

“Superior by Nature”? -Diagnosing dementia in northwestern Ontario

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners. I understand that my thesis may be made electronically available to the public.

Abstract

In 2025, Canada is home to approximately 771,939 people living with dementia and Ontario is projected to have the most new cases by province in the country by 2050. Northern Ontario makes up over 90% of the province's landmass and has 6% of its population. In Northwestern Ontario specifically, there is a higher proportion of people over the age of 65 compared to the rest of the province. This is important because prevalence of dementia nearly doubles every five years after the age of 65, meaning a population more at risk of developing dementia. Rural and remote communities in the northwest region are struggling to meet the basic healthcare needs of their residents. The Ontario Medical Association has labeled the state of the healthcare in this region a 'crisis' (n.d.(b)). This research explored the experiences of giving and receiving a diagnosis of dementia from the perspectives of physicians and caregivers of people living with dementia in northwestern Ontario. Existentialist phenomenology was utilized to uncover shared meanings and understandings about the diagnosis process, particularly how these experiences are situated in a remote and rural context. There were significant system gaps that impacted the experience of caregivers of people living with dementia and physicians in northwestern Ontario. Not being heard by physicians damaged relationships between caregivers and the healthcare system and created feelings of mistrust, frustration, and isolation. Physicians managed the emotional work of dementia diagnoses in private while working to overcome system shortages that impacted their ability to care for people living with dementia. However, despite the tension in relationships between physicians and caregivers, they often cited similar healthcare challenges that greatly impacted good dementia care. The struggles plaguing the healthcare system in northwestern Ontario appeared to impact everyone involved in dementia

diagnoses, and both caregivers and physicians were committed to overcoming challenges and providing the best care possible for people living with dementia.

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Chapter 1: Superior by Nature-Diagnosing dementia in northwestern Ontario

Introduction

In 2025, Canada is proposed to be the home of approximately 771,939 people living with dementia (Alzheimer Society of Canada, 2025). The *Landmark Study, Navigating the Path Forward for Dementia in Canada* conducted by the Alzheimer Society of Canada (2022), predicts a 187% increase in Canadians living with dementia by 2050, representing over 1.7 million individuals. This highlights the need for a strengthened healthcare system that can not only diagnose people with dementia efficiently but can provide continuing care as their conditions progress. Canadians will primarily rely on family physicians to diagnose dementia (Tang-Wai et al., 2020). However, Canada is struggling to provide quality dementia care, and research is needed to assist primary care physicians to provide the best care possible (Aminzadeh et al., 2012). Literature on dementia diagnosis has transitioned over the years from analyzing aspects of the process, including topics such as non-disclosure or truth telling, towards the impact of dementia diagnoses on physicians, caregivers, and people living with dementia. However, there is a lack of literature that looks at the experiences of these individuals within the context of a Canadian healthcare system. Moreover, there is little representation of the dementia diagnosis experience from the perspectives of caregivers and physicians in northwestern Ontario. This research seeks to expand the current literature on dementia diagnosis by exploring the experiences of caregivers and physicians in northwestern Ontario.

What is Dementia

Dementia is a term used to describe a group of progressive conditions that can result from various underlying causes that impact memory, thinking, behaviour, and activities of daily living unrelated to the normal aging processes (World Health Organization, 2023; Alzheimer's Society,

2022). Some of the most common forms of dementia include Alzheimer's Disease, accounting for approximately 60-70% of cases (World Health Organization, 2023), vascular dementia, dementia with Lewy Bodies, frontotemporal dementia, and mixed dementia (Public Health Agency of Canada, 2022). Symptoms vary among people living with dementia; there is no cure, and the condition will progress over time (World Health Organization, 2023).

Because there are various forms of dementia, and no one test to definitively determine that you have dementia, diagnoses are a process of elimination, ruling out other possible causes of clinical symptoms the person is experiencing. In Canada, our healthcare system has determined that family physicians are those most responsible for making a diagnosis of dementia (Tang-Wai et al., 2020). If a case is determined to be atypical, referrals to specialists, such as a geriatrician, neurologist, or geriatric psychiatrist would be made. Despite this aim, in reality, some family physicians take on responsibility for less complex cases while others refer automatically to a geriatric specialist (Pimlott et al., 2006).

The following sections will outline the typical journey of initiating a diagnosis and the standardized clinical tests and procedures considered 'best practice' for diagnosing dementia. It is important to note that there are both clinical guidelines that outline the best evidence for diagnosing dementia (e.g., that specify types of tests, etc. depending on clinical presentation and knowledge of patients, such as those recommended by the 5th Canadian Consensus Conference on the Diagnosis and Treatment of Dementia (Tang-Wai et al., 2020) as well as resources for physicians to communicate the diagnosis to patients based on best evidence from patient, caregiver, and physician perspectives (Alzheimer Society of Canada, n.d.). Both sets of guidelines were created to support physicians who are diagnosing people with dementia in their practice. It is crucial to understand the process to appreciate the impacts it can have on people

with dementia, their caregivers and physicians. While the components of a dementia diagnosis are the same for family physicians and specialists, family physicians are focused on here as they are recommended to diagnose most cases of dementia (Tang-Wai et al., 2020). In addition, there are few specialists in northwestern Ontario therefore, most individuals would be going to see a family physician for a dementia diagnosis.

Diagnosis Process: Clinical steps

Changes in memory, thinking, language, or ability to problem solve that impact daily life (Alzheimer's Association, n.d.) are some of the first symptoms people can experience and are characteristic of most types of dementia. These are not a normal part of the aging process. When symptoms reach a level that the individual is concerned with, some will reach out to a healthcare professional for answers. This marks the entry into the healthcare system and the beginning of many people's journey to being diagnosed with dementia. The following section outlines the process of a diagnosis in Canada.

Expected tests in initial appointment

It is important to note that a dementia diagnosis is a process, not a one-time event. The components of a dementia diagnosis include: gathering information on the medical history of the patient and family, performing mental status exam(s) (e.g., Montreal Cognitive Assessment, Mini Mental State Examination), conducting a physical exam, and ordering laboratory tests (i.e., blood work, imaging) (Alzheimer Society of Canada, 2023). Following these assessments, if other potential causes have been ruled out, a diagnosis of dementia is made. When a diagnosis is made, it is recommended that follow up appointments with patients include providing them with educational materials, knowledge of where to obtain social supports, and options for homecare, if appropriate (Alzheimer Society of Canada, 2023). While clear steps have been identified as best

practice for diagnosing dementia, the healthcare system within Canada is complex, and barriers exist to completing this process as recommended.

Challenges diagnosing dementia

Physician preparedness

Dementia diagnosis is a complicated process for physicians and preparation begins in medical school and post graduate training long before dementia assessments and disclosure appointments occur in practice. This process thus begins with understanding physicians' preparedness to diagnose people with dementia. This is the first important aspect of the diagnosis process to be considered as it could be a predictor of how the person with dementia and caregiver will experience the diagnosis. In the ShareD study, they found that only a few specialist physicians received training specific to delivering a dementia diagnosis, and many relied on basic principles from medical school about delivering bad news, that were not always applicable (e.g., delivering news of a condition other than dementia) (Bailey et al., 2019). Family physician respondents to a Canadian questionnaire about rural and remote dementia care in Saskatchewan revealed that 52% said they were 'fairly' comfortable with diagnosis and management of patients with dementia, only 19% felt very comfortable removing a driver's license, and 83% wanted more training on dementia diagnosis and treatment (Dal Bello-Haasm et al., 2014). Based on this literature, it is clear that more dementia specific education and training could increase physician preparedness and confidence.

Navigating the impacts of a dementia diagnosis

Although disclosure is common practice and diagnoses are not kept from patients and families, a systematic review of literature on caregivers, people living with dementia and healthcare providers found that physicians sometimes struggle to disclose a dementia diagnosis

and resort to using indirect terminology to describe dementia out of their own discomfort (Yates et al., 2021). Additionally, disclosure without sufficient conversations about the future, hope, and attention to patient emotion can have a negative impact on caregivers and people with dementia (Yates et al., 2021). In a study by Bailey et al. (2019) they found that physicians emphasized the importance of language and being aware of emotional responses to certain terms that may be viewed as stigmatized (e.g., dementia) and, therefore, incorporated conversations about medications to convey hope. Furthermore, Dooley et al. (2018) analyzed footage of 81 dementia diagnosis appointments and found that discussion around prognosis was lacking, and further research was needed to delve into aspects such as what information can be given to help people plan and facilitate hope. McLaughlin & Laird (2019) found that most of the general practitioners from their study felt knowledgeable about dementia and their ability to provide a timely diagnosis, but: “Fewer participants were confident about disclosing dementia than about diagnosing the condition, partly because of the stigma associated with the condition and their concerns about how patients and their families might react”(p. 5). Further, a systematic review of challenges receiving and disclosing a diagnosis of dementia by Yates et al. (2021) found that healthcare practitioners lacked confidence in delivering ‘bad news’, and would benefit from more training, use of a multidisciplinary team, and recognition of disclosure as a process. Overall, there is uncertainty surrounding multiple aspects of the diagnosis process from the perspectives of physicians. Future research is needed to start addressing some of the ways that physician’s confidence can be supported by clarifying some of the concerns they have within their practice about dementia diagnosis.

System barriers

A Canadian study in Quebec found that family physicians spoke of dementia as a time-consuming condition within their practices (Yaffe et al., 2008). Although care of people with dementia was considered as a time-intensive process (Yaffe et al., 2008) family medical practices in Canada operate with often brief visits of less than fifteen minutes (Pimlott et al., 2009). Family physicians were aware that caregiver/patients' understanding of dementia often develops with time (Bailey et al., 2019) but although time is beneficial, system constraints may prevent this, and physicians may be unable to provide the follow up appointments required (Bailey et al., 2019; Yates et al., 2021). Literature on rural dementia care in Canada is limited, but a study conducted in Saskatchewan, Canada, found that rural formal and informal healthcare providers felt there was a need for increased access to health and social services (e.g., specialists, long-term care, rehabilitative services, caregiver support), greater focus on the needs of Indigenous populations, and increased education about dementia (Dal Bello-Haasm et al., 2014).

Supporting physicians providing dementia care

Family physicians also reported a lack of guidelines for managing dementia (e.g. homecare, ability to drive) and wished for more support not only from specialists but other health professionals such as social workers, but knowledge of these services (i.e., availability and what they offered) was not consistent among physicians (Yaffe et al., 2008). Similarly, McLaughlin & Laird (2019) found that family physicians were concerned about not having enough community supports post-diagnosis. Additionally, family physicians with experience referring patients to RRMCs (rural remote memory clinics) in Saskatchewan, reported that health and social service provisions were not consistently available in these communities, wait times could be lengthy, and travel may be required to access supports (Kosteniuk et al., 2014). This desire for increased

involvement of interdisciplinary healthcare professionals suggests a preference for a team-based approach to dementia care. It is clear to see that dementia diagnosis and ongoing management, from the perspectives of family physicians, could be improved through interdisciplinary collaboration and increased education.

Similar need for multidisciplinary service access was echoed in a scoping review by Saragosa et al. (2024) on dementia care pathways. They found that most preexisting pathways revolve around diagnostics and management of the condition and lacked attention to coordination and community support (Saragosa et al., 2024). With a strong focus on pathways within clinical settings, and lack of coordination of services between primary and community health and social services, change can be made by considering the lived experience of people with dementia and caregivers when designing new pathways to meet their needs (Saragosa et al., 2024). Coordination efforts start with physicians and primary care teams' knowledge of services so they can appropriately educate and refer their patients. Access to specialists and community resources can be talked about as a facilitator of good dementia care but has clearly been identified as a barrier when resources are not available to these physicians to make the appropriate connections for their patients.

Memory clinics

There are successful examples of interdisciplinary collaboration within primary healthcare teams in Canada that have improved dementia care. An example of interdisciplinary team-based approaches within primary care settings are MINT (Multispecialty Interprofessional Team) Memory Clinics. There are over 100 MINT memory clinics in over 6 provinces in Canada (MINT Memory Clinic., n.d.). MINT memory clinics are described as: "...a not-for-profit organization that offers standardized nationally accredited training in dementia care for primary

care providers... [and offers training that] enables primary care teams to deliver comprehensive, compassionate care for people with memory concerns and their families within their own communities” (MINT Memory Clinic, n.d. para 1-2). Lee et al. (2022) stated: “There is an urgent need for models of dementia care that build system capacity and efficiency and that improve healthcare provider experience with care, leveraging the large infrastructure of primary care in Canada and other countries to better meet the needs of our aging population” (p. 106). Evaluation data has shown that MINT memory clinics can improve the quality of life of people diagnosed with dementia, lower healthcare costs (Wong et al., 2023) as well as improve family physician capacity for dementia and timely access to specialized care (Lee et al., 2010).

Two separate survey studies including physicians, nurses and allied health professionals participating in MINT clinic training reported that managing dementia in their practices was difficult, and they felt inadequately prepared (Lee et al., 2020a), but the MINT model made providing care less challenging, improved collaboration among health and social supports, and improved attitudes towards dementia care (Lee et al., 2022). Further, in a qualitative study of 12 healthcare practitioners (including 2 physicians) in Ontario memory clinics they found that despite the challenging nature of dementia diagnoses (e.g., taking a drivers license away, supporting patients and families), healthcare practitioners enjoyed working collaboratively in a team-based setting, and felt fulfilled by the work they do (Sheiban et al., 2018). Currently there are only two memory clinics in northwestern Ontario. With growing evidence of their efficacy in leveraging pre-existing primary care, and improving outcomes for people with dementia, these are models that could be considered for more widespread integration in northwestern Ontario.

Physicians caring for caregivers of people living with dementia

It is the role of family physicians in Canada to diagnose people with dementia and support them with ongoing care and treatment, but little attention has been paid to their role in supporting caregivers of their patients with dementia. A scoping review by Parmar et al. (2020) found that although family physicians regarded primary care as an appropriate place for caregivers to seek support, and caregivers would benefit from this, it was also emotionally challenging and time consuming for them in their practice. Barriers to providing support to caregivers included the caregiver not being a patient of the physician themselves, inability to bill for reimbursement, and not enough knowledge about supporting caregivers (Parmar et al., 2020). It has been suggested that interprofessional teams, knowing when to refer caregivers to other supports, and a more well-defined concept of caregiver-centered care are all ways that improved caregiver support can be achieved in primary care settings (Parmar et al., 2020). Further, a qualitative study of family physicians and primary care teams in Alberta, Canada revealed that the roles they could play in supporting family caregivers may include needs assessments and referring them to supports. However, current systems focus primarily on patient care, caregivers do not always identify themselves, and health and social systems with relevant supports can be difficult to navigate (Parmar et al., 2021). Similar concerns for lack of health and social services, and need for increased education of caregivers' needs, unfortunately echoes the same concerns for providing care for the person with dementia. It seems that system fragmentation is an issue that impacts the dementia diagnosis for everyone involved: people diagnosed with dementia, caregivers and physicians.

Emotional work of physicians

While navigating the impacts of a dementia diagnosis on their patients, physicians also experience the emotional toll of their work yet receive very little guidance as to how they can cope (Bennet et al., 2019). For example, breaking bad news to patients and family members is a challenging part of a physician's job. Training on how to share bad news is something that physicians receive in medical school, but this training may not have been about disclosing a dementia diagnosis specifically (Bailey et al., 2019). Bennet et al. (2019) indicated that approaches taught to help physicians break bad news do touch upon the emotions of the clinician in such situations but management of these emotions is not a focus of the training. Clinicians in this study reported the need to remain aware of their emotions because of how they could impact the person with dementia (Bennet et al., 2019). Similarly, in a study by Bailey et al. (2019) physicians reported that diagnosing people with dementia was emotionally demanding, training for breaking bad news was limited, and peer support was needed to prevent burnout and emotional disengagement. Frank et al. (2018) stated that: "A structured approach [to disclosing a dementia diagnosis] can help alleviate physician anxiety and improve the experience of the person living with dementia and caregivers. Most important, disclosure is not a single event but a dynamic, evolving process including pre-disclosure preparation, sensitive individualized disclosure, and follow-up education and support" (p.1). The focus of physician training is managing the patient, rather than managing themselves, but physician well-being is important and requires more attention in future research.

Caregiving in Canada statistics

National Canadian data on caregiving in Canada has highlighted the important impact of caring and demonstrated the need for health and social care systems to better support caregivers.

The Canadian Centre for Caregiving Excellence states: “Caregivers are unpaid family members, friends or other support for someone who needs care due to physical, intellectual or developmental disabilities; medical conditions; mental illness; or needs related to aging. Caregivers provide care because of a relationship, not as a job or a career” (2024 p. 2). A national survey on caregiving in Canada has found that one in four caregivers report poor mental health such as tiredness, worry/anxiety, and feelings of being overwhelmed (Canadian Centre for Caregiving Excellence, 2024). Further, two thirds of caregivers still work a job on top of caregiving, and one in five are over 65 years of age and require more support but are less likely to have accessed supports (Canadian Centre for Caregiving Excellence, 2024). Looking more specifically at the impact of caring in rural communities a mixed methods study in Alberta, Canada, by L’Heureux et al. (2022) found that lack of health and social services, care costs, and time caring all increased during COVID-19, while large proportions of caregivers reported poorer mental and physical health, and increased social isolation. This is important to note because the COVID-19 pandemic is still within the last 5 years, and will inevitably be a part of caregivers’ stories who have been providing care within recent years.

Caring for a person living with dementia

With the rising number of people living with dementia in Canada (Alzheimer Society of Canada, 2025) there will be many more caregivers who are providing unpaid care. National data has identified caregivers, as a whole, at risk of poor health outcomes without proper support (Canadian Centre for Caregiving Excellence, 2024). More nuanced research about types of caregiving is important to understand the specific ways in which we can support caregivers of people with dementia to mitigate negative outcomes to their health and well-being. On average caregivers of a person living with dementia provide 26 hours of care per week, are more likely

than other caregivers to be distressed, and in 2016 paid approximately 1.6 billion dollars out of pocket to cover costs associated with caring (Canadian Institute for Health Information, 2016).

Dementia is a progressive condition, and continual interactions with health and social care systems is not uncommon. Caregivers have an even bigger challenge caring in northwestern Ontario where they are facing an extreme shortage of both primary physicians and home care (Ontario Medical Association, 2021). A qualitative study in northern Ontario rural communities found that strong social connections in the community can create a “social safety net” and were beneficial to receiving informal support from community members in caring for someone with dementia (Wiersma & Denton, 2016). However, without strong preexisting relationships, fear of letting the community know you have dementia (stigma), or care needs that extend beyond what community members can offer can lessen the amount of support that is received (Wiersma & Denton, 2016). Despite the varying levels of community support in rural northern Ontario communities, DiGregorio et al. (2015) found that: “Unity and collective responsibility were part of the underlying rural culture within the communities” (p. 109). This could be an important asset to leverage to support both caregivers and people living with dementia in northwestern Ontario communities. However, strong community support, as evidenced, does not replace the need for formal health and social services.

Experiencing a dementia diagnosis as a caregiver

Caregivers are a crucial part of the dementia diagnosis process as they are an asset for both the person with dementia and the health and social care teams. Law et al. (2021) state that caregivers can be relied upon as a ‘natural resource’ within the healthcare system. Law et al. (2021) advocate for considering a caregiver’s role as a ‘care coordinator’ where the challenges they face navigating the healthcare system and bearing responsibility for care arrangements is

taken into consideration. Relying on caregivers as a resource in dementia care means respecting caregivers as members of a healthcare team, and their needs for managing their own health and well-being (Law et al., 2021).

Examples of things that can improve caregiver well-being include being able to come to terms with a dementia diagnosis, informal and formal supports, engaging in social and physical activities, and faith/religion (Branger et al., 2016; Hevink et al., 2024). Yates et al. (2021) found that caregivers felt disclosure of a diagnosis was important because it allowed them to plan ahead but they wanted more knowledge of what a diagnosis of dementia was going to look like in the future so they could prepare themselves for hardships as a caregiver. Lastly, the importance of the relationship between the caregiver and the person living with dementia is crucial to well-being as it can mediate the perceived identity change that has been shown to increase caregiver burden after a dementia diagnosis (Enright et al., 2020).

Dementia in northwestern Ontario

Living in northwestern Ontario adds another layer of complexity in the diagnostic experience for physicians, people living with dementia, and caregivers as it consists of metropolitan centres, rural and remote communities and First Nations Reserves. Northern Ontario makes up approximately 90% of the province's landmass and is home to 6% of its population (Ontario Medical Association, 2021). A map of northwestern Ontario below demonstrates the large geographic area where recruitment for this study took place (See Figure 1). Canadian census data from 2021 shows that 20.3% of the population in northwestern Ontario is over the age of 65 compared to 18.5% in Ontario as a whole (Statistics Canada, 2022; Statistics Canada, 2023). This is important because we know that the prevalence of dementia more than doubles every 5 years after the age of 65 (Canadian Institute for Health Information.,

n.d.). Having a greater percentage of adults over the age of 65 indicates a population of people more at risk of developing dementia – and thus more individuals will be in a position to experience the diagnosis process.

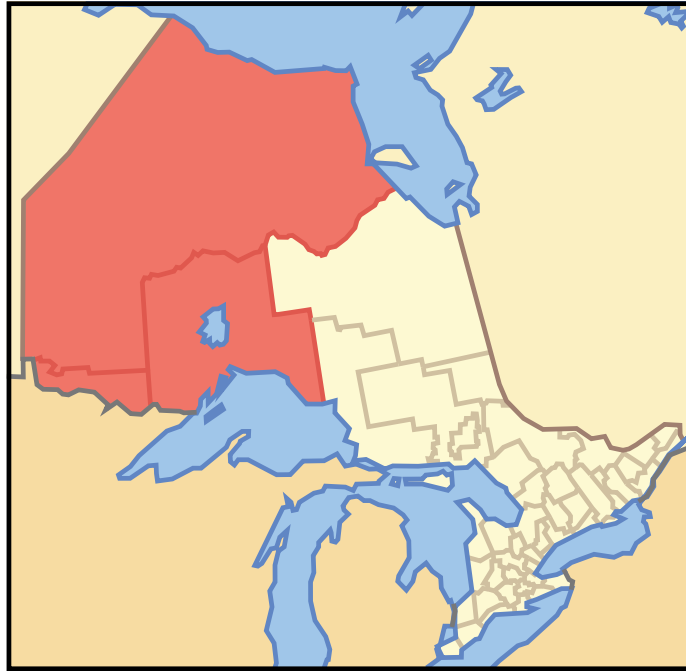


Figure 1: Map of northwestern Ontario

Northwestern Ontario is also struggling with unique healthcare system challenges and providing care in these regions. The Ontario Medical Association (2021) spoke about the challenges of the healthcare system in the region, saying: “The current system is plagued by physician shortages, long wait times, a serious backlog of services, inadequate mental health and addiction programs and insufficient home and community care among other problems” (p. 1). The state of the healthcare system in northern Ontario is adequately summed up by the Ontario Medical Association as “Save Rural and Northern Ontario” (2024). Residents of this region report poorer health outcomes, greater challenges accessing healthcare, and lower life expectancy than the rest of the province (Ontario Medical Association, 2024). Physician shortages in some northwestern Ontario communities are so severe that they have closed

hospitals resulting in an inability to take patients needing care. For example, in Red Lake, which is located approximately 6 hours northwest of Thunder Bay, patients were turned away and sent by ambulance to Dryden (Kitching, 2022), a two-and-a-half-hour drive away. As of 2023, the northwest region is looking to recruit more than 384 doctors, approximately 200 of which should be family physicians (Northern Ontario School of Medicine University, 2023). Countless calls to action have been put forward by physicians in the northwest, but the region is still failing to meet the basic care needs of these communities (Ontario Medical Association, 2021).

Knowing that there are severe physician shortages and a lack of home and community care, this thesis undertook a study exploring the experiences of physicians and caregivers involved in the diagnosis of dementia in northwestern Ontario. Presented in this chapter are only a few of many examples that illustrate the profound challenges experienced by healthcare providers in northwestern Ontario and the consequences to those who are seeking their help. If healthcare providers who work in these regions are struggling to meet basic healthcare needs, those with dementia and their caregivers will undoubtedly be affected when pursuing a diagnosis within a system that is fighting to keep its doors open.

Addressing the gaps

Despite the concerning state of the healthcare system in northwestern Ontario, people with dementia and their caregivers cannot be forgotten, nor should physicians be left without adequate support for their health and well-being. Ensuring that physicians feel confident and comfortable conveying resources and opportunities for continued care is essential to achieving good quality dementia care. Canada has been left out of a lot of this research, and the perspectives of physicians and caregivers of people living with dementia are not well

represented. Furthermore, little is representative of the challenges faced specifically in northwestern Ontario.

This research aims to address the gaps in diagnosis disclosure literature specifically within the healthcare system of northwestern Ontario. The goal of this research is to highlight the experiences of physicians and caregivers of people living with dementia who have experienced the diagnosis process so that we can better support physicians, those who will receive a diagnosis of dementia in the future, and their caregivers. As you enter into northwestern Ontario you will be greeted with a slogan ‘Superior by Nature’. But as this research is beginning to uncover, accessibility to healthcare is not something that is superior to the rest of Ontario. Telling the story of people who work and receive care in these regions will hopefully inspire change and raise awareness in the healthcare system and enable those who have chosen a career to help others do so in the best way possible. Careful consideration of what works in a remote and rural context will be essential to providing superior dementia care in northwestern Ontario.

Chapter 2: Designing the study

The following describes how the thesis has been organized. Chapter 1 included an introduction to the thesis topic and a review of the literature. Chapter 2 will describe the study design for the overall thesis research, including the methods and methodology.

Aims

Superior by nature?: Diagnosing dementia in northwestern Ontario had three aims:

- Exploring the experiences of the diagnosis process from the perspectives of caregivers of people living with dementia in northwestern Ontario;
- Exploring the experiences of the diagnosis process from the perspectives of physicians who diagnose dementia in people living in northwestern Ontario; and
- Exploring the challenges within the northwestern Ontario healthcare system and the perspectives of caregivers and physicians on the impact of the shortcomings.

The thesis also includes a knowledge mobilization resource in addition to the above-described aims that addresses key findings and highlights them in a more accessible format for lay audiences in the hopes that increased awareness could inspire change in dementia diagnosis processes in northwestern Ontario. The resource is to be shared as part of presentations to scientific and lay audiences. Development of this material is not traditional for a phenomenological study, but it was with that in mind that I decided I wanted to share the rich details of qualitative research outside of the expected academic publication formats. More details on this are included in Chapter 6: Knowledge Mobilization.

Methodology

Both receiving and disclosing a diagnosis of dementia is a unique experience shared among physicians and caregivers of people who have received a diagnosis. Specifically, the phenomena under study in this research are: 1) the experiences of caregivers of people receiving news of a progressive and life-limiting condition that will impact memory and functional abilities and; 2) the experiences of physicians who must tell someone this news. To understand how these groups of individuals experience this phenomenon, and what influences those experiences, a branch of interpretive phenomenology called existentialist phenomenology was chosen for this research.

To begin, phenomenology broadly: "...describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon. Phenomenologists focus on describing what all participants have in common as they experience a phenomenon..." (Creswell & Poth, 2018b). The purpose of phenomenological studies are to select a phenomenon to be explored (i.e., dementia diagnosis), select a group of people who have experienced this phenomena (i.e., purposefully sampling caregivers/physicians who have gone through the dementia diagnosis process), consider the subjectiveness of peoples' experiences (i.e., in interpretive forms of phenomenology), and develop findings that reflect the essence of the experience to explain why individuals have experienced and interpreted the phenomena the way that they have (Creswell & Poth, 2018b).

The specific form of phenomenology used in this thesis, existentialist, has its own defining features in addition to that characteristic of phenomenological studies more generally. Churchill (2022) describes existential phenomenology as: "...when one is seeking knowledge about what constitutes certain "kinds" of experiences, such as the various emotions....The

findings of such studies have implications for how we understand ourselves, as well as for psychological practice, because they yield general insights into the “lived meanings” of emotions, perceptions, and problematic behaviours (including their motivational contexts)” (p. 3) In this research, how people experienced (i.e. what emotions they had) about the diagnosis process were under study.

The choice to use existentialist phenomenology was both a decision that aligned with my own epistemological and ontological assumptions and the intended objectives of this research study. As a researcher, I align myself with an idealist ontology and an interpretive epistemology. An idealist ontology supports that there is influence from our lived experience that imparts upon our interpretation of research, and an interpretive epistemological assumption, meaning that I as a researcher cannot be objective about the findings because my own background plays a part in how I interpret this research (Giacomini, 2010). For these reasons, phenomenology supported both how my own lived experience impacted the research, as well as how the participants lived experience would impact their perceptions of a dementia diagnosis. For this reason, a positionality statement was written and included in this research (see section entitled: positionality statement).

To improve the diagnosis process, a deeper understanding of what makes it difficult to both receive a diagnosis of dementia and diagnose someone with dementia is necessary. It is not enough to explain the process and how it is carried out by physicians in a stepwise manner. Nor is it enough to explain how someone went about getting a diagnosis. Personal accounts of how the process impacted people emotionally, what they believe are shortcomings, and how they believe the process could be improved are all under consideration to provide contextual information specific to northwestern Ontario.

Consideration of the philosophies that have informed the creation of phenomenology are crucial to how researchers come to understand the phenomena under study (Giacomini, 2010). Starks and Brown Trinidad (2007) explain: “In phenomenology reality is comprehended through embodied experience. Through close examination of individual experiences, phenomenological analysts seek to capture the meaning and common features, or essences, of an experience or event” (p. 1374). The truth of an experience is something we can only know through embodied perception (Starks & Brown Trinidad, 2007) such as how the experience of dementia disclosure has impacted people differently based on their individual context (where they live, the healthcare system they are a part of, relationships etc.). This methodology was used to gain a more nuanced understanding of those who have experienced a dementia diagnosis alongside someone they care for and those who have experienced diagnosing someone with dementia in northwestern Ontario. These groups of people are not only sharing in the diagnosis process but receiving and giving care in a system that is struggling to meet the basic healthcare needs of their community.

Acknowledging the influence of people’s backgrounds (Given, 2008) and how the meaning of dementia is understood within the context of someone’s lived experience, supports the idea that health system challenges within the region could play a role in how people experience the diagnosis process. Peoples’ surroundings impact how they experience a certain phenomenon (Bourgeault et al., 2010) because it a part of their day-to-day existence.. This is particularly important to be cognizant of when layering on the experience of receiving a diagnosis or delivering a diagnosis of dementia within the context of a rural or remote healthcare system. These communities are facing challenges that are unique to their geographic area, and it will be important to acknowledge how this impacts the diagnosis experience.

A complementary aspect of interpretive forms of phenomenology is the disbelief in mind body dualism (Given, 2008). This rejection asserts that people's experiences are intrinsically linked to their social worlds, and that the mind and body are not separate from one another (Given, 2008). The concept of sentient beings links people together by their shared social meaning, skills, habits, and practices and when seen as shared make their experiences something that others can understand (Given, 2008). When applying this concept to research on the diagnosis experience, shared understandings about what makes the diagnosis process difficult or successful was brought out through the stories that caregivers and physicians told about their roles as part of the diagnosis process with someone who is being diagnosed with dementia. The shared nuances of these experiences are what helped tailor knowledge translation materials to be something targeted and meaningful to the world in which they existed.

Existentialist phenomenology

Existentialist phenomenology, situates people as active and creative subjects that create meaning from their experiences based on their social context (Thorpe & Holt, 2007). This rejects the notion of positivism and acknowledges that people and their social worlds are intertwined (Thorpe & Holt, 2007). Positivism has been conceptualized differently in health and social science research (e.g., positivism being akin to determinism, or specifically logical positivism) but more philosophically, positivism can be attributed to falsificationsim in that if we cannot prove a hypothesis is false than it must be true (Giacomini, 2010). This is a key component of phenomenology to explore, because the rejection of positivism emphasizes that the aim is not to establish fact in our research, but to explain what is true to the experience of participants within the context of a shared phenomenon. Jun (2011) describes social worlds as reflective of people's experiences, values, purposes, ideals, intentions, and relationships. It is understood that: "The

person has no existence apart from the social world, and that world has no existence apart from persons...” (p. 2). Thomas’s (2005) work demonstrated that the medical system views the human body as mechanistic but existentialist phenomenology can be utilized to learn more about the emotions behind people’s experiences. Challenging the separation of the mind and body within the healthcare system is something that can be applied to the interpretation of participant experiences and will be helpful to uncover if the diagnosis process is conducted in a way that values the integration of how people experience illness on an emotional level rather than just physical. The benefit of existentialism for this research is the ability to demonstrate the value in each person’s interpretation of their experience and how this can influence their actions (Thorpe & Holt, 2007).

Methods

Ethical considerations

This study was conducted in accordance with the University of Waterloo’s research ethics board. See (Appendix A & B) for information pertaining to the letter of consent.

Recruitment methods: Initial plan and participant groups

Recruitment strategies for this research were an ever-evolving process. The goal was to recruit 5-7 people who had received a diagnosis of dementia in northwestern Ontario and 5-7 physicians who practiced in northwestern Ontario. Purposeful and snowball sampling methods were utilized to identify recruitment targets and expand upon them with the knowledge and assistance of people who had agreed to help recruit. Initial recruitment consisted of emails, networking, and dissemination of hard copy posters. Organizations related to people living with dementia, or physicians were located through previous knowledge of this area based on my past

research, connecting with people in related organizations such as the Ontario Health Network, and online directories (i.e., Northwest Healthline). The initial target samples were the following:

People Living with Dementia (n=5-7)

- Have been diagnosed with dementia between 1-5 years
- Received their diagnosis in northwestern Ontario
- Are currently living in northwestern Ontario
- Speak English

Physicians (n=5-7)

*There was the potential to include other healthcare professionals (i.e., nurse practitioners) who may be a part of the diagnosis process in northwestern Ontario. This was an acknowledgment of the lack of physicians and potential team-based approaches to healthcare delivery in northwestern Ontario.

With little uptake after approximately seven months, the recruitment strategy needed to be enhanced and ethics was amended to include digital networking through LinkedIn. In addition, I leveraged even more personal connections to reach out on my behalf in hopes that it would inspire more uptake of recruitment materials. Posters went up on the Alzheimer Society of Canada web pages, thesis committee members assisted in identifying connections and joining in on emails to lend their support. Organizations related to health, elder/dementia care, and education/research who agreed to assist disseminated posters on my behalf to their online networks or in person at their organizations. Some of the larger organizations who helped to disseminate recruitment materials included the Canadian Mental Health Association, Centre for Education and Research on Aging & Health, Age Friendly, Alzheimer Societies of Canada & Thunder Bay, Schlegel-UW Research Institute for Aging, EPLED (Engagement of People with

Lived Experience of Dementia), Society of Rural Physicians of Canada, and the Northern Ontario School of Medicine University. In addition, smaller organizations, such as clinics, hospitals, and senior's day programs, were contacted and some shared recruitment materials within their personal environment.

Local news outlets were also contacted, and one reporter agreed to interview me and post about my research (See Appendix E) and recruitment in the local newspaper. With the newspaper interview, it was also up for airing on the local radio station. I also followed up and shared the interview on LinkedIn. To reach even more people, I made another REB amendment to broaden social media use and started a Facebook account to post the posters and tag streams related to health, aging, dementia, physicians, and healthcare. In response to the news article, I had the first response from people living with dementia. Three people contacted me about having a family member with dementia participate. Unfortunately, one was unable to proceed due to a change in health, one decided they were no longer comfortable sharing their story, and one caregiver requested to speak on their family members' behalf due to communication difficulty. A decision was made to not include that person as it would have only been an interview with the caregiver, and there would be no way to hear firsthand from the person with dementia.

There were very few obvious organizations to assist in recruiting physicians outside the medical school and clinics, and many that I reached out to did not agree or disagree to sharing my poster. In these cases, where no responses were received, I continued to email them or other people within the same organization. This was successful in a few cases, and some major healthcare organizations did assist me in disseminating posters. After approximately 10 months trying to recruit for people living with dementia and physicians, I decided to submit another REB amendment to include caregivers due to lack of uptake for people living with dementia. I did not

stop trying to recruit those living with dementia, but by including caregivers, I at least would have a perspective of the experience of hearing a diagnosis vs giving one if I could get caregivers who were a part of the diagnosis process.

Overcoming challenges with participant recruitment

Obtaining participants was the biggest challenge for this research. I knew from the start that recruiting people in the north would be difficult based on previous research that I had conducted here. However, I did not anticipate the difficulties I encountered. Initial recruitment started in October of 2023 and did not end until December 31, 2024, and required constant amendments and pivots in objectives to obtain sample sizes. Barriers to recruitment affecting all samples were general uptake and response to requests to display posters. Very few organizations responded to emails about circulating posters through their organization. However, I found out quite early on that it did not necessarily mean that they had not shared the poster. For example, my first participant was a physician, and I did not know where they came from until the time of the interview. It turned out they received a poster from a clinic that had not responded to my recruitment request but had clearly shared the poster. This made it particularly challenging to know how much uptake I was getting if organizations were not responding to either agree or disagree to disseminate posters. I just had to trust and hope that some of them did and keep sending follow up emails.

Besides general response and uptake of recruitment efforts, each participant group had their own challenges. These will be explained further in subsequent sections. Due to the inability to recruit people living with dementia, the biggest pivot in objectives was to amend the ethics application to include caregivers of people living with dementia who were a part of the diagnosis

process with whom they cared for. The goal was still to have a participant group that could speak to ‘receiving’ a diagnosis, not just the perspectives of people who gave the diagnosis. In addition, slight wording changes were made to the inclusion criteria for physicians to ‘diagnose people from northwestern Ontario’ so that I could pursue recruiting physicians outside the region for those who choose to travel to Manitoba either out of convenience or necessity. This amendment was made based on communication with a community partner who described some experiences of people in the far north end of the region who chose to travel to Manitoba vs Thunder Bay for a diagnosis because it was closer to home. The final recruitment targets were amended to:

Caregivers (n=5-7): Inclusion/exclusion criteria

- Cared for a person living with dementia that is/was a resident of northwestern Ontario at the time of diagnosis
- Are currently, or were their caregiver within the past 5 years
- Was part of the diagnosis process along with the person living with dementia
- Speaks English

Physicians (n=5-7): Inclusion/exclusion criteria

- Diagnose residents of northwestern Ontario with dementia
- Have experience diagnosing people with dementia within their practice
- Have practiced for a minimum of 1 year
- Speak English

Process of recruiting physicians

The biggest challenge I had with physician recruitment was time. Contacting a physician who was willing to participate was just the first hurdle. This was followed by a lengthy process of having them review the letter of information and consent, confirm their desire to participate,

and set up a time for an interview. Verbal consent at the time of the interview was one less step and piece of paperwork that helped shorten the time it took to get them to an interview, but the fastest time from recruitment to interview was a little over two months. The longest was five months. I had planned for interviews of 30-60 minutes with physicians given their busy schedules, but I had not anticipated the length of time it would take to complete recruitment, and the time from recruitment to interview, and this affected my overall timeline.

Communication with physicians generally was difficult. The fastest way to get communication through to physicians was to find someone within an organization that knew them and have that person initiate or follow up via email if I was not getting a response. For anyone in the future trying to recruit physicians, I would look to administrators, program coordinators, medical clerks etc. Anecdotally, I learned from one of my contacts that it was not a lack of desire to participate that was impeding the conversations, I was simply being lost in their inbox because my name was not sticking out to them as recognizable. This is where having someone with a pre-existing relationship with the physicians- a recognizable name- became the best way to get responses back.

Amending to expand physician recruitment

General amendments I made along the way to increase the likelihood of reaching physicians included expanding recruitment to telehealth physicians, as well as expanding to physicians outside of Ontario. Contact with community organizations provided more nuanced information about the process that residents of more remote communities in the northwest region went through to obtain a diagnosis. There are no geriatric specialists in northwestern Ontario outside of Thunder Bay, and those who required more testing or presented with a more complex case either had to be referred and travel to Thunder Bay, access a telehealth program, or travel to

Winnipeg, Manitoba. Often travel was not the most convenient, and a lot of people utilized telehealth, specifically the Ontario Telemedicine Network. Therefore, amendments were made to the recruitment criteria so that telehealth physicians who were not based in northwestern Ontario could participate, as well as physicians based in Winnipeg who provided diagnoses to residents of northwestern Ontario.

Pivoting to new target population: People living with dementia to caregivers

The second participant group was intended to encompass people living with dementia. Unfortunately, after approximately ten months of recruitment only two potential participants expressed interest, and one whose caregiver wished to tell the story on their loved one's behalf. Of the two people with dementia who wanted to participate on their own, one had a health change and could no longer participate and the other decided they were not comfortable participating any longer. Due to lack of uptake, a decision was made to change the objectives and amend the research to include the recruitment of caregivers. Recruitment of people with dementia never ended, but if I were unable to get anyone, at least I could include the caregivers and have a perspective of someone receiving a diagnosis and not just perspectives from healthcare workers who gave a diagnosis. Upon completion of this study, no people with dementia were successfully recruited.

The inclusion of caregivers became the largest amendment and required a pivot in research objectives. Upon receiving ethics approval, it proved much easier to recruit this group of individuals. It only took a few weeks to complete the sample size after the ethics amendment went through and another couple of weeks to have the interviews completed. Caregivers were able to provide valuable insight on the experience of diagnosis within the healthcare system as well as the experience with continued care afterwards, which became invaluable to this research

and uncovered experiences that are unique to the northwest region. In addition, it fit the underlying sentiment of this research of a ‘diagnosis process’ in that it is not a one-time event when a physician verbally makes the diagnosis but also includes the ongoing care and navigation of the healthcare system that coincides with a progressive condition.

Final recruitment sample

This research took place in northwestern Ontario, Canada. Recruitment targeted Thunder Bay and surrounding communities (e.g. Dryden, Kenora, Atikokan, Fort Frances, Geraldton, Terrace Bay, Nipigon etc.) to get diverse experiences of: 1) caregivers of people who are living with dementia and 2) physicians who diagnose residents of northwestern Ontario with dementia. The researcher aimed to recruit a diverse sample of participants and consider the representation of various sexual orientations, ethnicities, cultures, and genders.

Recruitment for the first participant group targeted caregivers of people living with dementia in remote and rural parts of northwestern Ontario. Purposeful sampling (Creswell and Poth, 2018a) focussed on dementia and Alzheimer specific organizations that support people living with dementia and/or caregivers such as the Alzheimer Society and the Canadian Mental Health Association, as well as smaller community-based organizations that provide services to people living with dementia and caregivers such as recreation and leisure programs. Recruitment also targeted the public via flyers, social media (to target online caregiver specific programs or advocacy organizations) and news outlets. Types of materials for recruitment included both physical and electronic documents to reach the most amount of people. Recruitment of these individuals largely relied on the ability to find recruitment partners within these communities who were able to assist the researcher in recruiting.

***It is important to note that the caregivers of people living with dementia in this research were not recruited through the physicians involved in this study, they were recruited as two separate groups of individuals.**

Recruitment for the second participant group targeted physicians (family physicians, geriatricians, geriatric psychiatrists) or other healthcare professionals who had experience diagnosing people living with dementia in northwestern Ontario (e.g., nurse practitioners). Purposeful sampling (Creswell and Poth, 2018a) was used in targeted clinics, hospitals, and specialist centers to find physicians who diagnose people with dementia in their practice. Types of materials for recruitment encompassed both physical and electronic documents to reach the most amount of people. The local university and medical school were also approached about partnering with the researcher to disseminate recruitment materials to physicians working in northwestern Ontario. Physicians themselves were not asked to recruit caregivers from their own patient pool or practices. In such small communities, there has to be consideration for the influence a person with status (physician/healthcare provider) could have over a patient when asking them to participate in a study. We did not want to introduce undue influence over whether caregivers chose to participate, or not, in this research.

Study characteristics and participant demographics

Caregivers

Research question: What are the experiences of caregivers who attended the dementia diagnosis process in northwestern Ontario?

The interview covered topics of the dementia diagnosis as well as the role the caregiver played during the process. Further probes were used to elicit how each experience described by the participant made them feel, to further understand the impact of the phenomena in this study.

Research questions broadly included the following topics (for full interview guide see appendix D):

- The experience being a part of a dementia diagnosis
- The caregiver’s role in the diagnosis process
- How they as a caregiver felt about the diagnosis
- The support that caregivers felt they needed
- Challenges and benefits of the diagnosis
- Advice caregivers would give to physicians

Four caregivers participated in this part of the study. They ranged in age from 38 to 58 years, all were female, and only one of four was retired. Three of the caregivers were providing care for a parent (two for mothers, and one for a father) and one was providing care for a grandmother. The regions that they were recruited from in northwestern Ontario were from both larger and more remote areas. Interviews lasted from 29 to 88 minutes in length, averaging 37 minutes. (see Table 1 below)

Table 1: Demographic data of caregivers (N=4)

Ages	Sex	Ethnicities	Work
~38-58 years	Female=4	Metis=1 Caucasian=3	Seasonal=1 Retired=1 Work full time=2

*One caregiver’s demographics had missing information

Physicians

Research Question (physicians): What are the experiences of physicians who diagnose northwestern Ontario residents with dementia?

Broadly, research questions explored the following (see appendix D for full interview guide):

- An example of how a dementia diagnosis has been conducted
- The emotions that they experience during the diagnosis process
- Where they learned how to diagnose dementia
- Experiences practicing in a rural/remote community
- Emotional impact (on themselves) of a dementia diagnosis
- Advice they would pass on to other physicians diagnosing dementia

Three specialists and two family physicians took part in this study. The participating physicians had practiced medicine for between 13-48 years. Three were female, two were male and their ages ranged from 40-71 years old. Two of these physicians provided care primarily to patients from more highly populated areas in the region, and three of the physicians provided care to more rural and remote populations. Interviews lasted 24 to 50 minutes in length, averaging 34 minutes.

Table 1: Demographic data for Physician Participants (N=5)

Ages	Sex	Years in practice	Type of medicine	Ethnicity
40-71	Female=3	13-48 years	Specialist=3	Caucasian=4
years	Male=2		Family physicians=2	Black/Caucasian=1

Physicians and caregivers

Research Question: Are there similarities or differences between the experiences of the diagnosis process from the perspectives of caregivers and physicians in northwestern Ontario in regards to challenges/successes?

The final findings chapter combines the two studies on the experiences of physicians and caregivers who are a part of the dementia diagnosis process in northwestern Ontario. While important to understand the phenomena of dementia diagnosis from each group's perspective, they are intrinsically interconnected; one cannot occur in absence of the other. Therefore, this section explores the diagnosis experiences from both caregivers and physicians' perspectives.

Interview process

Interviews took place virtually over Zoom due to the large geographic region being sampled. The interview guide for physicians (see Appendix D) was developed based on both the recurrent themes found within dementia diagnosis literature, as well as questions that highlighted the absent information on northwestern Ontario diagnosis practices (e.g., the emotional impact of diagnosis processes on physicians, system fragmentation, and lack of physicians in the region). The interview guide for caregivers (see Appendix D) was also based on dementia diagnosis literature, as well as questions that highlighted the absent information on northwestern Ontario (e.g., experiences of caregivers in this region within a unique healthcare system that reconciles challenges with professional shortages, large geographic spread, and limited community health/social supports). Questions were open ended and encouraged participants to respond in a storied fashion about how they have experienced the diagnosis process. Both caregivers of people living with dementia and physicians who took part in this research were asked to participate in one-on-one semi-structured interviews. Each interview was approximately 30-60 minutes in length. Interview guides were sent to participants in advance of the scheduled

interview so that they had time to read the questions and reflect on them if they wanted to. This provided the best opportunity to get in depth answers, which aligned with the goals of a phenomenological study that seeks to understand their experiences situated within their own social worlds. It also helped to encourage them to speak freely with the researcher without fear of other colleagues or caregivers hearing their stories.

Interviews of caregivers of people living with dementia and physicians were audio recorded through the Zoom platform and a backup handheld recorder and then transcribed using OtterAI. Zoom automatically records a combination audio/video recording as well as just an audio recording. Participants were made aware of this in the information letter and knew that only the audio recording would be kept. After each interview was complete, the researcher deleted the audio/video recording and just kept the audio file for transcription.

Strategies to enhance rigour

Before the interviews were conducted or recruitment took place, the researcher engaged in a reflexive activity to write a positionality statement (see section below entitled positionality statement). This statement covered the background and assumptions that the researcher brings to this research. Reflection was ongoing and documented in a journal as the research progressed and is reflected upon in the final chapters of this thesis. Topics for continued reflection included reasons for conducting this work, prior work or experience in this field, assumptions about findings or how the study could turn out, as well as epistemological and ontological assumptions. These reflections were considered throughout the analysis of the findings of this research. Throughout the interview process, the researcher also utilized the bottom of interview guides to record thoughts, ideas, and emerging themes after each interview. This aided in reliability and credibility of findings via constant reflection. Interpretive phenomenological methodologies

assert that one cannot be free of external influence, and this includes the researcher. By reflecting on each interview and actively practicing reflexivity, the product of the analysis includes how the researcher's own position impacted this study. The goal was not to record reflections so that they could be separated from participants' experiences, but an acknowledgement that the researcher themselves exists in a social world that they too cannot be free of. Documenting what that social world consists of and being transparent about those experiences will allow the readers of this research to see how intrinsically connected our social worlds are to our own stories and the stories we tell about others.

Analysis

Analysis was conducted concurrently throughout the interview process and continued thereafter. After each interview was over, the researcher reflected on the interview, wrote down any themes or ideas that stood out and made notes at the bottom of each interview guide used. Once more interviews began, notes started to contain a reflective component making comparisons or contrasting ideas, themes, or experiences between participants. After all the caregiver and physician interviews were complete, the researcher uploaded audio files to OtterAI for transcription. The researcher listened to the audio files within the OtterAi platform and compared it with the transcription for accuracy and corrected mistakes. Caregiver and physician transcripts were analyzed as two separate groups, and then re-analyzed as one group for research question #3 to see if there were any themes that were consistent between the groups.

The decision to analyze caregivers and physicians together was made after reading through the interview transcripts as separate entities. Both groups had very unique experiences to share about dementia diagnosis, but there was certainly agreement on things such as system barriers and desire to care for people living with dementia the best way possible. Transcripts and

notes that contained the researcher's memos were analyzed using a mix of hand coding and NVivo 12 software. Thematic analysis (Saldana, 2013) was used to categorize the data into themes. Thematic analysis allowed categories (or themes) to be identified from data rather than defining them before the analysis began (Saldana, 2013). It required the researcher to reflect on participant's meaning, interrogate how themes related to one another, and served as an interpretation of the data (Saldana, 2013). This analytic technique, like existentialist phenomenology, is interpretive and allows for the researcher to find shared meanings within unique accounts of personal experience and exemplify them in a way that makes them accessible for readers of the research. Thematic analysis also allowed for the researcher to include notes and reflections with the transcripts as part of the analysis. Existentialist phenomenology supports the idea that people's social context (their own biases, history, etc.) cannot be separated from how they interpret their experiences or ascribe meaning to a phenomenon. This applies to the researcher as well and thus the reflections and ideas that were captured throughout the interview process were all part of how the researcher was starting to find meaning and interpret the experiences of the participants.

Initial coding began in a traditional line by line manner, but it was quickly determined that this was too reductionistic, and the codes were too narrow and losing the nuance of people's stories which the researcher had already reflected on and written notes about in journaling exercises after each interview took place. It was then decided to take the data from NVivo and try hand coding. This was a much more successful method of coding for this thesis. It allowed the stories to be analyzed in bigger chunks, for notes and small summaries to be written in the margins and arrows and scribbles making connections between paragraphs and stories throughout the text. The research was dense and picking it apart line by line was reducing

peoples' stories to short and precise codes that did not capture their experiences. For example, the context in peoples' stories and how their lived experience had influenced how the dementia diagnosis process impacted them became lost in themes through my own interpretation.

The second stage of coding was developing mind maps. Mind maps can help visually represent experiences and explore meaning (Wheeldon & Åhlberg, 2012) and were useful as a supplement to traditional coding for this research. Wheeldon & Åhlberg (2012) stated that mind maps are used: "...as a means to gather unique, personal, and user-generated data to explore perceived relationships and unfiltered associations (p. 7). For this research, it was through the use of mind maps that the researcher was able to generate a more in-depth analysis of the interconnectedness of themes that exemplified the nuanced experiences of the dementia diagnosis process.

Each theme from hand coding was placed in large text within a border. From there, arrows to smaller themes with outcomes and consequences between themes helped to visualize the interconnectedness of themes, as well as similarities between and among groups (physicians and caregivers). Being able to expand beyond larger themes by writing contextual information on the connecting arrows allowed for a more story-like depiction of a traditional mind map that outlines major themes. For the purposes of fulfilling the tenets of existentialist phenomenology, I was also very conscious of the way that my interpretations of the phenomena under study, as well as the participants' interpretation of the phenomenon coincided. The process of mind mapping helped me keep contextual information from the participants at the forefront of analysis, not just my own interpretations of the data.

Mind maps can be explored using the links below. All the themes are located within boxes, and the presentation allows one to zoom in and out to follow the lines that connect the themes and describe the phenomenon in greater detail.

Caregivers mind map:

https://www.canva.com/design/DAGYR1nLm3E/faUD2_iBFaiyFIRYxZJBPA/edit?utm_content=DAGYR1nLm3E&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton

Physician mind map:

https://www.canva.com/design/DAGYW-XdOMM/zHKH7fubgXacQJJ50ZoHcw/edit?utm_content=DAGYW-XdOMM&utm_campaign=designshare&utm_medium=link2&utm_source=sharebutton

Upon completion of the mind maps, two transcripts were shared with the supervising researcher to be coded. A meeting was then held to review our codes and themes for similarities and discrepancies. Mind maps with more detailed concepts were also shared to ensure they captured key themes that both researchers found within the transcripts.

Anonymization of the data collected extended beyond the initial cleaning of the transcripts for obvious identifiers like places and names. Personal identifying information was removed from the transcripts and pseudonyms were used to distinguish participants. Careful consideration about what is ‘identifiable’ was essential to maintain the anonymity of the participants, as this research took place in communities where the populations were quite small, and people’s stories contained information that could make them identifiable. As a result, demographic data were grouped together in a table and not associated with pseudonyms (and thus the quotes included in the thesis) to further ensure that anonymity was maintained.

Additional measures to protect anonymity of participants included being careful not give too much personal detail in the context of the analysis and the exclusion of some quotes or stories that were too personal and could lead to a particular person.

Positionality statement-Written prior to when research commenced

This research is being approached with both a personal and an academic background related to dementia. My first experience with dementia was with my grandfather during my teenage and early adult life. When I first went to university, I wanted to learn more about the biological processes that cause neurodegenerative diseases, and pursued courses that I believed would help me understand my experience watching him change as the disease progressed. I have to admit, I did not find what I was searching for, and I did not walk away with any more understanding of him and what he had gone through. After my undergraduate degree I still wanted to pursue research in dementia and ended up working with a supervisor who looked at dementia very differently than I had. Where I sought answers in understanding dementia as a biological process, she sought to understand the people who had dementia. This fundamentally shifted the way I approached research as I became less concerned with why they got dementia and how I could work with people to improve the way they lived with dementia.

During my master's I lived and attended school in Thunder Bay, Ontario and still call this region home. The people living with dementia that I worked with and were part of my masters research were residents of northwestern Ontario as well. Through various contract jobs as a research assistant and living here myself, I noticed how different it was compared to living in southern Ontario (where I am from originally). The healthcare system and challenges that it faced had impacts on people living with dementia. There was a lack of information about these experiences, and often northern Ontario seemed forgotten. When searching for solutions to

problems experienced within our healthcare system, we often had to look to southern Ontario practices and try to adapt them based on our knowledge of how the healthcare systems functioned here. I would often find myself getting excited when I heard someone speak about doing research in northern Ontario or came across a published article, only to be disappointed that 'northern' meant North Bay or Sault St. Marie (approximately 13 and 8 hours south of Thunder Bay, respectively). Although still important research contributions, I could not help but feel like our northwest region had been forgotten, and I knew that what was being experienced here was different and worthy of understanding. For these reasons, I chose to pursue dementia research in my PhD and dedicate that work specifically to those who are living with dementia and caring for people with dementia in northwestern Ontario communities.

Organization of the thesis

The findings of this research are presented in three individual chapters (Chapters 3-5), with each of the three chapters focused on a specific research aim. The titles of these chapters are: 1) A precarious attachment: Caregivers experiences of a dementia diagnosis in northwestern Ontario's healthcare system; 2) Shouldering the weight of the system: Physicians experiences diagnosing dementia in northwestern Ontario; and 3) Diagnosing dementia in northwestern Ontario: A case of acute insufficiency, that come together to tell a story about the phenomena under study; caregiver and physician experiences of dementia diagnoses in northwestern Ontario. Chapter 6 covers the knowledge mobilization process undertaken to transform results from a traditionally qualitative methodology into something more accessible and condensed to share with broader audiences. Chapter 7 is the discussion section for the three findings chapters, including implications, strengths and limitations, and final researcher reflections. The thesis concludes in Chapter 8.

Chapter 3: A precarious attachment: Caregivers' experiences of a dementia diagnosis in northwestern Ontario healthcare systems

Introduction

There are three main themes in this chapter. Firstly, “*at least we knew what was happening*”: *Impact of a dementia diagnosis*, which describes the initial phases of noticing changes in the person they care for and the process towards obtaining a diagnosis. This is where their relationships with healthcare professionals began. It also describes the emotions that caregivers experienced when a diagnosis was made. Next, *Communication shouldn't be a one-way street* that describes the importance and value of strong communication between physicians and caregivers. Initial benefits of good communication were being able to elicit critical information about the person with dementia's personal and medical history along with changes that caregivers noticed that deviated from their normal baseline. This information was crucial to physicians in being able to diagnose dementia. However, communication greatly affected ongoing care, and ultimately their relationship with physicians, as caregivers fought to advocate for support and services that would provide the best quality of care for the person with dementia. Lastly, “*I get absolutely no support from the medical teams*”: *Incompatibility of resources and supports*. This theme described the many experiences of services and supports that were incompatible with the needs of caregivers and the people with dementia they cared for ultimately, causing emotional distress among caregivers.

The graphic below illustrates the structure of themes in this chapter. Blue boxes contain the main themes, and sub themes are represented as bulleted points below the main theme they are associated with.

"At least we knew what was happening": Impact of a dementia diagnosis

Communication Shouldn't be a one way street

"...I get absolutely no support from the medical teams": Incompatibility of resources and support

- Consequences of caring alone

Findings

In hearing the stories of caregivers of people diagnosed with dementia in northwestern Ontario, it seemed that when relationships with healthcare providers were strained, it took a toll on caregivers emotionally. This section begins in the same place where caregivers and those diagnosed began; a move towards a diagnosis when changes in the person they cared for became evident.

"At least we knew what was happening": Impact of a dementia diagnosis

A diagnosis of dementia was often no surprise to the caregivers in this study as they could see the changes in their loved ones. Initiating a diagnosis was done out of concern for the symptoms and changes that the person they cared for was experiencing and was approached with the hope that they would receive help from physicians to understand what was going on.

This was the experience of the caregiver described below. She was not surprised when her mother was diagnosed with dementia because she had noticed that she was struggling with

activities of daily living. She could no longer trust that her mother was taking care of basic personal needs.

“Not shocked because it was, it was coming. You know, not being able to make her own breakfast anymore, and supper.... I realized when I went in the bathroom with her when she was brushing her teeth, she didn't know how to brush her teeth anymore” CPI

Noticing that her mother could no longer complete daily tasks as she once did was an obvious sign that things were changing. The idea that she was struggling with her memory and daily functioning, ultimately culminating in a diagnosis of dementia, came as no shock to this caregiver. All the caregivers in this study were aware that something was wrong with the person they cared for, and medical intervention was needed to determine the cause. One caregiver described the diagnosis as a relief because it was an opportunity to get her father some help:

“Like, relief, lots of relief, because we knew, like, you know something's wrong. So, you're like, okay, this poor man is suffering” CP4

Additionally, a diagnosis was not just an opportunity to obtain immediate help with some of the challenges the person was facing, but an ability to prepare for the future. One caregiver described it as a relief because she could anticipate the changes as the condition progressed. She knew that her grandmother's dementia would advance and felt that she could prepare herself for those changes.

“When I heard the news, it was no surprise to me.... it was just overwhelming relief. And then knowing okay, so she's at this point now. Now I can anticipate that this is what the changes in her are going to be in the future as well. So, then it was just kind of like, okay, so we know now, and we can kind of work with it. So, it's just kind of relaxation, and then just, yeah.... I don't think if I...[had] the background that I have, I probably would have freaked out a little bit more, you know?... But it's so natural, to just be like, alright, we need to put these plans in place now, because if we don't get her into the routine now, it's gonna be a lot harder in the future” CP3

This caregiver's previous career gave her knowledge of dementia that aided in her “*relaxation*” and confidence so that she could plan and start a routine that worked for her grandmother.

Previous knowledge or experience of dementia is not something everyone will have, but for the two in this study who did, they agreed that their background was an asset. Seeing worrisome changes in a person's behaviour or abilities can cause concern for several reasons. There are many more conditions that can cause similar symptoms, and sometimes knowing it was dementia came as a relief because it ruled out other causes that could pose significant risks to a person's health.

“Well, at least we knew what was happening, right? Like, it wasn't an aneurysm, it wasn't a brain function, like, well of as far as, like, an injury, you know, taking the wrong meds” CP2

A diagnosis gave the opportunity to move forward, but it did not mean that it was not an emotional time. There were concerns for the person with dementia, including fear, sadness, and grief that could coincide with the relief they felt knowing what was causing the changes they

witnessed in the person they cared for. Caregivers spoke about the emotions that came along with a diagnosis and what it meant for them and their families.

For one caregiver, a diagnosis of dementia caused her to mourn what she perceived as an inevitable change in her mother's identity as the family matriarch.

“Fear for her, sadness for her, because, if there was anything, you know, she was our cheerleader.... she was the organizer of the family, right? She was the one that brought everybody together and made plans for all the holidays. She was the one that cooked everything.... and this was all going to go away for her. That's how she belonged in the family, to take that away from her, that sense of belonging and that feeling of I'm needed, I'm wanted was going to go away from her. And she recognized that.... It's just she knew...you could see how painful it was for her to see herself as a burden” CP2

This caregiver was saddened and empathetic towards her mother having to relinquish her role within the family as her condition progressed. For herself as a caregiver, the diagnosis became synonymous with a loss of control. She felt that since her mother's diagnosis she had been unable to fulfill her mother's wishes and provide her with what she wanted. For her, the transition into the healthcare system was very distressing. Not only did she feel that her mother's place within their family was transitioning, but her place in society was as well.

“So had I had my choice I never would have had a diagnosis, we'd have more control in our lives. I would have hid it. If I would have known that this is how it was going to progress, and

this is how she was going to be treated, and this is where it would end up. Her and I would have went to the cabin and stayed out there” CP2

Regret over obtaining a diagnosis stemmed from a loss of autonomy, respect and rights afforded to her mother. This caregiver felt she and her mother would have been better off to have hidden the diagnosis than enter a healthcare system that she felt didn't work to the benefit of her mother's wishes. The diagnosis of dementia was just the beginning. The ability to move on and live well necessitated the ongoing care and support from health and social care systems. That is why the diagnosis process was conceptualized in this research as not just a one-time event when the diagnosis is made but included the ongoing care and support that was required for people with dementia and their caregivers to live well.

For all caregivers, the diagnosis was an emotional time. There was a sense of relief from an understanding of what was going on, but also mixed emotions related to changes in their loved ones and navigating new caring roles.

Communication shouldn't be a one-way street

Communication between healthcare providers and caregivers is essential to having a strong relationship. It allows caregivers to share wishes and values for care, identify where they need more assistance, and give important health and personal information of the person they care for to the healthcare provider that can assist in the diagnosis. However, not all caregivers feel as though they are listened to. This lack of communication can make diagnosis and ongoing care decisions difficult.

After feeling unheard and like she was unable to obtain the support that she needed from healthcare providers, this caregiver saw some hope in having a social worker present during

upcoming conversations with the medical team caring for her mother. Unfortunately, she felt greatly let down when she received no backup and was just as alone in advocating for her mother as she had been up until this point.

“...the social worker never even opened their mouth during the meeting to help me. This doctor said that I was incompetent and that she should be able to go home, and that's my problem, and that there's money out there for this. I wasn't after money. I was after safety, right?” CP2

This caregiver felt that the knowledge of her mother was being dismissed, and more shockingly her intentions towards her mother's care were being questioned. She hoped that an appointed social worker would have been on her side and helped her advocate within a medical setting; a medical setting that, arguably, would be new and unknown to most people going through a diagnosis of dementia. This caregiver felt abandoned and like nobody was supporting her. She wanted a strong relationship with the healthcare team, but instead she felt like they were on two different sides.

Similarly, another caregiver felt passionately about the knowledge of her loved one's condition and knew that something more complex than a typical dementia diagnosis was going on. Disagreeing with a diagnosis or wanting a second opinion can be a challenging position to be in. In this case, she felt she needed to speak up and share why she felt that the diagnosis was not aligned with what her and her family were experiencing with their father on a daily basis. Communicating the wishes of their family to seek a second opinion was a difficult conversation to have with the diagnosing physicians, but they knew it had to be done for the sake of their loved one's care.

“...sometimes you have to question these things, especially if you feel like you're not being listened to. So, I think I was just more tenacious at really pushing the issue in an appropriate and professional way that...this is what we're telling you, and you're not hearing us. So, it was frustrating, for sure...” CP4

This caregiver balanced her relationship with the diagnosing physician through intricate conflict resolution so not to create negative feelings towards her, her family, or father in future interactions. This seemed to be a very delicate situation trying to navigate her way through a professional environment with the concern of maintaining a positive relationship with those responsible for the care of your loved one.

“...so, we kind of channel that more into...being willful, right? We were like, okay, we're going to get something done.... we'll do what we have to do, even if we have to go somewhere else to get a referral. We tried all the appropriate channels, it's not like we were trying to skip over people and act like we knew better, but they just weren't listening” CP4

It was never their intention to make the physician feel incompetent or like they ‘knew better’ but she believed the information she had about her father was invaluable to his diagnosis and needed to be heard and taken seriously. Fostering a collaborative environment where caregivers and physicians can work together to achieve the best outcomes possible requires good communication. Listening and receiving the knowledge that a caregiver can provide is one way

to strengthen this relationship. This will ensure that caregivers and people living with dementia are able to communicate their values and wishes for care.

Knowledge of a person with dementia's history can be crucial to identifying what health and social care options are of most importance to them and their family. When trying to express to a physician that her mother was an avid walker and cyclist, she felt dismissed when the physician told her that it was not an appropriate form of physical activity. Their relationship with this physician was damaged and care advice was sought elsewhere.

"...it was funny because he asked if mom got out. I said, 'Yeah, she gets out all the time because we go for walks all the time, [Dr. Said] 'while walking isn't an exercise.' And I thought, are you kidding me? [Dr. Said] 'You got to do weightlifting and things like that.' And I thought, for somebody who wasn't 79 yet, maybe 76 or something like that, she's not going to be lifting any kind of weights. She loves to walk. She rode her bike all her life because she never drove. But to say that walking isn't an exercise, I just I don't like this guy.... And when mom got out of that meeting with him... 'I said, Mom, you want to come back to this guy? I don't like him'... [mother responded] 'I didn't like him either'. There was just something kind of arrogant about him" CPI

Caregivers wished to be heard and work alongside physicians to care for the person with dementia. They all believed that they had valuable knowledge of their loved ones and for those who felt dismissed it only hurt their relationships with healthcare professionals.

Examples of positive relationships with physicians exemplified a partnership and ability to work together to provide the best care for the person with dementia. Knowing that the diagnosing physician was going to continue to be there for support and guidance, providing

resources and materials to access support, were all ways that physicians strengthened bonds with caregivers.

“[The physician] eased me because I knew he was there for me, for us, right? We're not alone in this, he's there. He knows this, all about this condition... So, for me, I don't know if mom... she could have cared less. In the office, she was just wanting to go home. But it eased my mind, because I knew I had this guy here. And, you know, if you need anything, anything changes, just give us a call. You know that sort of just helps with the oh, there's somebody in our corner that's great. Kind of feeling we're not alone in this” CPI

Communication between caregivers and physicians was crucial. They had valuable knowledge of the person they cared for that could not only aid in diagnosis but help them uphold the values and wishes for care of the person with dementia. Communication, whether good or bad, impacted the relationships caregivers had with healthcare professionals and resulted in either positive emotions towards the healthcare system or negative ones. Improved communication is an opportunity to strengthen relationships between caregivers, physicians and other healthcare professionals to elicit more positive emotions and, thus, more positive experiences surrounding the dementia diagnosis and ongoing care.

“... I get absolutely no support from the medical teams”: Incompatibility of resources and support

Living in northwestern Ontario provides some unique challenges. There are not only healthcare shortages to compete with, but there is also a lack of home care and social services for ongoing support for caregivers and people living with dementia. The impacts of these shortages are experienced from day one when a person decides that they are going to pursue getting an

appointment to discuss the possibility of dementia. One caregiver described their experience having to seek healthcare in Toronto because they were unable to get the support they needed in our region.

“Yeah, I think honestly, if we hadn't gone this way, he wouldn't be here, because if he had... stayed on the trajectory of just relying on the diagnosis and only the things available to us immediately here, he probably wouldn't have made it because Aricept was making him so sick, it was causing a whole host of other problems, and they were really forcing the issue of keeping him on it. And I think that would have been a challenge to actually keep him alive, to be honest. And I'm not trying to be extreme, but that's the way it looked like it was going... we just don't have the right medical professionals here to diagnose” CP4

Feeling as though the absence of medical support in your community was a life-or-death situation signals a healthcare system where the needs of people with dementia and caregivers are not always compatible.

In addition to challenges with primary care, living in a community that has very limited, or no home care because of its rurality, can also be extremely challenging for caregivers. One caregiver described having to force the hand of the medical system to enact support because she was receiving no help to care for her loved one.

“Overall, I mean, that initial diagnosis was [in] 2022 and we didn't start seeing any action till summer 2024 from any of the supports. So, it wasn't until I dragged her, and formed her in the hospital that they finally said, ‘Oh, geez, maybe we should do something... maybe we should help out a little bit’....So even after that, it's two years almost of being diagnosed...there was nothing

for her until I was like, No, this needs to happen. This is happening, and even now, the supports are minimal” CP3

Absence of supportive care in the community does not absolve the need for them. These caregivers were left to pick up the pieces and fight for every resource they could to care for people with dementia. Unfortunately, you could see that out of desperation, one caregiver was reaching out to any and every place they could. Not knowing where to go for help, she said: “*I went down a list [and] called every single one of them [resources that might be related to dementia care]*” (CP2) as her way of desperately trying to find help. Sometimes the people with dementia these caregivers cared for ended up in systems and places that were inappropriate for care such as emergency rooms or social services that were not compatible with their needs.

“So, it started with a lot of empty promises, like, we're gonna do this, we're going to do this. We're going to replace everything, you know, all of the furniture to make it so that it's more accessible for her, like recliner chairs that stand up. We're going to put a handrail on her step. We're going to give her a ramp. We're going to do this. Nothing happened with it. It was a lot of talk at the beginning, and so it wasn't until two weeks ago that the band office finally caved and called me, and they said, ‘well, we can't find anybody who wants to go in there’.... now they're paying for the companion care, but nothing else” CP3

Being promised support that the community had no way of following through on was one example of how some communities just lack the infrastructure to support people living with

dementia in the community. It was no surprise that this caused immense frustration for this caregiver.

Where there is support available in the community for people living with dementia, there is the second question of ‘are they compatible with the needs of the person’? For this caregiver, her mother ended up in a day program that was for people much further along in their condition, and the experience ended up scaring her.

“They sent us over to a [day program] and said, ‘Oh, well, she could go to seniors daycare’. Okay, so I take her over there. She was still a good mind, like, yeah, she had word loss, but she was of good mind still... and she walked in there to all these people just sitting there...in a wheelchair, nobody moving. And she ran out of there crying. [She] said, ‘I’m not those people’.

And she wouldn't go, and I don't blame her, right?” CP2

Working hard and spending a lot of time seeking out people or places that could help care for their loved ones was frustrating enough, but to end up connected with inadequate support only added to the frustration. Ensuring that there isn’t wasted time and energy by simply seeking out help is one way we can improve the care for people with dementia. One caregiver suggested:

“Number one would have been to hook up with a resource that knows all the resources, so something like [name of community organization], right? Like somebody that can guide you through it, and counselors. And nothing was offered in that manner. So, there was no mediation assistance between the family members trying to care and everybody's at high peak stress, right?” CP2

Not only could streamlining the process of seeking out health and social care in the community save time and energy for caregivers, but it would afford them an opportunity to evaluate each program against what they wanted support for to determine the best fit.

Being let down by our health and social care system was evident among caregivers. For one caregiver it created a deep sense of resentment and distrust of the system. Her job went from advocating for her mother to fighting for her.

“It becomes nobody's issue, except for mine and my mom's. Then I start to reach out to family. Things start to get incredibly frustrating, right? Broken promises and then I think, okay, now I'm going to attempt to reach out to some nonprofits in the community, because they seem to be the only ones that will even touch it, the medical group I've given up on. So I now go to them and I say, you know, I really need some assistance. And. Um, and I go to a program that you know they're giving out money so you can keep your parent at home, and so I reach out to them, and that's fine, and you can have your family and friends assist you at home. Alright? Well, family makes promises, but then they don't follow through, which then starts disrupting our lives big time, and the fact that I have to continue to keep calling in sick and taking all my vacation on days where they're not going to show up, they're not going to help” CP2

It appeared that in all the interviews with caregivers that a dementia diagnosis, and the relationships they have with the health and social care system don't just impact the person with dementia. Families and support networks can all end up involved, and experiences with the

system, particularly negative ones, have an impact throughout the person with dementia's support system.

Every caregiver in this study wanted the best for their loved ones. They wanted to provide them with everything they could, but caring for someone with dementia is not something you should be doing alone. Unfortunately, they expressed how the lack of resources in our region negatively impacted the care that they were able to provide for a person with dementia.

“It's mainly family. So, we ended up, yeah, they don't have the staff they need. So, Home Care won't work with her because she's on reserve, and the health center on the reserve is supposed to be doing it. The health center on the reserve is not doing it, and so now the band office has said we will pay like her siblings when they go visit her, if they're there for a certain amount of time...” CP3

Another caregiver detailed how the lack of support that she received to provide home care for her mother resulted in repeated hospitalizations. Arguably, hospitals typically provide acute care and that was exactly what this caregiver was getting. Nothing long term was being initiated that would prevent future need to be hospitalized, and she was put in a place where she felt that she had to start demanding action.

“... back to the hospital, and the hospital continuously getting irritated and stressing her out in there. So I stated that, you know, I need help here. And I'm either going to call the Human Rights thing where somebody needs to help me during this pandemic....this isn't okay” CP2

Having a caregiver to advocate for the care and treatment of a person with dementia is a crucial asset. But, when the relationships between caregivers and the healthcare system are so strained they can cross a dangerous line from advocating to protecting out of a distrust of the system. This caregiver described what she felt her role in her mother's care had become.

"By protecting her. My role was to protect her and make the calls that she wanted" CP2

The diagnosis of dementia is only the beginning. It is a progressive condition that will ultimately change the needs of not only the person living with it, but the people caring for them. It will require ongoing interactions with primary care physicians, and thus there is more than the initial diagnosis where physicians can play a part in caregivers' knowledge and ability to access home and community care. This caregiver detailed what information she was given by the diagnosing physician.

"[the] Doctor gave us a few brochures about what you could do with your, you know, with your parent, you know, you could go to these places, or these places, like just meeting places, really, it wasn't anything, I didn't think anything substantial. It was just, you know, if you want to take them out and socialize them with other people with the dementia, it was more of that, yeah, that's, that's all that was really" CPI

For this caregiver, they were not interested in day programs that would provide socialization. She was not upset by the information given to her; she felt that she was able to care for her mother at that point in time. In a later interaction with paramedics called to aid her mother, she found out

about respite services. She was very grateful that there were people out there who would come and watch over her mother and give her a break. Respite was more in line with her needs as a caregiver compared to socialization opportunities.

Continuous interactions with services that did not meet the needs of the caregiver exemplified the incongruity in the goals of care. This caregiver felt that the needs and values of care differed greatly between herself and the primary care providers.

“... that was the only person that was effective in our life, was a nutritionist from the geriatrics.

The rest of it was they were more excited about taking her driver's license away and more excited about, you know, rating her condition all the time, and ‘what color is this?’ But it doesn't matter, what was the purpose of your assessing? What was the purpose? And there was none, there was none. It was like, Oh, I see. It's just, we want to see how fast it's progressing, and what are you going to do about that when it progresses. What service are they going to put her in?

What are you going to help us with? Right?” CP2

Similar frustration with the lack of services could be seen when caregivers were promised something that would have helped them, but no one followed through.

“No, there's nothing. The Health Center said that they would be doing all these, these visits.

They said we would get some friendly visitors, and they just showed up once for 10 minutes, the person, and they never went back” CP3

The negative consequences of a strained healthcare system extend beyond the person with dementia. Caregivers also suffered from lack of support. They lost time, money and even relationships trying to care for someone with dementia.

“Completely lost family connections...” CP2

One caregiver’s story showed that a frustrating experience being connected with inadequate support could have potentially been mediated through education. It was too late when this caregiver finally found someone with knowledge of what is available and who could have connected them with more appropriate services- or at least saved them the time of being connected with inappropriate ones.

“I walked in there, broke down, said to her, this is what's happening. What do you have here that can help me? And then she blew steam and said, ‘This is so wrong. There are so many services that could have helped you along the way. It's too late for most of them now. But here's your rights’. That would have been nice to know. Here's who can help you speak. Here's who can walk you through it, and could have and should have walked you through it” CP2

Education plays a key role in preventing some of the emotional turmoil on caregivers trying to find support without being informed of what was available to them. Some caregivers had past knowledge or experience of dementia and were able to draw on that to help themselves find resources and supports. This was viewed as crucial to their journey, giving them access and expediency that others would not have been afforded.

“It makes me feel very lucky that I have the background that I do, because I thought if this was my mom in this position that I'm in, or my sisters or anybody else without it, I just I think that they would be burnt out very, very quickly. Because of my job. I've got a whole bunch of different resources in my back pocket. I've got a whole bunch of dementia care activities and things like that that I can just pull those out. They don't have that. So, unless they're finding information on Google, there's nothing really right for them” CP3

Lack of education among healthcare professionals can also cause strain on the relationship they have with caregivers. One caregiver described her experience with nurses who were assisting with administering memory tests for her grandmother. Based on her previous knowledge of dementia, she stepped in to correct them when the nurses' actions could have jeopardized the legitimacy of her grandmother's test results.

“I just think the nursing staff wasn't well versed in dementia care either...they [could] use a lot more training on it.....Because they would correct her. And I'm like, you can't correct her. She's in the middle of a test..... you can't answer for her. Don't try to correct her, because you're, you're gonna, you're gonna fudge [the answers].... And she's like, ‘Oh, I didn't realize’. So I think more training on for the staff members” CP3

The same caregiver encountered more nurses during an emergency room visit where she felt that their treatment of her grandmother lacked the understanding of a person with dementia's capabilities.

“Or even, like, I had to take her into the emergency room, and even those nurses were just, it's, it's just like they had no knowledge whatsoever on the process of the disease and whichever. I think the treatment could be better towards people, because, again, they pick up on it, right? If you have dementia, you pick up on those emotions that people have. And so then, if she was getting angrier in the emergency room, because, you know, she's being told that she needs to be quiet. She's being told, oh, five minutes, and then it's not happening. And so, I just think overall, it just needs a vast improvement” CP3

Similarly, when discussions for goals of care were not collaborative among caregivers and primary care providers, this too could be perceived as a lack of knowledge of the importance of certain topics such as the future of this disease. For one caregiver, the adversarial relationship between herself and the healthcare providers was described in her quote as ‘*up against*’ the medical staff, and highlighted that she felt they were on opposite sides.

“They diagnose her with Alzheimer's. And throughout this entire process of going to all the geriatric specialists, the family doctors, every medical person that we came up against, not one of them talks to us about the future of it” CP2

Clearly, there was a lack of knowledge that this caregiver valued a conversation about what dementia was going to look like for her mother in the future. The physician not having this conversation with them created a sense that both parties valued different things and were not working together. Lack of knowledge among physicians about the questions, concerns or topics

of most value to caregivers and people with dementia can cause feelings of distrust between them and caregivers. Ultimately, caregivers felt unsupported, and this created feelings of frustration, anger, and distrust.

Consequences of caring alone

Caregivers played many different roles in the care of a person with dementia. They were transportation, keepers of information and appointments, support, and most importantly advocates. Roles may differ slightly among caregivers, but what was the same was the dedication to the person they cared for. Being a caregiver was not always easy and sometimes it came with personal sacrifice.

“... I said, That's it. I will take it over. So, it was the advocating for her to get her into the appointments. Then physically, she lives 30 minutes outside of Dryden, and it's an hour and a half to get her here in a car, because you can only go 20 [km/hr] so I drove her to all of her appointments, all of the follow ups, and then working with the band office in order to get her other services, so pretty much the whole step of the way, yeah” CP3

This caregiver sacrificed a great deal of time ensuring that appointments were made and attended, and services were coordinated. In addition to the time spent caring, one caregiver described the sacrifice of her own personal life.

“But there's a reality there that, you know, initially, how did I feel? I didn't feel like I'd lost it because I hadn't lost it yet, it was her losing her, you know. So, I needed to stand by her to let her know I was always there, right? So, then you get the sense of, I need to staple myself and go

nowhere and cancel life, because if I separate from her, she goes [motions down] emotionally. So, you're kind of imprisoned, you know, where you can't go out with your friends, you can't go for lunch, you can't do anything” CP2

It became evident throughout the analysis of this set of transcripts that the relationships between caregivers, physicians and the overall healthcare system was at the forefront of their experiences. Ultimately, negative experiences impacted how they felt towards healthcare professionals. It was from this observation, and my reflections on its meaning, that this section exemplifies a conceptual framework, that relationships between caregivers and physicians follow the same tenets of any good relationship: communication, trust, and compatibility.

Lack of resources and support in the community are not something that a physician can mend. However, they do play a crucial role as the primary person responsible for the diagnosis and treatment of dementia, for having open conversations about the caregivers needs, and setting honest expectations for the types of support available (or not) in the community.

This first section of findings explored how caregivers experienced the dementia diagnosis in northwestern Ontario. It seemed that the quality of the relationships they had with physicians and other healthcare professionals greatly impacted how they felt about the diagnosis process and the prospects of continuing to care for their loved ones at home. When they were unsupported, negative emotions such as anger and frustration distanced their relationships and made navigating ongoing care more difficult. Caregivers wished for better communication between themselves and healthcare professionals, and it appeared that for those who had experienced this, their perceptions of their relationships were more positive.

Chapter 4: Shouldering the weight of the system: Physicians' experiences diagnosing dementia in northwestern Ontario

Introduction

The following section of findings focusses on the physicians who were interviewed as a part of this study. In total, five physicians were interviewed about their experiences diagnosing residents of northwestern Ontario. There are four main themes that are described in this chapter. The first, *Not a rare occurrence: Diagnosing dementia in northwestern Ontario practices* describes the frequency that these physicians are diagnosing people with dementia in this region. Among the sub themes, physicians spoke to both the art and science of giving a diagnosis of dementia. This encompassed how they make the clinical diagnosis, including communication strategies, the importance of being prepared to handle tough questions, and how they learned to do all of this. Secondly, the theme *Reactions to a dementia diagnosis: As individual as the people who receive them* describes the various emotional responses of patients who are diagnosed with dementia and how physicians support them. The theme *"I don't think you can do anything in medicine without it having an emotional impact on you: Emotional work of physicians* highlights that physicians too experience emotional responses to diagnosing people with dementia and includes their reflections of how they manage. Lastly, the theme *"I feel like I am doing something of value: A rewarding opportunity*, emphasizes the passion that all the physicians in this study had for people with dementia and their commitment to improving dementia care. Interviews explored the diagnosis process from physicians' perspectives as well as the emotional impact of those processes and how it affected their experience diagnosing people with dementia.

The graphic below illustrates the structure of themes in this chapter. Blue boxes contain the main themes, and sub themes are represented as bulleted points below the main theme they are associated with.

Not a rare occurrence: Diagnosing dementia in northwestern Ontario

- Steps to making a diagnosis: "...making sure that you're aware of the patient's life"
- Communicating the diagnosis
- Preparedness: Being ready to handle tough conversations
- Hands on experience: "...nothing they can do is going to fully mimic that till you're actually in there"

Reactions to a dementia diagnosis: As individual as the people who receive them

- "wait till you say you can't drive"

"I don't think you can do anything in medicine without it having an emotional impact on you": Emotional work of physicians

"...I feel like I'm doing something of value": A rewarding opportunity

- Advice to other physicians

Findings

Family physicians in northwestern Ontario play a significant role in diagnosing dementia in this region. Most people will be diagnosed by family physicians regardless of where they live, but for people who need to see a specialist, they are not available in many communities in this region. In speaking with community partners and physicians who participated in this study, it was discovered that specialists in northwestern Ontario are located within Thunder Bay, representing a very small portion of the communities in this region. Additionally, there can be provisions made to access a specialist via telehealth or in neighbouring Winnipeg, Manitoba if that is a closer distance for the patient than Thunder Bay. In speaking with both specialists and family physicians in this study, it seemed that they diagnose dementia frequently within their practice.

Not a rare occurrence: Diagnosing dementia in northwestern Ontario practices

“...I probably diagnose people with dementia, at least four to five diagnoses every month in the [alternate clinic they work at], for sure, in my individual practice, it, probably is another one to two diagnoses per month... I've been finding that the amount of dementia diagnosis is increasing, but I do find that's largely related to our older population and perhaps my practice aging with me...” HP2

Another physician described the workload in her practice after taking on patients from another physician in the community. She also highlighted that her new patients have a higher average age than before, possibly accounting for a higher frequency of dementia diagnoses.

“I just took over a practice of 2000 people in the last six months, and I probably diagnosed...{talking to researcher} Yeah, it was a lot. That's why I have had a hard time finding space for you. [chuckling] my life is literally eat, work, sleep, repeat. I'd say, in the last six months, I've probably diagnosed about five or six now, which for me, was high like prior to that, maybe once a year” HP3

For specialists, the number of diagnoses is even higher with one describing it as very frequent in their practice.

“...I was in clinic last week, so I probably communicated diagnosis 8 to 10 times to new consults” HP4

Both family physicians and specialists were well versed in diagnosing dementia within their practices. Their practices consisted of a mix of people from more rural and remote populations, as well as more densely populated areas. But for all of them, diagnosing dementia was something they were familiar with.

Steps to making a diagnosis: “...making sure that you're aware of the patient's life”

Diagnosing dementia is an art and a science. Learning what tests and procedures one must follow to come to a diagnosis is only part of it. Physicians talked about the ways they gauge patients' ability to receive information, how they prepare to navigate emotions and questions, and how they have developed these skills over their career. The first step was collecting a comprehensive patient history and emphasizing how important it was to get to know your patients. A specialist physician described their process.

“...having extensive documentation prior to the consultation is really wonderful, and, you know, we don't always have that, but I think because of this close relationship that we [...] have developed with the team we've developed this process of getting a really rich package of information ahead of time, and so that allows me to spend some time prior to the consult reviewing that....that actually gives us more time to spend really getting to know the person.... you know, you're assessing someone who's 80, 90, years old. They've got a long life, a lot of history there, you know. So it's a lot of information to try and get, and even trying to get all the medical information can be extensive...so getting this package ahead of time means we can really concentrate on getting to understand the person, what they're going through, what they're experiencing, what feelings they may have about what's happening, little bit about the relationships and supports they have, as well as sort of reviewing the key components of the

history to find out, you know, first of all, to validate and make sure it's accurate. And then to make sure we've gotten all sides of the story” HP1

For this physician, having more information available about the patient before the appointment provided important questions about the patient (i.e., medical history) before they even met. This meant that less time during the appointment was spent asking procedural questions and more time was spent getting to know the patient. The team members who collected this information and prepared it ahead of time were invaluable to the success of diagnosis appointments.

All physicians spoke of the importance of having knowledge of a patient beyond just their medical history. Sometimes this was obtained within an appointment by asking questions of the patient, sometimes it was information gathered from family members. It was important to know patients to make informed diagnoses, as well as gauge how they may react to a diagnosis. One physician cited an example of how she helped a patient who was feeling down about seeing herself fail cognitive testing and reassured her that this was only to help her.

“That was her words, 'like I failed. And I said, 'no, you didn't fail. I said, this isn't about a pass or a fail.' I said, 'it's about finding out where you are and seeing if there's things that you know show up on your tests that indicate to us you need help and you need support.' And so that helped her a lot. And I think that discussion, I think, more than anything, helped to forge that bond”

HP3

Multiple physicians spoke of the importance of knowing what your patient needs from you and adjusting your approach to a dementia diagnosis based on the information that you believe they can handle. Being able to provide patients with information in a way that lessens negative emotional responses is something that all physicians practiced and was attributed to ‘knowing’ their patients. Even with their best intentions, a dementia diagnosis inevitably has a big impact on someone’s life and no one could ever fully ameliorate all negative emotional reactions. The kindness shown by the physician above to encourage and support her patient that was struggling emotionally demonstrated the important role that physicians can play in managing emotional responses and thus how dementia diagnoses are experienced by patients.

Part of knowing your patients is understanding the context in which they live. This included their family and support structures, their personal history, and how a diagnosis could potentially impact them.

“...so I would say making sure that you're aware of the patient's life. You know, not doing it from a completely ignorant space, like making sure that you have knowledge of their lives, their families, the impacts that this is going to have, the fallout, so to speak, and being, you know, sympathetic to that, and being able to do it in a gentle way, in a way that honors the patient and their story and their life, and then having that plan ready for them, so that it's not just like dropping this on them and then leaving them with no direction, right? Having those supports ready for them” HP3

Knowing your patients meant you could tailor how you delivered the information of a diagnosis to them. One physician described this process of tailoring dementia diagnoses to

patients as something that he learned over his career. He describes the ability to gauge from patients in front of him how best to deliver information by adjusting things such as language.

“I think you get a little more smooth and more comfortable with your approach. I also think that you're always getting a signal level from the person in front of you or their families of what they can tolerate. And you know, some people are fine with dementia, but they don't want to hear Alzheimer's. And you know, so you're always trying to sense out, how do you deliver the information you know, you get the retired woodworker who just wants everything black and white versus a more gentle approach for someone who's got a lot of anxiety, and that's part of the Art of it. And so that's always evolving. I think I'm more comfortable in my own skin, and also, having done it, you know, probably certainly greater than 1000 [times] I'm not sure that I'm at 10,000 yet, it certainly helps” HP4

Physicians adjusted their diagnosis process for the patient they were seeing based on what they knew about that patient. Their assessments of what a patient could handle dictated how a diagnosis was conveyed, the level of detail given, and the language used. This was done in an attempt to make the diagnosis process the best it could be for patients to experience.

Communicating the diagnosis

A family physician would be the first person most people would look to if they or someone they cared for were concerned about their health. If the individual is not presenting with an atypical form of cognitive impairment, a family doctor is most likely the one who will communicate the diagnosis to the patient. However, collaborative efforts between family

medicine and specialists do take place frequently. One family physician describes the process that is typical within their practice.

“...in Thunder Bay, that's sort of the process is you diagnose, you send to the geriatricians, they do their full workups, and then they confirm, for lack of a better word, the diagnosis, and then offer meds or whatever, and they have all of the access to, like different programming at [geriatric/rehab hospital in Thunder Bay], so it kind of just gets them into the system” HP3

Even though there are no specialists outside of the city of Thunder Bay, and residents from the district must travel or be connected to a specialist via the Ontario Telemedicine Network, being diagnosed by a family physician is normal and may have benefits that are not always highlighted. The family physicians in this study spoke to the importance of family medicine and the advantages that it has in building relationships with their patients and the impact it has on the dementia diagnosis.

“Oh, yeah, that's family medicine. Totally. It's the relationships, and it gives you more understanding of where they're coming from. But I think also the patients and the family, also, because you've had that long term relationship and trust that they are more open to hearing, you know, not so wonderful information from you, right? And so, I think it's, it's more helpful to have that sort of longitudinal relationship, for sure, rather than the episodic care that sometimes people get, that we're going to see more and more. I think our healthcare system is probably going to be moving towards that to improve access to everyone, which means more episodic care

and probably less chronic care, honestly. So that's going to be an interesting move in the next bit" HP2

One family physician described a patient that had such a rapport with her that she transferred practices to keep the relationship and comfortability.

"She's actually hopped practices with me. When I left that practice, she actually followed suit, because she felt a really good rapport with me, and like the husband did as well. So, I followed her through, sort of the beginning parts of her journey, and towards, you know, the end where it's been a couple of years now, and she's progressed significantly such that she doesn't actually remember me. She just knows she likes me. So, it's been an interesting one, where I've got to see it from start to almost finish kind of thing. And I think there was probably a little bit more, like a bit of a bond that was forged between myself as the doctor and then this entire family that has seen me in some capacity over the last couple years" HP3

Even though changes in this patient's ability to remember the physician by name were gone, the relationship superseded the memory; she still knew she 'liked' this physician. Relationships and personal knowledge of patients were highlighted as an asset and important to dementia diagnoses by all physicians in this study.

Those who practice family medicine highlighted the special opportunity they have in building long term relationships with patients that can aid in diagnosis and ongoing care. You could even see this in the above comment about 'aging' with their practice, that exemplified the opportunity to follow patients over their lifetime. Next was to uncover how physicians learned to

diagnose people with dementia, navigate relationships, and manage the impact of their practice on themselves.

Preparedness: Being ready to handle tough conversations

Part of being able to diagnose patients successfully came from preparedness that took place prior to appointments. This helped physicians plan to manage emotions, tough questions, and what information would need to be conveyed in that appointment.

“I've learned to how to prepare. I mean, I think it helps to have experience and have scripts. So, you know, have an established way of explaining things, and, you know, have experience with all the different types [and] range of emotions, and so I'm prepared for the people who are sad, the people who are angry, the families who are sad. You anticipate the different reactions and are ready to respond to them” HP5

Preparedness seemed to be for both the patients' benefit and the physician's benefit. Having procedures in place, anticipating questions and emotions, can all help physicians ensure that they are able to balance their own emotions as well as the patients.

“...when I tell somebody they have dementia, I'm initially making sure...I'm preparing myself.... There's some anticipation, like, what questions might they ask me? Do I have the answers for those? Or am I going to do one of those, ‘That's a great question. I'll get back to you on it’. So just trying to be as fully prepared to answer all the questions and provide the resources they need, trying to make sure I have the time to do it and I'm not feeling rushed.... that anticipation piece is huge, and then if I have that all kind of in a row, then I'm feeling more confident about going in and being able to do this. Like, skill wise, and then just trying to be, not empathetic, I

guess, because I can't be truly empathetic, but sympathetic to the situation, and just trying to be gentle about it. And, you know, offer a lot of time for questions, because it's something that is a

big topic, it's a big diagnosis” HP3

Navigating diagnosis conversations by conveying hope is another way that a few physicians described preparing for these difficult diagnoses. Sometimes hope was offering treatments like medication, informing them of available support or resources, and reframing conversations towards what is gained and not lost.

“...I feel it's really important to use hope and a hopeful approach, even if you're, you know, really providing what might be considered bad news. But you know, I think it's really important in healthcare to consider how important hope is, and no matter what the situation, even in people who are in palliative care, I think, I think there's still significant role to play with hope”

HP1

When taking something from a patient such as a driver's license, one physician described her response to remind the patient of what could be gained.

“...but it's also that door closes, but other doors open, right? Well, now you can visit your family, or they'll drive you around, or maybe you get to go on handy transit. You can make new friends, right? It's trying to sell the options that they haven't thought about necessarily” HP2

Physicians' preparedness was a practiced process of anticipating the questions and potential tough emotional conversations and reactions that a dementia diagnosis could bring. Learning to do this was something they practiced over time, but the benefits were clear. It helped them manage their patients' emotional reactions to the diagnosis, and it helped them manage their own emotions in response to their patients.

Hands on experience: "...nothing they can do is going to fully mimic that till you're actually in there"

Diagnosing dementia was not something these physicians learned to do in medical school. They did learn and practice how to deliver 'bad news' with simulated patients, but all of them believed they learned the most in their post graduate training during residency as well as learning from hands on experience as they practiced on their own.

"So I've learned it along the way. So I started doing a lot of this work about 10 years ago, largely because I was starting to see more of it in my practice and recognizing that more needed to be done.... So, that being said, that's all my own learning and journey on that as my career takes me in different places..." HP2

Residency or post graduate training was the most predominant method of learning to diagnose dementia in addition to being able to practice it yourself. One physician remarked that they didn't believe medical students were exposed enough to dementia.

“...So at that time, training in dementia, I would say, was quite limited. We certainly learned about it. And I think, I think it was certainly an important component of the residency.... I think medical students still don't get enough exposure” HP1

In contrast, a different physician believed that dementia was *“too big a diagnosis for a medical student”* HP5. Another sentiment expressed was that medical school is for learning the basics and there is not much that they could teach you to fully prepare you for diagnosing dementia.

“I feel like medical school and residency could never prepare a doctor for any of it. Like there's that level where you learn the basics, you learn the pathophysiology, you learn the book stuff, and then you get a taste of it through medical school and residency. But the biggest goal I found through medical school is just teaching you how to know what you don't know and where to find the answers and who to ask if you need assistance, knowing when to ask for help” HP3

One physician remembered being trained to do ‘difficult interviews’, but the test patients had alternate diagnoses not related to dementia.

“...certainly we did some work with a difficult interview, not so much dementia. I'm going to suggest for me, it would have been HIV and cancer. I certainly remember 'practicing' if that's the right term, you know, disclosing those sorts of information. I don't remember, specifically 'oh here we're with someone with dementia'. Obviously, when I got into geriatrics, that, you know, senior residency is very different, because obviously we were immersed with lots of cognitive issues. So, medical school, difficult interviews, yes, specific to dementia, I will say no” HP4

For physicians, learning to diagnose dementia was a more hands-on process of watching other colleagues and being able to practice it yourself to develop your own processes that worked for you over time.

“...watching other skilled colleagues, watching videos. There's been a couple of really nice video series about talking to people with dementia. So, it's been a combination of watching colleagues, educational material and then clinical experience” HP5

Not learning the intricacies of how to diagnose dementia in medical school meant that these physicians had to take personal initiative to learn from others and adapt their processes over time to suit their patients.

Reactions to a dementia diagnosis: As individual as the people who receive them

Dementia is a life-limiting progressive condition for which there is no cure. Disclosing this to someone can bring about many different reactions. Thus far, the physicians in this study have spoken to the complexities of the diagnosis process, the importance of communication techniques and the required preparedness to improve the experience of the process for both themselves and their patients.

Next, physicians spoke about some of the emotions that they witness from patients when diagnosing them with dementia, how they manage those reactions, and how seeing their patients' emotional responses impact them. Some of the dominant reactions they witnessed from patients were described as shock, denial, tearfulness, and fear.

“Fear. I think it's fear of the actual diagnosis of dementia, because right now, people know that it's a chronic progressive illness that there's no way out of.... Currently, there's a lot of research in the area, but there's no great treatment, and I think...people fear that that loss and loss of independence” HP2

Emotional reactions are not something that anyone can accurately predict, and some people can have stronger emotional reactions than others.

“So in this case, the lady's reaction was quite distressed.... I got the sense it came as a shock to her. I was actually communicating this information to her, and she was quite, quite tearful and sad about what I was telling her, quite distressed really, and more, much more so than I usually see actually” HP1

One physician described how just as patients have mixed emotions about a diagnosis, she can too.

“And then I also see a small subset of people that are in denial, I guess, but that is part of dementia too. Is that an agnosia where they just don't have the insight, and so then it's obtaining permission to speak with their family members, to really rally the supports around them? Yeah.

And sometimes patients, even though they're resistant to the diagnosis, are happy to get the supports right, and it's personally how I feel about diagnosing it. I think it again, mixed bag, helpful and grateful that I can be part of people's dementia journey, which is different for every individual and different for every type of dementia, because everyone looks a little bit different,

and I think people in general are appreciative of that support, and I'm happy to be able to offer that and reassure them” HP2

This physician exemplified how she too is impacted by the dementia diagnosis. Even though she acknowledged the difficulty of the diagnosis for patients, she felt grateful that she could offer help and support to them. Not all patients show as much emotion in appointments. One physician described how potentially already having come to terms with something being wrong, or being in later stages can temper the emotional reactions to a diagnosis. This further exemplifies the unpredictability of people's reactions to being diagnosed with dementia and the challenge physicians face in navigating these complex situations.

“I find that many people either already have a sense that that's what is going on and are particularly surprised, or someone's already talked to them about it, or for whatever reason they don't show a lot of emotional reaction to it, and don't have a lot of questions. And that's more often I find in people who's who maybe have already entered into, say, the more moderate stages of dementia” HP1

Another important aspect of the diagnosis process was the importance of having a family member or friend present. These individuals were there for many reasons, primarily to offer comfort and support, but also to give important insight about the patient and take in important information about the diagnosis. Having a person there during what could be an emotional time for people being diagnosed with dementia was seen as beneficial. Physicians highlighted how they initiate bringing in a support person to a diagnosis.

“...generally, my rule of thumb is when I'm dealing with dementia, I ask permission if the person's capable to have somebody there, and 99% of the time, they're like, 'Yeah, that's a great idea.' And if they're not capable, that tends to be where I get pushback, because they kind of know something's wrong, and they don't want me to find this out. But I do try to get permission to have the person there” HP3

Including a support person in the diagnosis process can help physicians and the person being diagnosed. They can give background information on a patient, as well as describe changes and symptoms that can aid the physician's ability to make a diagnosis.

“And so she was an important part of the interview as well. Having this close friend, more often than not, we have, we'll have a family member present, you know, either a spouse or often a child of the client” HP1

“wait till you say you can't drive”

Removing a driver's license was cited by all physicians as an extremely difficult conversation to have with patients. It was a loss of independence and people often had an emotional reaction to this news. One physician specifically described a time she diagnosed someone with dementia and immediately had to remove their license. The patient was very upset with her and she worried about the impact it had on their relationship.

“...there were severe concerns about [their] driving. And I said, like, right off the bat, ‘I have to do this. I’m really sorry, but your safety and the safety of people on the road is important’, and I had to pull [their] license the same day that we made the diagnosis. And so that was a huge contention, like between us. And while [they] understood it, [they] didn’t understand it.... that was difficult, and [they] didn’t come back to see me for quite a while..... it did take a little bit out on our on our relationship that was just starting. Like we had just met each other” HP3

Another physician described their experience removing a driver’s licenses as worse than telling someone they had dementia.

“I find telling people about their diagnosis of dementia is way easier than sending a letter to ministry of transport. So, people might be upset about having dementia, wait till you say you can’t drive, right? That’s a much more difficult conversation. Still really uncomfortable, because I find there’s a hostility that emerges when you’re saying, oh, I have to report you to... [patients may say] ‘Well, I was in the war. I did this. This is a free country’, you know? So, that can be very difficult” HP4

Removing the ability for someone to drive was seen as removing a part of their independence. This elicited strong emotional reactions from patients and had the potential to damage the relationship between them and the diagnosing physician. In addition to being difficult on the patient, it seemed that removing a driver’s license was hard on these physicians as well. The physicians witnessed negative emotional reactions from their patients, some of

which were directed at them, and they felt bad for having to remove this privilege that clearly represented something of great value to their patients.

“I don't think you can do anything in medicine without it having an emotional impact on you”:

Emotional work of physicians

Patient reactions appeared to be varied throughout the diagnosis process, and navigating all types of emotions is something that physicians had to learn. One physician said: “...*from my point of view, I don't think you can do anything in medicine without it having an emotional impact on you. And if you do, I think you probably shouldn't be in medicine*” HP3. Seeing someone upset or distressed by a diagnosis is not easy for anyone to witness, including physicians. They spoke about the impact that their patients have on them and how they navigate their own emotions.

“.... I find the emotional, most of the time I'm grateful and happy with what I can offer them, but I do find that there are some families that are incredibly resistant to any to the diagnosis, resistant to the services of assistance that we can offer them, and that they just want to forge their own path. I guess you can say, and I do find I get, I don't know if it would be angry or just, well, I don't know what would be the emotion for that just saddened that you, you know, as a provider, what that trajectory is going to be for that patient, and that they're not accepting the supports that maybe can slow that trajectory, or help them access services that might be helpful for them. I find that, I would say, maybe frustrating, but maybe that's not the right word, but that you just hope that they let that whole issue sit for a while, and maybe you hear back from them,

and sometimes that's the case, right? A few months later, they're like, 'oh, you know, we really didn't want to hear that, but now we're ready', and that's okay, too, right?'' HP2

One physician described the anxiety she experienced through a particular diagnosis and the fear that this negative news and the subsequent removal of a driver's license would negatively impact her relationship with the patient.

“So I mean, initially, getting her to agree to be tested was a little bit tricky, because in her mind, there were no issues, and it's her family being unreasonable. So, I always find that part a little tricky and a little bit anxiety provoking. When you're you know you're treading lightly around someone's life, right? You're going to tell them something that can basically change their entire outlook, and all the plans that they had and things that they had planned to do, can potentially, you know, in a few minutes, change once you make that diagnosis and explain what it means. So that's always nerve wracking. I think for this case, it went as good as it possibly could have. It wasn't a bad memory, you know, going through that with her. It was more sad because I knew how independent she was and how many things she liked doing on her own, driving on her own.... So that part always is hard, because I want to keep that relationship, but taking away somebody's right to drive is a huge, a huge hit, and so you hope that at the time you do it, they're with it enough. To say, like, 'I get why you did it. I don't hold that against you.' In this case, she was aware, and she had kind of felt the same thing herself.... But there's been times where I've done it and it's been like, 'You're ruining my life, doctor'. And I'm like, great, like, not what I want to hear from my patients, but this was an opportunity where it went well, and I think it was, it was a positive, a positive experience'' HP3

Emotional responses from physicians ranged from being sad or empathic to the negative emotions expressed by their patients, to frustration or anger towards their inability to convince them to accept help. Either way, physicians understood the gravity of the diagnosis and their ability to ease the emotional distress of patients seemed important to their job satisfaction. Another physician described the empathy she felt towards patients she knew did not have the support system they needed.

“I also find it very difficult when I see a person with dementia who doesn't have family support and who doesn't have a POA, who doesn't have a will, and then it's very frustrating sometimes, because you need to get the consent and capacity board involved and the PGT [Public Guardian and Trustee] involved. And I find that very stressful for myself, because it's a very obtuse procedure [chuckles] and not easily accessed. And in our area, we don't have a consent and capacity person. They come from Thunder Bay, which is 500 kilometers away, and those assessments run at about \$2,000 and many of these people cannot afford that. So, it becomes very problematic and very distressing for my team to try to find those supports for these individuals” HP2

Patient emotions and physician emotions seemed to mirror each other. If a patient reacted negatively towards a dementia diagnosis, it triggered empathetic feelings like sadness in the physicians.

“When, when it's clear, like in like the person I described earlier, when it's clear that that person becomes really distressed and. Um, then, for sure, there's an impact, and makes you feel bad for the person. And then you always wish you could give them better news, or tell them there's nothing really wrong with them, you know, but I think for sure, it's always hard to give people a diagnosis” HP1

All of the physicians in this study had some sort of response to the reactions of their patients. A couple of the physicians spoke about how not monitoring your own emotions as a doctor can have negative consequences to their personal well-being

“.... You burn. You can burn out emotionally. You know? There's the whole aspect of transference and all that kind of stuff. And I'm not saying we're at that level, but just being able to understand somebody and where they're coming from, and taking that time to try to connect with them on their level is important. And I mean, I don't think that I necessarily do that perfectly or near perfectly every time, if we're rushed, if you know there's time constraints, you're behind all that kind of stuff. You know that's going to definitely change your, you know, your interactions. But I think you should, there should be some, some emotional capacity there between doctor and patient. That's what makes this relationship as a physician, you know, and a patient, so special, so that you do have access to all this information about someone's life, they are, they're coming and telling you about, you know, the things that are happening at home that impact their health. So, for you to be like being objective, yes, but for you not to be affected by some of the stories that we hear would be inhuman” HP3

This physician spoke to managing the emotional toll of their job as learning to "use the gas in the tank wisely". It was unclear when in their journey they developed this mode of thought, or learned this as a skill for personal protection, but regardless a balance was to be struck between empathy and emotional responsiveness to patients and ability to distance oneself at the end of the day.

"So it's a good question, and we hear a lot about empathy or compassion fatigue and those sorts of things. I don't know that I necessarily felt that way, and maybe I have recognized it. I think just whether it's the frequency it's done, or whether it's just, I don't feel that I'm jaded and that, you know, I don't care, I just think I've been able to set it in a compartment where, where I can keep I want to say the correct emotional distance from it, or emotional signal strength that it's not as fatiguing. I think the volume of people that I see in the last since COVID has increased. So I'm doing more work in the last 4 or 5 years anyways, and whether that's played into it or not, I don't know, but that's also possible, that you know, you know, you have 30 more people to see instead of 10, you have to use the gas in the tank as wisely or as you know, judiciously as possible. So I guess it's complicated. I don't really know for sure all the variables. I certainly don't feel like I don't care anymore, and I hope people I'm seeing aren't thinking, 'Oh, he doesn't' right? I'm hoping that I still demonstrate an empathy. But I don't feel it's a burnout thing. I don't feel it's a jaded thing. I just not entirely sure if it's better expertise or a necessity for higher volumes, or some combination of all of those things" HP4

Learning to navigate your own emotions and find outlets is something that most physicians learned to do with experience.

“...I think I had much more anxiety earlier in my career, and I think I felt the emotional weight of it a lot more than I do now. I hope that that's not insensitivity. But, you know, you need the signal level, but you don't need to be swimming in the same pool as them.... how do you keep that separation? Do I get anxious? I think very little now. I have empathy, and I see people cry.... So I'm understanding. I don't think I take it on, maybe as much as I did earlier in my career” HP4

Methods of navigating patient emotions and regulating their own were described by some physicians and included strategies like preparedness and peer support.

“I try to make sure. Sure that, like, again, my preparedness level going and knowing, like, sort of what I'm going to say and what kinds of responses I can get, and just kind of in my head working out some of that I think is helpful. I do have my own sort of tribe of medical professionals that not just that a consult that I know will help me, but also my tribe that I'll go to when I need to be able to debrief about something. When I'm in a group setting where I'm working with a group of doctors, it'll be one of, you know, potentially one of those. But even having someone who you know I can go and speak to and say, it's been a really crappy day, you know, like, this is what happened. And, you know, keep it in in a confidential way, but being able to say, like, I'm just feeling really shitty because I had to tell someone that, you know, their life is changing, and, you know, that kind of thing. So just having somebody to allow me to vent and to give me feedback, and, you know, I did, I did it this way, and it just...didn't go very well. And then being able to say, well, you know, next time, you know, maybe try this or that” HP3

Physicians are supporting patients and the varied emotional response that they go through during a dementia diagnosis, but they too needed outlets to manage the emotional impact on themselves. Unfortunately, it was not clear how this process of managing your own emotions was accomplished besides years of practice and self-reflection. There were no clear teachings on how to do this; it seemed like it was just done over time out of either necessity or desire.

“...I feel like I'm doing something of value”: A rewarding opportunity

The passion that all these physicians had for people with dementia was evident throughout this research. They knew the gravity of a diagnosis and the importance of the role they played in ensuring that there was support for continuing care put in place.

“...I feel like I'm doing something of value. People are scared. People don't know what's going on. Not to diminish anyone else's work, but neurology, the brain is still pretty mysterious. Got a big, swollen knee, right? You know, you got arthritis. Pretty simple, cognitively you can get your head around it. I think when, when our brain starts not working as well as it should. There's lots, lots of behaviors, lots of emotional stuff, obviously cognitive things people don't know this normal? Is it abnormal?... what's going on and it can be quite anxiety provoking. It also can be, you know, scary for family members, scary for patients going through it and, yes, so I think it's very valuable. I've enjoyed my career. I can't imagine redoing it and saying, Oh, I would have liked to do that more than what I'm doing now. I still enjoy it. So again, is that adding anything, I don't know, but it's an excellent place to practice medicine, geriatrics, cognitive stuff, and you know, so much variability and presentation, and then the story of the people in front of you there, right? These people, there's all kinds of human connection and human interest that I don't know

if you get as orthopedic surgeon.... So, as a geriatrician, I think it's very rich practice. Yeah, wouldn't go back. Haven't found anything else. I think I'd rather do more” HP4

Despite all the struggles that the northwestern Ontario healthcare system is facing, the physicians who are diagnosing people with dementia are dedicated to making it better for patients and their families. The interviews concluded by asking them what they would want to tell other physicians about diagnosing dementia based on their experiences.

Advice to other physicians

The physicians in this study were very familiar with diagnosing dementia and have learned valuable lessons and techniques during their careers that have helped them. They shared some advice that they would like other physicians to know about diagnosing dementia.

“...first one is to keep a pretty open mind about what the diagnosis might be not to jump to any conclusions and really having a really wide differential diagnosis and being careful to rule out underlying medical causes....and then recognize that there are a lot of different subtypes of dementia, and that's important to try to figure out.... And the other advice is to, when providing a diagnosis of dementia, is to do it in a very supportive manner, and to take time, take the time to do it as well as possible” HP1

This physician encouraged attention to detail and paying attention to the process of ruling out other causes before making a diagnosis. Another offered encouragement that family physicians are well equipped to make a diagnosis but should know the medical community is there to help if they need it.

“... my advice for family physicians is that it is within their wheelhouse to diagnose straightforward cases of dementia, so things that are in keeping with an Alzheimer's Dementia and an older adult that's definitely within their wheelhouse. They just need to get a bit more comfortable with it, but...they should always feel that anybody who's presenting atypically...they can reach out for help” HP5

Finally, one physician emphasized the importance of practice and dedicating yourself to gaining more knowledge of dementia if this is something that you will end up doing a lot in your clinic.

“And so you need the foundational knowledge, and then you need the exposure experiential knowledge. And one comes with time, another one comes just hard work and get a feel for all these different types of dementia. So you have to decide you're going to dedicate the time or not. But if you're going into a memory clinic, yes, absolutely dedicate the time because it will Pay off in spades” HP4

It appeared throughout the interviews with physicians that they all were passionate about dementia care. They were well aware of the impact they, and a diagnosis, can have on people and their families and did their best they could to support them. While looking after their patients, physicians also looked after themselves and described that despite the emotional toll that diagnosing someone with dementia can have on them, they appreciated the opportunity to be a part of someone's journey and were fulfilled in their career.

In addition to the themes described in this chapter, there was an underlying lesson learned that most aspects of the dementia diagnosis, beyond use of clinical assessments, were self-taught

and practiced over time post-graduation. This is an important take away as it lends itself to the importance of mentorship. Those who took part in this study had learned valuable lessons over their time practicing medicine and had advice for other physicians that could be shared. What they have practiced has helped them manage not only their patients' emotional responses to diagnoses but also how to manage the emotional work required of them.

Chapter 5: Diagnosing dementia in northwestern Ontario: A case of acute insufficiency

Introduction

The final section of the findings plays an important role in this thesis overall. It demonstrates that both caregivers and physicians, although they have unique struggles in their own roles within dementia diagnosis, both see the same issues and are passionate about improving the care for people with dementia. It highlights healthcare system challenges, particularly accessibility issues, their impact on caregivers, and the creative ways physicians are bridging gaps for their patients. The main phenomena under study in this thesis was the experience of diagnosing dementia in northwestern Ontario. It is clear in this section that the diagnosis is merely the beginning of a relationship between physicians and caregivers, and each party is individually impacted by the healthcare system challenges in northwestern Ontario. The diagnosis of dementia is ultimately a process that far exceeds the act of communicating the diagnosis to a patient. It marks your entry into the healthcare system, and the beginning of a unique relationship with your healthcare team.

This section contains six main themes. The first three themes focus primarily on caregiver experiences. First, *Not a waiting game: Initiating a diagnosis of dementia* highlights the impact of accessibility issues on getting a timely diagnosis. Next, *Beyond primary care: Health and social care in the community* covers why a diagnosis of dementia does not end once a physician tells someone they have this condition. Caregivers continually seek help caring for the person with dementia, accessing both home and community health and social services. It explores the impact of system fragmentation, and unavailability of supports in parts of northwestern Ontario, that would assist them in caring for someone with dementia in the community. Lastly, *Positive experiences with the healthcare system* highlights the successes

within communities where caregivers have accessed supports and services that have made a huge difference in their ability to care for the person with dementia.

There are three more themes, two that focus on physicians, and one that emphasizes that physicians and caregivers see the same issues. To begin, *Working to bridge the gaps* covers the ways that physicians in the region have been able to successfully improve service accessibility and make obtaining a diagnosis easier for people in northwestern Ontario. Then, *Caring beyond the initial diagnosis: Resource shortages* mimics the theme of the caregiver section above but shows how some of the system fragmentation impacts the experiences of physicians diagnosing dementia. It culminates with the theme *One the same side: Physicians and caregivers see the same issues* where quotes are laid out side by side to show that both parties are calling out the same issues in the healthcare system and how it negatively impacts the ability to receive a diagnosis and access care thereafter.

The graphic below illustrates the structure of themes in this chapter. Blue boxes contain the main themes, and sub themes are represented as bulleted points below the main theme they are associated with.

Not a waiting game: Initiating a diagnosis of dementia

Beyond primary care: Health and social care in the community

- Positive experiences with the healthcare system

Working to bridge the gaps

Caring beyond the initial diagnosis: Resource shortages

On the same side: Caregivers and physicians see the same issues

Findings

Throughout this study, caregivers' stories contained adversarial language such as '*fighting*' or '*protecting*' their loved ones while advocating for care. They were frustrated, angry and disappointed by our healthcare system and lack of support that they received. It made relationships with the healthcare system seem like it was 'us against them'. Physicians took a lot of blame for insufficiencies, not because they themselves did a poor job throughout the diagnosis process, but because they *represented* the healthcare system and the constant disappointment caregivers faced when trying to receive adequate care.

Not a waiting game: Initiating a diagnosis of dementia

Challenges for caregivers began when they first attempted to contact a physician to initiate an appointment to inquire about changes they were noticing in their loved ones. Northwestern Ontario has an unprecedented shortage of family physicians, and there are only four specialists in the region that diagnose dementia. The wait time to see a family doctor is

lengthy, and not something that families are willing to accept when they notice changes in their loved ones.

“...I had tried to make an appointment with our family doctor, and I was told it would be six months for her to get to into her family doctor. So then, you know, doing the math, six months waiting in to get into the family doctor, and then for her to make the referral....Waiting six months could have been the difference between a pleasant person with dementia and somebody with aggression issues” CP3

Having a family doctor does not equate to expediency receiving care. Even though this caregiver had a doctor to call on, the wait times were very lengthy and for a progressive condition like dementia, she worried that it would be too late to delay development of new symptoms.

Another caregiver described her wait times after her family physician retired, forcing her to use walk-in clinics to move the diagnosis process along.

“...our doctor retired and then we waited a year and a half until we had to start going to geriatric specialists, we had to go to [a] walk in, because Ontario had no doctors for us here”

CP2

In addition to the challenges accessing a family doctor, the lack of specialist physicians in this region was also challenging. After a family disagreed with a diagnosis, it was a difficult process to get a second opinion. The diagnosis that they received was not consistent with the

family's knowledge and experience of their loved one on a day-to-day basis. They felt it did not explain his symptoms and on the current treatment plan, he was getting worse not better.

“... [we] identified that things were getting worse on Aricept and that we wanted a second opinion... by a behavioral neurologist and possibly [a] spec scan. We don't have spec scans either in Thunder Bay, so you have to have that sent [referral to get SPECT scan elsewhere] so they wouldn't do it” CP4

It took a lot of convincing, advocating, and time for this caregiver and their family to get their diagnosing physician to refer them to a specialist for a second opinion about their loved one's diagnosis. Once it happened, the person was diagnosed with a different form of dementia, and the treatment plan was changed accordingly. The caregiver believed “*he wouldn't be here*” if they hadn't pushed for a second opinion and received the accurate diagnosis.

Due to healthcare shortages in the northwestern Ontario, accessing a physician is the first instance where caregivers can face barriers. For some, frustrations with the healthcare system started immediately in the process of trying to get a diagnosis and damaged the relationships between physicians, caregivers and patients. In addition, caregivers felt that the system was difficult to navigate, and it created even more tension between themselves and healthcare professionals.

One caregiver faced significant challenges having to travel to see a physician outside of their community because there were no doctors where they lived. After not hearing back about the results of initial doctor's appointments, it was not until three years later that a diagnosis of dementia was made when a different family member took over navigating care.

“Somebody did take her for an MRI in 2019 which indicated that she did have mild cognitive impairment.... but she was never informed of the results.... They never called anybody in the family to bring her back. And so, until I took her for the testing in 2022 nobody knew that she even had anything wrong with her officially.... how would that have changed her course of progression, right? If she had been on meds in 2019 as opposed to 2022” CP3

It took this caregiver taking over and restarting the process to find out that the diagnosis had started three years prior, but no follow ups were made. This left the caregiver with questions about how her loved one's condition could have progressed differently if treatment had been initiated earlier.

Beyond primary care: health and social care in the community

Obtaining a diagnosis from a primary care team is only one aspect of dementia care. Continuing health and social care supports are part of the dementia diagnosis process that extends into caring and maintaining the well-being of the person with dementia post-diagnosis.

Like experiences accessing physicians, the continuity of care and communication between varying health professionals that would be involved in continuing care of someone with dementia proved to be challenging in northwestern Ontario

“... the quality of services that you get, and the understanding that the medical professionals have of dementia is absolutely lacking, and the ability to have a relationship with the members that are caring for the person with dementia is not there” CP2

This caregiver expressed clear frustration over the absence and quality of care that was available for people with dementia. Her reflections on multiple healthcare providers at various places she tried to receive support resulted in her concluding that this is a system issue, not an individual person issue.

“...It's the system [that] is the issue. If I heard one more time through the medical people, 'it's the system'.... A system has a process that has a positive outcome. You don't have a system, you have chaos” CP2

‘The system’ is not just referring to the brick-and-mortar clinics where your family doctors practice. The healthcare system included primary physicians at a clinic, hospitals, homecare and social care that are all required to keep someone with dementia healthy. These services were absent and/or very fragmented in the region and made caring for someone with dementia exceedingly difficult for most caregivers.

It seemed that there needed to be more discussion between physicians, caregivers, and people living with dementia to let them know they are all on the same team. Caregivers were often left to navigate continuing care on their own. Unfortunately, in northwestern Ontario, it is common that those supports are limited or non-existent. It left caregivers constantly being bounced from one person to the next, hearing denials and ‘we can’t help you’. It is no wonder anger and frustrations mounted.

“She's connected to the Alzheimer society, so she gets support there, she gets group support. We hired our own PSW to help at first, because you have to apply for funding, and it takes so long.

So again, that took probably about a year for her on the list to get that so we paid out of pocket to help support her with a PSW...” CP4

Just because funding is available, doesn't mean you will receive it. This caregiver applied for funding but ended up paying out of pocket because the process took so long, and they could not wait

Another caregiver firmly called out the provincial government for pushing the ‘caring in the community’ sentiments, because the lack of follow through on those promises cost her personally and financially.

“You know how Ontario has this ‘Oh, you know, keep your parents at home’. Just walk in the hospital and say you refuse to care, because you're never going to want to go through what we went through. I almost lost my job....I lost my family” CP2

In the absence of being able to secure adequate resources to care for your loved ones at home, caregivers may look to long-term care homes. But here lies another roadblock. Those are grossly limited as well in northwestern Ontario, and alternatives like assisted living facilities are not necessarily any safer than being at home or appropriate for someone with dementia.

“They wanted us to move her into a supported living environment in [nearest city], take her off the reserve. And I said no to that, because if she's off the reserve for six months, they can take her status away from her, and OHIP will pull over and do the funding. And my concern was it wasn't a secure facility. She's already a wanderer....It's not a long-term care, right? And so, I

said no to that, because it would have been more dangerous for her. So, they were pushing for that. They could have had her in in the next week.... but long-term care, six to seven years” CP3

If funding, systems, and number of professionals are all lacking in this region, caregivers are shouldering the weight of caring for the person with dementia on their own. One caregiver reflected on the healthcare system and wished for more compassion for families going through the dementia diagnosis process but recognized that our healthcare professionals are also in need of help.

“...it's pretty sad, because our medical community... is so overworked, or they just don't have the time. And I understand that, but we're, you know, you're looking at people that this is a big diagnosis too, for families, there's a lack of compassion I feel...I wish I could say that to all the practitioners like this is huge for families. Unless you've been...in these shoes, it's huge” CP4

Caring for people living with dementia required stronger relationships between physicians, caregivers and home and community support services. Having stronger connections between health services could help caregivers with system navigation, and awareness of what was, or was not, available in their communities. Knowing what is accessible would save them time, energy and frustration from being turned away or denied support.

Positive experiences with the healthcare system

Amidst the hardships that caregivers faced when trying to access support to keep their loved ones at home, there were positive experiences that they cited within the healthcare system

that were beneficial to them. These resources were extremely helpful to caregivers and the person living with dementia's health and well-being.

Unaware of supports in the community that she could access to help care for her mother at home, one caregiver willingly did everything by herself. Social supports were available in her community if she wanted them, and her primary physician made her aware of these, but the ones she knew of were not consistent with what her and her loved one needed. It wasn't until they interacted with two paramedics that she found out about more services that provided care she could use.

"...I'm the kind of person who just does things on their own.... And it wasn't until mom had a TIA and we had to call the ambulance....the paramedics were two ladies; they were so amazing. Your mom has dementia? Yes. 'Would you like us to sign you up for this program?'.... all these community things...the Alzheimer's Foundation, Westway, I said, 'Yeah', and it was amazing. Within the week we were signed up to all these things that have been helping me. Like it was unbelievable. Yeah, but, but up until then, I was like, 'no, I can do it myself. Don't worry about it'. Sort of a person. That's the kind of person I am.... they've been really great, especially Westway. Because they're my respite" CPI

Highlighting the challenges is important to know where gaps in the system exist. Hearing that there are people and services who are providing valuable support to caregivers is also important to ensure that we can pass the knowledge on to other communities who are struggling. For the above caregiver, all it took was someone to inform and offer her support that was available to create a positive experience.

Working to bridge the gaps

Although physicians were often identified as some of the frustration with the healthcare system, they too are negatively impacted by the lack of supports and services they can offer. Physicians knew there were shortcomings in the system and believed the care available for people with dementia and caregivers was lacking. Physicians themselves faced challenges due to the lack of resources for dementia care and support. This has forced the creation of new strategies to increase accessibility and allow people to access specialists that are unavailable in this region.

One example of this is the Ontario Telemedicine Network (OTN). Residents of northwestern Ontario, particularly those in rural and remote communities, can access specialist care via OTN with a referral from a primary care physician. Local Canadian Mental Health Association representatives can also help people secure a referral if they do not have a primary care physician. Some seeking a diagnosis also choose to travel to Winnipeg, Manitoba to see a specialist in person. Both options have increased the amount of care that is available to people in northwestern Ontario. Physicians talked about the benefits and challenges associated with a dementia diagnosis through these options.

“Now, there are things that are not so good. You can't you often can't see the whole person.... By that, I mean sometimes there may be tremors or various physical symptoms or physical findings that may be a little harder to pick out.... hearing is sometimes a big problem. So now that can be the same person who's in the room with you, but it's exacerbated a bit by the video conferencing process, so sometimes we have to use a family member, another member of the team, to repeat the questions. That usually works out okay, but it slows things down and usually works out okay.

So overall, I think it's still pretty effective, and certainly saves huge traveling for the person and their family” HP1

Specialists based in northwestern Ontario can also be connected via OTN to someone in the district (i.e. outside Thunder Bay) if necessary. If someone chooses to travel to Winnipeg because it is closer to their hometown, leaving the province creates jurisdictional issues that both families and physicians have to overcome.

“[They] need a PET scan...so to arrange it in Manitoba...it was a huge process.... Ontario has to sign off on funding a Manitoba PET scan. And ultimately, Ontario refused to fund a Manitoba PET scan” HP5

Although the option is available, and Winnipeg doctors do welcome northwestern Ontario residents, it is not always easy, and the provincial government can decline funding for certain tests. This physician cited that in this case, the scan would then not happen. There is no option to pay out of pocket.

In addition to bureaucratic roadblocks to receiving care in a different province, there are also a great deal of administrative barriers to the dementia diagnosis process that physicians and their teams must contend with.

“... usually I do a chart review, so I'm going through any records I can access or that have been sent....Manitoba has an E chart system, which allows me to see all the diagnostics, blood work...pathology reports, for people in Manitoba. So that is a challenge for Ontario, because I

don't have access [to E chart system].... so I'm relying entirely on what the family physician has sent to me...” HP5

This quote demonstrated that care in another province seemed to require a great deal of administrative work and communication between healthcare systems and professionals to assist in the diagnosis process.

Overcoming shortages of physicians in rural and remote areas has worked well to bridge some of the gaps in the system. Particularly with the Ontario Telemedicine Network it has provided access to specialists and allows patients to stay in their communities. Additionally, it has been an extraordinary example of teamwork among healthcare professionals. For example, OTN physicians work alongside allied health professionals in the region such as psychogeriatric resource consultants who are in the room to assist with assessments and communication with patients.

“I think they view me as a member of the team as well, so even though I'm far away, yeah, and because we have such a long history together” HPI

This physician describes the OTN model as a team effort, and that the healthcare professionals present in northwestern Ontario communities are crucial to providing OTN physicians with test results, medical histories, and assistance facilitating virtual appointments.

“...whenever they bring in new staff... [they] always asked me to meet with them and provide some education. And one thing we've done as well over the years is worked out an assessment process.... and they usually actually do a host of other standardized screenings as well. So,

they'll screen for depression, anxiety, and they'll assess function in using a particular scale”

HPI

Caring beyond the initial diagnosis: Resource shortages

Beyond initial contact with the healthcare system to receive a diagnosis of dementia, much like caregivers, continuing care and support was also seen as a challenge by physicians. Many expressed their frustrations trying to help patients access social and practical support like housing and respite services.

“So, trying, yeah, so trying to get more urgent housing. So, what that looks like is quite variable. Often, unfortunately, it is long-term care which has long wait lists. Sometimes these people end up in the hospital for a lengthy period of time before they can get into long-term care. And I don't think that's necessarily the most appropriate place. We do have a coordinator that deals a lot with trying to get these individuals ODSP or CPP or on welfare, getting their disability tax credits so they get more income that can then subsequently help them obtain supportive housing in an apartment locally, but currently, our wait list for supportive housing in our apartments here are between five and eight years...” HP2

The lack of long-term care homes causes extremely lengthy wait times, but the lack of long-term care homes also represents a potentially traumatic experience for our First Nations populations. Coming off reserve to the only long-term care home anywhere close to their homes means facing a disturbing reminder of abuse to themselves or their ancestors.

“Same with going into long term care, incredibly traumatizing [the LTC home] is literally three kilometers from an old residential school that many of them went to, right so it becomes really difficult, and we see a lot of traumatic behaviors that need to be managed if they do come to our long-term care. And it's just, it's all historical, and recognizing that, not only for the patient, but their families too” HP2

In addition to long-term care or assisted living facilities, support to care for a person with dementia at home was also seen as an issue.

“Now, another thing that often is not available, though I think, in terms of dementia care, is home care. So, I mean home care is not great anywhere in Ontario in terms of what's supplied or what's provided for people with dementia.... But I know in some of the smaller communities in the north you just can't get the staff. There's a real shortage of staff, and even people who qualify for significant amount of care... often, it's just logistically difficult to provide it” HP1

On First Nations reserves in northwestern Ontario, it is even more difficult and can lead to negative outcomes for those who are diagnosed with dementia.

“....there's no home care.... there's a loosely community organized, Meals on Wheels for elders kind of...it's not overly consistent. So, they really depend on family members, right? And unfortunately, with a lot of addictions there, even the family members are not necessarily able to support those elders, right?...those elders often end up in crisis in our emergency rooms, which is even more scary as somebody who is slipping [term first nations individuals use for dementia]

or has dementia in a very noisy environment that increases their likely[hood] of delirium, and their behaviors come out, and then they're admitted, and it's just, it's not a nice... so it would be lovely to have more elder supports in the indigenous communities. And it is not there at all [exaggerated tone], right?" HP2

Despite the many challenges highlighted by physicians, they did talk about the advantages of interprofessional collaborations such as with pharmacists, or other healthcare professionals that assist with virtual consults over OTN. Unfortunately, although there are great examples of teamwork and successful bridging of gaps, it is still not enough to meet the demands of the northwest region.

On the same side: Physicians and caregivers see the same issues

Having seen the experiences from both physicians and caregivers who are working in and accessing a system that is under a great deal of stress, the issues identified were similar for both groups. Even though the healthcare system, primarily physicians, are the ones who are facing the disappointment and anger of people struggling to access care, they themselves are aware of the shortcomings and are impacted negatively as well. The table below illustrates that caregivers and physicians are on the same page when it comes to wanting improved dementia care in northwestern Ontario.

Caregivers	Physicians
HEMECARE	
<i>"It's mainly family.... they don't have the staff they need. So, Home Care won't work with</i>	<i>"Now, another thing that often is not available, though I think, in terms of dementia</i>

<p><i>her because she's on reserve, and the health center on the reserve is supposed to be doing it. The health center on the reserve is not doing it, and so now the band office has said we will pay like her siblings when they go visit her, if they're there for a certain amount of time” CP3</i></p>	<p><i>care, is home care. So, I mean home care is not great anywhere in Ontario in terms of what's supplied or what's provided for people with dementia. Hopefully things are going to get better in the future, but I know in some of the smaller communities in the north that you just can't get the staff. There's a real shortage of staff, and even people who qualify for a significant amount of care...often, it's just logistically difficult to provide it” HP1</i></p>
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Specialists and Imaging

<p><i>“...if you lived in Toronto, we wouldn't have gone through this.... Your family physician would have referred you to a behavioral neurologist, and we wouldn't have spent three years like we did, like this” CP4</i></p>	<p><i>“...the negative aspect of things like just finding the resources for people sometimes can be difficult. It's frustrating for patients too. My other frustration is sometimes with more complex forms of dementia that getting consult service like we're really good at the [clinic name] Clinic. We're lucky that we have a neurocognitive neurologist that we can access.... Sometimes they do say that these patients need to be assessed like in person. That's problematic because our resources are</i></p>
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in Toronto and Thunder Bay, and we are two hours from Winnipeg, and so often I have to ask my colleagues in Winnipeg our neurologists, particularly in the movement disorders clinic, to see them. And sometimes that's an issue, even to travel there to get a diagnosis. And again, that's with more of the sometimes complex Parkinson's or multi system atrophy or primary progressive neuropathies that can be more difficult to access those supports, and that's frustrating for me, because I feel that I do not have the skill set to diagnose the like, to recognize the subtleties between those diagnoses. Yeah, so that's a frustration” HP2

“...the availability to get neuroimaging. We don't necessarily need neuroimaging to make a diagnosis, but the majority of people in a big urban center will get some neuroimaging. And I think less so in rural areas.... I think that there are some unusual cases that emerge, sometimes with dementia, where

	<p><i>there's an atypical history, maybe a bit of an unusual subtype of dementia that it's very hard to identify. And I think you know those people are best looked after or assessed in a... subspecialty clinic, like a memory clinic, often in a big center.... So, you know, triaging those making sure those people can get that assessment is more difficult in a rural area”</i></p> <p><i>HP1</i></p>
<p><i>Interprofessional collaboration</i></p>	
<p><i>“It’s not a circle of care” CP4</i></p>	<p><i>“And then how do you maintain a circle of care and support, and I think that's maybe more difficult in the North but not having really any real experience in the South. I only have vicarious knowledge of what's happening” HP4</i></p>

*It is important to note that the caregivers and physicians who took part in this study were not recruited as dyads. They were recruited as two random samples from all over northwestern Ontario. This table does not reflect a patient and their physician’s opinions on the same issue. Merely that caregivers and physicians from the region are both aware of the shortcomings within our system and want better for people with dementia.

This final section of the findings underscored the importance of highlighting this solidarity as a meaningful step in building stronger relationships between physicians and caregivers. Healthcare shortages in northwestern Ontario that impede time to diagnosis, health system coordination, specialist care and testing, all require a great deal of extra work. Physicians work hard to try to bridge gaps and give their patients what they need, but sometimes there is nothing that can be done to overcome the absence of infrastructure. The individuals paying the biggest price for the healthcare system shortages are the caregivers and people living with dementia. Caregivers are taking on more responsibility to care for people at home and spending more time and energy trying to find and access whatever support they can. What is consistent among physicians and caregivers is the identification of the supports and services that are missing, and it is with that information that more can be done to address the accessibility of services in northwestern Ontario.

Chapter 6: Knowledge Mobilization

In conclusion of this research a knowledge mobilization process was undertaken to make the findings of this research more accessible to a broader audience. The aim of this section was to critically evaluate the information gathered from caregivers of people living with dementia and physicians to share the results of this research with broader audiences, and demonstrate some of the concerns people in northwestern Ontario have when diagnosing dementia or receiving that diagnosis. The material created is meant to be educational and raise awareness of the struggles faced by people living with dementia, caregivers and physicians.

This knowledge mobilization process aimed to create a tangible product from a traditionally theoretical qualitative methodology that illuminates the personal experiences of those who have been diagnosed or practice medicine in northwestern Ontario. This process highlighted areas where the personal experiences of physicians involved in this research and the caregivers intersected with policy and procedures to raise awareness of the complex issues facing dementia diagnosis processes in northwestern Ontario. A short informational video was created that translated the findings of this study into lay language for the general public to be used during presentations.

Creation of the video followed the concepts of the Knowledge to Action Cycle (Graham et al., 2006) and utilized the Barwick (2008) planning template for knowledge translation. For the purposes of this research the term knowledge mobilization will be utilized to align with the most current terminology used by health and social service research organizations in Canada. Knowledge mobilization is defined as: "...an umbrella term encompassing a wide range of activities relating to the production and use of research results, including knowledge synthesis, dissemination, transfer, exchange, and co-creation or co-production by researchers and

knowledge users” (Social Sciences and Humanities Research Council, 2019 para. 4). Subsequent sections will go on to explain the goals and purposes of undergoing a knowledge mobilization process as part of a research project but will include the terms used by various organizations in keeping with the source materials, as there are many terms used to describe this process. However, anything created as a result of this research will be referred to as knowledge mobilization materials/resource.

The Canadian Institutes of Health Research (CIHR) definitions emphasize that the goal of the knowledge translation process is to use what is learned from research to develop resources and make changes with the goal of improving outcomes or efficiencies within the healthcare system (Graham et al., 2006). This is particularly suited to this research, as the information obtained from interviews is most applicable to people who live and work in northwestern Ontario. The healthcare system in northwestern Ontario, as highlighted in previous sections, operates with unique challenges that are not experienced in other parts of the province.

The knowledge to action cycle was utilized to define the purposes and steps required to integrate knowledge gained because of this research into an informational video that summarizes this research for the general public in northwestern Ontario.

The Knowledge to Action Cycle functions in two parts 1) knowledge creation: where existing information or materials is combined with knowledge from research that can be used within healthcare and 2) the action cycle: whereby that knowledge is transformed via various processes and implemented into practice (Graham et al., 2006). In a review of action processes Graham et al (2006 p. 20) found common themes within this phase of knowledge translation:

- Identify a problem that needs addressing

- Identify, review, and select the knowledge or research relevant to the problem (e.g., practice guidelines or research findings)
- Adapt the identified knowledge or research to the local context
- Assess barriers to using the knowledge
- Select, tailor, and implement interventions to promote the use of knowledge (i.e., implement the change)
- Monitor knowledge use
- Evaluate the outcomes of using the knowledge
- Sustain ongoing knowledge use

As mentioned in previous sections, there are many terms, often used interchangeably, to refer to the creation of knowledge-based materials. The model of knowledge to action presented here supports the Canadian Health Services Research Foundation’s definition of ‘knowledge exchange’ and: “In contrast, with knowledge translation and transfer, there is no expectation that the same stakeholders will be involved in all phases of the process. Indeed, it is often assumed that there would be different individuals involved at different steps in the KTA journey” (Graham et al., 2006 p. 17). This is important for this research as recruitment within a strained healthcare system was a challenge, and maintaining physicians and caregivers for the duration of this thesis would have been unattainable. To guide the process of developing these materials, the Barwick (2008) planning template was utilized. This template assisted with the planning and execution of this process by highlighting key components of developing these materials (see appendix C).

Although the goal was to co-create these materials with physicians/healthcare providers and caregivers of people living with dementia, this was not feasible due to recruitment struggles.

Instead, the researcher took lessons learned and common experiences to transform the data into an educational video. A short video demonstrating the challenges and triumphs of receiving a diagnosis from the perspectives of physicians and caregivers was created. This video aims to show the emotional impact and the difference that adequate care and support could make for both physicians and people living with dementia. The goal of this was to bring awareness of these issues to lay audiences.

The results of this research were presented within this thesis in traditional ‘chapters’ within a much larger document that will most likely never be seen in its entirety by anyone outside of my academic committee and reviewers. For part of this thesis, I combed through news articles and social media posts about healthcare in northwestern Ontario. It was so frustrating to read paper after paper, post after post, and hear the same stories about the struggles of our healthcare system. We have incredible physicians, some who participated in this work, others who consistently advocate in the media etc. to try and get help for the healthcare system in our region. Despite the Ontario Medical Association (n.d.(b)) deeming our healthcare system ‘a Crisis’ it still seems to be falling short of making anyone's top priority. It seems unfair that we keep asking for ‘proof’ and valuable time of our already strained healthcare providers to advocate for change when the data is in, and we are in fact in crisis. There were so many pieces of information from physicians in this region who were speaking about the challenges that they face in their practice in northwestern Ontario. Although the topics spanned various types of care the message was all the same; we need help. I reflected on this a lot throughout this thesis. Due to severe shortages of physicians in this region and seeing the consequence of that-such as ongoing hospital closures due to staffing issues- physicians were all taking what time they could to raise awareness and ask for help. Despite this, the struggle continues. This research did not

uncover a solution to the healthcare crisis; there is no one solution. But it did uncover the impact of the crisis on caregivers, physicians, and people with dementia and the willingness of people to speak up for change. The numbers in this region are small, and I can only assume (and hope) that we must make more noise to appear as big as other parts of the province.

This is what inspired the knowledge mobilization resource for this research. While it is important to include the unique perspectives of northwestern Ontario in published literature, there was an opportunity to translate findings into a more accessible format for lay audiences that could serve to make the general public aware of the population of physicians, caregivers, and people living with dementia in this region that are greatly impacted by the shortages in the healthcare system.

(See attached knowledge mobilization video)

Chapter 7: Discussion

This thesis explored the perceptions of caregivers and physicians who were a part of the dementia diagnosis process for residents of northwestern Ontario. Knowing that the healthcare system in this region has unique challenges (e.g. physician shortage, lack of home care) the aim of this thesis was to understand how these potentially impacted the experience of the dementia diagnosis process. The findings chapters (3-5) detailed the experiences of caregivers, physicians, and then compared their experiences to each other to see where there were similarities/differences in their experiences. This discussion chapter will follow the same format starting with caregivers, then physicians and then concluding with a section on caregivers and physicians. Following the discussion of findings is a section on significance and expected outcomes. This section outlines the research and theoretical implications of this thesis including suggestions for future work that could be done on this topic. Next, is the practical and clinical application of these findings to dementia diagnosis processes in northwestern Ontario. Finally, this chapter concludes with post research reflections to enhance transparency and includes the researcher's positionality statement written after the completion of this research.

Caregivers

Physicians are often pictured as the person giving a diagnosis and responsible for continuing care, but they are only one of many people that caregivers and people with dementia will interact with throughout a diagnosis process. In an ideal situation, a person would see a family physician first. They will often make a diagnosis if it is a typical presentation of cognitive impairment, and if needed refer to a specialist if it is an atypical case. One could then expect to be referred to community health and social services for continued care and support. As simplistic as that seems, in the northwest region of Ontario many people do not have a family physician or

cannot easily access one. Wait times are long and services are sparse or non-existent in many communities. The system is incompatible with the needs of caregivers and people living with dementia.

The goal of this research was to learn about caregivers' experiences of the dementia diagnosis process in northwestern Ontario. It appeared from the findings of this thesis that caregivers' experiences of the dementia diagnosis process in northwestern Ontario included how their continued interactions with healthcare professionals shaped their ability to care for the person with dementia. Throughout this research it became evident that caregivers' relationships with physicians could be very strained. This always stemmed from some incongruence between knowledge and wishes for care not being heard or met.

Sometimes doctors can only provide their patients what they have available to them, despite knowing that more should be done. However, people often go to physicians thinking they have all the answers and knowledge and when they feel that they are not being given enough, they can be frustrated by the lack of care and support they receive. Better communication between physicians and caregivers regarding wishes for care and what services are and are not available, could help temper expectations. In many stories, the knowledge caregivers possessed of the situation was crucial to obtaining the most valuable support. This information could have helped to guide conversations towards what mattered most to them during diagnosis appointments if communication between physicians and caregivers was more open. For example, Yates et al. (2021) found that although caregivers saw value in the dementia diagnosis disclosure, they wanted more emphasis on prognostic conversations so they could plan ahead and know what challenges they could be up against. This was prevalent among caregivers in this thesis as well. They were more concerned about planning ahead to support their loved ones at

home than they were about the disclosure itself. It is therefore important that we encourage caregivers to have the confidence to ask questions and tell healthcare providers what their concerns for caregiving in the future are. If an environment can be fostered where those things are communicated with physicians early on, hopefully they can direct patients and caregivers to someone that can help facilitate services and support that suits their needs.

Additionally, a review by Szymczyńska et al. (2011) found that lack of training among healthcare professionals, inability to access services to support caring for someone with dementia post diagnosis, and not enough research on rural memory clinics all need to be addressed as barriers in order to better support people living with dementia and caregivers in rural areas. Although clear communication could lead to proper support, it needs to be acknowledged that sometimes the wishes for care cannot be met. Northwestern Ontario has limitations in the services available (Ontario Medical Association, 2021) but work can be done to make what is available more easily accessible to ensure that caregivers do not feel like they are alone in caring for someone with dementia. It is not the responsibility of caregivers to bridge gaps between the healthcare system and social support services. There needs to be connections in place to save caregivers time and energy so they can focus on the person they care for.

While caregivers within this thesis described lack of support and services available to them, simply implementing more is not a quick solution. The support that is valuable to a person with dementia and their caregivers will most likely differ from one person to another. Current literature on dementia caregiving experiences highlights the significant gaps in knowledge that exist in rural and remote regions, but point to some strengths that may be unique to these settings that could be leveraged in future research initiatives. A systematic review of qualitative studies by Campbell-Enns et al. (2023) revealed that family caregivers of persons with dementia in rural

areas identified trustworthy and helpful relationships within their communities that could create a sense of safety and aid in caring for people with dementia, similar to the concept of “social safety nets” identified in northern remote communities in northwestern Ontario (Wiersma & Denton, 2016). However, despite these helpful relationships experiences of stigma were also present in these rural communities (Campbell-Enns et al., 2023; Wiersma & Denton, 2016) and are an issue that requires further attention. Further, another review of informal caregiving for dementia in rural and remote areas had similar findings of lack of formal support and education for caregivers, stigma, and the need for more research on the needs of family caregivers of people with dementia in rural settings (Innes et al., 2011). Leveraging social connections and addressing stigmatizing views of dementia is a start to improving dementia care in rural and remote regions. Future research should focus on caregivers and people with dementia’s values and needs for support so that health and social support systems are changed to address their unique needs.

Sacrifice is a selfless act that all the caregivers in this study undertook to provide the best care and support possible for the person with dementia. Regardless of hardship, they all willingly stood by their person to the best of their ability. Caregivers, physicians and other health professionals are always going to have to be in contact with one another. Law et al. (2021) called them a ‘natural resource’, but respect for caregivers of people with dementia as part of a healthcare team is crucial to maintaining their well-being. With these implications in mind, relationships should be strengthened between healthcare professionals and caregivers, so both sides feel like they can communicate effectively their wishes and values for care. Increased communication gives the opportunity to show support and solidarity to caregivers, and transparency about what is and is not available to them to save time searching for things that

aren't there. The goal is doing what is best for the person with dementia and maintaining their quality of life.

Caregiver stress

Caring for seniors with dementia has been found to increase caregiver stress nearly twice as much as compared to someone caring for a senior without dementia (Canadian Institute for Health Information, 2016). However, in northwestern Ontario, stress associated with caring is exacerbated due to the health system shortages (e.g. lack of homecare, physicians).

A study conducted in northwestern Ontario by Bowd & Loos (1996) identified challenges that caregivers of people living with dementia faced in this region nearly 30 years ago. The authors conducted a survey with 68 caregivers of people living with Alzheimer's disease in the region (Bowd & Loos, 1996). Resources that were identified as most important included family support, home care, physicians, friends, Alzheimer Society, public health nurses, caregiver support groups, and other social services (Bowd & Loos, 1996). The results of this thesis expanded upon this research and identified ways to support caregivers by utilizing a qualitative methodology that let caregivers tell personal stories of how the healthcare system has influenced their experience of a dementia diagnosis and ability to care for someone. While accessibility of diagnostics and specialist care has increased for those in northwestern Ontario by leveraging platforms such as telehealth, the examples of system gaps and nonexistent services were in each participant's stories. Bowd & Loos (1996) called out increased support for caregivers in northwestern Ontario to improve their well-being over a quarter century ago. Unfortunately, this was something that caregivers in this thesis still wished for. Take the caregiver who could not obtain homecare on reserve because no such infrastructure existed resulting in police finding her mom wandering around after being missing for hours. Although there are different levels of

federal and provincial government responsible for providing healthcare to First Nations individuals (Government of Canada, 2023) creating jurisdictional issues, First Nation reserves are a part of our population and make up a significant portion of northwestern Ontario compared to the rest of the province. It is important that future work endeavor to learn more about the ways that Indigenous people in northwestern Ontario can be better supported, regardless of where on or off reserve.

Another example was the caregiver who wasn't able to place her mom in a long-term care home and was told she should be able to look after her at home because there is 'help for that', all while she continued to work a full-time job and had to move to a locked apartment complex so her mother couldn't escape and get lost. It was incredibly sad to hear that similar need for help was identified by Bowd & Loos (1996) almost thirty years ago and yet caregivers are still suffering the consequences of a broken system. Further, a study conducted in Saskatchewan by Stewart et al. (2016) found that female caregivers of people living with dementia in rural settings reported more burden and severity of distress compared to men. This is an important finding to highlight, because this thesis consisted of a sample of only female caregivers. Future research could further examine the differences/similarities between female and male caregivers in northwestern Ontario.

Physicians

Diagnosis processes

Physicians in northwestern Ontario face many challenges diagnosing and caring for people with dementia. Diagnosing dementia is a complex process that physicians learn primarily through hands on training post-graduation. The SPIKES protocol is a procedure developed for disclosing a cancer diagnosis to patients (Baile et al., 2000) but is adapted and used as a

‘breaking bad news’ protocol for many other conditions. Physicians in this research cited this as the teaching they received in medical school that would be applicable to dementia, but it was not enough to learn how to effectively diagnose someone. As previous research has found, the breaking bad news protocols that are taught in medical school are lacking any component that speaks to the emotional impact of diagnoses on physicians themselves (Bennet et al., 2019). The physicians in this study clearly stated that they learned to diagnose people with dementia, including how to tailor their conversations to individual patients, by learning from others and through practice during post grad training and throughout their careers. Managing their own emotions was something that they seemed to just figure out on their own. Some cited getting more confident with yourself as a physician, having other healthcare professionals that you could talk to, and preparing yourself to address difficult emotions of patients. Interestingly, the family doctors in this research also believed that having a strong relationship with the patient also helped them. It made them more amenable to hearing bad news from them, lessening strong emotional reactions, and thus making the physicians feel better about how the diagnosis went.

In northwestern Ontario there are severe shortages of physicians with more than 200 spots open for family physicians alone (Northern Ontario School of Medicine University, 2023). The shortage of physicians in this region means that the physicians who do currently work here are most likely facing greater workloads, putting them at risk for burnout. A family physician in this research had remarked that it took so long to schedule an interview because they had recently took over a practice and said: *"my life is literally eat, work, sleep, repeat"*.

In an article by West et al. (2018) top reasons for physician burnout included excessive workload, work inefficiency and lack of work support, lack of work-home balance, loss of

control and autonomy, and loss of meaning from work. Similarly, physicians in this thesis cited the lack of dementia care availability (e.g. home/community care, social supports, housing) as well as the lack of physicians and specialists. This is important because these are contributors to physician burnout, meaning that those who diagnose dementia in northwestern Ontario could be at a higher risk.

Learning to regulate your own emotions is not enough. There should be more emphasis on resources and supports for physicians who are dealing with the emotional impact of their practice. The Canadian Medical Association reports that 1 in 2 physicians report high levels of burnout, and family physicians are more at risk than other specialties (Canadian Medical Association, n.d.). Further, Underdahl et al. (2024) stated that physician burnout, emotional exhaustion, and depersonalization are at a crisis and there is no current solution to address this rising concern.

A helpful tip for managing physician emotion could be targeting aspects of a diagnosis that cause distress. For the physicians in these studies, removing a driver's license was sometimes worse than telling someone they had dementia. As mandated reporters (Ontario Medical Association, n.d. (a)) they have requirements for assessing and reporting patients that they believe have met criteria for removing a driver's license. Often taking away this privilege was associated with taking away someone's independence and had the potential to damage the relationship between them and their patient. Patients blame physicians for this decision even though it is a provincially mandated regulation. More information and resources for doctors on how to manage emotional reactions because of removing a license could strengthen bonds with their patients and lessen the emotional toll of taking away something so meaningful.

The physicians in this study gave valuable insight into the emotional work that they experience throughout a dementia diagnosis. They were left to be self-directed when it came to managing their own emotions and relied on preparedness and support from colleagues. Frank et al (2018) states that: “A structured approach can help alleviate physician anxiety and improve the experience of the person living with dementia and caregivers. Most important, disclosure is not a single event but a dynamic, evolving process including pre-disclosure preparation, sensitive individualized disclosure, and follow-up education and support” (p.1). Medical school and residency were stepping stones in their career that taught them foundational skills, but learning to read people and tailor diagnosis conversations was experiential.

The importance of remaining cognizant of your emotions to mediate your patients' reactions (Bennet et al., 2019) was also something that physicians in this research spoke to. Each one had their own way of preparing themselves for managing their own emotions and people they turned to for help to prevent burnout. Bailey et al (2019) reported that physicians peer support was needed to prevent burnout and emotional disengagement. This too was a concern for the physicians in this study, as they spoke to the importance of their peers not just for learning but talking about difficult diagnoses. Even though physicians in our region face a greater workload, and dementia diagnosis can present emotional challenges, they were all extremely passionate about providing the best care they could for people with dementia in northwestern Ontario.

Bridging gaps in the healthcare system

We know that people in northwestern Ontario are at higher risk of mortality, multiple chronic conditions and inability to access healthcare professionals compared to the rest of the province (Health Quality Ontario, 2017). Yet, when the healthcare system is discussed, the

province of Ontario is looked at as a whole – the unique needs and circumstances of the northwest are not considered separately. Despite this, the stories told within this research from both sides of the healthcare system, caregiver and physician, highlight that they are fighting the same battle. So far, it is not clear who is listening. In a CBC news article from May of 2024, the government argues: “We will illustrate that there is no concern of a diminished supply of physicians. Across Canada, Ontario has the best record in attracting medical graduates to train in Ontario. Further, Ontario has enjoyed a growth in physicians that far outstrips population growth” amidst negotiations with the Ontario Medical Association who is highlighting the concern over physician shortages and compensation in Ontario (Jones, 2024 para. 12). Despite the vastly different opinions on the state of the healthcare system in Ontario between both parties, qualitative data has a chance to illuminate the issues behind the numbers that have been blanketed across the entire province and used as justification for ignoring personal, human experiences accessing healthcare. This phenomenological study sought to uncover the stories and faces behind those experiencing ‘the crisis’. Humanizing the impact of our healthcare system on physicians and their patients will hopefully add depth and understanding to some of the current issues in northwestern Ontario for those seeking a dementia diagnosis.

Addressing accessibility issues in northwestern Ontario

Rural Health Hubs

A potential solution to bridge system gaps and strengthen the healthcare system in northwestern Ontario is the concept of rural health hubs and patient medical homes. The Ontario Hospital Association states: “Rural Health Hubs will allow local health and social service providers, through formal agreements and partnerships, and on-going community consultation, to improve the coordination and effectiveness of care for a defined population and/or geographic area. Each rural health hub will be locally defined and tailored to the community. A rural health

hub is flexible, not one size fits all, is innovative, based on local need and provides coordinated access to care” (2015 p. 6). A pilot project was conducted on the concept of rural health hubs and patient medical homes in northwestern Ontario. A total of 12 participants (4 patients, 1 physician and 7 individuals in managerial positions within local healthcare settings) believed that the structure of these concepts could be helpful such as shared electronic medical records systems, improved patient navigation via coordination of care, a common governing body, and strengthening a culture change focussed on a model of patients first (Newbery & Malette 2021). This coincides with the findings of this thesis as well. Shared electronic medical records, improved patient navigation, and focusing on people with dementia were all cited by physicians and caregivers as important aspects of good dementia care. To better understand what this could look like in the community, a Rural Health Hub would consist of the following (Ontario Hospital Association, 2013 p. 2):

1. Emergency and Inpatient Care typically provided by small hospitals¹ (i.e., acute, rehabilitation and complex continuing care);
2. Comprehensive Primary Care – family physicians working with a team of allied health professionals (e.g., Family Health Teams and Community Health Centres) with a strong focus on population health and chronic disease management;
3. Home and Community Long-Term Care – long-term care home beds, assisted living units, community support services for seniors and professional homecare services (nursing, therapies etc.); and,
4. Mental Health and Addictions – community-based treatment and support services, access to specialty beds (when required), and traditional healing services for First Nation communities.

Strengthening the interconnectedness of these various medical settings would improve communication among health care providers and help caregivers who are accessing different healthcare settings at different times to coordinate continuing care. The concept of Rural Health Hubs addresses key issues that the participants in this study raised. Particularly, it would leverage the obvious awareness of both physicians and community members (e.g. people living with dementia and caregivers) knowledge of what their community needs, and would be supported by the objective to be “locally defined and tailored to the community” (Ontario Hospital Association, 2015 p. 6). As outlined in Chapter 5: *Diagnosing dementia in northwestern Ontario: A case of acute insufficiency*, physicians and caregivers were on the same page when it came to the disparities in dementia care in their communities and what was needed to improve services.

Interprofessional care

In the model of Rural Health Hubs above, family physicians may be leading a team of interprofessional individuals, but other models of practice highlight the shared responsibility among different disciplines. The World Health Organization (2010) describes collaborative practice when: "... multiple health workers from different professional backgrounds provide comprehensive services by working with patients, their families, carers and communities to deliver the highest quality of care across settings" (p. 13). An example of a collaborative model of care, called an Integrated Care Team (ICT) was: "...created to reduce fragmentation and improve efficiency. The goals of the ICT are to promote ageing in the community, optimize quality of life, support self management of chronic conditions, and avoid ED [emergency department] visits" (Heckman et al., 2025 p. 193). The ICT model has been found to help

improve quality of care, reduce system fragmentation, increase accessibility to community services, and reduce the amount of emergency department visits (Heckman et al., 2025). These are all things described by both caregivers and physicians in this study as barriers to good dementia diagnosis and care. Models such as these could be implemented to improve interprofessional collaboration and enhance dementia care by creating team environments with healthcare professionals from various disciplines that work together.

Telehealth: Bringing care to the north

During the initial phases of this thesis, multiple health organizations in northwestern Ontario were contacted. A respondent from one of those organizations became very influential in providing background information on how many people in northwestern Ontario, particularly those living outside Thunder Bay in smaller communities, obtained a diagnosis of dementia. Due to accessibility issues in these communities, people can access a specialist via a telemedicine service and obtain a diagnosis of dementia. Telemedicine/telehealth is described as: "...the delivery of various types of healthcare when patient and provider are geographically separated — it can involve video conferencing, telephone calls, electronic data transmission, and other ways of communicating over the internet" (Canadian Agency for Drugs and Technologies in Health, 2016 para. 1). In northwestern Ontario, The Ontario Telemedicine Network (OTN) has bridged a huge gap for the district and allowed patients to access specialists virtually. Those referrals would come from a family or emergency room doctor, either initiated by direct contact between patient and physician, or through geriatric mental health service providers who would assist them in obtaining a referral. The OTN enables people to stay within their communities and receive specialist care (i.e., geriatrician, geriatric psychiatrist) as opposed to travelling outside the province, usually to Winnipeg, Manitoba, or to Thunder Bay, to connect with a specialist.

Most often these specialists are based out of Toronto, but geriatricians from Thunder Bay can also provide care through the OTN platform. People who access care through the OTN can continue to see the treating physicians for ongoing care and follow up appointments. A physician from Winnipeg who diagnoses people with dementia from northwestern Ontario was recruited and provided great insight into the struggles of multi-jurisdictional healthcare. Although some choose to travel out of comfort or ease of access, most people choose telehealth so that they can stay within their communities. It seems that travelling to Winnipeg is not often chosen to receive a diagnosis of dementia unless certain tests, such as a spec scan are required. The only other option for this type of scan would be Toronto. Therefore, whichever is easier to access would be the one chosen (Toronto or Winnipeg).

The northwestern Ontario based telemedicine program was evaluated for its impact using a combination of retrospective chart assessments, analysis of patient and staff evaluations, a survey of referring physicians and focus groups of health professionals who are involved in the process (Conn et al., 2013). This telepsychiatry service has been provided via the Ontario Telemedicine Network since 2002 in partnership with Baycrest Centre in Toronto and District Mental Health Services Older Adults Program (DMHSOAP): “to provide telepsychiatry consultations and/or tele-education on a rotating weekly basis to six communities in Kenora and Rainy River Districts of Northwest Ontario, which are approximately 1800 km from Toronto and cover an area with a radius 1,200 km” (Conn et al, 2013 p. 1796). The most common diagnosis made via this service was dementia (54%) (Conn et al., 2013). Overall, telemedicine was regarded highly in the northwest region, but barriers identified within the focus groups included timely implementation of recommendations, and buy in from community health professionals about the usefulness of telemedicine (Conn et al., 2013). Further use of telemedicine in rural and

remote populations was examined in a study by Morgan et al. (2014) which found that caregivers and patients using telehealth to access the Rural and Remote Memory Clinic (RRMC) in Saskatchewan, Canada reported high satisfaction on the 10 item Telehealth Satisfaction Scale. Evaluation of the effectiveness of this psychometric scale was also conducted and found to show strong factor structure and internal consistency and reliability (Morgan et al., 2014) strengthening the findings of this evaluation of the success of the RRMC.

Accessibility to healthcare is a primary issue that needs to be addressed in northwestern Ontario. Yaffe et al (2008) identified in their research that physicians in smaller practices felt there was a lack of access to specialist care for their patients. This was confirmed in this thesis as well. Physicians who worked in Thunder Bay seemed to perceive less of a barrier than those in district communities. This made sense, as all specialists were located in Thunder Bay and access would be less challenging compared to those who lived hours away from the city. Telemedicine use is one way that district communities are increasing the accessibility of dementia care in their communities.

Physicians supporting caregivers

In a study that included a survey of 85 family physicians and 8 follow up interviews, the top areas that physicians wanted to learn more about to support family caregivers (FCGs) were: “assessing FCGs’ needs in an organized way (91% interested or highly interested), assisting FCGs to access resources and overcome barriers (89%), address system and practice barriers to support FCGs and reduce your own angst (80%), and supporting the emotional and psychological needs of FCGs (78%)” (Parmar, et al., 2024 p. 4). Some participants in the qualitative interviews suggested there is a lack of support for family caregivers, there was more reliance on them as physicians, and rural physicians noted that more care was done by family

because of the lack of resources (Parmar et al., 2024), pointing to the notion that practicing in rural areas increases the amount of work for physicians because they are relied on more to bridge gaps. Physicians also noted barriers such as a lack of integrated home and community services, care coordination and navigation, and knowledge of resources available (Parmar et al., 2024). All of these areas were also highlighted within this thesis. Having rural physician perspectives is helpful to understand that isolation from specialized care is a real issue. They reported frustrations trying to bridge gaps for patients, that other physicians working in larger urban centres would probably not have to do. The physicians in the study by Parmar et al (2024) also noted improvements are needed to address respite, funding and home care, and some believed that social workers may be better suited to assist caregivers in obtaining the support they need. Much like the idea of a rural health hub by the Ontario Hospital Association (2015) physicians felt that: “Primary care should have close relationships with home care, other local health services (hospitals, specialists, congregate care), and broader community social supports to address FCG’s and the person’s receiving care non-medical needs seamlessly” (Parmar et al., 2024 p. 7).

Further, in a study by Podgorski et al. (2021) they proposed a bio-psychosocial ecological model to demonstrate how family relational factors could influence the experience of dementia for both the caregiver and the person living with dementia. They stated that: “A relational approach to dementia care acknowledges that a dementia diagnosis often represents a significant life event for a family as it generates ripple effects far beyond the symptoms of the one diagnosed” (Podgorski et al., 2021 p. 12). Implementing this approach to care could be improved through use of a common electronic medical record systems to bring together health and social service providers and strengthen their ability to meet the needs of caregivers and people living

with dementia (Podgorski et al., 2021). Strengthening the interconnectedness of health and social services in northwestern Ontario was also recommended to address the barriers to good dementia care. Further, the bio-psychosocial ecological model aligns well with the design of this thesis and the use of existentialist phenomenology. This model also considered that relationships between the individuals involved in a diagnosis are intrinsically connected to people's perceptions and experiences of care. Podgorski et al. (2021) stated that: “Dementia care at the family level is relational, transactional, and often delivered in ways that reflect the nature and quality of family relationships. An awareness of relational influences help clinicians develop safe, effective, and sustainable care plans” (p.12). Lessons from this thesis about the relationships between caregivers and physicians, how physicians learn from, and are impacted by emotional responses for those they diagnose all demonstrate real life examples of this model.

Further exemplifying the importance of relationships, a study by Elliott et al (2018) found that providing care for older adults in rural communities had unique challenges, and healthcare providers felt that relationships were essential to their ability to provide care. Having trusting relationships with patients helped increase likelihood of them accepting supports, and relationships among providers helped with coordination of services (Elliott et al., 2018). This further exemplifies how improving relationships between healthcare professionals and caregivers could be instrumental in improving dementia care.

Caregivers and Physicians

Although caregivers in this research told the stories of loved ones receiving a diagnosis of dementia in northwestern Ontario as one of a gross lack of resources and frustrating inability to access the healthcare system for continued care and support, physicians also described the shortfalls. The blame for insufficient care will be the face a person is most familiar with, their

own doctor, but are they supposed to shoulder the blame? This research highlighted that caregivers and physicians are not on different pages when it comes to the concerns over dementia care in northwestern Ontario.

Encouraging a revolt or distancing the relationship between caregivers and physicians would be detrimental to efforts to improve dementia care in northwestern Ontario. Physician interviews all emphasized the importance of knowing your patients personal and medical history, and for caregivers to feel that they are integrated and respected as part of the care team. Both of these are sentiments that reflect a relationship between parties that allows collaboration and movement towards a shared goal; providing the best care possible for the person with dementia. It is important to encourage a strengthening of relationships and communication so that the most can be made out of the resources that exist and work together to make up for those that do not. Physicians too know and feel that there are gaps in the system. Unfortunately, there are so many issues to tackle that some get left unaddressed. It appeared from some caregiver's stories that a lot of frustration could have been saved if values and wishes for care were discussed more comprehensively. It is better to be honest about what they can expect than let them figure it out on their own.

Indigenous dementia care

The introduction of telehealth in northwestern Ontario is one example of working together, that has made a huge difference for people in communities, especially those outside of Thunder Bay. It provides access to specialists for diagnoses where there aren't any, and specialist services that do not exist in this region. In a systematic review of telemedicine for dementia in rural and remote communities, they were not able to conclude that it improved dementia care, but it does solve access issues (Sekhon et al., 2021). Furthermore, more focus should be paid to

Indigenous populations who use these services as much of these rural and remote areas have Indigenous populations (Sekhon et al., 2021). This is especially true in northwestern Ontario, as we have a large population of Indigenous people across 88 First Nations (Move to northwestern Ontario, n.d.). Although the sample in this thesis only consisted of one individual who identified as Metis, and one physician who spoke to her Indigenous patient population, it seemed that they faced different challenges compared to those who lived off reserve.

One of the first challenges in understanding the health inequities is understanding who bears the responsibility for providing health care for Indigenous people. The Government of Canada states: “With respect to health care for Indigenous peoples, which include First Nations, Inuit and Métis, the federal, provincial and territorial levels of government share some degree of jurisdiction. The Canadian health system is a complex patchwork of policies, legislation and relationships. Indigenous peoples are included in the per capita allocations of funding from the federal fiscal transfer and are entitled to access insured provincial and territorial health services as residents of a province or territory. Indigenous Services Canada funds or directly provides services for First Nations and Inuit that supplement those provided by provinces and territories, including primary health care, health promotion and supplementary health benefits” (2023, para. 6). Based on this explanation, it is hard to determine what services and supports would or would not be provided by certain levels of governments. Halseth (2018) stated that there is an ‘urgent’ need for dementia specific care for Indigenous peoples and their caregivers that respects their culture and addresses the current gaps in their ability to access appropriate care in Canada. Further, while Chakanyuka et al. (2022) set out to conduct a scoping review of reviews on culturally safe healthcare, with a focus on dementia care, they did not find any that mentioned culturally safe dementia care for indigenous peoples. It is clear that this is a significant gap in

dementia care literature. While myself, and this thesis were not positioned to conduct a culturally safe study on Indigenous populations of dementia care in northwestern Ontario, it would be remiss to not include the experience passed on to me by these participants. Hopefully, it acts as a signal for further investigation and development of a culturally inclusive study that looks specifically at the dementia diagnosis experiences of the Indigenous population in this region.

Missing infrastructure

There are not only access issues for receiving a diagnosis and having an ongoing family physician, but there are few or non-existent community health and social supports. This negatively impacted caregivers because they were unable to care for their loved ones at home without a great deal of struggle. It also impacted physicians emotionally because they felt they were not able to provide the care required by their patients. Currently, Bill 121, aimed at improving dementia care in Canada, is nearing acceptance (Russell, 2024). However, concerns over the success of the bill included physician shortages, lack of support for caregivers, and low wages for those providing home care (Duggal, 2024). If these issues are not addressed in northwestern Ontario, then this bill will certainly only be a hope for better dementia care, not a solution. It is not the current healthcare professionals we have that are doing a bad job at caring for people with dementia; we just don't have enough of them to meet the demand.

Further, the Ontario Medical Association is spearheading a movement “Stop the Crisis” (Ontario Medical Association, n.d.(b)) drawing attention to the brokenness of the current healthcare system in northwestern Ontario. Unfortunately, as seen in this research the crisis has already had negative impacts on both caregivers and physicians. The experiences they’ve gone through, and continue to experience, should be motivation to not just stop the crisis for future patients and improve conditions for current doctors, but to put in place measures to deal with the

impacts the system has already caused. Hopefully, the findings of this study humanize the issues faced by both sides and serve as a call to action to advocate for change in northwestern Ontario.

Some of the literature that reflects on improving dementia care, or healthcare in areas that are struggling with systems gaps could point to unique solutions to the problems faced in this region. One of these models is the primary care collaborative memory clinics (PCCMCs) (Lee et al., 2020). This research highlighted that physicians gain most of their dementia diagnosis training via experience post-graduation (Lee et al., 2020b). PCCMCs are unique in that family medicine residents are trained to diagnose dementia by other family medicine doctors rather than by specialists as would be traditionally done (Lee et al., 2020b). This aligns with the demographic of physicians in northwestern Ontario as well, because there is a lack of specialists who would be teaching geriatric rotations. Lee et al. (2020b) state that: “Within PCCMC settings, residents are exposed to cases that are typical in family practice such as patients with subjective cognitive impairment, mild cognitive impairment (MCI) and dementia in the early or mid-disease stages. In contrast, in specialty settings, residents are typically exposed to cases referred to specialists that are atypical or complex or later in the stage of illness” (p. 449-450). More training and recognition of dementia in northwestern Ontario could improve the experiences of both physicians and caregivers. Further, in a qualitative study of caregivers and people living with dementia Franco et al. (2022) found that despite the belief that person centered care was essential to good dementia care, current health systems were not set up to support this. The more advocacy there is for better dementia care and awareness, the better the community can communicate about the needs and desires for care preferences and bring attention to system gaps where there needs to be improvement. A retrospective observational cohort study of data from a Rural and Remote Memory Clinic in Saskatchewan by Kosteniuk et

al. (2023) found that health service use started to increase approximately 4 years before receiving a diagnosis. Further, over a ten-year period (five years prior, and five years post diagnosis) family physician visits and all type and dementia specific drug prescriptions increased (Kosteniuk et al., 2023). Decrease in proportion of patients hospitalized and number of specialist visits decreased over the five years after a dementia diagnosis (Kosteniuk et al., 2023). This points to the success of a memory clinic model for rural residents, and expansion on this concept in northwestern Ontario could be explored to improve dementia care.

Significance and expected outcomes

Research/theoretical

The research implications of this study were not only to uncover a more nuanced understanding of the diagnosis experience, but to raise awareness that diagnosis processes are situated within a particular social context that influences how people experience it. There is a gap in research in northwestern Ontario, and particularly in an understudied area such as dementia diagnosis. This research raises awareness that although the healthcare system in these regions is suffering, dementia care should be prioritized. Physicians and other healthcare providers have a critical opportunity to set people up on a positive path to incorporating and living well with dementia. Even though there is nothing they can do to cure dementia, there is a lot they can do to show their support and make people feel like there is hope to still enjoy and live life the best way they can.

The use of existentialist phenomenology provided a new way of studying the healthcare system that encompassed the person centeredness and in-depth study of qualitative research, while creating knowledge that can be utilized by healthcare professionals and the public. Learning about caregiver and patient experience and hearing first-hand what impact the

healthcare system can have on an individual level will hopefully inspire adoption of knowledge gained through this research into practice. It is also a hope that by making the findings of this research personal and emphasizing the social experiences of these individuals it will inspire ‘champions’ of this cause among either healthcare professionals or caregivers of people living with dementia. The government certainly prioritizes achieving basic health needs of communities, but if personal stories can raise awareness of the impact of a dementia diagnosis and the struggles of northwestern Ontario’s healthcare system, hopefully the findings of this research will raise awareness for improved dementia care.

Clinical/practical

Clinical and practical implications for this research were to exemplify the areas where healthcare providers can make a significant difference in the experience of the dementia diagnosis process. Findings from this research created an opportunity for knowledge mobilization and new literature that raises awareness of how dementia diagnosis processes are conducted in northwestern Ontario, and where we can focus efforts to improve the experiences of patients, caregivers, and physicians. This research acknowledges that what works for southern parts of the province, may not be applicable here. The aim is to provide information that respects the unique challenges that physicians, caregivers, and people living with dementia face when seeking a diagnosis in this region of the province. Sharing the experiences from physicians and caregivers will hopefully bring awareness to how impactful the relationship between both parties is in providing the best care for people living with dementia.

This research also highlighted the emotional work that physician in northwestern Ontario experience. This was of interest as it has been documented that diagnosing dementia can be emotionally demanding and support was needed to prevent burnout (Bailey et al., 2019).

Evidence of the workload these physicians had was clear from initial recruitment (e.g. time it took from agreeing to complete an interview, to interview availability) through to the exasperation and emotion they expressed about the challenges they experience within their practice. Further investigation is warranted into how they can be better supported and their emotional well-being can be addressed.

Strengths and limitations

This study utilized existentialist phenomenology which examines in-depth experiences within small sample sizes of participants. It is, therefore, not a goal of this study to be generalizable to the entire northwestern Ontario population.

The strengths of hearing in-depth stories from the perspectives of physicians and caregivers within northwestern Ontario is that it highlights, that despite challenges, they are on the same team. Existentialist phenomenology (Thorpe & Holt, 2007) considers the inescapability of people's experiences and interpretations of things that happen in their life from social contexts. For this region, information obtained from this research is very specific to northwestern Ontario and can highlight deeper issues faced in the region such as the need to bridge system gaps and strengthen communication between caregivers and physicians to ease tension and improve relationships.

Another strength of this research was the diversity of physicians. A combination of family doctors and specialists from all means of obtaining a diagnosis of dementia for someone living in northwestern Ontario (i.e., via primary care clinic, specialist office, Ontario Telemedicine Network, and outside the region to Winnipeg, Manitoba). This provided great insight into some of the structural barriers to obtaining a diagnosis and the context for why it can be so complicated for caregivers and people living with dementia to navigate the system.

A limitation to this study was the inability to recruit people living with dementia. I was incredibly frustrated and saddened that I was unable to speak to these individuals and hear their firsthand experiences of being diagnosed in this region. I have dedicated the last 6 years of my academic career to doing research with people living with dementia and know firsthand the powerful impact they have on research findings and resulting materials. Although I never quit trying to recruit them, the study ended due to time constraints. If not me, anyone else in the future doing research in this area should try to recruit people living with dementia. Anecdotally, I learned from a community connection I made that their organization also faces great challenges connecting with people with dementia in the region. Their only advice was time and making your face known. Unfortunately, time was not on my side and neither was my seventeen-year-old vehicle that has limited long road trips left in its lifetime. The vastness of our region could take more than 9 hours in one direction toward a town with a significant population seeing not much more than trees in between. Although, the ability to travel around in person and make connections face to face would be the best bet to recruiting people with dementia in the future. The community partner was not shocked when I told her of my struggles, she replied “people in the north aren’t ones to join others”. For anyone in the future looking to recruit people with dementia in this region, it will take a great deal of trust, time and travel to make yourself one of them.

A further limitation to be mentioned is the potential to recruit participants who have a particular passion for dementia. For physicians, you could argue that those more passionate about dementia care in their practice were the ones who took notice of such a study, and thus took time out of their busy schedules to participate. For caregivers, those who have had a negative experience may be more motivated to speak out. A larger sample size in the future

would be beneficial to see if the experiences are more widely shared across northwestern Ontario.

Lastly, because the sample sizes were small and only one interview was conducted with each participant, there were limitations to the amount of interpretation that could be drawn from their experiences. Including more participants in a future study or conducting multiple interviews with the same participants would assist in identifying more patterns within meaning of people's experiences diagnosing or going through the diagnosis process. Existentialist phenomenology is about collecting rich data and multiple interviews with the same participants could have yielded even more insight into what influences their experience of the diagnosis process. Due to recruitment and retention issues, this was not possible for this thesis, but future studies could look for ways to achieve this with a greater amount of time allotted for recruitment and conducting interviews.

Lessons learned

There are many lessons learned, personal and professional, that will influence how I go about doing another research project in this region in the future. The first one is that I would not stage recruitment strategies with the attempt to escalate as I go along. Recruitment strategies I had used in the past in this region did not yield the same results this time around and I kept having to go more unconventional with my recruitment attempts. There was not one strategy that worked better than others, so I might as well roll them out all at once; there is no need to strategize the most prolific first. I learned many new ways to recruit that I had not considered or tried in the past and next time I would include all in my ethics and apply them all at once now that I know the extent that it can take to get the uptake needed.

The second lesson learned is that you are one in a million other emails. This should not be underestimated, especially in a post pandemic era of email blindness. It is not that I believed people's attention would be caught immediately by emails, but I did assume that with time eventually people would get around to responding. This was not the case. I genuinely believe, and anecdotally confirmed, that people are just consumed with emails and unless there is a recognition of who is sending the email it will be lost in their inbox. This is where having the help of people that I knew who were willing to lend their name to emails, or poster dissemination, helped me in reaching participants and organizations that otherwise I would not have. I would not underestimate the use of influence next time and would aim to leverage it more. People need to notice the research if they are going to participate in it.

The third lesson was persistence can feel uncomfortable. I really struggled reaching out so many times to the same people and places. I often questioned whether I was bothering people who did not want anything to do with the research but had no time to respond and say so. Or they did disseminate my poster, as some did, and never responded to tell me. Sometimes I did not get the answer I wanted from someone and had to look for someone else. I took what I felt were extreme attempts to get responses from people and organizations that I have not had to do in the past. Despite the lack of comfortability, I got the most response in these persistent attempts to connect with people. I would not spend so much time questioning myself next time.

On a positive note, my organizational skills paid off when navigating my recruitment. There were so many unanswered emails, responses to tell me I had the incorrect email, people who retired, getting passed off to someone else, etc. Having a spreadsheet of who responded, who I was talking to, and notes for suggestions on where to go next was the only way to keep it

all straight. It also helped me identify the most responsive people and take chances emailing again to ask for advice or alternative organizations that they knew of in their respective regions.

The last lesson I learned, and probably the hardest, was learning when it is time to pivot and let go of your original plan. I very firmly held onto the hope the I could get people living with dementia to be a part of this project, but unfortunately, I had to come to terms with letting that vision go. I had tried for over a year, and there were limitations to the only remaining opportunities to draw up participation. Doing a poster drop off tour of the northwest region would have required days of driving, a much newer and reliable vehicle, and money that I just did not have for travel expenses. Not to mention, you cannot just show up unannounced if organizations are not responding to you, because that would mean you are also not getting an invitation to join them in person. I genuinely believe that successful uptake in these regions for future work will be familiarity. I need to be someone that is recognized as not just a name on a computer, but a face. It would take a great deal of time and resources to bridge connections and create relationships out in the district, but there is an unwritten approval process to gain the trust of people in our region, and besides a lot of time and persistence you won't get through.

Post research reflections

The following section acts as a post research reflection that coincides with the positionality statement at the beginning of this work. Part of existentialist phenomenology is the belief that one can not be separated from their social world, or the context in which they exist. For me as a researcher, I reflected on why I chose this work and pursued the topic. This section creates even more transparency as it reflects on the rest of the research process as I conducted literature reviews, interviews, analyzed data and negotiated all of this with my own experiences to create this final piece of work.

It's not us, it's you-Relationships with the healthcare system

The Alzheimer Society of Canada released National Dementia Guidelines for Disclosing a Diagnosis that consists of a toolkit, infographic, and report on best practices for medical professionals who diagnose dementia within their practice (Alzheimer Society of Canada, 2023; Alzheimer Society of Canada, n.d.). The infographic and toolkit provide valuable information for healthcare providers on how to deliver a diagnosis of dementia in a way that is compassionate, hopeful, and considerate of the person's individual needs and preferences (i.e., having caregivers present, cultural and ethnic understanding of illness, etc.) (Alzheimer Society of Canada, 2023; Alzheimer Society of Canada, n.d.). However, as this research has explored the diagnosis of dementia as not a one-time disclosure of an illness, but as an ongoing process, we saw an intimate building of a relationship between the person diagnosed and their family with their immediate health and social care systems. As in all relationships, success relies not on just one person, but many, and although communication is critical, so too is mutual understanding and compatibility. Although in recent years we have seen communication between healthcare providers and people living with dementia and their caregivers improving via avenues such as telehealth, there is still room for improvement in compatibility and understanding. Particularly in northwestern Ontario, where the healthcare system is not compatible for people being diagnosed with dementia and receiving adequate care and support thereafter. It is not an individual physician problem; it is a system problem that is incompatible with the needs of both parties.

Future work could expand upon the conceptualization of relationships in dementia care practices as a way to improve the diagnosis process and add to toolkits and information on how to improve practice. Although a small sample, this research demonstrated many instances where physician and caregiver perceptions of the diagnosis process were influenced by relationships.

For example, the caregiver who was told by the physician that she should be able to care for her mother at home and needed to take her back from the hospital. That caregiver felt abandoned, and resentful. She remarked that the system was broken and felt she may have been better off never having gotten a diagnosis for her mother in the first place as it could have kept her away from a system that was only causing distress.

System fragmentation is a major issue faced in this region. It is a struggle to meet basic healthcare needs of the communities, let alone handle the needs of those with chronic and life-limiting illnesses. There is a severe shortage of family physicians and specialists, and a lack of community health and social services to provide and maintain adequate care and support for the person with dementia and their caregivers, which would ultimately take burden off physicians.

The lack of understanding is not within the minds of healthcare providers, or caregivers of people living with dementia. They are extremely aware of the shortcomings and what could be done to improve them. The fierce advocacy of the healthcare providers in this region speaking out about the struggle to provide the care their community needs was clear. The most critical gaps can be identified by listening to caregivers who have had to bridge them on their own to support someone living with dementia. The lack of understanding is also a system problem. There is a disconnect between the experiences of healthcare providers, people living with dementia, and caregivers, and the governing bodies who create and enable these systems to continue to operate as they do. The physicians who took part in this research know the problems. The caregivers who took part in this research know the problems. Both are struggling with the realities they must work within, and what they know is best.

Recognizing power imbalance

Despite recognition that primary care clinics must be more vigilant in diagnosing and catching Alzheimer's disease in earlier stages, the phrase "Time lost is brain lost" was also used to describe the importance of catching symptoms early and the patient and caregiver's responsibility in a paper by (Liss et al., 2021). While the sentiment of learning to recognize signs and symptoms or increasing awareness and education so that caregivers and people experiencing symptoms can initiate a diagnosis, more careful use of language should be considered. The authors conclude that time lost is brain lost "...should be applied to the Alzheimer's disease continuum to encourage patients and family members to recognize the signs and symptoms of emerging cognitive decline, and to motivate clinicians to intervene whilst patients are cognitively intact or are only minimally impaired" (Liss et al., 2021 p. 326). I believe this use of language fails to recognize the stigmatized view of people living with dementia and emphasizes a sentiment of dementia from a deficit perspective. In addition, encouraging caregivers/patients to "motivate physicians" to recognize signs and symptoms of early dementia before independence is lost is also damaging. It's not a caregiver/patient's responsibility to be more educated than medical professionals to notice signs and symptoms and take the responsibility to 'motivate' doctors to diagnose. Education is empowerment, and as a society we need to do a better job at destigmatizing and spreading awareness of dementia so that people can not only recognize symptoms but feel safe enough to ask for help. Secondly, relational care practices create space and strengthen relationships between caregivers, patients and physicians so they can express concerns and feel like there is an open line of communication, but it is not caregivers' responsibility to save 'lost brain'. It appears that some caregivers in this thesis struggled to advocate against care or decisions that physicians made, unsure of what consequences it would

lead to. One caregiver wished she would have ‘hid’ her mother’s condition and never received a diagnosis to prevent how she was being treated within the healthcare system. Another who feared disagreeing with a diagnosis would cause some form of retaliation from their doctor. There are power imbalances at play that are not recognized when recommendations are made to shift responsibility onto caregivers and patients to motivate physicians. You could see power imbalances in the way caregivers expressed frustration towards the healthcare system that they seemed to be working against instead of with.

Researcher’s post research positionality: Polarizing experiences

One thing that I was saddened by yet again is the polarizing experiences of caregivers and people living with dementia. After hearing people’s stories in various research projects that I have been a part of over the years and all the varied experiences, the endings were sharply summed up as horrific or it was ‘fine’ considering the circumstances. It constantly wore on my mind how people within the same system of care in Ontario could have such different takes on a dementia diagnosis. As I considered people's stories, I realized that no one thing could be held accountable for their negative experiences. It wasn't a ‘bad physician’ that made the diagnosis unbearable, poor communication, or lack of resources single handedly. People with dementia and their caregivers are incredibly resilient, and although not an excuse for poor experience, people bounce back and thrive despite encountering challenges. I could see this in the stories of those who reported positive outcomes, despite having faced some trying times throughout the process. It seemed that just as the diagnosis was not a one-time event neither were the causes of these negative experiences. People diagnosed with dementia whose illness progressed clinically in ways that made them more reliant on caregivers and necessitated more medical support were the ones that ultimately reported poor experiences. Having to access the health and social care

system repeatedly is what wore them down. One negative experience trying to get a diagnosis such as having to wait months for an appointment, searching for information and getting nowhere, fighting and advocating that seemed to fall on deaf ears-people can overcome. Repeating this over and over again leaves them feeling hopeless, ignored, and overwhelmed trying to get the support they need. Increased reliance on the healthcare system increased the likelihood that people would describe the diagnosis as a negative experience.

Chapter 8: Conclusion

Caregivers are invaluable members of the care team for people living with dementia in northwestern Ontario. However, they are not always accepted into the healthcare team and valued for their knowledge like a professional would be. Not being heard by physicians damages relationships with the healthcare system and creates feelings of mistrust, frustration, and isolation for the caregiver. If dementia care in northwestern Ontario is to be improved, there is a need to assist caregivers in navigating the healthcare system, hear their needs and desires for care, and have honest conversations about what our healthcare system can do to support them with the fragmentation and lack of services that it deals with.

Physicians in this region are also struggling. They are faced with a heavy burden in their practice generally, and navigate their own emotions and system constraints throughout the dementia diagnosis process. System gaps identified in this thesis that impacted the experience of diagnosing people with dementia were due to lack of resources to follow up care and support for their patients. But it also told the story of the emotional work that physicians do in private that impacted them, and arguably their ability to provide the best care to their patients. More attention is needed to understand how we can offer support, training and management strategies to physicians to deal with the emotional toll of their jobs and prevent burnout.

Despite the clear tension in relationships between physicians and caregivers, it appeared physicians were not unaware of the problems. More open and honest conversations about expectations may help to improve relationships. Each party needs their own resources to help them navigate the dementia diagnosis and provide the best care possible for people living with dementia in their care.

Healthcare in northwestern Ontario is struggling no matter what you are accessing it for. For people with dementia, they will be constantly met with accessibility issues as this is a lifelong progressive disease. A diagnosis only marks the entry into the healthcare system. Healthcare shortages in these communities need to be addressed. In 2023, there were 1200 hospital service closures (Financial Post, 2024) and up until the writing of this thesis, hospitals are still suffering closures. Increasing access to primary care will impact dementia care in northwestern Ontario. Prevention is just as important as treating those that already have a diagnosis.

Despite challenges, significant gaps in the system are bridged by the ingenuity and hard work of preexisting healthcare professionals and caregivers in this region. Unfortunately, caregivers especially are bridging gaps at a great cost both emotionally and financially. Finally, there needs to be more consideration for Indigenous peoples' access to primary healthcare and dementia support within their own communities, especially on reserves. Navigating provincial and federally funded care means that people are getting lost in the system and not receiving the support they require. Although there were not enough participants in this study to draw conclusions, future work should consider looking specifically at the challenges this population faces. Dementia in northwestern Ontario can be superior, but we need to leverage the existing knowledge of those here to make this a reality.

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participants/application-process/samples-and-other-supporting-materials/information-consent-samples#GuideToCreating

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Appendices

Appendix A Checklist for creation of a consent letter

<https://uwaterloo.ca/research/office-research-ethics/research-human-participants/application-process/samples-and-other-supporting-materials/information-consent-samples#GuideToCreating>

UNIVERSITY OF WATERLOO OFFICE OF RESEARCH ETHICS

Checklist for Evaluation of Information Letter and Consent Form

- Name of Faculty Investigator/Faculty Supervisor and Student Investigator (where applicable)
 - Departmental affiliation and contact number/email for Faculty Investigator/Supervisor and Student Investigator
 - Statement that the study involves research
 - Purpose and/or rationale of the study
 - Description of all procedures in sequential order
 - Description of all known and/or anticipated benefits to participants from taking part in the study; if no benefits to the participant are expected, this should be indicated.
 - Description of all known and/or anticipated risks or discomforts to participants from taking part in the study; if no risks are anticipated, this should be indicated. For clinical trials, include a statement (if applicable) which identifies any risks specific to a woman who may become pregnant, a pregnant mother, nursing infant, embryo or fetus; if risks for these participants are not known, include a statement to this effect.
 - Safeguards to offset/mitigate risks are detailed
 - Details of time commitment required for participation in the project (and each component/session)
 - Details about any plan to re-contact participants for follow-up sessions or subsequent related project
 - Procedures to be used to ensure confidentiality of data and any limits to participant confidentiality
 - Procedures to be used to ensure anonymity of participants
 - Details of financial compensation or other remuneration of participants, including pro-rating for partial completion of study. Inclusion of the [finance statement](#). For a clinical trial include any anticipated expenses associated with participation.
 - Information on length of retention of data, as well as security and disposal of data
 - A statement indicating who or what groups will receive a copy of the report or thesis
 - A statement that participation is voluntary
 - A statement indicating participants may withdraw agreement to participate at anytime during the study without reprisal, and details on how the participants should communicate this decision to the researcher
 - Details on how to contact the researchers in the event of additional questions about the study
 - A statement indicating that the project has been reviewed and received ethics clearance (i.e., This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Committee (ORE#XXXX - insert your ORE file # here). If you have questions for the Committee contact the Office of Research Ethics, at 1-519-888-4567 ext. 36005 or ore-ceo@uwaterloo.ca.)
- Other Considerations with regard to the Information Consent Letter (ICL)**
- Language is clear and/or not too complex to be understood by participants

Appendix B Information and consent letter template

<https://uwaterloo.ca/research/office-research-ethics/research-human-participants/application-process/samples-and-other-supporting-materials/information-consent-samples#GuideToCreating>

Information-Consent Letter Guide

This guide provides: (a) suggestions for headings and lead-ins for each section of your letter, (b) bullet points that indicate the key elements of information that each section of the letter should provide, and (c) additional guidance for some sections located in the text boxes.

(to be printed on UW letterhead, see [E-letterhead and MS Word Template](#))

Title of the study: Insert title

Principal Investigator/Faculty Supervisor: Include affiliation (e.g., University of Waterloo plus Department, Faculty, Institute), telephone number and email address. If an international study, include "Canada" as well.

Student Investigator (if applicable): Include affiliation (e.g., University of Waterloo plus Department, Faculty, Institute), telephone number and email address.

"To help you make an informed decision regarding your participation, this letter will explain what the study is about, the possible risks and benefits, and your rights as a research participant. If you do not understand something in the letter, please ask one of the investigators prior to consenting to the study. You will be provided with a copy of the information and consent form if you choose to participate in the study."

Invitation to participation/What is the study about?

"You are invited to participate in a research study about ..."

- Indicate the purpose and objective(s) of the study in a clear statement using language that the participant population will understand.
- Include the rationale for the study or a statement about why the research is being conducted (e.g., "This is important as..." or "Past research has shown...").
- For student research, include the level of research project (i.e., for a course project/thesis/pilot study, etc.).

Additional Guidance

- Be sure to use lay language when explaining the purpose and rationale of the study, and throughout the letter. If you are recruiting from the general public or general student population, then discipline specific terms and jargon should be avoided, so a non-specialist can understand.
- The reading level of this section, and the letter as a whole, should be appropriate to the participant population. A grade five reading level is recommended for the general public.
- For some participant populations (e.g., elderly, people with low vision) the font size of the letter should be increased.

***This sample is for researchers to use in developing their study information letter and contains language applicable to most studies. Please read through and make the appropriate changes to ensure the information applies to your study.

Appendix C Knowledge translation template

Barwick, M. (2008). Knowledge Translation Planning Template. ON: The Hospital for Sick Children.

(Full template can be found here)

<https://www.sickkids.ca/en/learning/continuing-professional-development/knowledge-translation-training/knowledge-translation-planning-template-form/>

Knowledge Translation Planning Template[®]



INSTRUCTIONS: This template was designed to assist with the development of Knowledge Translation (KT) plans for research or non-research projects. It is universally applicable to health and other disciplines. Begin with box (1) and work through to box (13) to address the essential components of the KT planning process. Two e-learning modules are available for additional support: <https://bit.ly/2rh0LZo>

(1) Project Partners	(2) Partner Engagement	(3) Partner Roles	(4) KT Expertise
<div style="text-align: center;"></div> <p>Who could benefit from this evidence?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Researchers <input type="checkbox"/> Practitioners/service providers <input type="checkbox"/> Public <input type="checkbox"/> Media <input type="checkbox"/> Patients/consumers <input type="checkbox"/> Decision makers <input type="checkbox"/> Policy makers/government <input type="checkbox"/> Private sector/industry <input type="checkbox"/> Research funders <input type="checkbox"/> Volunteer health sector/NGO <input type="checkbox"/> Other: <ul style="list-style-type: none"> <input type="checkbox"/> _____ 	<div style="text-align: center;"></div> <p>When will partner or knowledge user (KU) engagement happen?</p> <p>Integrated KT</p> <ul style="list-style-type: none"> <input type="checkbox"/> From idea formulation straight through <input type="checkbox"/> After idea formulation & straight through <p>End of Grant</p> <ul style="list-style-type: none"> <input type="checkbox"/> At point of dissemination & project end <input type="checkbox"/> Beyond the project <p>Note: Not all partners will be engaged to the same extent or at the same point in time. Some will be hired for specific activities.</p>	<div style="text-align: center;"></div> <p>What will partner(s) or KUs bring to the project? How will they assist with developing, implementing or evaluating the KT plan?</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Note: Capture their specific roles in letters of support to funders, if requested.</p>	<div style="text-align: center;"></div> <p>Do you require KT expertise and how will this be accessed?</p> <ul style="list-style-type: none"> <input type="checkbox"/> Scientist(s) with KT expertise <input type="checkbox"/> Consultant with KT expertise <input type="checkbox"/> Knowledge broker/specialist <input type="checkbox"/> KT supports within the organization(s) <input type="checkbox"/> KT supports within partner organization(s) <input type="checkbox"/> KT supports hired for specific task(s) <p>Note: If your KT involves <i>implementation</i> for practice or behaviour change, include an implementation specialist or scientist.</p>

Appendix D
Interview guides

Interview Guide-People Living with Dementia

- 1) Can you tell me about your experience receiving a diagnosis of dementia?
 - a. When did you first notice changes with your thinking/memory?
 - b. How long did it take you to receive the diagnosis?
 - c. If you could change something about the diagnosis process, what would it be?
- 2) Can you tell me about how you felt when you were told that you had dementia?
 - a. Shocked, angry, sad, relieved etc.?
 - b. What do you remember most when you think back to that moment/time?
- 3) What type of pf support did you feel you needed during the diagnosis process
 - a. Who provided you with those supports?
 - i. physicians/healthcare providers (primary care provider or specialist?),
family, friends etc.
 - b. How did this support/lack of support make you feel? (positive, sad, grateful etc.?)
- 4) What do you think were some unique challenges or benefits of receiving a diagnosis where you live (considered to be in a rural/remote community)
 - a. If you had to seek care elsewhere, was that a positive or negative experience?
- 5) What would you want to tell physicians/healthcare providers about your experience of diagnosis?
 - a. What advice would you give them for diagnosing other people with dementia in the future?

- b. What impact would it have on someone with dementia if they had a positive experience with their physician during diagnosis? (Less stress, less fear etc.?)

Interview Guide-Physicians/Healthcare providers

- 1) Can you tell me about a time that you diagnosed someone with dementia?
 - a. How often do you diagnose people with dementia in your practice?
 - b. What parts of the diagnosis went well? Have you adjusted your process as you have made more diagnoses?
 - c. Has there been a time that you diagnosed someone and were unhappy with the way that it went?
- 2) Can you describe to me the emotions that you experience when you are going through the dementia diagnosis process with a patient?
 - a. Apprehensive, sad, confident etc.?
 - b. If describing something negative, follow with: Do you think there is something that could make those emotions more positive? (i.e. support)
- 3) Do you feel (medical school, post grad training, experience etc.) prepared you for diagnosing people with dementia?
 - i. If unprepared, what would you suggest? Change in curriculum, policy change in clinical setting, additional training post-graduation etc.
- 4) Does practicing in a rural community pose challenges to diagnosing dementia?
 - a. Can you describe some of those challenges? If not, what makes practicing in a rural community a benefit to diagnosing someone with dementia?

- b. If there are challenges, how do they make you feel? (Frustrated? Angry? Etc.)
 - c. If there are no challenges, how does that make you feel? (Grateful? Happy? Etc.)
- 5) Do you feel that diagnosing someone with dementia has an emotional impact on you?
- a. Does it impact you in a negative/positive way?
 - b. Do you feel supported throughout the diagnosis process? (By colleagues etc.)
- 6) What advice would you give to other physicians who are going to be diagnosing people with dementia in their practice?
- a. Is there anything else that you would like to add/tell me about your experiences diagnosing people with dementia?

Interview Guide-Caregivers of People Living with Dementia

- 1) Can you tell me about the experience when your family member/friend received a diagnosis of dementia?
- a. When did you first notice changes with their thinking/memory?
 - b. How long did it take them to receive the diagnosis?
 - c. If you could change something about the diagnosis process, what would it be?
- 2) Can you describe to me what your role was in the diagnosis process?
- a. Support, advocate, transportation to appointments, communicator etc.?
- 3) Can you tell me about how you felt once they had a diagnosis of dementia?
- a. Shocked, angry, sad, relieved etc.?
 - b. What do you remember most when you think back to that moment/time?
- 4) What type of pf support did you feel you needed during the diagnosis process?

- a. Who provided you with those supports?
 - i. physicians/healthcare providers (primary care provider or specialist?),
family, friends etc.
 - b. How did this support/lack of support make you feel? (positive, sad, grateful etc.?)
- 5) What do you think were some unique challenges or benefits of receiving a diagnosis where you live (considered to be in a rural/remote community)
- a. If you had to seek care elsewhere, was that a positive or negative experience?
- 6) What would you want to tell physicians/healthcare providers about your experience of diagnosis?
- a. What advice would you give them for diagnosing other people with dementia in the future?
 - b. What impact would it have on someone with dementia if they had a positive experience with their physician during diagnosis? (Less stress, less fear etc.?)

Appendix E
Recruitment strategy: TBNewswatch article

<https://www.tbnewswatch.com/local-news/researcher-reaches-out-to-people-with-dementia-and-their-doctors-8778899>

The screenshot shows the TBNewswatch.com website interface. At the top, there is a navigation bar with the site logo, a search bar, and links for 'FREE local newsletter', 'Your Business', and 'Sign in or register'. Below the navigation bar, the main content area features a large image of an excavator on a construction site. The article title is 'Researcher reaches out to people with dementia and their doctors'. The author is Gary Rinne, and the article was published on May 22, 2024, at 4:05 PM. A video player is embedded in the article, showing a portrait of Katelyn Wheeldon. To the right of the article, there is an 'Ads by Google' section with a 'Stop seeing this ad' button and a 'Why this ad?' link. Below the ad, there is a 'COMMUNITY POLL' section for the 'THUNDER BAY GOLF TOURNAMENT' on July 8, 2024. On the far right, there is a sidebar with the heading 'SPECIALIZING IN:' and a list of services: Power and Communications, Line Construction, Industrial Electrical Work, Heavy Civil Construction, and Aggregate Production.