providers.

Can you tell me a little about the work that you do and your experience working with people living with young onset dementia?

What are some of the most common concerns and issues that clients encounter?

Do the issues that people with young onset dementia face differ from older adults with dementia?

What do you think the biggest challenges are for younger people with dementia and their families?

What are some important sources of support?

[*Probe: What about resources such as information about the illness, or information for family members?]*

Have you worked with children who have family members affected by young onset dementia? Can you comment on the impact on children, or their needs for support?

What do you think could be done to improve services for younger people with dementia?

What advice would you give to other providers who are working with individuals or families affected by young onset dementia?

Is there anything else you'd like to add?

Is there anyone else you'd recommend I speak to about this topic?

Appendix C. Interview guide for participants living with dementia

First, I'd like to learn a little bit about you, and then I will ask you some questions about your experiences of health care.

- Are you currently working? What kinds of jobs did you have in the past?
- Can you tell me a bit about your family? [Probes: marital status, children, living situation]

I'd like to learn about your experience with the health care. Can you tell me about when you were diagnosed with memory issues/dementia?

- What was that experience like for you? [Probes: Can you tell me about your doctor(s)? Did you have any cognitive tests? What was that experience like?]
- Can you tell me about the experience of receiving a diagnosis? [Probe: how was it delivered?
- Were you given any information about dementia? What kind of information do you think is important for people with young onset dementia to have? [Probes: prognosis, services, financial/employment issues, care, etc.]
- Have you continued to see the [doctor/specialist] since?
- What has the experience been like for you and your family since the diagnosis?

Have you been to any programs for people with dementia (e.g. a support group, day program or education session?) How was that experience for you?

- Have you met any other younger people living with dementia? [If not: is that something you would like to do?]
- What kinds of programs or services do you think would be helpful or enjoyable for you?
- Would you prefer to do activities with other people your age?

What do you think is important for me to know about your experience living with dementia?

What has been most helpful for you?

How do you feel about participating in a research study? [Did you have any concerns about participating? How were the questions?]

Is there anything else you would like to add?

Appendix D. Interview guide for family members

When did [*family member*] first show signs or symptoms of dementia?

How old was he/she at the time?

Can you tell me about the process of getting a diagnosis?

- What were [his/her] first symptoms?
- When did [*family member*] first discuss her symptoms with a health care provider?
- Was [*family member*] referred to any other doctors?
- When did [he/she] receive a diagnosis?
- Was [he/she] diagnosed with any other medical conditions?
- Was [he/she] diagnosed with a specific subtype of dementia?

Can you tell me about the experience of receiving a diagnosis? [Probe: how was it delivered?]

What was the experience like for you? What was it like for [*family member*]?

Were you given any information about the illness? What kind of information do you think is important for people with young onset dementia and their family members to have? [Probe: prognosis, services, financial/employment issues, care, etc.]

Have you continued to see the [doctor/specialist] since?

What has the experience been like for you and your family since the diagnosis?

Do you provide care to [*family member]?* What has this [caregiving] experience been like for you, so far? [Probes: feelings, stresses, rewarding/positive aspects, challenges.]

What would you say is the biggest struggle for you and your family right now?

Have you or [*family member*] accessed any services? [Probes: day programs, home care, respite, support groups, long-term care]

- If yes: what was your experience like accessing/using that service?
- If no: would you consider accessing any services or programs? Why or why not?

Have you had any positive experiences with health or support services?

If they have transitioned between health or long-term care settings: Can you tell me about your experience transition from (setting) to (setting)?

What kinds of supports or programs do you think would be helpful for you and your family?

Would you prefer to access services that are geared towards younger people with dementia, or their family members?

What do you think is important for me to know about young onset dementia?

Is there anything else you'd like to add? Or anything you've told me that you wish to clarify?

Demographic questions

First, I'd like to ask you a few questions about [person with dementia]

What is [*family member's*] age? _____

How old was [*family member*] when his/her symptoms of dementia first appeared? _____

How old was [*family member*] when he/she was first diagnosed with dementia? _____

Is he/she employed? If yes: What type of occupation? _____

If no, was he/she previously employed?_____

What type of occupation? _____ Why did he/she decide to stop working?_____

Does he/she live alone or with other family members?

Does he/she have any children? _____ If so, how many? _____ Do they still live at home?

What is the highest level of formal education that [*family member*] has completed?

- Elementary school or less____
- Some high school____
- High school graduate____
- Some college (including CEGEP) or trade school____
- Diploma from college or trade school____
- Attended university____
- University degree____
- Post-graduate degree____
- Other (please specify)_____

Now I'd like to ask a few demographic questions about yourself.

What is your current age? _____

How old were YOU when [*family member's*] symptoms first developed? _____

Do you provide care or support to [*family member*]? _____

If yes: About how many hours a week, on average, do you provide this kind of help for [*family member*]?_____

Do you have any children? _____ If so, how many? _____ Do they still live at home with you?

Are you employed? FT/PT/not at all/self employed (how many hrs per week)?

What is your type of occupation?_____

What, if any, is your primary ethnic/cultural identification? _____

What is the highest level of formal education that you have completed?

- Elementary school or less____
- Some high school____
- High school graduate____
- Some college (including CEGEP) or trade school____
- Diploma from college or trade school____
- Attended university____
- University degree____
- Post-graduate degree____
- Other (please specify)_____

Considering your average annual NET household income, in which general category would you place yourself:

- Below $19,999/year___
- $20,000 - $39,999/year___
- $40,000 – $59,999/year___
- $60,000 - $79,000/year___
- $80,000 - $99,999/year___
- $100,000 or more___

Appendix E. Sample Follow-Up Interview Guide

Note: Follow-up interviews were tailored for each participant based on information from the previous interview. The following questionnaire is a sample of questions commonly included in follow-up interviews.

We last spoke in [ ]. How have things been for you since our last interview? Have there been any changes (symptoms or care needs)?

The last time we spoke, you mentioned you had [forms of support]. Have there been any changes in terms of services or supports? [Probe: How has that been for you and your family?]

How have you been doing? What has the impact been on you?

Have you had any interactions with health care providers or other care providers since we last spoke?

Have you looked into, or accessed any services?

One of the recommendations that came out of the first round of interviews is to develop community based programs specifically for younger people with dementia. I want to get a little bit more feedback from participants about what they would like to see, and what works for families.

- First of all, how do you typically access information about services and programs? [Probe: the internet, home care, the Alzheimer society]
- Do you think the program should be run like other day programs through personal care homes, or through other (non health care) organizations such as a community centre?
- What kinds of activities would be meaningful or enjoyable for you/your partner?
- Is there anything that might make it difficult for you to participate?
- What would help to make a program more accessible?

Is there anything else you'd like to add? Or anything you've told me that you wish to clarify?

Appendix F. Participant Information and Consent Form for Providers

Participant Information and Consent Form for Providers and Stakeholders

Title of Study: "Perspectives on Health and Support Services for People with Young Onset Dementia"

Principal Investigator: Sheila Novek, PhD Candidate, Department of Community Health Sciences, University of Manitoba

Supervisor: Dr. Verena Menec, Professor, Department of Community Health Sciences, University of Manitoba

Sponsor: Canadian Institutes of Health Research

You are invited to take part in a research study examining the available health and support services for people with young onset dementia (onset before 65 years of age) and their families from the perspectives of patients, family members and providers.

Project Description

The purpose of this research is to examine health and support services for people with young onset dementia and to identify barriers and facilitators to care, areas of unmet need, and promising practices. These finding will be used to develop recommendations to improve and expand services for people with young onset dementia and their families.

The study involves semi-structured, qualitative interviews with 10-15 health care and service providers involved in the diagnosis, treatment and support of people who have young onset dementia as well as individuals engaged in dementia policy, administration or advocacy. Interviews will also be conducted with approximately 10 to 20 individuals who are living with young onset dementia or who have a family member affected by the disease.

What Participation Involves

Your voluntary participation will involve one interview conducted in person or over the phone. In person interviews will take place at a location chosen jointly with the principal investigator, Sheila Novek. It is estimated that the interview will take 30 minutes to one hour. These would be recorded with your consent using a digital recorder and later transcribed by a professional transcriptionist. Participation is voluntary, and you can stop at any time.

What kinds of questions will I be asked?

Clinicians will be asked questions about their experience diagnosing and treating patients with young onset dementia including their approach to diagnosis and disclosure, post-diagnosis supports, and the treatment of patients and families over time. Service providers will be asked about their experiences working with people who have young onset dementia, any issues or challenges they have encountered, and strategies and programs that work well. Policy stakeholders and administrators will be asked questions regarding the organization and delivery of dementia care in Manitoba, the availability of specialized services for people with EOD, and how age affects the way dementia care is organized and delivered. Recommendations to improve services will be sought from all participants.

Confidentiality

Although data will be kept confidential, it may not be completely anonymous for all participants, especially those in very specialized employment positions. There is a minor risk that such participants may be identifiable by their employers or colleagues in disseminated findings. The following steps will be taken to mitigate this risk and to protect the confidentiality of your information:

Transcripts and participant names will remain confidential. An anonymous, alpha-numeric coding system will be used to identify and organize data from participants. Interview transcripts will be stripped of all names and identifying details (e.g., specific hospitals or organizations), within a minimum of two weeks after their transcription.

Signed consent letters will be stored separately from transcripts (in a locked filing cabinet).

Transcripts and audio recordings will be kept in password-protected electronic format on the principal investigator's work computer. Paper copies will be kept in a locked filling cabinet in Sheila Novek's office.

Audio recordings will be deleted within one year after the project is completed.

You will not be named in published reports. Particular case examples or situations that may identify a participant will be used cautiously, with potentially identifying details removed or altered slightly.

Communication of Results

Results from this research will be published in Sheila Novek's PhD thesis, academic journals, and shared at academic and professional conferences. A summary of the results will be offered to all participants, and may also be shared with relevant stakeholders. All possible steps will be taken to maintain your confidentiality.

Risks and Benefits

There should be no significant physical or psychological risks to you as a result of your participation in this study. Although you will not be asked to divulge sensitive details of your relationship with your employer, there is some risk to confidentiality for employees who occupy very specific positions. All possible steps will be taken to protect your confidentiality, as listed above; however, you should be aware that in some cases we cannot ensure complete anonymity. In the long-term, we hope that the information we learn from you can inform improved services and programs for people with young onset dementia and their families.

Consent

Your signature indicates that you have understood to your satisfaction the information regarding participation in this research project and agree to participate. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit.

The University of Manitoba Research Ethics Board may look at your research records for quality assurance purposes.

This research has been approved by the Health Research Ethics Board at the University of Manitoba. The project has also been approved by the Winnipeg Regional Health Authority Research Access and Approval Committee.

If you have any concerns or complaints you may contact Sheila's supervisor, Verena Menec, at 204-272-3184 or by email at Verena.Menec@umanitoba.ca.

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at 1-204-789-3389.

A copy of this consent form has been given to you to keep for your records and reference.

I agree to be contacted for future follow-up in relation to this study: Yes _____ No _____

Participant's Signature: _____ **Date:** _____

Participant's Printed Name: _____

For the Researcher:
I, the undersigned, have fully explained the relevant details of this research study to the participant named above and believe that the participant has understood and has knowingly given their consent.

Researcher's Printed Name: _____

Researcher's Signature: _____ **Date**: _____

Do you wish to receive a **summary** of the findings? ( ) Yes ( ) No

How do you wish to receive the summary? ( ) E-mail ( ) Surface mail

Address: _____

Appendix G. Participant Information and Consent Form for Participants with Dementia

Participant Information and Consent Form

Study: Perspectives on Health and Support Services for People with Young Onset Dementia

Researcher: Sheila Novek, PhD Candidate, Department of Community Health Sciences, University of Manitoba

Supervisor: Dr. Verena Menec, Professor, Department of Community Health Sciences, University of Manitoba

You are invited to take part in a research study about the experiences of people who have young onset dementia and their family members. Please take your time to review this consent form and discuss any questions you may have.

What is the purpose of this study?

The purpose of this study is to learn about how people with young onset dementia and their families experience health care and support services. We want to understand the views, experiences and preferences of people with young onset dementia and their families so that we can make recommendations to improve available services. We expect about 10 to 20 people with dementia and their family members will take part in this study. We also plan to interview between 10 and 15 health care providers and stakeholders to get their perspectives.

Who is participating in this study?

- People who have young onset dementia – that is dementia that begins before a person turns 65 years old.
- Family members of people who have young onset dementia
- Health care professionals and support service providers who work with people who have young onset dementia

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide to take part in the study, you can stop at anytime. If you prefer not to answer certain questions, you don't have to answer those questions.

What will happen to me if I take part?

This study involves two interviews that will take place about six months apart. The interviews will last between 30 minutes to one hour. With your permission, the interview will be audio recorded, but your identity will remain confidential at all times.

What kinds of questions will I be asked?

You will be asked to talk about your experiences of dementia and any services you have used. For example, you will be asked to talk about your first symptoms, taking cognitive tests, getting a diagnosis, and taking part in programs such as support groups. You will also be asked questions about what kinds of information or supports you think are important for people with young onset dementia.

How will my information be managed and kept safe?

Any information gathered in this study will be kept confidential. All recorded and transcribed information will be identified only by a number and kept in a locked filing cabinet Sheila Novek's office or a password protected computer. Audio recordings will be deleted within one year after the project is completed.

When we are finished with this study we will write a report about what was learned. This report will not include your name or that you were in the study.

Will my information be shared with my family members?

Any information gathered in this study will be kept in confidence. If other members of your family choose to participate in this study, we will not share any of your personal information with them.

There is some risk to confidentiality if more than one family member participates in this study. Although we will never use your name in reports or presentations, it is possible that your family members will be able to identify you or information about you. If another member of your family chooses to participate in this study, it is also possible that you will be able to identify information about them.

To protect confidentiality, information that may identify a participant will be used cautiously, with potentially identifying details removed or altered slightly. However, you should be aware that in some cases we cannot ensure complete anonymity.

Are there any risks or benefits from taking part in this study?

There are some possible risks to taking part in this study. Some topics might be upsetting or cause you to feel distressed. It is important to know that you do not have to answer any questions that you don't want to, and you can stop the interview at any time.

There is some risk to confidentiality if more than one family member participates in this study. All possible steps will be taken to protect your confidentiality. However, you should be aware that in some cases we cannot ensure complete anonymity.

There may be a short-term benefit of having the opportunity to talk about your experiences. In the long-term, we hope that the information learned from this study will help to make policies and services that better support people living with young onset dementia and their families in Manitoba.

Who is coordinating and funding this study?

The research is being carried out by Sheila Novek, a PhD candidate in Community Health Sciences at the University of Manitoba under the supervision of Dr. Verena Menec. This study is funded by the Canadian Institutes for Health Research.

Who has reviewed the ethics of this study?

The study has been reviewed and approved by the Health Research Ethics Board at the University of Manitoba.

Who can I contact for further information?

If you have any questions about this project, or if you want to talk to somebody before taking part, please contact Sheila Novek by telephone at 204-272-3184, or by email at umnovek@myumanitoba.ca

Complaints: If have any concerns or complaints about this study, please contact Verena Menec at 204-272-3184 or by email at Verena.Menec@umanitoba.ca.

For questions about your rights as a research participant, you may contact The University of Manitoba, Bannatyne Campus Research Ethics Board Office at 1-204-789-3389.

Consent Form

Title of Study: Perspectives on health and support services for people with young onset dementia and their families

Name of Researcher: Sheila Novek

If you agree to each of the following, please place a check mark in the corresponding box. If you do not agree, please leave the box blank:

1. I have read, or had read to me, the details of this consent form. ☐

2. My questions have been answered. ☐

3. I understand that members of my family may also participate in this study. ☐

4. I agree to have the interview audio-recorded. ☐

5. I agree to take part in this study. ☐

6. I agree to be contacted in the future about this study ☐

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Name of researcher	Date	Signature

Would you like to receive a summary of the research findings? ( ) Yes ( ) No

How would you like to receive the summary? ( ) E-mail ( ) Surface mail

Address: _____

Is there anyone else you would like to receive a summary of the research findings?

Name_____

Address:_____

Appendix H. Participant Information and Consent Form for Family Members

Participant Information and Consent Form for Family Members

Title of Study: Perspectives on Health and Support Services for People with Young Onset Dementia

Researcher: Sheila Novek, PhD Candidate, Department of Community Health Sciences, University of Manitoba

Supervisor: Dr. Verena Menec, Professor, Department of Community Health Sciences, University of Manitoba

Sponsor: Canadian Institutes of Health Research

You are invited to take part in a research study about the experiences of people who have young onset dementia and their family members. Please take your time to review this consent form and discuss any questions you may have.

What is the purpose of this study?

The purpose of this study is to learn about how people with young onset dementia and their families experience health care and support services. We want to understand the views, experiences and preferences of people with young onset dementia and their families so that we can make recommendations to improve available services. We expect about 10 to 20 people with dementia and their family members will take part in this study. We also plan to interview between 10 and 15 health care providers and administrators to get their perspectives.

Who is participating in this study?

- People who have young onset dementia – that is dementia that begins before a person turns 65 years old.
- Family members of people who have young onset dementia.
- Health care professionals and support service providers who work with people who have young onset dementia.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide to take part in the study, you can stop at any time. If you prefer not to answer certain questions, you don't have to answer those questions.

What will happen to me if I take part?

This study involves two interviews that will take place about six months apart. The interview will last between 1 to 2 hours. With your permission, the interview will be audio recorded, but your identity will remain confidential at all times.

What kinds of questions will I be asked?

The interviews will be conversational, and they will be guided by open-ended questions. Every interview is different, all answers contribute to our knowledge, and there are no correct answers. Questions will explore the onset and progression of your family member's illness, the process of obtaining a diagnosis and accessing services, and the impact on the family. At the end of the interview, participants will also be asked a brief series of demographic questions about themselves and their family member such as age, marital status.

How will my information be managed and kept safe?

Any information gathered in this study will be confidential. To protect your personal information, all recorded and transcribed information will be identified only by a number and kept in a locked filing cabinet in Sheila Novek's office or on a password protected computer. Audio recordings will be deleted within one year after the project is completed.

When we are finished with this study we will write a report about what was learned. This report will not include your name or that you were in the study.

The University of Manitoba Research Ethics Board may look at your research records for quality assurance purposes.

Will my information be shared with my family members?

Any information gathered in this study will be kept in confidence. If other members of your family choose to participate in this study, we will not share any of your personal information with them.

There is some risk to confidentiality if more than one family member participates in this study. Although we will never use your name in reports or presentations, it is possible that your family members will be able to identify you or information about you. If another member of your family chooses to participate in this study, it is also possible that you will be able to identify information about them.

To reduce this risk, information that may identify a participant will be used cautiously, with potentially identifying details removed or altered slightly. However, you should be aware that in some cases we cannot ensure complete anonymity.

Are there any risks or benefits from taking part in this study?

There are some possible risks to taking part in this study. Some topics might be upsetting or cause you to feel distressed. It is important to know that you do not have to answer any questions that you don't want to, and you can stop the interview at any time.

There is some risk to confidentiality if more than one family member participates in this study. All possible steps will be taken to protect your confidentiality. However, you should be aware that in some cases we cannot ensure complete anonymity.

There may be a short-term benefit of having the opportunity to talk about your experiences. In the long-term, we hope that the information learned from this study will help to make policies and services that better support people living with young onset dementia and their families in Manitoba.

Who is coordinating and funding this study?

The research is being carried out by Sheila Novek, a PhD candidate in Community Health Sciences at the University of Manitoba under the supervision of Dr. Verena Menec. This study is funded by the Canadian Institutes for Health Research.

Who has reviewed the ethics of this study?

This study has been reviewed and approved by the Health Research Ethics Board at the University of Manitoba.

Who can I contact for further information?

If you have any questions about this project, or if you want to talk to somebody before taking part, please contact Sheila Novek by telephone at 204-272-3184, or by email at umnovek@myumanitoba.ca

Complaints: If have any concerns or complaints about this study, please contact Verena Menec at 204-272-3184 or by email at Verena.Menec@umanitoba.ca.

For questions about your rights as a research participant, you may contact the University of Manitoba, Bannatyne Campus Research Ethics Board Office at 1-204-789-3389.

Consent Form

Title of Study: Perspectives on health and support services for people with young onset dementia and their families

Name of Researcher: Sheila Novek

If you agree to each of the following, please place a check mark in the corresponding box. If you do not agree, please leave the box blank:

1. I have read, or had read to me, the details of this consent form. ☐

2. My questions have been answered. ☐

3. I understand that members of my family may also participate in this study. ☐

4. I agree to have the interview audio-recorded. ☐

5. I agree to take part in this study. ☐

6. I agree to be contacted in the future about this study ☐

_____	_____	_____
Name of participant	Date	Signature
_____	_____	_____
Name of researcher	Date	Signature

Would you like to receive a summary of the research findings? ( ) Yes ( ) No

How would you like to receive the summary? ( ) E-mail ( ) Surface mail

Address: _____

Appendix I. Participant and Stakeholder Research Report

Health and support services for people living with young onset dementia

A study of health and support services for people living with young onset dementia from the perspectives of people living with the condition, family members and care providers.

Report prepared by:

Sheila Novek, MSc, PhD(c) and Verena Menec, PhD

Department of Community Health Sciences, Max Rady College of Medicine, Faculty of Health Sciences, University of Manitoba

November 2019

University of Manitoba

Acknowledgements

We would like to extend our deepest thanks to all the participants who contributed their time and shared their experiences and expertise. We are also grateful to the organizations that supported this project and assisted with recruitment including the Alzheimer Society of Manitoba, the University of Manitoba Centre on Aging, and Riverview Health Centre. This project received financial support from the Canadian Institutes for Health Research.

For further information contact:

Sheila Novek at umnovek@myumanitoba.ca
Visit: youngonsetdementiastudy.com

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Summary

About this study

The purpose of this study was to learn about how people living with young onset dementia and their families experience health care and support services. We also wanted to understand the views of care providers who work in this area. In total, we interviewed 36 people; six people living with young onset dementia, 14 family members and 16 health professionals and service providers. The study was conducted in Winnipeg, Manitoba.

What is young onset dementia?

Young onset dementia refers to dementia that develops before the age of 65. Dementia is an umbrella term for a group of conditions characterized by progressive impairment in cognitive function. Symptoms may include problems with language, memory, planning and problem solving, visual perception, movement, and behavior. Although age cut-offs are arbitrary, evidence suggests that younger individuals have unique needs and experiences.

How many people have young onset dementia?

Based on the best available research[1,2], there are an estimated 15,000 people in Canada, and 500 people in Manitoba with a diagnosis of young onset dementia. The actual figure is likely higher because many people have a hard time getting a diagnosis.

What did we find?

We found that people living with young onset dementia and their families had a hard time getting the help they needed. From getting a diagnosis, to accessing information, supports and long-term care, participants struggled to navigate a system that lacks dedicated services for young onset dementia. Health care and service providers also found it challenging to deliver quality care without adequate resources or service coordination.

1 Kvello-Alme, M.,et al. (2019). The Prevalence and Subtypes of Young Onset Dementia in Central Norway: A Population-Based Study. *Journal of Alzheimer's Disease*, 479-487.

2 Withall, A., et al. (2014). The prevalence and causes of younger onset dementia in Eastern Sydney, Australia. *International psychogeriatrics*, 26(12), 1955-1965.

Summary of key findings and recommendations:

1. The lack of awareness and understanding of young onset dementia makes it harder for people to access care and contributes to stigma.

   Recommendation: Enhance the public's understanding of dementia by showing the diversity of the condition, its symptoms, and the impact on families. Promote education and awareness of young onset dementia among health care providers.

2. There is currently no clear pathway for people under 65 with suspected dementia to get assessed and diagnosed. Participants were often unaware of available specialists, and many were referred to specialists who lacked experience treating young onset dementia.

   Recommendation: Clarify the pathway to assessment and diagnosis for people below 65 with cognitive impairment or suspected dementia.

3. Age restrictions create barriers for people under 65. Many important services for people living with dementia are not open to individuals under 65.

   Recommendation: Review age restrictions for dementia-related services and ensure people of all ages have equitable access to resources and services.

4. Diagnosing and supporting people living with young onset dementia requires many different health professionals but participants lacked access to multidisciplinary care teams.

   Recommendation: Develop multidisciplinary services for young onset dementia to streamline the diagnostic process and improve care coordination.

5. Most participants reported receiving unclear or insensitive communication about the diagnosis, prognosis, treatment options and supports. Health care providers also found it challenging to deliver diagnoses without supports such as counselling.

   Recommendation: Promote sensitive and honest communication between health care providers and families. Families should be offered supports to help them cope with the diagnosis and connect to local services.

6. Participants described the profound impacts of young onset dementia on the entire family and highlighted the need for family-centred services and psycho-social supports from diagnosis to end-of-life.

   Recommendation: Identify providers and services with expertise in supporting families dealing with young onset dementia. Encourage care providers to address the needs of the entire family.

7. Navigation work refers to the work that people do to find and access the care they need. We found that families faced demanding navigation work.

   Recommendation: Review ways to improve access to services and reduce the demands on families. Consider developing a program to help families navigate health and social care.

8. Participants had a hard time finding information about their illness, treatment options, income supports, and community services.

   Recommendation: Develop informational resources specifically for people living with young onset dementia and their families. Ensure patients and families have access to a care provider who can provide individualized information.

9. Families had a hard time accessing home care. Their experiences suggest that current home care services may not meet the needs of some people living with young onset dementia. Participants valued Family Managed Care, but identified the work required to access the service as a significant barrier.

   Recommendation: Review the needs and gaps in home care services for people living with young onset dementia and their families. Improve access to Family Managed Care for people living with young onset dementia.

10. Participants identified several barriers to long-term care and questioned whether current facilities can accommodate the needs of younger residents. Providers cautioned that some facilities may be reluctant to admit younger people, and pointed out that fees may be prohibitive for families with children.

    Recommendation: Review ways to accommodate the needs of people with young onset dementia in long-term care. Examine potential barriers to admission and review personal care home fees for families with children at home or in school.

11. Participants living with dementia talked about their experiences of social isolation and pointed to the need for supports to help them maintain active, meaningful lives.

    Recommendation: Develop a range of options including:

    1) specialized group programming
    2) one-on-one supports
    3) making existing recreational activities dementia-friendly

What is young onset dementia?

Young onset dementia refers to dementia that develops before the age of 65. Dementia is an umbrella term for a group of conditions characterized by progressive impairment in cognitive function. Symptoms may include problems with language, memory, planning and problem solving, visual perception, movement, and behavior.

How many people have young onset dementia?

Based on the best available research[3,4], there are an estimated 15,000 people in Canada, and 500 people in Manitoba with a diagnosis of young onset dementia. The actual figure is likely higher because many people have a hard time getting a diagnosis.

What are the causes of young onset dementia?

The causes of young onset dementia are heterogeneous and include Alzheimer's disease, frontotemporal dementia, vascular dementia, Lewy body dementia, alcohol-related dementia, prion diseases, traumatic brain injury, multiple sclerosis, Huntington's disease, Parkinson's disease and Down syndrome.

3 Kvello-Alme, M.,et al. (2019). The Prevalence and Subtypes of Young Onset Dementia in Central Norway:A Population-Based Study. *Journal of Alzheimer's Disease*, 479-487.

4 Withall, A., et al. (2014). The prevalence and causes of younger onset dementia in Eastern Sydney, Australia. International *psychogeriatrics*, 26(12), 1955-1965.

About this study

There is growing recognition in Canada and around the world that all people living with dementia should have access to quality, comprehensive care and supports that help people to live well with their condition. For people living with young onset dementia, finding the right care is often difficult, as most services are set up for older adults. Without dedicated services for people with young onset dementia in Manitoba, we don't know how people access health and social services and whether available services meet their needs.

The purpose of this study was to learn about how people living with young onset dementia and their families experience health care and support services. We wanted to understand their views, experiences and preferences to make recommendations to improve services. We also spoke to health care professionals and service providers who work with people living with young onset dementia to better understand how care is delivered. The study was conducted in Winnipeg, Manitoba.

Who conducted this study?

This study was conducted by Sheila Novek, a PhD candidate in the department of Community Health Sciences at the University of Manitoba. The project was supervised by Dr. Verena Menec, a professor in Community Health Sciences at the University of Manitoba.

Who participated in this study?

In total, 36 participants were interviewed for this study between February and November 2017. Participants from 12 families took part in the study, including six people living with young onset dementia, 11 spouses, two adult children, and one niece.

We also interviewed 16 health care and service providers who work with individuals living with young onset dementia and/or their families. These providers came from a range of professions (neurology, psychiatry, geriatrics, family medicine, psychology, nursing, social work) and settings (health care, long-term care, non-profit agencies).

The majority of participants lived in Winnipeg; three lived in rural communities outside of the city. All interviews were included in the analysis; however, this report focuses primarily on services delivered in Winnipeg.

What did we find?

We found that people living with young onset dementia and their families had a hard time getting the help they needed. From getting a diagnosis, to accessing information, community supports, social activities, home care and long-term care, participants struggled to navigate a complicated system that lacked dedicated services for young onset dementia. Health care and service providers also found it challenging delivering quality care without adequate resources or service coordination.

We also identified potential strengths in our health services, such as the Self and Family Managed Care Program, the Adult Day Program, and the availability of specialists with expertise in young onset dementia. With some planning and investment, these resources could be enhanced to better meet the needs of people living with young onset dementia and their families.

The following sections outline key findings from this study as well as recommendations to improve and expand existing services.

Key findings

1. Lack of awareness and recognition of young onset dementia

Dementia is an umbrella term for a diverse group of brain diseases with a wide range of symptoms that affect people of different ages. Yet, dementia is widely understood as a disease of old age primarily associated with memory loss.

We found that misperceptions of dementia impacted the lives of people living with young onset dementia and their families. In the early stages of the illness, participants struggled to make sense of the changes they noticed in themselves or their family members. Because dementia is strongly associated with old age, families often didn't consider the possibility of dementia for months or even years. Participants also felt that a lack of awareness of young onset dementia among health care providers contributed to misdiagnoses and delayed the diagnostic process.

Some participants described young onset dementia as an invisible disease. They felt that other people often did not understand the symptoms of dementia and their daily struggles. As one participant commented, *"There are times where some people just say 'Well, no, you look fine and you're doing well.' But, um . . . it's not something that's consistent. You know, the next day might be just totally off."* This sense of being invisible also applied to their interactions with care providers and services that didn't recognize their needs. The lack of awareness and understanding participants encountered in their social lives added to the experience of stigma.

"I just want people to know it's not always a memory thing." (Family member)

"It's one of those invisible ones, right? … When you're dealing with the mind—and I guess just like with a mental illness, it's much more difficult for people to cope with." (Family member)

Key recommendations:

- Promote more inclusive representations of dementia that reflect the various subtypes of dementia, their symptoms, and the diversity of people who are living with the condition.
- Improve education and awareness of young onset dementia among health care providers.

2. No clear pathway to assessment and diagnosis

There is currently no clear pathway for people under 65 with cognitive impairment or suspected dementia to get assessed and diagnosed. There are several specialists in Manitoba from different medical specialties (Psychiatry, Neurology and Neuropsychology) who can assess and diagnose young onset dementia, but they are not clearly identified to the public or to primary care providers.

We found that families and providers were not aware of available specialists in Winnipeg, and they were often referred to specialists who lacked experience treating young onset dementia. With no clear assessment pathway, it can take years and many referrals before patients see the right provider. This delays access to treatment and supports, and can be very stressful for families.

"I have to say, in terms of there being sort of a clear pathway to getting help, that doesn't exist." (Health care provider)

"Yeah 2010 is when we started down this road … and it was the end of 2014 when we actually got the diagnosis. So it was a long four years, it was harsh … I don't even know how we made it through." (Family member)

Key recommendations:

- Clarify the pathway to assessment and diagnosis for people under 65 with cognitive impairment or suspected dementia.
- Specialists with expertise in young onset dementia should be identifiable to other health care professionals and the public.

3. Age restrictions create barriers

Several key services for people living with dementia in Winnipeg have age restrictions. Age restrictions are often used when services are geared towards older adults, but are not dementia-specific. Although these services are not specifically for dementia, they are important resources for older adults living with dementia. Winnipeg does not have a dementia clinic. Instead, many dementia services have developed within geriatric programs. Without alternative options for younger people, their access to care and supports is limited.

Examples of services in Winnipeg with age restrictions:

- Geriatric Program Assessment Team (GPAT) and Geriatric Mental Health Team (GMHT)
- Geriatric Day Hospital Services
- Some specialists' private practices
- Community-based support services such some adult day programs

Age restrictions also make it harder for health care providers to help patients with young onset dementia because they can't access the same resources that are available for older patients.

> ***"We were told we could not access [the Geriatric Mental Health Team] until she's 65…I didn't call until she was after 65 anyway… but if that kind of intervention and support had been there earlier it might've been more helpful." (Family member)***

Key recommendations:

- Review age restrictions for services that could benefit people with young onset dementia.
- If age restrictions are considered necessary, then alternative services for people with young onset dementia should be identified.

4. Diagnostic services are fragmented and uncoordinated

Assessing, diagnosing, treating and supporting people living with young onset dementia and their families requires many different health professionals. In ideal care models, practitioners work together in collaboration with patients, families and family physicians, to provide continuous care as the disease evolves and needs change.

We found that there are currently no multidisciplinary services in place to coordinate the diagnostic process, or to connect patients with young onset dementia to health care providers and supports.

Unlike dementia in older adults, diagnosing young onset dementia requires multiple medical specialists and additional brain imaging and laboratory tests. Without a multidisciplinary team or a process for coordinating assessment, families were referred to one specialist after another, waiting for long periods of time between each consultation. This process often took years, and several families received conflicting information and opinions from one-off consultations. This left participants with considerable uncertainty around their diagnosis and prognosis.

> ***"They say we'd like you to go do this test and then you would go to that test and then you would go to another test, many tests unfortunately… it's a very arduous and slow process." (Participant living with dementia)***

Health care providers also expressed discomfort with diagnosing and managing young onset dementia in isolation. According to health care providers, neurology, psychiatry, neuropsychology and neuroradiology all play a key role in the diagnostic process, and physicians feel more comfortable treating people with young onset dementia when other health professionals are involved. As one physician commented: *"[Ideally] you'd probably start off with a neurologist to make sure you don't have sort of a treatable neurologic disease. Second is to be seen by a psychiatrist to make sure you don't have a treatable psychiatric illness… and then probably a neuropsychologist … So probably right now you'd need to make three stops, three referrals, three different waiting lists, so it's really…cumbersome."*

Health care providers also emphasized the need to involve nurses, social workers, occupational therapists and other allied health professionals, to provide ongoing assessment, management and care coordination. They also identified the need for counselling, education, and psycho-social supports for family members. Without access to multidisciplinary teams, physicians expressed feeling ill-equipped to help families with issues that fall outside of their usual scope of practice, such as disability benefit applications, setting up long-term care or providing family counselling.

> ***"We had a memory clinic running at one point where neurology was available, geriatrics was available, psychiatry was available, social work, nursing. We all kind of collaborated. It was very efficient." (Health care provider)***
>
> ***"The family doc can't sort out [disability income], and I don't know anything about that. So things like social work become really helpful…I don't think the system recognizes how complex things can be for younger people." (Health care provider)***

Key recommendations:

- Young onset dementia care should involve a comprehensive assessment and ongoing care from a multidisciplinary team of key professionals including neurology, psychiatry, psychology, neuroradiology, nursing, social work, and other allied health professionals. These professionals should have relevant training and expertise in young onset dementia.

- A multidisciplinary dementia clinic or specialist young onset dementia team has the potential to streamline the diagnostic process, provide tailored supports and care coordination, and enhance the skills of health care providers.

5. Communication is a challenge

Receiving a diagnosis of dementia is extremely difficult. Participants described feeling shocked and devastated by the news. For some, the diagnosis came as a relief, reflecting the long and stressful journey leading up to it. Health care providers also find it difficult to convey a diagnosis of young onset dementia, especially when resources aren't available to help patients cope with the news, such as counselling or social work. As one health provider commented: *"It's usually a little bit more of a shock…Emotionally it's harder for everybody. And sometimes it can be a lot more of a challenge."*

Most participants reported receiving unclear or insensitive communication about the diagnosis, prognosis, treatment options and supports. Some families felt that their doctors were uncomfortable delivering the diagnosis, and avoided using clear language. They also reported feeling like their concerns weren't taken seriously, and many received inadequate information about the assessment process. For some, the diagnosis was delivered in clear language, but participants did not feel their physician took the time to explain it, to help them cope with news, or to connect them with local supports.

> ***"I remember actually having to press [the doctor] a little bit because, up until that point, it was more sort of around the diagnosis instead of actually naming it." (Family member)***

Families felt overwhelmed when physicians discussed issues around planning for the future in the same appointment that they delivered a diagnosis. Conversations about wills, power of attorney, finances, driving cessation, safety, and continuing or discontinuing work are important. Scheduling a follow up appointment to discuss practical issues gives families time to process the news and to come up with questions to ask their doctor.

> ***"So we were hit with 'Get your affairs in order, she can't look after your finances, she can't drive…if you don't have a will get a will in'…including, 'you know you should quit your job'." (Family member)***

Individuals who were originally diagnosed with mild cognitive impairment, or who were diagnosed with dementia other than Alzheimer's disease tended to report poor communication from their physicians, and more uncertainty around the diagnosis. For example, one participant learned of her husband's progression from mild cognitive impairment to Alzheimer's disease through paperwork: *"The [neurologist] wrote early onset Alzheimer's …that was part of applying for the disability benefits…There was no conversation about it. It was just something that… seemed to happen along the way, which is really weird right; like we can't even speak it."*

Health care providers emphasized the complexity of the diagnostic process, the heterogeneity of young onset dementia, and the importance of monitoring people over time. Providers acknowledged that they were often more cautious when diagnosing younger people, and expressed concern about the impact of a dementia "label". At the same time, they felt it was important to communicate the diagnosis once they reached a determination.

Providers also emphasized the impact of a dementia diagnosis and felt it was particularly difficult for younger families to process and cope. Sharing a diagnosis of young onset dementia is also difficult for providers, and can leave a lasting mark. As one physician commented, *"I find it much more emotionally difficult. You know, they have nine-year-old children and it's just altogether a different situation than, you know, an 85-year-old."* Providers identified the need for counselling and/or social work to help families cope with the diagnosis.

What is good diagnostic communication?

Families valued clear and sensitive communication from their health care providers. Before a diagnosis was reached, participants valued health care providers who took their concerns seriously, and who provided feedback about their condition. They also valued providers who explained the assessment process including the time and tests involved.

While a few participants questioned the value of a dementia label, the majority wanted an explanation for the changes they experienced in themselves or their family members. Families spoke positively of health care providers who they felt delivered the diagnosis with compassion, took time to answer questions, and offered to connect them with supports. For many families, it was important to know the specific dementia subtype, in order to better understand the condition, the prognosis and treatment options. Families who did not receive a clear diagnosis often tried to figure out the dementia subtype on their own. Participants also suggested providers offer a sense of hope and strategies to live well with dementia.

> ***"The reality is people still need to live with dementia. As we walk out of their offices, we're not dead…It doesn't mean that you can't still live your life to the best that you can, and there's supports that are out there can assist you, you know there still needs to be hope that's given." (Family member)***

Key recommendations:

- Promote sensitive and honest communication between health care providers and families
- People need time to process the diagnosis. Consider setting up a second appointment to discuss next steps and answer questions.

- When an individual has mild cognitive impairment, the progression to dementia should be clearly communicated.
- People with young onset dementia and their families should be offered supports to help them cope with the diagnosis and connected to local services.

6. A need for family-centred services and psycho-social supports

Participants described the profound impacts of young onset dementia on the entire family, and highlighted the need for family-centred services and psycho-social supports from diagnosis to end-of-life. Participants living with dementia recounted the challenges and changes they faced. They also shared their strategies for coping with change, and emphasized the role their families played in supporting their well-being. For example, one participant explained his perspective on living well with dementia: *"So I don't, you know, just sit there and stare at it…you know carry on as best you can. That's about all you can do."*

Family members discussed the emotional and psychological toll of grief and caregiving, financial losses, changing roles and relationships within the family, and the stress of providing increasing levels of care. Two participants discussed their experiences of violent and aggressive behavior from their partners, highlighting the risks some families face and the limitations of available services. Participants worried about their children, and some felt ill-equipped to discuss the diagnosis or ongoing care arrangements.

> ***"It just keeps changing and so your grief just continues to change along with it and it never seems to end; and you're continually coming up with new ways to manage different things, from her leaving, to getting dressed, to her medication, to having someone there when I'm at work, to every aspect of our life." (Family member)***

Interviews with adult children and parents identified a range of stresses that children face including: making sense of the changes they observed in their parent and learning new ways to interact with them; worrying about their well parent; sharing their experience with friends; and worrying about their own risk of developing young onset dementia. These findings underline the need to develop family-centred services that include supports for children.

> ***"I was just like, you know, is this gonna happen to me? That was a big one, that's something I still really kind of struggle with." (Adult child)***

The impact on participants' mental health was significant, but access to support was limited. Some participants accessed mental health professionals through private insurance or other means, but others had a hard time finding help.

Several participants attended a support group for caregivers of people with young onset dementia. Participants valued the peer support and the opportunity to meet other people dealing with similar life circumstances. Their comments suggest that caregivers are more comfortable participating in programs tailored for young onset dementia.

Key recommendations:

- Identify health care providers and services with expertise in supporting families dealing with young onset dementia.
- Encourage all dementia care providers and services to address the psycho-social needs of each family member.
- Children have questions about their parent's diagnosis, prognosis, genetic inheritance, and often need help understanding changes in their parent. Family meetings with health care providers offer children an opportunity to ask questions and receive support.

7. Navigating the system is challenging

Navigation work refers to the work that people do to find and access the care they need. When a person has dementia, this work continues throughout the course of the illness as care needs change and increase.

We found that family caregivers were engaged in continuous, complex and demanding navigation work. This work included seeking information and researching local resources, negotiating with gatekeepers (e.g., home care case coordinators), filling out applications and following bureaucratic procedures, care coordination, and advocacy.

The level and scope of navigation work placed a considerable burden on families. Many were juggling caregiving, full time work and had children at home. Participants described feeling stressed and overwhelmed by the work, and some chose not to pursue services they viewed as too burdensome to access such as Family Managed Care or finding an alternative specialist.

The demands of navigating a fragmented system with limited services compounded an already stressful situation. The complexity of navigating health and social care raises the possibility that people with fewer family supports, resources or skills face additional barriers to care.

> ***"Maybe I should've gone to a different doctor or a different neurologist and tried to find some different support if you're unhappy with one source. But I didn't do that because all this takes…energy and stress and time and emotions." (Family member)***

Key recommendations:

- Review ways to improve access to services and reduce the demands on families.
- Consider developing a program to help people with young onset dementia and their families navigate health and social care such as Australia's Younger Onset Dementia Key Worker Program[5].

5 For information about Australia's Young Onset Dementia Key Worker Program please see: www.dementia.org.au/services/younger-onset-dementia-key-worker-program

8. Difficulties finding the right information at the right time

Participants had a hard time finding pertinent information about their illness, treatment options, income supports, and community services and supports. Many felt that available information was not tailored to people living with young onset dementia or topics that mattered to them. Participants were often turned off from information sessions or resources that were geared towards older adults or people in the later stages of dementia.

> ***"I feel like…I'm forever reinventing the wheel and every time I need to know something I'm making a million phone calls, I'm digging up, I'm researching ... and I shouldn't have to do that because there's a million other people have already done that already." (Family member)***

Young onset dementia affects people's ability to work and has profound financial impacts. We found that families had a difficult time accessing relevant information about their employment, disability benefits, and sources of income support or tax relief. Several of the families in our study were not aware of benefits they were entitled to for years, and many struggled to navigate financial information and procedures. For example, one participant commented: *"It took a couple of years before I actually realised, oh my goodness, there's this funding available through disability pension. And fortunately it's retro-active, but…it didn't go back far enough to cover the whole time."*

Key recommendations:

- People living with dementia and their families should have ongoing access to information about their diagnosis, prognosis and treatment options.
- Develop informational resources specifically designed for people living with young onset dementia and their families.
- Before or immediately following a diagnosis, people living with young onset dementia should be provided with information about employment and income support strategies.

9. Home care is essential but often inaccessible

Participants viewed home care as an essential service. However, accessing home care proved challenging for many families. Participants' experiences suggest that the focus and scope of home care services may not meet the needs of some people living with young onset dementia. Family members and health care providers felt that home care services were designed to provide care to older adults with physical limitations. But many people living with young onset dementia are physically well; what they need is assistance or encouragement to participate in self-care and other activities.

As a result, several families who wanted home care did not meet eligibility criteria. Others qualified but declined or discontinued services because they felt the services offered did not meet their needs. While some families switched to family managed care, others were left without supports.

> ***"I had to retire because I didn't know what to do with him … I was told by Home Care that they only provide services, they don't provide all day care if…his ADL's aren't bad enough." (Family member)***

Family managed care

Several families switched to Family Managed Care because it afforded them more control, flexibility and consistency. Participants expressed a strong desire for home care services that support social and recreational activity. A key benefit of Family Managed Care identified by participants is that care providers can take clients outside of the home and take part in social activities. Participants and their family members who used this service went on walks, shopping trips, trips to the movies, volunteered and attended support groups, church groups and other recreational activities

The other key benefit participants identified is the ability to develop relationships with care providers. Accepting help can be really hard. Some individuals did not believe they required help, and others had a hard time accepting the loss of their independence and autonomy. Having consistent care providers fostered relationship building and ultimately helped participants accept outside help. As one participant commented: *"We didn't know them at the beginning but we've learned to know them. And instead of having 10 people there's just two, it's so nice." (Participant living with dementia)*

While Family Managed Care was highly valued, participants identified some issues with the program:

- The work required to access and administer the service was considered a significant barrier, especially for families who were already overwhelmed with the caregiving. This means that families who are most in need of care may not receive it.
- The program is not well known, and participants felt it wasn't well advertised by the home care program.
- The funding that participants received to pay care providers was lower than the cost to hire care providers through agencies.
- Family members expressed concern about their ability to manage the delivery of home supports in the face of changing care needs.

> ***"I just think like having to hire people and find those people ourselves and then manage that would just be another task on our to-do list…If you don't find the right person then it would just be frustrating, really frustrating." (Family member)***

Key recommendations:

- Review the needs and gaps in home care services for people living with young onset dementia and their families.
- Enhance access to information about Self and Family Managed Care.
- Consider ways to assist families with the application and bureaucratic procedures of Family Managed Care.

10. Finding suitable long-term care is challenging

Participants identified several challenges related to long-term care. Family members faced difficult decisions about placing their loved one in long-term care and finding the most suitable facilities, and many felt unsupported during the process. Living in a long-term care facility at midlife is unexpected and falls outside of social norms, adding to the stigma and guilt families experienced. For example, one participant talked about placing his mother on a waitlist for a personal care home: *"A lot of people have this feeling like: 'Oh I would never do that to my parents', like it's like a punishment, or it's a sign of neglect, or sign of being a bad child … But I also know that we can't have her live here … it's just too exhausting… And my dad is… not going to be able to sustain what he's doing for much longer."*

Family members and health care providers expressed the view that people with young onset dementia don't always fit into mainstream long-term care facilities. Residents of personal care homes are older than ever, and participants felt that the environment and recreational activities may not suit younger, more active residents. Families expressed a strong desire for long-term care options that are tailored to the needs and preferences of people living with young onset dementia.

Health care providers also pointed out that individuals with young onset dementia who have demonstrated reactive or aggressive behaviour may face barriers to long-term care placement. According to participants, facilities are often reluctant to admit residents who pose a risk of violence, and individuals who are able-bodied may be viewed as potentially more dangerous than older or frail individuals who have exhibited similar behaviours. As one health care provider commented, *"Long-term care [is reluctant] to take people who might pose a behavioural issue and who [have] young, healthy bodies. Maybe there is an alterative place that isn't a personal care home that should be created."*

Affordability was another issue identified by providers. Personal care homes are subsidized, and charge fees based on a sliding scale. Some participants pointed out that the fees can be prohibitive for families with children at home or in university: *"If your loved one needs a nursing home and you've got kids in school and a mortgage … an extra thousand dollars a month for a nursing home is a heck of a lot of money. I have sadly seen people have to sell [their house]."* Participants also noted that cost of supportive housing varies and may a barrier for families.

Examples of young onset dementia programs in other Canadian cities:

- **Vancouver's Paul's Club** is a social and recreational program for people living with young onset dementia offered three days per week. For more information visit paulsclub.weebly.com
- **Calgary's YouQuest** is piloting a weekly recreational program for people living with young onset dementia. For more information visit youquest.ca
- **The Alzheimer Society of Toronto's Boomer's Club** is a weekly social program for people living with young onset dementia and their caregivers.
- **Waterloo's Young Onset Dementia Association (YODA)** offers a weekly social group for people living with young onset dementia. The program provides lunch, activities and outings.

Key recommendations:

- Review ways to better support family decision-making about long-term care.
- Consider specialized long-term care options for young onset dementia.
- Review ways to enhance recreational programming for people with young onset dementia living in long-term care.
- Examine admissions processes to assess whether younger people face additional barriers.
- Review personal care home fees for families with children at home or in school.

11. Opportunities for social activity and social inclusion are needed

Participants living with dementia recounted experiences of social isolation and boredom, and expressed frustration over the lack of opportunities for social participation. All of them were coping with significant changes and losses: their careers, their driver's licenses, the ability to carry out household tasks or to leave the house on their own. As one participant commented: *"When it bothers me is when I'm just stuck here in the house … and you just sit here and there's nothing to do."*

Stigma contributed to social isolation as many participants were uncomfortable sharing their diagnosis and shied away from social situations to avoid embarrassment. Family members also felt the impacts of social isolation and emphasized how hard it is to find respite and accessible activities. Those without supports struggled to maintain active lives and a sense of purpose.

> ***"We searched high and low and there was just nothing out there. There's tons of stuff for over 65 but nothing for under 65" (Participant living with dementia).***

Participants identified the need for range of options that reflect the diverse interests, needs and abilities of people living with young onset dementia, including:

1. group programming
2. one-on-one supports
3. making existing recreational activities dementia-friendly

Group programs

There are currently no group programs specifically for people living with young onset dementia in Manitoba. Several participants had tried out group programs that are primarily attended by older adults including support groups, Adult Day Programs, the Alzheimer Society's Minds in Motion program, and an educational group for people living with mild cognitive impairment. Some had positive experiences and emphasized the benefits of feeling understood and accepted. As one participant commented: *"I was reluctant to go… but once I finally got into it ... because those people that were there were exactly like me with the same issues. And you can relate to those people. You can sit there and you can laugh at yourself and they can laugh at you, and it's all good."*

However, many participants felt out of place in group programs because of their age, interests or abilities. Participating in group activities is not easy for everyone. Many felt anxious in social situations, group settings and unfamiliar environments. To overcome these barriers, participants identified the need for programs that help them to feel included and accepted.

Participants expressed a strong desire for Adult Day Programs for people living with young onset dementia. Many participants tried Adult Day Programs, but dropped out soon after. For example, one participant commented on his experience: *"It just didn't hit yes. It was no, this is not for me."* Overall, participants felt that mainstream Adult Day Programs were not suited to the interests and abilities of people living with young onset dementia.

When asked about their discomfort with Adult Day Programs, participants tended to focus on the older age of most members. However, further discussion revealed more nuanced barriers, including:

- The lack activities that matched their interests
- Discomfort with group settings and unfamiliar environments
- A sense that they don't belong
- The location and environment (e.g. hospital and care homes were a turn off)

Key recommendations for young onset dementia programs:

- Offer a range of activities that cater to different interests and abilities.
- Understand the various types of dementias and the range of symptoms and abilities.
- Consider ways to incorporate volunteering.
- Hold programs in familiar environments such as community centres. Avoid personal care homes and hospitals.
- Allowing participants to bring a support person can help them feel comfortable.
- Consider ways to accommodate the schedules of working families such as flexible start times or offering evening programs to provide respite to working caregivers.
- Consider other ways to involve family and friends such orientation sessions or family and friend events. People might be less reluctant to join if they can get to know the group in the company of family and/or friends.
- Include affordable transportation options.

Beyond group programming: one-on-one support and dementia-inclusive communities

For some, group programs do not fit their needs. They may require one-one-one assistance to participate in social and recreational activities. Some were able to secure this type of support through Family Managed Care. However, access to this form of support varied.

Participants also identified the need to improve access to existing social and recreational opportunities in their communities. Many participants wished to maintain the activities they took part in prior to developing dementia (e.g. volunteer work, religious groups, and physical activity). However, they encountered barriers to participation such as access to transportation, support workers, or information to help them identify dementia-friendly options.

> ***"People should be able to go volunteer…[My husband] can do a lot but he needs some guidance and he needs that safe environment. But we just can't find people to do it." (Family member)***

Key recommendations:

- Develop group programs for people living with young onset dementia.
- Expand access to one-on-one care providers who can support social participation and inclusion.
- Encourage dementia-friendly initiatives that expand opportunities for social participation and volunteering, and enhance social inclusion.

What are some of the limitations of this study?

- This study included a small number of participants and is not representative of the diversity of people living with young onset dementia and their families.
- This study did not include people living with an intellectual disability and dementia. This group has unique needs, care pathways and barriers that require additional research.
- This study identified several issues, but there are many other important topics that were not discussed in-depth such as primary care and end-of-life care.
- Most of the participants were from Winnipeg, so we cannot comment on services in other areas of Manitoba.

Ways forward

According to Canada's national dementia strategy, addressing gaps in services and removing barriers for people living with young onset dementia is a matter of health equity[6]. Based on our findings, we have put forward recommendations to guide the development of inclusive services that address the needs of people living with young onset dementia and their families. We will share these recommendations with organizations such as the Alzheimer Society of Manitoba, the Winnipeg Regional Health Authority, and Manitoba Health as well as service providers. We also hope that this report will be a useful tool for people living with dementia, their families and supporters in their efforts to advocate for service improvements.

6 Public Health Agency of Canada (2019). *A Dementia Strategy for Canada: Together We Aspire*. Ottawa: Public Health Agency of Canada.

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