Why Do You Care?
Exploring the Experiences of Health Care Providers Supporting Patients with Dementia in Primary Care Memory Clinics

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

Background: Alzheimer's disease and related dementias (ADRD) are often improperly or under-diagnosed in primary care; yet, it is expected that community-based care will be an increasingly important source of support for ADRD patients. In Ontario, primary care has continued to expand its services to include health team models, such as family health teams (FHTs) to provide multidisciplinary collaborative care for patients. Within such teams, memory clinic teams have also been implemented, which are clinic days set up typically once or twice a month to provide interprofessional collaborative care specifically for ADRD patients by trained health care providers (HCPs).

Objective: Little is known about the experience of HCPs who work in primary care memory clinic team settings to provide care for ADRD patients. This study explored these experiences. Specifically, questions were asked around the rewards, challenges and motivations with working in the memory clinic structure and providing support to ADRD patients.

Methods: A phenomenological approach was used. One-on-one semi-structured interviews were completed with 12 interprofessional team members in two primary care memory clinic teams. Interviews were transcribed and analyzed using Colaizzi's (1978) method of analysis.

Results: Overall, seven subthemes were found which describe the HCP experience. The first two subthemes describe *experiencing the journey with the patient and caregiver*. HCPs want to *support patients while maintaining the patient's dignity.* They also *balance emotional dilemmas with responsibilities.* The next two subthemes describe *experiencing the journey* *with the team*. HCPs feel *valued and connected to their team members*. The memory clinic structure offers *unique care provider experiences.* Lastly, three subthemes were found which describe the *personal and professional rewards of the experience*. HCPs found *thrilling complexities* within the patient population in the memory clinic and that working in the clinic they are able to experience *ongoing learning opportunities.* HCPs also described that the memory clinic offers *personal and professional fulfillment.*

Discussion: HCPs described an overall positive experience working in the memory clinic to support ADRD patients. HCPs take pride in being able to support patients and caregivers. Knowing that they are making a difference and doing good work are motivations to continue to work with complex populations, such as ADRD patients. HCPs enjoy working in close proximity to one another, respect their team members, and enjoy learning from each other. Team members motivate each other to stay and work with the ADRD population in primary care memory clinics. HCPs reap many rewards associated with working in a “tight-knit” memory clinic team setting for ADRD patients. As the number of HCPs working in team settings continues to grow in Canada, it is important to look at the experiences of these teams to understand the rewards, challenges and motivations of team members.

Conclusions: These findings provide more context in understanding how to motivate future HCPs to work with more complex populations such as ADRD patients. Future research should address the outcomes of these clinics by exploring patient and family caregiver experiences with specialized teams, as it is important to gain their experiences to enhance the care practices for these individuals.

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Dedication

To Dad, Mom, Billy and Labib.

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Chapter 1

Introduction and Background

1.1 Introduction

The prevalence of Alzheimer's disease and related dementias (ADRD) in Canada is expected to almost double by the year 2038, affecting 1,125,184 individuals—2.8% of the Canadian population (Alzheimer Society of Canada, 2010). With the expected increased prevalence of ADRD, the total economic burden of this disease in Canada is substantial and predicted to increase steadily, from $15 billion in 2008 to $153 billion in 2038 (Alzheimer Society of Canada, 2010); similar trends are also seen globally (Wimo & Prince, 2010; Prince et al., 2013).

It is projected that community-based care will be the primary source of support for ADRD patients due to the estimated increase in prevalence of ADRD diagnosis, as well as an expected shortage of long-term care beds (Alzheimer Society of Canada, 2010). Though these predictions are expected, dementia care is seen as challenging in primary care settings (Lee et al., 2010; Van Hout et al., 2000). Currently, ADRD is often improperly or under-diagnosed in primary care (Lee et al., 2010; Wilkins et al., 2007; Van Hout et al., 2000).

In Ontario, many health care providers (HCPs) in primary care work as part of team to provide multidisciplinary care for patients. Some of these primary care teams have further adopted a primary care memory clinic model to provide trained, collaborative, interdisciplinary support to patients with ADRD and their caregivers (Lee et al., 2010).

Gaining an in-depth understanding of individuals who share a common experience is important for informing practice guidelines and policy research (Lester, 1999; Creswell, 2007). Previous studies have looked at the experiences of those working with ADRD patients in other settings, such as acute care (Nolan, 2006) and in psychiatric care (Rasmussen and Hellzen, 2013). Another study in Ontario explored the challenges of ADRD care among family physicians (Pimlott et al., 2009b). The current study sought to explore the experiences of these HCPs who work in primary care memory clinic team settings to provide support to patients with ADRD and their caregivers. Specifically, questions were asked around the rewards, challenges and motivations of working in a memory clinic team to provide care to those with ADRD.

1.2 Background

1.2.1 ADRD: Prevalence and Impact

ADRD is a chronic disease which affects approximately half a million older Canadians (Alzheimer Society of Canada, 2010), is a primary cause of functional disability (Agüero-Torres et al., 1998) and often leads to long-term care placement (Agüero-Torres et al., 2001; Alzheimer Society of Canada, 2010). Dementia is the "umbrella term" used to describe a wider variety of disorders in which the brain becomes damaged, affecting one's thinking and memory (Alzheimer Society of Canada, 2010). In 2008, 7% of the Canadian population over the age of 60 experienced some form of dementia, while 55% of the population over the age of 80 were diagnosed with dementia: these rates are expected to increase to 68% by 2038 (Alzheimer Society of Canada, 2010).

Accounting for two thirds of all dementia cases, Alzheimer's disease is the most common form of dementia (Canadian Study of Health and Aging Working Group, 1994; Alzheimer Society of Canada, 2010). Alzheimer's disease symptoms typically appear after the age of 65, and the disease is progressive and degenerative, involving a loss of brain cells and reduced brain function (Alzheimer Society of Canada, 2010).

The second most common form of dementia is vascular dementia, which is characterized as a lack of blood supply to the brain, and leads to damage of the vascular system (Alzheimer Society of Canada, 2010). Conditions such as heart problems, high cholesterol and high blood pressure are often seen in vascular dementia patients (Alzheimer Society of Canada, 2010). Many individuals with this form of dementia are subsequently diagnosed with Alzheimer's disease (Alzheimer Society of Canada, 2010). Other forms of related dementias, which are not as commonly diagnosed, include frontotemporal dementia (including Pick's Disease), Lewy body dementia, and Creutzfeldt-Jakob Disease (CJD) (Alzheimer Society of Canada, 2010).

1.2.2 ADRD in Primary Care: Challenges in the Current System

In Ontario, individuals who have chronic diseases frequently utilize primary care services (Canadian Institute for Health Information (CIHI), 2011). Primary health care services in Canada typically include regular access to a primary care provider, such as a physician or a nurse practitioner (HCC, 2012). Primary care plays an important role in chronic disease management, as it is typically the first point of contact individuals have with their health care system (Fleming, 2012). Though this is the case, the primary health system was initially designed to manage and treat acute illnesses, which normally consist of shorter patient-physician consultations, quick diagnoses, and simpler cures (Ministry of Health and Long-Term Care (MOHLTC), 2007). Ontarians who suffer from chronic diseases such as ADRD are seen as more challenging to care for, as the system was not designed to fit these patients' long-term, complex needs (MOHLTC, 2007).

Individuals diagnosed with ADRD typically present with other chronic diseases that require care (Schubert et al., 2005; Sanderson et al., 2002). Schubert and colleagues (2005) found that the top chronic diseases present in ADRD patients in primary care were diabetes (39.3%), coronary artery disease (20.6%), stroke (10.3%), chronic obstructive pulmonary disease (12.2%) and cancer (8.4%). These researchers found that on average, ADRD patients in primary care often had an average of 2.4 chronic conditions (not including their ADRD diagnosis) (Schubert et al., 2005).

Managing chronic diseases requires a smooth coordination of services across settings as well as integration between the health care providers involved (MOHLTC, 2007; Bergman et al., 1997). The shorter consultations that often take place in primary care make it challenging for physicians to manage patients who present with multiple chronic issues (Pimlott et al., 2009b). Challenges to proper management of chronic diseases relate to receiving the proper care during early identification, as well as time constraints and improper coordination of care services, which sometimes impede appropriate information exchange (Muntinga et al., 2012).

Diagnosing ADRD is challenging in primary care, due to its fast-paced environment, shorter consultations, and lack of knowledge on dementia diagnosis (Lee et al., 2010; Lee et al., 2013). Studies have shown a lack of comfort among primary care physicians regarding ADRD diagnosis (Van Hout, et al., 2000; Morgan et al., 2009; Lee et al., 2010). In Canada, it has been estimated that as few as one-quarter of persons with

ADRD in Canada are diagnosed and treated properly (Callahan et al., 1995; Feldman et al., 2008). ADRD is often confused with other cognitive issues, such as delirium and depression (Lee et al., 2013). In a study by Wilkins and colleagues (2007), it was found that primary care physicians were often able to diagnose patients with severe cognitive impairment, but had difficulty diagnosing those with milder cognitive impairments. Differentiating between the different types of dementia is also viewed as a difficult task within primary care (Van Hout et al., 2000).

Accurately diagnosing ADRD is important in primary care, as older adults prefer to remain in their households and receive community-based care (Dye, Willoughby and Battisto, 2010). One study found 64% of community-dwelling seniors who actually had ADRD were not diagnosed with the disease (Sternberg, Wolfson & Baumgarten., 2000). In 2008, approximately 55% of ADRD patients 65 years of age or older remained in their households, and were receiving community-based services. This estimation is expected to increase to 62% in 2038 (Alzheimer Society of Canada, 2010).

One goal of primary health care is to provide a way of managing patients' chronic illnesses while allowing them to remain in the community (HCC, 2012). With the expected increased prevalence of ADRD patients remaining in the community and receiving primary care services, it is important to look at services and practices that are currently happening in primary care. With this increase of patients comes an increase in demand of innovative ways to enhance ADRD support in primary care.

1.2.3 Changing the Face of Primary Care

1.2.3.1 Implementation of Health Teams

Bringing together experienced health care providers within primary health care settings is essential to providing more comprehensive, collaborative care for patients (MOHLTC, 2005). Primary health care has continued to expand its services to include interprofessional collaboration by implementing health teams (Orchard, Curran & Kabene, 2005; HCC, 2012). Collaborative health care allows various types of health care providers to work to bring together areas of expertise and knowledge in order to achieve high quality care (MOHLTC, 2005). Health care providers who are part of an integrated health team may include nurses, physicians, social workers, pharmacists, and dietitians (HCC, 2012; MOHLTC, 2005).

Although there are a number of team delivery models in primary health care, [e.g., Community Health Centres (CHCs), Comprehensive Care Models (CCMs), Family Health Groups (FHGs), Family Health Networks (FHNs), and Family Health Organizations (FHOs)], this thesis will focus on Family Health Teams (FHTs) as they are the most widely implemented model in Ontario, with over 200 established FHTs across the province (Collier, 2011). FHTs were implemented as a strategy to integrate care for patients and are defined as a team of health care providers who work together to coordinate and provide tailored care to patients (MOHLTC, 2005). One of the mandates of FHTs is to effectively manage chronic diseases by providing integrated care services (MOHLTC, 2005; HCC, 2012).

1.2.3.2 Introducing Primary Care Memory Clinics

In Ontario, many FHTs have implemented a model within their team setting to provide more enhanced care for patients with ADRD. These teams have been trained to adopt a “memory clinic model” within their setting. The next two sub-sections will discuss the history of memory clinics in health care, and more specifically, primary care memory clinics, which are increasingly being adopted in Ontario.

1.2.3.2.1 History of Memory Clinics

Memory clinics were first developed in the 1980s to treat patients with cognitive impairment, as well as strengthen dementia research (Passmore & Craig, 2004; Jolley, Benbow & Grizzell, 2005). Typically these specialized memory clinics take place in a hospital or outpatient setting and are associated with specialist services (van Hout et al., 2000; Logiudice et al., 1999; Luce et al., 2001; Jolley, Benbow & Grizzell, 2005; Morgan et al., 2009). Services are provided by HCPs such as psychiatrists, nurses, psychologists, geriatricians and neurologists (Morgan et al., 2009). Memory clinic team members are trained to more accurately assess the type of dementia (van Hout et al., 2000). Research has looked at the effectiveness of adopting a specialized memory clinic versus other means of care. Having access to a memory clinic team could potentially assist general practitioners to ensure a proper ADRD diagnosis (van Hout et al., 2000). Van Hout and colleagues (2000) found that when compared to an outpatient memory clinic team, general practitioners were moderate in the accuracy of detecting dementia among patients, but had trouble identifying the type of dementia. Specialized memory clinic research has also showed an improved overall psychosocial health in relation to the quality of life in caregivers (Logiudice et al., 1999). These clinics were also found to diagnose and treat their patients approximately two years earlier than Old Age Psychiatry (OAP) services (Luce et al., 2001).

With a shortage of specialists (Frank, 2010), it is necessary to develop a model of assessing memory in a timely manner in primary care. Woods and colleagues (2003) discuss the complex nature of ADRD and the need for educators to think beyond the focus of training primary care physicians to accurately diagnose and manage the disease. Multidisciplinary training is an important component (Woods et al., 2003). Attaining a primary care team approach for the assessment of ADRD along with access to specialist services when required will assist in the timely recognition of the disease, bettering the patient through the prevention of crises and early access to treatments and services.

1.2.3.2.2 Primary Care Memory Clinics

The specialized memory clinic model has been adapted to fit a primary care structure, training already-established primary care teams on how to adopt a memory clinic model within their current primary care practice (Passmore & Craig, 2004). These clinics have been developed to properly diagnose and treat ADRD in primary care settings (Lee et al., 2010). The memory clinic model in Ontario offers a multidisciplinary team training approach to better assist in the diagnosis and treatment of ADRD among health teams (Lee et al., 2010). This five-day training program has been established with the collaboration of the Ontario College of Family Physicians (Lee, Kasperski & Weston, 2011). Team members are trained to work in this clinic, and provide comprehensive, collaborative assessments to patients who present with memory issues (Lee, Kasperski & Weston, 2011). These clinics offer an intermediate level of care between primary and specialist care for patients who present with symptoms of ADRD. With a shortage of specialist care, such as geriatric care, comes longer wait times for access to these services (Frank, 2010). This model is being developed in Ontario by primary care health teams to address the needs of patients with symptoms of ADRD as early as possible in order to provide proper treatment plans (Lee et al., 2010). FHTs are among the most common health team to embed this model within their current practice setting. Although not all memory clinic teams are identical, various health care providers such as physicians, nurses, pharmacists, social workers, and occupational therapists are the roles that are typically seen in the memory clinic structure in Ontario (Lee et al., 2010).

Health team members are trained to run the memory clinic collaboratively, typically one or two days per month to assess patients who are referred to this clinic. Referrals to the memory clinic may come from the health team's physician during their regular clinic hours, or from other physicians within the community. During these memory clinic days, health teams will typically only see the patients who were referred for memory testing. Initial comprehensive assessments of patients typically take on average two hours to complete, and follow-up appointments take about 1.4 hours on average (Lee et al., 2010). Comprehensive assessments assist in identifying and managing the cause of a condition and are an effective way of managing ADRD patients (Downs & Bowers, 2008).

Preliminary research related to the impacts of these clinics has already been completed in this setting. The clinic has been shown to have shorter wait times (average of one to three months) than a typical geriatrician referral (average of four to six months) (Lee et al., 2010). This primary care memory clinic was also shown to decrease the number of unnecessary referrals to the already limited number of specialists (Lee et al., 2010). Chart audits completed by two geriatricians found a high level of agreement with the diagnosis that was being made within the clinic. The memory clinic model has permitted more appropriate and necessary referrals to specialists (Lee et al., 2010). In addition, high patient and caregiver satisfaction was noted, as 84% of respondents agreed that the clinic educated them on their symptoms and conditions, and overall, they found the memory clinic to be a valuable addition to care provided by their family physician, as this intermediate level of care increases the capacity of primary care to handle more diverse, complex issues (Lee et al., 2010).

1.2.4 Working Together: Interprofessional Collaborative Practice

Collaborating in a primary care team environment has been shown to improve the quality of care, and is linked to positive health outcomes for patients (Collier, 2011). Patients also responded positively to team-based care, reporting greater satisfaction in the care received (Collier, 2011). Callahan and colleagues (2006) completed a randomized controlled trial to assess if working in a collaborative team environment improved care strategies for Alzheimer's disease patients. The researchers assigned physicians to either work in a solo environment, or collaboratively with a team of geriatric nurses, care managers, and psychiatrists. Patients were randomized to their physician's same care group. Collaborative team care was shown to have significant improvements in the quality of care that was received. Receiving care from the team was associated with patient improvements in behaviour and psychological symptoms (Callahan et al., 2006).

In other studies, physicians reported higher satisfaction when practicing medicine in a team environment (Collier, 2011). One study by Campbell and colleagues (2001) found higher rates of teamwork were associated with improved continuity of care, access to care, and patient satisfaction. Other reports have found that working in an interprofessional collaborative environment assists in improving the safety of the care delivered to patients (World Health Organization (WHO), 2005).

Although evidence exists for positive experiences when working and receiving care from teams, teams have been shown to be less than ideal when the team does not function as a collaborative entity, whereby dominant members prevent team members from feeling like equal contributors (Collier, 2011). Additionally, sharing the same skills as other members of the team has been shown in some cases to cause tension in the team setting (Collier, 2011).

In order to achieve collaboration among health care providers, teams must understand the factors associated with successful interprofessional collaborative practice. Orchard and colleagues (2005) have identified four enabling factors towards proper interprofessional collaborative practice including: clarifying roles of each team member, valuing each role, developing trusted relationships within teams, and sharing power with the team. Understanding other team members' roles is vital to achieving effective team collaboration (Collier, 2011). In a study by Goldman and colleagues (2010), health care providers reported the need to re-examine traditional roles, as it was difficult to determine how much of their own professional expertise would be needed within the team setting (Goldman et al., 2010). For example, physicians' attitudes towards collaborating with a team varied. Some felt it would be challenging to try and integrate different scopes of practice and share the responsibility for the patient.

Encouraging interprofessional collaboration by engaging in the creation of team policies and being part of the hiring process for other team members is an essential part of a FHT (Goldman et al., 2010). Developing organizational practices to assist with time management and keeping other members up-to-date on a patient's care within the FHT is also seen as an important aspect of working effectively and collaboratively (Goldman et al., 2010). Utilization of tools such as the electronic medical record (EMR) assists in keeping all members of the team up-to-date on a patient's care (Goldman et al., 2010).

Allowing care to be shared among a team of different disciplines is an enabler of better health outcomes (Goldman et al., 2010). Developing good rapport with team members and working closely with each other for a period of time assists in building the comfort and experience necessary to work effectively in a team setting (Collier, 2011). A shared care approach allows patients to be seen by a team of providers who all have different expertise, making it easier to care for particular problems (Goldman et al., 2010).

Chapter 2

Study Rationale and Research Objectives

2.1 Study Rationale

The aim of the current study was to explore the experiences of health care providers who support patients with ADRD in family health team-based memory clinics in Ontario. Previous literature has looked at health care providers' experiences working with patients with ADRD to gain an understanding of working with these patients in an acute hospital or long-term care setting (Nolan, 2006; Rasmussen & Hellzen, 2013). Other studies have looked at physician experiences working with ADRD patients in primary care (Pimlott et al., 2006b). These studies aimed to assist in understanding the meaning of caring for patients with ADRD (Rasmussen & Hellzen, 2013), in understanding the challenges of caring for patients with ADRD (Pimlott et al., 2006b), and in illuminating the experience of working with patients with ADRD (Nolan, 2006; Rasmussen & Hellzen, 2013). Increasing knowledge of the experiences of HCPs involved in chronic disease management is important for informing practice guidelines and policy (Lester, 1999; Creswell, 2007). Examining the experiences of health care providers who work with the ADRD population assists in relating existing knowledge about ADRD care with practical experiences (Nolan, 2006). For example, through a qualitative study involving semi-structured focus groups, Pimlott and colleagues (2009a) found physicians believed that the individuals who developed practice guidelines for dementia care had little knowledge and understanding about the actual experiences working with the ADRD population. Focusing on the experience of HCPs may provide a more enhanced understanding of the true responsibilities that are experienced (Nolan, 2006). These understandings may potentially lead to more practical and effective strategies for enhancing care.

The full effectiveness of primary care memory clinics and their impact on the communities they serve has still not been fully understood, as only a number of smaller studies have been completed. One study by Lee and colleagues (2010) has shown that a primary care memory clinic implemented in Ontario decreased the number of unnecessary referrals to specialists. Further, physician satisfaction surveys found that physicians believed being involved in the memory clinic improved the quality of care they provided to their patients (Lee et al., 2010). Understanding the experiences of front-line staff workers assists in developing strategies to enhance and improve primary care services (Moore et al., 2012). Exploring the experiences of HCPs who are involved in this clinic and their perspectives of the benefits this clinic brings to patients and caregivers is an important step in gaining a deeper understanding of the potential role and impact this clinic has on the community and the patients it serves.

Working in team settings to provide care to patients with complex chronic issues has been shown to enhance the quality of care of older adults in residential care facilities (Boorsma et al., 2011). Furthermore, working in a team of various health care providers has been shown to enhance the quality of care of ADRD patients (Callahan et al., 2006). As Canada is committed to expand interprofessional team models (Health Council of Canada, 2009), it is important to provide a way of diagnosing and treating ADRD properly within a team setting. Understanding the experiences of teams who have implemented a way of addressing these concerns is an important component of influencing future strategies that will be developed to address the needs of those with ADRD.

2.2 Research Objectives

The overall objective of this study was to explore the experiences of health care providers who work in primary care memory clinics to provide care for ADRD patients. This study explored the following main research question and sub-questions:

1. What is the essence of the experience of health care providers working in primary care memory clinic team settings in Ontario to care for patients with ADRD?
    a. What are the rewards, challenges and motivations associated with working in a primary care memory clinic team?
    b. What are the rewards, challenges and motivations associated with working to provide support for ADRD patients in the primary care memory clinic setting?

Chapter 3
Methodology

3.1 Qualitative Research Approach

A qualitative methodology was used to explore the proposed research question: *What is the essence of the experience of health care providers working in primary care memory clinic team settings in Ontario to care for patients with ADRD?* Specifically, a phenomenological approach was taken to grasp a deeper understanding of the "very nature" of the shared experience of these individuals (van Manen, 1990; Creswell, 2007).

3.1.1 Phenomenological Approach

Crabtree and Miller (1999, p. 28) describe phenomenology as a methodology that is used to understand the lived experience of individuals and their intentions within their "lifeworld"…. [Phenomenology] answers the questions: "*What is it like to have a certain experience? What is the essence of this particular experience?*" The purpose of phenomenological research is to "reduce individual experiences with a phenomenon to a description of the universal essence" (Crabtree and Miller, 1999, p.58).

Phenomenology has been used extensively in health and social science research (Crabtree and Miller, 1999; Creswell, 2007). This approach allows researchers to gain a deeper understanding of a common lived phenomenon that individuals share and its essence (Creswell, 2007). Phenomenology has been chosen because of its goal of gaining the perspectives of those who share a similar experience. Phenomenology differs from other types of qualitative approaches such as ethnography in its research purpose. Ethnographic approaches are utilized in qualitative research studies to look deeper into a cultural group, and normally describe experiences through careful observations and interviews with participants (Creswell, 2007). In contrast, phenomenological studies attempt to dig deeper into a common experience individuals share. Utilizing in-depth interviews, phenomenological researchers attempt to look at the common experience through the participants' eyes rather than their own (Creswell, 2007).

3.1.2 The Experience of Interest

This study's main experience of interest is health care providers who care for patients with ADRD in primary care memory clinics. These health care providers share a common experience of working in an enhanced model of primary care (memory clinic) and in a team practice setting to provide care for ADRD patients.

3.1.3 Developing the Interview Guide

As previously mentioned, phenomenology commonly utilizes semi-structured interview approaches (Creswell, 2007). Interviews enable "uncontaminated" responses from participants, as the participant is alone with the researcher talking about his or her own experience (Webb & Kevern, 2001). This study utilized semi-structured interviews in order to answer the research question. In phenomenological research, researchers typically ask participants about their experiences of the phenomenon (Moustakas, 1994) and about what has influenced their experiences of the phenomenon (Creswell, 2007). These are the main questions that should be asked during interviews with participants. As Creswell (2007) notes, other questions may be asked, which should stay open-ended. Questions typically involve the use of the terms *why* and *how* to gain a deeper understanding of experiences with the phenomenon (Creswell, 2007). The interview guide for this study was developed using Moustakas' (1994) main questions (summarized by Creswell, 2007, p.61): "*What have you experienced in terms of the phenomenon?*"

and, "*What contexts or situations have typically influenced or affected your experiences of the phenomenon?*" The researcher further adapted this guide to ask specific questions based on literature within the field of primary care memory clinics, caring for persons with ADRD in primary care, and working in multidisciplinary team settings. Probes were further developed to ask questions around the rewards, motivations and challenges of caring for ADRD patients in a primary care memory clinic team setting. The interview guide contained open-ended questions and probes, allowing the participant to think about and expand on certain ideas, enabling the researcher to gain in-depth knowledge about the participant's ideas (Sorrell & Redmond, 1995) (see **Appendix A** for the full interview guide).

During the development of the interview guide, the researcher piloted the guide informally with a nurse who works in a geriatric setting. This pilot assisted in gaining a better sense of which questions were redundant, the probes that should be included and used, and the timing of the interview. The guide was further adapted to include additional probes, which were sought to assist in gaining a deeper understanding of experiences.

3.2 Sample and Setting

Health care providers who work in primary care memory clinics in Ontario were recruited to participate in this study. Participants were asked to take part in a one-on-one interview with the researcher. According to Creswell (2007), ten participants is typically the average sample size in a phenomenological study. These interviews are relatively long and in-depth (typically one hour). For this study, participants were recruited and interviews were completed until saturation was reached (no new themes and ideas emerged) (Creswell, 2007).

3.3 Recruitment of Participants

Before recruitment began, this thesis project received clearance through the University of Waterloo Research Ethics Committee. The Executive Director of a Memory Clinic in Southern Ontario put the primary researchers in contact with two trained family health teams in Ontario. Upon receiving contact information, researchers contacted the Director of each clinic via email to explain the importance and relevance of the study, as well as the study procedures. Directors were asked to forward the study's information letter (**Appendix B)** to their memory clinic team members. To decrease coercion and assist in ensuring honesty during interviews with participants (Shenton, 2004), interested team members were asked to personally contact the primary researcher to set up a date and time to be interviewed. Participant recruitment followed a criterion sampling approach, as the purpose of this study was to gain the experiences of only those who worked in family health team based primary care memory clinic teams. Criterion sampling assists in recruiting participants who meet some condition or criterion, and is normally used in phenomenology research, as the main inclusion criteria involves experiencing the phenomenon of interest (Creswell, 2007). In order to be eligible for participation, health care providers were required to meet the following inclusion criteria: 1. Currently working in a family health team-based primary care memory clinic in Ontario; 2. Fluency in English. All participants were required to sign a consent form (**Appendix C**) at the time of the interview before participation.

3.4 Ethical Considerations

The researcher removed any identifying information of participants and teams during the transcription of the audio-recorded interviews. Codes were utilized when referring to health care providers. Before interviews began, the participant was asked to read over the information letter, outlining the purpose of the study, what their participation entailed, as well as the benefits and risks of participating (see **Appendix B**). During interviews, the researcher ensured that there were no misconceptions of participant answers by reiterating their answer and probing to gain more in-depth responses (Moustakas, 1994). Individual participant debriefing took place after the interview in which the researcher asked the participant if they had any concerns (Moustakas, 1994). The researcher's contact information was provided to participants, and they were told to contact the researcher if any concerns arose after the interview. Furthermore, a feedback letter (see **Appendix D**) was sent electronically after interviews to thank participants, update them on the progress of the study, and to reiterate the confidentiality measures that have taken place.

3.5 Approaches Taken to Enhance Qualitative Rigor

When utilizing a qualitative research approach, it is important to consider the steps that will be taken to ensure qualitative rigor is maintained. The four criteria researchers must keep in mind for enhancing qualitative rigor have been applied within this study. Table 1 defines the four criteria based on Baxter and Eyles' (1997) and Shenton's (2004) definitions - credibility, transferability, dependability and confirmability - and describes the ways in which the researcher attempted to enhance the rigor of this study.

Table 1: Maintaining qualitative rigor

Credibility	Transferability	Dependability	Confirmability
How true are the representations of the experience?	**What is the extent to which these findings fit outside the study?**	**What approaches did the researchers take to minimize idiosyncrasies of the data?**	**What is the extent to which biases, motivations, interests or perspectives of the researcher influence interpretations of the data?**
• Utilization of member-checking to validate the ideas that were found • Frequent debriefing sessions	• Interviewing participants from one urban and one rural setting • Using thick descriptions	• Audio-recording data (low inference descriptors) • Peer debriefing sessions	• Bracketing own assumptions, values and beliefs to account for own interests and motivations

Note: This table was adapted from Baxter & Eyles (1997)

Credibility allows the researcher to feel confident that the findings of the study are true to the actual experiences of the participants (Baxter & Eyles, 1997). Utilizing methodologies such as member-checking to validate the ideas that were found enhances the credibility of the study (Shenton, 2004). After completing the analysis of the results, the researcher contacted all participants to ensure that the findings were true representations of their actual experiences working in the memory clinic team to support patients with ADRD. Debriefing sessions with the researcher and her supervisor as well as the thesis committee members took place to assist in determining any flaws or biases during data analysis (Shenton, 2004). Transferability allows the study's findings to fit outside of the context in which it took place (Baxter & Eyles, 1997; Shenton, 2004). The researcher attempted to enhance the transferability of the current study by interviewing participants from both a rural and urban setting, and using thicker and detailed descriptions of the methodology which took place as well as the findings. Enhancing the dependability of the study relates to assurances that the interpretations of the data during analysis are not biased and true to the participant's experiences (Baxter & Eyles, 1997; Shenton, 2004). Dependability was enhanced by audio-recording each interview and double-checking that the transcriptions were truly depictions of the audio-recording. Peer-debriefing with colleagues and committee members also took place during the analysis stage of the research project to ensure the dependability of the findings. Confirmability was enhanced to minimize any biases, motivations, interests or perspectives that may be influenced by the researcher (Baxter & Eyles, 1997). Confirmability was maintained through the use of an audit-trail, tracking the steps which were taken during data collection and analysis (Shenton, 2004). The concept of bracketing (Creswell, 2007) was also utilized by the researcher to maintain a neutral perspective.

3.5.1 Bracketing Experiences

In studying the phenomenon of interest, the concept of *Epoche* or *bracketing* was used. Bracketing is used in phenomenological research in order to gain a neutral perspective (Creswell, 2007). This study employed bracketing, as it suspended the researcher's own presumptions in exploring the phenomenon of interest (Valle and King, 1978). As described by Creswell (2007), researchers bracket their experiences by "set[ting] aside their experiences, as much as possible, tak[ing] a fresh perspective toward the phenomenon under examination" (p. 59-60). Following Hamil and Sinclair's (2010) steps of bracketing in qualitative research, the researcher attempted to bracket her own experiences and assumptions of the research. This was achieved by utilizing a reflective journal to write down her assumptions of the experiences participants would have before starting data collection. Further, the researcher kept the reflective journal to note any thoughts and feelings throughout data collection and analysis. Hamil and Sinclair (2010) advise the researcher to ask themselves “why are these themes emerging and who are they important to—me or the participants?” (p. 20). This question was asked throughout the analysis of the data to ensure that themes emerging were true representations of the participants’ experiences (Hamil and Sinclair, 2010).

3.6 Data Analysis

Interviews were recorded and transcribed verbatim. In phenomenological studies, data are analyzed in a way that looks for significant statements, meanings, and textual and structural descriptions, which describe the “essence” of the phenomenon (Creswell, 2007). Colaizzi’s (1978) steps for analyzing phenomenological data were used:

1. *Review of Transcripts:* Each participant’s transcript was reviewed by the researcher by reading what they stated during their interview. This step allowed the researcher to gain a sense of their experience.
2. *Extracting Significant Statements:* After reviewing each transcript, the researcher went back to the transcripts to “extract” phrases that pertained specifically to the phenomenon being explored.
3. *Formulating Meanings:* The researcher established the meaning of each statement by “formulating meanings.” This step required the reader to move beyond the statement itself, and instead determine the meaning of each statement while keeping the original transcription in mind. In addition, attempting to include all

data and not discarding those that may not seem to fit was another crucial component of analyzing the transcripts. This step was repeated for each transcript.

4. *Clustering and Validating:* Meanings of statements were organized into a "cluster of themes" in this step. Comparing these themes to the original interview transcripts took place, which assisted in validating them by referring to what was originally stated by participants.
5. *Exhaustive Descriptions of Themes:* Results of the themes were used to construct a description of the topic under investigation. This description was clearly written and as close to the essence of the original statements as possible.
6. *Final Validation:* This step involved asking participants about the findings to determine whether the analysis coincides with their experience and to ensure that all ideas were captured correctly.

Creswell (2007) states that written reports containing phenomenological studies must aim to explain the "essence" of the experience shared by the participants.

Chapter 4
Findings

4.1 Background of Participants

A total of 12 HCPs from two memory clinic teams participated in a one-on-one interview. Each interview lasted between 25 and 30 minutes. One team was from a rural setting while another was an urban setting. Each team consisted of one primary care physician, nurses, a social worker, and other health care providers (such as an occupational therapist, a pharmacist or a physician assistant) (Table 2). The number of years of experience in the memory clinic ranged from just over one year to seven years (Table 3). The number of years of experience in total as a health care provider ranged from approximately one and a half years to thirty-three years (Table 3).

Table 2: Roles of participants

Role	Number of Participants
Nurse	4
Pharmacist	2
Social Worker	2
Physician	2
Physician Assistant	1
Occupational Therapist	1

Table 3: Number of years of experience

Memory clinic (years)	Total (years)
4	9
3.5	17
1.5	10
2.5	11

3	23
5	26
7	33
6	17
5	17
1.5	1.5
7	26
2	6

4.2 Main Findings

Through analyzing the data, the researcher found that the health care providers' (HCPs') experiences involve three main themes. Table 4 provides a summary of the themes and subthemes.

Table 4: Summary of main themes and subthemes

Main Theme	Subthemes
Experiencing the journey with the patient and caregiver	Supporting patients while maintaining patient dignity
	Balancing emotional dilemmas with responsibilities
Experiencing the journey with the team	Feeling valued and connected to team members
	Unique care provider experiences
The personal and professional rewards of the experience	Thrilling complexities
	Ongoing learning opportunities
	Personal and professional fulfillment

HCPs described their *experiences guiding the patient and caregiver through their journey.* HCPs' experiences revolved around their professional responsibilities and personal experiences with patients and caregivers. Supporting patients was important to HCPs, as they work in the memory clinic to assist them, along with their caregivers, throughout diagnoses and treatment. Often times, an ADRD diagnosis may change a patient and caregiver's lifestyle (for example, losing a driver's license). It was important for HCPs to maintain the patient's dignity when supporting them along their journey. The emotional experiences of an ADRD diagnosis at times affected HCPs. Balancing their own responsibilities with emotional dilemmas is important, as understanding how to do so allowed for properly supporting patients and caregivers.

The *experiences of taking this journey with the team* were also described. HCPs discussed the benefit of working with team members who have different provider backgrounds, and value these perspectives. Feeling valued and well-connected with the team was discussed in-depth. Working in a tight-knit team setting was described, as HCPs compared and contrasted various team settings to the unique memory clinic experience.

Lastly, the third theme focused on HCPs' *personal and professional benefits of their experiences*, explaining their interest in the complexities of the patient, and the ongoing learning opportunities of working in the memory clinic. Feeling as though the memory clinic is a good fit personally and professionally was also described by HCPs.

1. Experiencing the journey with the patient and caregiver

As patients and their caregivers enter the memory clinic and the journey of ADRD diagnosis and treatment, HCPs feel as if they are guiding them through this journey.

HCPs are present as the patient and caregivers receive a dementia diagnosis and a treatment plan, and are followed up throughout. HCPs discussed the importance of supporting patients while maintaining the patient's dignity. They also discussed the memory clinic as being an emotional place of work, and the need to be a responsible HCP for these patients and their caregivers.

Supporting patients while maintaining patient dignity

The first subtheme discussed under the overall theme of *experiencing the journey with the patient and caregiver* is *supporting patients while maintaining patient dignity.* HCPs described loving their experience in the memory clinic, and wanting to help patients and caregivers. During the interviews, HCPs stressed that they love being part of a clinic that reaches out to assist patients and caregivers going through an ADRD diagnosis and treatment plans, and believe that they, as HCPs, are able to be a source of support for patients and caregivers:

> "[dementia] Just affects so many people and I thought I want to be part of this. Like it affects the people who work with the elderly, it affects the nursing staff and everybody's affected. It's hard work. …. Amazing though, I just thought if this work affects everybody in different ways and I just wanted to be part of it, you know, that whole," [HCP01].

Loving to work with a relatively older population was described by one HCP as an opportunity to build an understanding of the patient's behavioural or social changes from a long line of history. Understanding the health and social history of the patient allows HCPs to develop a clearer understanding of the patient's life story and personal identity. Patient history was important to have during the diagnosis of ADRD:

> "I just… I love working with people who are older because they have such such history and you can kind of build from that and you can sort of see the resilience they sort of have from that and yeah. I think it's just I just like that and there's just more things you can kind of do. When they have dementia you can kind of understand," [HCP04].

While discussing the journey with the patient, one HCP described the memory clinic as a "soft place to land" for patients, allowing them and their caregivers the opportunity to be cared for in a setting where HCPs take their time to fully assess and treat the patient:

> "…we have some horrific cases and you're like, why they? But [caregivers] still want to keep them in the home and they're trying so that's where we… I like to think of it like we're a soft place to land, you know? So we can sort of help buffer whatever hell or nightmare they're going through so if I could do that in any way and if they come away going 'wow somebody cares' that makes it all worthwhile," [HCP11].

In trying to respect the patient's dignity, HCPs understand that having an ADRD diagnosis can take a toll on patients and their caregivers. As one HCP stated:

> "You know, I had a patient say once 'if I had cancer, people would 'oh my God' and surround me and give me flowers but when you tell them you have dementia they look the other way and speak to the wife' like they it's almost like you lose your identity," [HCP11].

While supporting ADRD patients, HCPs described the importance of maintaining the patient's dignity. Maintaining the dignity of the patient is important to HCPs who work in the memory clinic, as they understand that patients are more than their diagnosis:

> "…some of the patients we have are more like professors, doctors, lawyers, nurses, and to see them knowing what they were and sort of how the disease has

> progressed, you're like, you just, you just want to help them in any way you can, and the families," [HCP11].

Other HCPs described how receiving a diagnosis of dementia could lead to struggles with maintaining a patient's dignity. One HCP explained:

> "I think that the most challenging part would be, I guess, dancing around the whole dignity piece. Many people don't want to hear the word dementia, they don't want to hear the word Alzheimer's or any of those types of words so it's being able to deliver the language or the concerns with still maintaining who they are and the dignity behind that person and that's probably the most challenging thing," [HCP03].

HCPs understand that part of this journey involves maintaining the patient's identity. During interviews, it was evident that HCPs understand the stigma around an ADRD diagnosis. Maintaining the patient's identity is an important responsibility for HCPs:

> "These [patients]… like many of us have had many productive fruitful lives, you know? Really contributing to society, high level of intelligence and they're losing something that is very hard to lose which is your intellectual capacity. And for many of these people that's what defines them—these teachers, these doctors, these lawyers—their whole social identity is where it revolves: around their intellectual capabilities," [HCP08].

Being supportive HCPs while maintaining the dignity of the patient is important to HCPs. During the patient and caregiver's journey of a diagnosis of ADRD and treatment plans, HCPs understand that at times, the patient feels stripped of their identity. Understanding the stigma associated with an ADRD diagnosis has allowed HCPs the ability to attempt to diminish that stigma and make the patient and caregiver journey in the memory clinic as smooth as possible.

Balancing emotional dilemmas with responsibilities

The second subtheme under the main theme of *experiencing the journey with the patient and caregiver* is *balancing emotional dilemmas and responsibilities*. HCPs understand and feel the emotions behind the patient and caregiver journey of ADRD diagnosis and treatment, but they also feel a responsibility they need to maintain as HCPs throughout this journey. Delivering a diagnosis of ADRD is an emotional experience for HCPs. When delivering a diagnosis, HCPs describe this task as difficult:

> "I think of, breaking bad news could be difficult," [HCP06].

When asked how breaking bad news made this HCP feel, the response discussed how feelings often depend on the patient's reaction to the diagnosis:

> "You know, it actually, it often depends on the patient's reaction. Sometimes if they're really sad or upset or angry then definitely, I feel that too. Like I feel sad for them and, and stuff. But some patients are very understanding and they understand. They're like 'yes, ok it makes sense,' so it actually, I probably sort of react according to how the patient reacts. If they're ok with it then I feel ok with it. If they're really upset and sad then I feel really upset and sad too (laughs)," [HCP06].

Although at times a diagnosis may cause an emotional reaction, it is part of the role of some HCPs to provide that diagnosis. Depending on their specific role, some HCPs are not the one to present the diagnosis to the patient. Rather, they are present at various points of the patient journey: assessing the patient before the diagnosis is made, present with the patient during the delivery of the diagnosis, or afterwards, when a treatment plan is being set up. These HCPs still described their feelings for the patient and caregiver, and also for the HCP delivering the diagnosis:

> "…it's certainly very anxiety-provoking leading up to [the diagnosis], and it really depends on how it's received, how the message is received on the other end, will dictate how I feel. So for example the client, this morning [the physician] just delivered a dementia diagnosis, you know? Early stage Alzheimer's, and the, the client took it quite well. Well, if they take it quite well the caregiver seems to be taking it quite well, it makes the rest of it very easy," [HCP03].

> "It can be a very like emotional visit…I've definitely had days where it's pretty emotional to see what the families go through that sort of thing so, so that could be challenging just to, you know, see what that patient's reaction to the diagnosis and what the family is going to go through…" [HCP05].

HCPs understand the emotional visits associated with an ADRD diagnosis, and feel for the patient and caregiver. HCPs also described emotional follow-up visits, as with an ADRD diagnosis improvements are often not seen:

> "…I mean, we follow [patients] kind of longitudinally as well so we keep seeing them back so a lot of times we do see an improvement but a lot of times there is a decline and so I think that could be like a challenge is to kind of like that emotional piece of it is hard," [HCP05].

> "The emotional effect of caring for these persons for a long period of time is very tough because you get to know them and you really feel for them when they're losing so much," [HCP08].

> "The degree of suffering you see these people these families go through that's the challenges definitely, the other stuff you know we could work with but that's the hardest part," [HCP11].

The quotes above demonstrate the difficulty of observing a decline over time due to the ADRD diagnosis. HCPs also feel for the caregivers. HCPs spoke in greater detail to their responsibilities of working with ADRD patients and their caregivers. Once a diagnosis is made, HCPs feel responsible for helping patients and their families adjust through this emotional journey. As one HCP described:

> "I think there are always challenges to working with this population and in… I think particularly in primary care, like in this environment we get people who are newly diagnosed and I think the challenges are a little bit added there because we need to address some lifestyle things like future planning and driving," [HCP07].

One responsibility most often described by HCPs evoking an emotional dilemma revolved around revoking driver's licenses. As driving is a crucial component in some of these patients' lives, it is a tough and emotional act for HCPs to revoke licenses.

> "…certainly when you deal with driving that could be challenging, especially if [patients] choose to fixate on that issue. So at subsequent visits that's all they can really remember about the memory clinic and there's a lot of emotion around driving, right, that somebody's independence and sense of self a lot of identity around driving so that is a that's a hot topic," [HCP10].

> "Reporting licenses? Huge, huge. Like the hardest thing you have to do, definitely. People hate you, scream at you, yell at you, walk out, storm out. We've had you know one case where a fellow we said we were going to take his license. He threatened to kill himself. He took off. We had to call 911. He had to be formed, brought to the hospital. His wife didn't drive. She was here. Like it's

> really hard, it's really hard, people and you hate doing it. It, it's not something you want to do at all. Yeah, that is probably the most difficult thing when driving is an issue it's awful," [HCP11].

These quotes illustrate how managing one's responsibilities as HCPs evoke feelings of distress for patients and themselves as HCPs. When asked how revoking licenses made them feel as a HCP, many described feelings of sadness due to the predicament. One HCP described:

> "Terrible, you don't like it at all because you always recognize yourself. I've always, since the day I graduated, thought *how am I going to approach what I'm going to do…* I thought, *if I'm lying in that bed or if I'm in the other side of the table how do I want to be treated* and I'm thinking, you know, that would be awful for somebody to say 'you can no longer drive.' It's, it's horrible… so you always feel for them, always because they're losing… so you know they're losing a little bit more and a little bit more and a little bit more and that's really hard that's really hard to watch and to have to say to somebody now you can't drive now you can't go get your hair done you know or Zehrs (supermarket) to get your groceries and so it's it's really tough, it's really hard," [HCP11].

An ADRD diagnosis not only changes the patient's life, but often times, their caregivers have to adjust to new responsibilities. HCPs realize this change, as one stated:

> "Most of these [caregivers] are seniors. This isn't how they planned their future retirement life… the amount of grief, the suffering, the loss—the slow loss of a partner in life—but beyond that, the increasing demands on care. And they're fantastic caregivers, people who are meant to be caregivers, and there are others that just, you know, that's not what they planned for the rest of their life," [HCP08].

HCPs observe and notice the caregivers' experiences and emotions and this impacts their own emotional feelings and responsibilities. Caregiver support is an important component to the memory clinic, from diagnosing ADRD properly to supporting the patient throughout the life course with ADRD. Often times, if caregiver support is inadequate, it makes it challenging for HCPs to provide support, knowing that the patient is not well supported outside of the clinic:

> "I think the challenge comes when there's not for me at least… when there's not a lot of family support because I feel like we can't be kind of the eyes and ears in the home and so if there's not a good kind of family support there already or somebody that's able to be drawn in it makes it much more difficult to know if any of the changes that you're making are the right things to be doing… or if it's making a difference so I think that's probably the most challenging," [HCP02].

> "How that caregiver needs to still maintain a certain relationship with that loved one as well even though it's changing on so many different levels. Even sometimes we have to do such a delicate balance of the information we get from that caregiver plus the information that we sometimes get from the client, and kind of bringing it all together that that can really be a big challenging part," [HCP03].

HCPs understand the emotional journey of caregivers. Although at times HCPs are faced with challenging circumstances, they describe the need to maintain responsibility and gain all the necessary information of the patient in order to make an accurate diagnosis of ADRD. HCPs also feel responsible for handling emotional situations, especially when family abuse is involved. One HCP explained a case of abuse, and the difficulty surrounding this issue:

> "So we've had a case even where there's someone really vulnerable who's giving out their money to family members and to neighbours and, and the one of the family members didn't know any of this going on. So by the time they figured that out, they had lost most of their life savings that her husband kind of left her with… that other people had kind of eaten away… So those things are really difficult because… because of the disease they're not able to process things," [HCP04].

The situation above illustrates the challenges associated with a lack of family support and when family abuse occurs. At times, HCPs described the difficulties of maintaining responsibility when patients or caregivers are in denial of their diagnosis. One HCP described how a "lack of insight" can become a barrier:

> "Well sometimes what is challenging is the lack of insight and so they might decide that they don't need to come back when it's important that they that they come back or so that would be a challenge I think the lack of insight or even that they yeah that they don't see that they have a problem so it's not necessary." [HCP10].

> "I'd say that that's a challenge to working with the population... So we do get a lot of people that patients that are at that stage where their insight are impaired or denial from both family members and [patients]," [HCP07].

When there is a lack of insight or denial, HCPs are put in a dilemmatic position. Sometimes patients and caregivers choose not to attend follow-up clinic appointments, hindering HCP support. At times, HCP responsibilities are challenged by patient adherence to treatment. One HCP described the difficulty of not seeing eye-to-eye with patients:

> “Once in a while you get somebody who just says I don't want the pills I don't want this I don't want I don't want anything and you know they have things really wrong with them that you could help with,” [HCP09].

HCPs understand what the patient and caregivers have to go through is oftentimes tough, yet having the responsibility of guiding and making their journey as smooth as possible is a benefit of working in the memory clinic:

> “…I know that we do good work here that we can help we can help perhaps lessen those stressors of you know those early stages of a dementia where the caregiver is feeling frustrated and confused by what is happening with their loved one,” [HCP03].

> “You see those changes and so even though it is emotionally difficult I think one thing that makes it manageable is the fact that it's a team it's not just me seeing these people,” [HCP10].

> “I just love the fact that so many people surround this family and kind of a safety net and so I think that's really rewarding and you can see the difference that that makes and how much people will appreciate that kind of care,” [HCP10].

The above quotes illustrate the emotional experiences HCPs share, but working together to provide care to patients with ADRD and sharing the responsibility makes it easier for the HCP. The journey with the patient and caregiver is at times emotionally challenging, especially when an ADRD diagnosis is made, and when lifestyle changes occur. HCPs described the emotional dilemmas surrounding their own experiences and responsibilities they have as HCPs. There is a balancing act of feeling for the patient and caregiver when giving them difficult news such as an ADRD diagnosis or revoking a license, but staying responsible as a HCP by using their role and expertise to assist them.

2. Experiencing the journey as a team

The second theme - *experiencing the journey as a team* - describes the HCPs' experiences working in a memory clinic team, and within the structure of the clinic. HCPs described feeling valued as part of the memory clinic team. HCPs also spoke about the strong connection they have with their team, feeling part of a "family" and being a source of support for one another. HCPs described the unique experience of being part of the memory clinic, describing the difference between the memory clinic versus other health teams, specifically other family health teams. Two major subthemes describe *feeling valued and connected to team members* as well as having *unique care provider experiences*.

<u>Feeling valued and connected to team members</u>

The first subtheme within the major theme of *experiencing the journey as a team* is *feeling valued and connected to team members.* This subtheme describes HCPs experiences of feeling closely connected to their teammates. HCPs feel valued and value their team members within the memory clinic team. HCPs described the value of each specific role of all team members involved in the memory clinic. When asked about the role of others, HCPs responded with enthusiasm to describe the importance of each role. They believe that having more than one HCP present allows for more unbiased, holistic care as gaining the perspectives of an entire team of HCPs allows for a complete assessment of the patient:

> "I think the disciplines all bring their own lens, their own perspectives. They see things the this situation the case and bringing that to the table and having a really open, fulsome discussion is a much richer, much more fulsome assessment than

> any individual physician can have in their office visit. And sometimes medicine’s important because it provides access to care options that wouldn't happen otherwise,” [HCP08].
>
> “One of the nice things about a fresh perspective from somebody with a different background is it's not tainted or biased by their training I mean it is but it's not tainted or biased by your own training and sometimes what happened though is they may have a thought or an opinion about something to do with a patient's medication and the real context is well it wouldn't work and you wouldn't know that because you're not an expert in that area but that you could say that about any one of our inputs,” [HCP09].

HCPs clearly recognize the value each role provides to the memory clinic team. HCPs also described the personal experience in their own roles and felt valued in their role with their team. One HCP described a personal situation where the team brought their different perspectives and worked together to come up with a treatment plan:

> “[the other HCPs are] quite respectful in regards to if I see something differently. They’re pretty good about trying to look at it from that way. So if there’s, there was a client a little while ago where there was some behavioural stuff that was going on, but I was trying to, they were going to look at medication to see if they could treat the behaviour and I was trying to figure out if there was a, a pattern that was happening with the behaviour because maybe it was some social understanding to why that behaviour was happening instead of just medicating the behaviour, and they’re quite, they were quite open to that. But there’s just different perspectives, so it’s nice to be able to bring that perspective that’s not just medication medical wise and it’s it’s a yeah a good team because they, everybody’s quite respectful in regards to having different perspectives and able to hear them out,” [HCP04].

Another HCP described feeling as an important part of the team and wanting to be part of a team:

> “I don’t think I want the team to go ahead without me I’d feel like I, it’s part of a family and you want to be part of that family and you want to be kind of involved. And I think that there’s certainly… I feel like there is a significant role there for [me] and that without it there would be something missing. So I think you’d want to be able to provide that kind of full, rounded health care and full service to our clients and if we’re not all there then maybe we’re missing a piece,” [HCP02].

Recognizing everyone’s value and respecting the contribution of other HCP roles was evident during interviews. When asked about motivations, HCPs often responded by explaining that their team motivates them to stay and work in the memory clinic:

> “It’s rare, it’s very rare because I’ve worked with a lot of people over the years and a lot of women men doesn’t matter they can be really catty and backstabbing and I just don’t see that here we just really it’s my family, I call it my second home - they get you through really tough times stuff we’d yeah that’s what motivates me,” [HCP11].

> “Working with the team it's the biggest aspect it's a great team and it's a good group of people, and it's like I said it's a fun day that's one of the biggest motivation I'd say is the people working with the people,” [HCP06].

> “First and foremost, the people that I work with are fantastic… [The memory clinic team is] just an absolutely lovely group of people to work with,” [HCP12].

The above quotes demonstrate the value HCPs have for their teammates, and how they, in turn, motivate them. HCPs described also the structure of the memory clinic, and how the clinic is a neutral playing field, where all perspectives were taken into account:

> “It's a flat hierarchy or relatively flat hierarchy where every discipline uses its own perspectives and own strengths,” [HCP08].

> “It's a level playing field - anybody can say anything and contribute and nobody, there is usually no hierarchy,” [HCP09].

> “Even though we all have a different role to play and we all we all just get there and we’re just like the best of friends and we all just get along so well and nobody feels like if I say something, ooh, you know, they’re going to think… we’re just, we’re all on a level playing field,” [HCP11].

Having a level playing field allows HCPs to feel more valued in their role and comfortable stating their opinions during a team consultation. Although different perspectives are respected by HCPs, having too many conflicting perspectives could sometimes cause difficulties. As one HCP describes:

> “I think you could call it a challenge like that someone thinks the complete opposite of what I'm thinking or like you might think that that might provide a challenge but really no I don't think that I think that - that's what we're looking for, the different perspectives,” [HCP05].

> “Sometimes I find you know [some HCPs] are a little bit, they focus a lot on the psychosocial stuff whereas often I just want to know if they're demented or not, do you know what I mean? Like it's probably just a bit or training you know just a bit of training… but that's not even a challenge just a different perspective,” [HCP06].

> “I think there’s sometimes a challenge in terms of perspectives and identifying what the what the benefit to the patient might be at that time so I think because we have a medical background to our clinic like people are coming to us you know for a diagnosis or for medications that sometimes those things we have we’ve put

> ahead of other things and I think often times where the perspectives blur are just our interprofessional perspectives…" [HCP07].

Although at times varying perspectives and opinions of HCPs in different roles could be seen as difficult, HCPs understood the benefits to gain different perspectives, and are respectful of each other, even if they sometimes do not see "eye to eye":

> "Well we all have different perspectives (laughs) yep. Yep. So it's just chal… not challenging in, I don't know, I think one of our teammates and one of the other teammates sort of explains it well like we're a family so we kind of agree to disagree sometimes or like we're respectful about the fact that we see things differently when we don't have to agree on seeing things differently," [HCP04].

Even if at times HCPs will have a different viewpoint on a specific treatment plan, other HCPs will hear them out, and respect the differing opinion. Feeling as though the team is like a "family" allows HCPs to speak freely and state their opinions. HCPs feel as a "…very well connected team" [HCP01]. They feel comfortable to speak up with differing opinions, and respect all opinions heard. They are able to come together at the end, agreeing on the final decision plan. As one HCP described:

> "We can have differences of opinion and hash it out and kind of really come to together where everybody feels comfortable. I feel like we always hear everybody's opinion, work it out and by the time everybody leaves the room we've all kind of come to an agreement. So I think that's one of the things that makes our team work well. And we're all very different, we come from, you know different health professions as well so we all have our own set of eyes on it our own perspectives, but I think it comes together quite well," [HCP02].

HCPs work well together and feel as though this team fits nicely together. As one HCP described:

> “Well I, I would think like in a team because there's more people there's more opinions and different personalities but do you know what in our - I can't really say that that's been a problem on this team. I think we all (laughs) that our personalities blend and I think the people who ended up on this team were well chosen or it's a good fit…” [HCP10].

Often times, HCPs described feeling like a family, working together to provide care for ADRD patients:

> “So we truly do function as a family (laughs), which is one of the things that I think makes us work really well together,” [HCP02].

> “It’s become like this little family, our team. I mean even when we had… whenever we had a new member, it’s like yup, come on. So it’s like we welcome new people, you know, it’s a very welcoming team,” [HCP01].

> “Well, it's a very comfortable and I've been here on this team for five years so it just tends - I guess over time it feels it's very comfortable. It feels like a family sort-of-feel, so I enjoy the people I work with,” [HCP10].

The above quotes illustrate the level of comfort HCPs feel towards their teammates and the value of that comfort. HCPs described feeling well connected to their team members. Having a well-connected team brings advantages to caring for ADRD patients. HCPs described how this experience with the team brings forth more holistic care strategies for patients, as patients are able to gain different health care professional insights and opinions:

> "So we're covering lots of different bases from being from lots of different backgrounds and professions. So and I think, I don't know, we've got such a nice, like we've all got to know each other really well so it's got a nice flow to it the conversation, always has a nice flow to it. We kind of allow everyone to add information where needed so that we can you know basically come up with the best strategy for these people," [HCP05].

HCPs also explained the importance of having a supportive team to do this kind of work. One HCP explained this twice during the interview, stating:

> "Just being able to have a team you couldn't do this without a supportive team, you wouldn't survive. It would not survive," [HCP11].

> "I think because you're so supported, you always know that there is somebody else to pull up the slack. If, you know, we've had times where one of us is sick or has to go home sick or something's come up you know that there's somebody there that could fill in for your role," [HCP11].

Having HCPs with different areas of expertise is important when attempting to properly diagnose and treat patients in the memory clinic. Being part of the memory clinic team is a positive experience for HCPs as teammates act as sources of support and are very connected to one another.

Unique care provider experiences

The second subtheme that emerged from the main theme of *experiencing the journey as a team* is *unique care provider experiences.* Working in the memory clinic structure is a unique experience, one that is different than other experiences working in various health care settings. HCPs described how the memory clinic differs from other primary care settings, such as other family health teams. HCPs found that the "tight-knit" memory clinic team, and how the clinic is structured, allow for face-to-face consultations with teammates, something rarely seen in family health team settings:

> “[The memory clinic is] truly a team functioning as a team, whereas as a family health team we have different practitioners working side by side - often still in a bit of a silo in terms of we’re still doing our own thing. We’re consulting with each other every now and then, and sometimes we have the same patient who we see but we’re still doing our own thing with them and then we may consult but often things kind of don’t work as fluid, as fluid as it does in the memory clinic. We truly are working as that team,” [HCP02].
>
> “I think working with the family health team there's much more distance in time between us whereas the memory clinic team is more tight-knit, a little family maybe… a little family within a big family… if that makes sense,” [HCP03].
>
> “…with the memory clinic we’re such a tight smaller team that we just you just have time you know what and too sometimes you just get to know your team members a lot better… when you’re working in clinic, which I do, you’re flying like you’re just, so you don’t sometimes get to know who you’re working with just as well,” [HCP11].

The above quotes provide examples of how the memory clinic is viewed as a smaller team as opposed to other family health teams. The memory clinic allows HCPs to work in close proximity to diagnose and provide care to patients and their caregivers. HCPs described the memory clinic team as a “little family within a big family,” the bigger family being the family health team. HCPs also described the memory clinic team versus other health teams they have had experiences working in (ones that are not necessarily family health team specific). HCPs explained how the memory clinic allows HCPs to see the patient during the same appointment, as opposed to working in separate silos and consulting with the patient at different times:

> “I think [the memory clinic is] a true team environment and it's a fun team, whereas in all the other settings you're kind of doing the dual role but we're not actually a team—we’re more kind of different cogs in a machine, do you know what I mean? As opposed to a team, yeah so I'd say that's the biggest difference is that, yeah,” [HCP06].

> “Just seeing the whole team, like usually when you're working, working in the community and even to some extent to private practice you have a team generally that you, is involved with the patient but they're never usually right there at the same, seeing the same patient at the same time, right? So I might see a patient before I see a patient on Thursday and I could have some observations and the physio might see them on a Wednesday and say ‘oh no I didn't notice any of that’. So it's nice to actually have the same view,” [HCP07].

> “Not only is it I think more accurate and more efficient to do it this way as opposed to usual care where you might give a social worker's assessment and then wait and then get the physician's assessment, wait and then get the maybe get the specialist assessment and by that time you know so much time has elapsed that the original assessment may or may not apply,” [HCP08].

> “It’s nice that we can kind of have that team approach, all talking about the client all on the same day, is completely different than we each having separate assessments and, and then doing them on completely different days. So I think, it’s, I think it’s a betterment for the client to have all those perspectives on the same day for one assessment than if they just saw a geriatrician, kind of, yeah,” [HCP04].

The quotes above illustrate the differences HCPs found working in the memory clinic versus other practice settings. Working together to provide care to patients with ADRD is important, as it provides the team with more accurate information about the patient. Other HCPs described that the amount of time spent with the patient was something unique to the regular structure of primary care. Having more time to properly consult with the patient was seen as a beneficial part of the memory clinic:

> "I just found it so hard to do in the regular structure of practice—that, that ten minute office visit. With these seniors, your ten minutes are really oriented to deal with the most acute problem and memory problems are not acute until they hit crisis. So that all just got pushed to the back burner and then, you know, nothing would be done. You know, you just couldn't do it in a way that I thought would be helpful," [HCP08].

> "When I think of my past work experiences, it's just busy. We're running all the time and you're doing so many tasks in a short period of time. This isn't so task-oriented, it's a little bit more. Well, each appointment is two hours long so there is time to just sit and, and to talk. It's, I guess, it is a big difference from the past," [HCP10].

As noted above, one HCP described how the regular structure of primary care does not allow time for a proper assessment of a chronic issue to take place. Having extra time to assess the patient's chronic symptoms is an important part of providing an accurate ADRD diagnosis. HCPs described how the length of time each appointment takes positively impacts their time spent with the patient and caregiver:

> "...you get to spend so much time with them in the appointments so it's not just about like doing memory clinic testing, but you get to remember their lives and

> like, it’s a nice long appointment so you feel really connected to the people that you’re working with,” [HCP05].
>
> “You feel connected to the patients and their families, yeah. So it’s a nice opportunity that you don’t often have in medicine is that extra time to be able to spend with the patient,” [HCP05].
>
> “I really like that we get to see patients consistently. I know a lot of times when people are diagnosed with things like dementia or kind of even, any kind of life-altering news, it's often, you know, you're told that and you never see that doctor again or you never see those people again and I feel like that we are consistently seeing people at follow up. So you know if there was that person who may be struggled then we don't have to just wonder and hope that they're doing okay, so I like that part,” [HCP07].

Extra time allows HCPs to feel more connected to their patients, allowing for the understanding of the patient and caregivers. HCPs also believe that the extra time during clinic hours may allow patients and caregivers feel more connected and comfortable with the team. Having the opportunity to follow-up with patients with is another benefit of the memory clinic structure. Following-up with patients allows HCPs to feel as though the care they are providing is continuous, seeing patients every few months:

> “I mean, we might see them only every six months three months maybe a year but they, there is a real continuity of, of care when you, when you feel like you've get to know them quite well,” [HCP10].
>
> “Even in primary care, in the office and whatnot, you know, there are still patients that, you know, could be quite sick and you can have a hand in in helping them. But it’s not in such a degree that we don’t, I don’t personally get the same follow

> up for those patients as I do in the memory clinic because we tend to see the same people over and over and over and over again, right?" [HCP12].

With this continuity of care, patients are seen by the same group of HCPs, which makes it easier to spot improvements or decline during follow-up appointments:

> "Often our nurses, like we always get the same, as best we can get, the same nurses to test each person over time and they have a really good sense over time if the person is declining. And sometimes it's very subtle, there could be, you know, there's just something about him that you know, is not right. He's worse. Even though his cognitive test scores seem the same, there's something about him that's not right and invariably they're right. There's something else because it goes beyond cognitive test scores. Sometimes it's behavioural, sometimes it's, you know, there's so many aspects to, to how a person functions. Those pieces of information will get lost if there wasn't this real time discussion," [HCP08].

The way the memory clinic is structured, HCPs are able to see that continuity of care with patients and caregivers. The memory clinic runs one to three days a month, and typically the members of the team are the same. As illustrated in the quote above, having the same team following up with patients is important for HCPs, as these HCPs are able to notice changes from their last appointment with the patient. The memory clinic's structure allows HCPs to follow-up with patients and their caregivers at different points during their ADRD journey:

> "Working with the elderly you're working at all parts of the system—right from primary care to long-term care. So you're meeting people along the way. You know, you meet them at this part but you might meet them again at this end and all points in between. So it's that helping them get to the next place that they need to be…" [HCP01].

The memory clinic structure allows HCPs to build contacts with various resources for their patients' needs. A benefit of the memory clinic was described by one HCP:

> "It's helping people adjust, helping people get in touch with the right resources to help them at the right time," [HCP01].

Although the structure of the memory clinic allows HCPs to provide resources for patients with ADRD, at times navigating certain parts of the system is a unique task for HCPs. One HCP described the difficulty of trying to navigate the system for ADRD patients with behavioural issues:

> "I think it's the behaviours that are the challenge. Where do these people go in the system? You know… sometimes there's a brick wall and it seems like everybody loses," [HCP01].

Working with a population of patients who are diagnosed with ADRD is a unique experience for HCPs, especially when attempting to contact the proper resources. One HCP explained the difficulty of trying to find resources available to patients whose licenses have been revoked, something that happens often with patients who are diagnosed with ADRD:

> "I would say [a challenge is] trying to figure what's out there and what resources are available and how we could get those services in place for people. But I think specifically around the driving. So it's when you're wondering if there's a diagnosis of dementia and you aren't sure if they should be driving and you want to have the driving assessed, it's a huge cost to the family and there's nothing really locally. Some of the driving assessments that we get back are very vague. That's probably one of the pieces, and that's not the memory clinic, that's just the system," [HCP05].

This HCP continues to describe the frustrations behind not being able to provide sufficient resources to patients and their caregivers:

> “But those kinds of frustrations are hard, not just for us but for the families, and I think, in turn, that makes it hard to us because we want to be able to offer these families a good support and good strategies and then to have, you know, pieces of the process that aren’t as strong, you know? You hope, you hope it does not reflect badly on what we’re doing for them,” [HCP05].

Another HCP also described the frustrations of attempting to navigate the system, this time describing the difficulty with waitlists in long-term care:

> “The waitlists for a lot of things if long-term care you know sometimes people have to be placed waitlists for that, it's frustrating,” [HCP11].

Although HCPs described the frustrations around navigating certain parts of the system for patients with ADRD and their caregivers, they also described the benefit of linking with partners in the community, and how these partners assist with ensuring a smoother journey for patients and caregivers:

> “Those community partners that we’ve connected with as well—with the day program, the Alzheimer’s society, with CCAC… and all other community networks. There’s been some amazing links there as well,” [HCP03].

Working as a memory clinic team to provide resources for patients and their caregivers is important for HCPs. The structure of the memory clinic allows HCPs within that “little family” to become ongoing supports to the “bigger families.” HCPs described the benefit this structure has on community physicians:

> "We're actually there to support the physicians in our community, we can be someone that our, our FHO (Family Health Organization) and our FHT can lean on. I like that feeling," [HCP03].

The memory clinic allows HCPs to work outside their usual realm of care to provide support to those with ADRD and their caregivers. The clinic structure allows HCPs to work in close proximity with one another to diagnose, treat and support patients. Having the opportunity to be an ongoing source of support for these patients is beneficial, as HCPs are able to notice changes in patients during follow-up appointments. Navigating resources is at times difficult, but having community partners allows HCPs to provide more support to patients. Supporting physicians in the community who have referred patients to the memory clinic is also seen as beneficial.

3. The personal and professional rewards of the experience

The last theme describes *the personal and professional rewards of the experience.* HCPs described how they have grown personally and professionally from working in the memory clinic team with patients and their caregivers. HCPs enjoy working with the complexities of the patient, and find that these complexities allow them to have ongoing learning opportunities, as "no two patients are the same" [HCP01]. Working together to diagnose and support patients is described as trying to put together pieces of a puzzle. Three subthemes emerged from this main theme. The first describes the *thrilling complexities* HCPs find working with a relatively older complex patient population. The next subtheme describes the *ongoing learning opportunities* for HCPs. The last subtheme describes finding *personal and professional fulfillment* working in the memory clinic and supporting patients with ADRD.

Thrilling complexities

The first subtheme under the main theme of *the personal and professional rewards of the experience* is *thrilling complexities.* When asked about their motivations for working with the ADRD population, HCPs described finding patient complexities intriguing, and having the chance to dig deeper into patients' past medical histories, medications and conditions in order to come up with a treatment plan. Having the opportunity to work with complex patients allows HCPs to experience the rewarding feeling of doing so, as patients are able to receive a proper diagnosis. One HCP described the differences of patients in the family health team setting versus in the memory clinic setting, stating:

> "What we do in geriatrics is so much more different than what I call the boring, single disease state of 'whoa, we have your blood pressure at a great number, whoopee' and that's easy to do, relatively speaking. We have your diabetes, your lipids under control. That gets old too, I mean that that's why I love what I do because it's much more complicated—a lot of other pieces to consider—and to try to figure them out in a way that makes sense for the patient, because again every patient is really literally and figuratively quite different," [HCP09].

The above quote illustrates the different approaches HCPs take when supporting a more complex population. HCPs found working with complexities of patients interesting and fun, as one HCP explained:

> "This is probably the funnest place to work I think. I think that breaking down a complex problem into its little bits and then bringing it all back together and discussing it…" [HCP06].

Having the opportunity to build from the “little bits” of information is important for HCPs when working with the ADRD population, and having the team there to discuss the complex problems is beneficial. Working in a memory clinic allows for more time to be spent with patients, which allows HCPs to dig deeper into the complexities to try and find the proper treatment strategies. As one HCP described:

> “…who wants to take the time?... I knew patients that, I have two new patients on Wednesday, they’re two-hour appointments. Who, who wants to do that, right? Like who wants to? All you know we all look at different parts of medications and behaviours and how we can help and it’s a long process and a lot of people are like ‘wooo I don’t want to take that time with everything’. I think we live in a society where everything is quick and easy, right? We can go to a restaurant and someone hands you supper through a window. You know, five minutes you can be having a dinner. Everything’s fast and this isn’t fast... A lot of people [say] ‘well I don’t want to deal with that I want pretty medicine’ you know, so but yeah they don’t know what they’re missing…” [HCP11].

Other HCPs described working in the memory clinic as trying to solve a puzzle or mystery, as there are many components to a patient, making them complex, and these components must fit together in order for the patient to receive proper care. One HCP describes the experience as trying to solve a mystery board game, such as the game Clue™:

> “It’s like a game of Clue™, have you ever played Clue™? It’s like we’re all part of this detective game, we’re all doing a piece to put in, you know?” [HCP01].

The professional experiences stated above demonstrate the thrill and excitement these HCPs feel towards working with a more complex population. Another HCP spoke towards this feeling, explaining their experience as trying to solve a puzzle by understanding the health and social history of the patient:

> “I really like the fact that you can kind of figure out the puzzle by understanding their kind of social history. So that's kind of why I really… it's just, it's the past maybe (laughs),” [HCP04].

In addition to feeling as though there is a puzzle or mystery to be solved, HCPs also discussed the importance of using a team approach to solve these puzzles and mysteries:

> “I think I’m relying a lot more on the people around me to build the picture to fill in the missing pieces of the puzzle,” [HCP05].

> “We’re truly kind of all coming together, putting everything together, it’s kind of… so it’s kind of like putting a puzzle together. We’re all in the room with all the pieces, versus you all have a quarter of the puzzle and they may not be all the pieces that fit together… but you’re all in your own offices trying to put this pieces together but it doesn’t work unless you all come together in the same space,” [HCP02].

HCPs feel as though solving a puzzle is similar to tackling more of a complex issue due to the fact that more than one piece of information needs to be presented. Relying not only on team members, but also on the patients themselves as well as their caregivers to collect different pieces of information and bringing all of the pieces together is important for properly diagnosing and supporting ADRD patients:

> “It's a big puzzle because there's no clear diagnostic test because anything that you're getting from a history point of view is, it's what the patient remembers or wants to tell you and same things with the family member. It's what they, they choose to disclose to you or not. It's a triangulation of evidence of what they're telling you and also with the cognitive testing to support or refuse it. It often

> times, it's more ‘does it all fit together?’ ‘Are we sure we've got the right diagnosis and right management?’ And there's nothing like having a team approach to that,” [HCP08].

The above quote illustrates the importance of having a triangulation of evidence before attempting to diagnose ADRD or treat patients. These patients are typically more complex, so it is important to gather information from the patient, the caregiver and other members of the team during their assessments. Another area of complexity HCPs described was working with patients who have various behaviours. At times, HCPs find themselves challenged by patient behaviours:

> “Probably [the] most challenging is behaviours, trying to get behaviours under control,” [HCP11].

Another HCP described a scenario where HCPs had to step in and support a patient and his wife due to the patient’s aggressive behaviour, a symptom of his dementia diagnosis:

> “If you get the challenging behaviour where, through nobody’s fault that they’re violent, or that, you know, you have to put them in a place where they’re locked up and I could think of one patient actually we were talking about this one patient this morning and you couldn’t help but like him but he ended up, he’s a retired boxer, and he was still fit as a fiddle and but just hyper and we ended up we had to Form 1 him because he held his wife hostage for six days, she couldn’t get out of the house. So finally, once she was able to get help, we Formed 1 him and really he was healthy in every way. It’s just, so he was locked up, you know, it’s sad but his wife can’t live like that, you know. So I think it’s those challenging behaviours…” [HCP01].

As demonstrated in the quote above, patient behaviours can become complex with an ADRD diagnosis. Working in the memory clinic allows the team to work together to develop innovative and creative ways of supporting patients with various symptoms. In one example, a HCP described a patient diagnosed with Lewy Body Dementia, and the approach the team took to help him with his hallucinations:

> “We have a patient right now who, who's still in my heart and [name] is, was an accountant, very well connected to the community, lovely people, did so much and he has Lewy Body, and he sees these elaborate creatures that come out of the wall at him at night. And just to see what they go through as a couple and how people actually work together as couples in that in the hardest of times it's not easy and if I could help them in any way absolutely they're it it's an a amazing wonderful work…if it’s something as simple as if he sees these creatures coming out of the wall at night. So we came up with, let’s put a spot light in his room at night and put it towards that part of the wall and a fan so in his mind the light goes on there and the fan blows them away. So something that simple so he could sleep through the night. So we kind of come you know strategies and roles and supportive ideas…” [HCP11].

This HCP describes feeling rewarded by the experience of being able to assist patients in any way they can. When patients present complex issues, these HCPs take these issues and try to solve them in order to properly diagnose and treat patients. HCPs are intrigued by patient complexities, and they find taking the time to solve “these puzzles” with the help of their teammates, the patients, and the caregivers as a rewarding experience for all parties involved.

Ongoing learning opportunities

The second subtheme under the main theme of *the personal and professional rewards of the experience* is *ongoing learning opportunities.* HCPs found that the rewarding experience of working in a memory clinic team, and with ADRD patients, allowed them to further enhance their knowledge about ADRD as well as learn about the roles of other HCPs. Many HCPs see the opportunity of professional growth through working in the memory clinic. The memory clinic offers learning opportunities, which other clinics may not provide. As one HCP described:

> "We've learned from each other. There have definitely been some situations, that even outside the memory clinic, so when I'm in my office working solo, that things that I now think of that I wouldn't have thought of before…" [HCP02].

The above HCP quote describes the opportunity of learning from other team members with different clinical backgrounds, and being able to think of other strategies that have been learned through working with team members. Other HCPs described how these learning opportunities provide satisfaction to their curiosity.

> "I love it—that I'm always learning something new. Like I've always wanted, part of me I think has always wanted to be a doctor, but I didn't find out until near my thirties. (sigh) I would have loved, you know? I took medical terminology back in oh and I thought this is so interesting. You know, I had children then, it's too late to go back to school, I couldn't afford it anyway. So this kind of meets that need because I'm learning you know… I guess that's interdisciplinary, we learn from one another and 'ohh I didn't know that.' Like pharmacy, it's like, it fills the curiosity. It satisfies the curiosity. It's like 'wow, yeah' so maybe that too? And there's always a surprise (laughs) you know…it never gets old. It's like, wow! Some of the behaviours people do, the brain is amazing," [HCP01].

Working closely with other disciplines allows HCPs to understand how other disciplines respond differently to certain situations, and to learn from the other disciplines. HCPs described this unique learning opportunity:

> "I mean, as healthcare professionals, we're always constantly in this learning curve… I think certainly, like I'm at that part of my career where I, yeah, trying to absorb as much as I can and in a team environment that is when we're going to learn so much from other people…there's a lot of personal growth and keeping my skills up and like learning to be head when you're in a team environment compared to when I think when you're working independently. I think that people around you that can offer you suggestions and you know in turn make you better health professionals so you know, yeah," [HCP05].

> "I learn something from every one of them almost every week too, you know. Not just about them, but about what they do, you know, what their role is, or how they approach patients and families. Some of the things they might say, you know, to try and explain what we're trying to tell them. Everybody has their own way of of saying it or maybe a funny little expression that they might use with the family to get them to understand or, yeah so I think I just learn so much from them and have fun doing it…" [HCP12].

The above quotes provide examples of learning opportunities HCPs find working in the memory clinic. Being part of a team setting allows for personal and professional growth. Having these learning opportunities are rewarding experiences for HCPs. Working in the memory clinic has offered HCPs the opportunity to be trained in how to diagnose ADRD more accurately. One HCP described the experience prior to working in the memory clinic, explaining the difficulties around the diagnosis, stating:

> "…prior to, to working here quite honestly, I probably did come across people with you know Alzheimer's or you know some sort of dementia but I wouldn't have recognized that. Like I had zero training other than I'm sure we touched upon it in school. But when we, when I was actually working in the hospitals, I wouldn't have known necessarily, you know? I would just think they're old or they're difficult, you know? Like in your head, you don't have enough

> information to really know why they're behaving the way that they're behaving. So it wasn't actually until I started working here that I even knew anything about it at all," [HCP12].

The above quote suggests that the training within the memory clinic provided this HCP with an increased knowledge of ADRD. Ongoing learning experiences allow for personal and professional growth opportunities. HCPs overall described feeling benefited by the learning opportunities they receive in the memory clinic.

Personal and professional fulfillment

The final subtheme under the main theme of *the personal and professional rewards of the experience* is *personal and professional fulfillment.* Feeling personally and professionally fulfilled through their experiences of working in the memory clinic was described by all HCPs during interviews. Knowing that HCPs are making a difference is important, and motivates them to stay and work with the ADRD population. As one HCP described:

> "…I walk away here, even though at the end of a memory clinic day, I'm utterly exhausted. I think we're all utterly exhausted. We know we've done good work, we've made a difference. And, and I think that that's my motivation—that knowing that we're making a difference for the good," [HCP03].

This HCP described feeling as though the memory clinic allows for good work to be done, which is a motivation for continuing to work in the memory clinic. Although the day exhausts HCPs, this stress does not deter them away from the work. Another HCP explained a time where it felt as though the team had made a difference, describing noticing patient improvement during follow-up appointments:

> “We've had a recent case of, that where a patient was just really psychotic had a real interesting common illusion of infidelity great deal of stress for the family for the patient, for everybody. So with a little bit of fiddling around with one medication after a couple of weeks, day and night difference so that's great because it's one of those few things where you can just say ‘wow you've made a difference.’ And so it's always rewarding,” [HCP09].

Making a difference in the patient’s health and life is rewarding for HCPs. Other HCPs described the memory clinic as being meaningful work, having the ability to assist ADRD patients and being passionate about the work that they do:

> “The rewards of ‘you're doing something so meaningful’—it's just, it's if you didn't have a passion for what you were doing I don't think you could do because it's a really tough clinic. But the passion keeps me going, absolutely keeps me going, one hundred percent. And knowing that there's such a need—these people need help and a lot of people don't want to help them and you know so that's what keeps me going the passion for doing what I’m doing,” [HCP11].

As described in the above quotes, HCPs believe that only those passionate enough to do this type of work would find it meaningful. "Just knowing it's effective and like good work” [HCP07] is another motivation HCPs described to stay and work in the memory clinic.

> “Knowing that we're doing I think we're doing a pretty good job like in terms of supporting the family and the patient…” [HCP06].

Supporting the patient and caregivers also allows HCPs to feel like they are doing something meaningful. Receiving positive feedback from patients and families was described as motivating:

> “And certainly we've had some tremendous feedback from patients and families about how caring and compassionate the service was that they got from the memory clinic. And so hearing really good feedback from that is motivating to, you know, keep going back and doing a really good job for these families...” [HCP05].

> “You come across patients that really touch you. Their stories touch you. Maybe you can’t do much for the patient but you’re doing so much for the family. You know and it’s so obvious when you meet with them and they’re so thankful for everything that you do for them. I think that’s really motivating,” [HCP12].

HCPs felt as though helping patients and caregivers was a “good fit” with their personality traits and professional background. Many HCPs had background educational experiences in gerontology, and this interest carried on as their careers moved forward. When asked about the influences, which brought HCPs to work in the memory clinic to support ADRD patients, one HCP responded, “Well it actually was a long time ago when I did my practicum placement in gerontology,” [HCP04]. Another HCP described:

> “I’ve always had an interest in like seniors my background through university is gerontology and health studies so I think just that interest the exposure to the population has been kind of always there…” [HCP07].

Other experiences, such as previous work opportunities, and mentors also allowed HCPs to become motivated and influenced them to continue their career in geriatrics.

> “I remember my boss. It just affects so many people and I thought I want to be part of this. I remember my boss saying ‘you know, if you need to stare out the window and you see me coming, you know, the boss coming, continue staring out the window if that’s what you need to do to kind of get through your shift or get through your day,’” [HCP01].

> “When I was doing that practicum placement at a nursing home we were, I was with the recreational therapist and one of my rec therapists who was my supervisor, we’re working in a a dementia unit of that of that nursing home, and I really really enjoyed working in that area and with the clients and all of that sort of thing. So when I was thinking of going into [another field] then my supervisor had asked if I had thought about doing [my current line of practice] because [this practice] would be in that unit but the [other field] would just be doing just sort of equipment stuff but not really involving themselves and like the family and like the clients and not really looking at the perspectives so that really got me interested in doing work with people with dementia,” [HCP04].

The above quotes illustrate how past professional experiences shaped HCPs’ motivation to continue working with a more complex population. Mentors were described as individuals who understood the demanding task of working with the ADRD population, and these mentors also shaped the careers of these HCPs. HCPs also discussed how their personality traits influenced why they chose to work in the memory clinic, and with ADRD patients. Many believed that the field of geriatrics takes a “special kind of person” to work in the field, and they feel as though they are that person:

> “This is my little, oh.. I always say I’d do this for free if I had to, you know, because I love it- but why do I love it? I love it because it just suits the way I think,” [HCP01].

> “I also feel motivated to work with this population because it’s something that does take a special maybe person to work with the geriatric population and it’s nice to be able to you know connect with like elderly people as well so yeah it’s nice, good…” [HCP05].

> ‘I don't know. I can't see myself doing anything else. This is just kind of I really enjoy that the population in general and I find the job rewarding,” [HCP07].

HCPs also described professional fulfillment with this type of work. They often described working with the ADRD population being a “good fit” to their professional background and training:

> “I think (laughs) maybe a little more humble in terms of I feel like that's my job. That's why I became a [health care provider] was to help to ensure that there's safe [medical] practices,” [HCP02].

> “Dementia is a very social issue. Like once someone’s been given the medical diagnosis it’s only so far the medical part of it can go…. [my profession] and dementia I think were made for one another (laughs) because it’s a very social issue. It’s never just about the dementia,” [HCP01].

> “I felt a calling maybe in a sense, and it feels like a good fit,” [HCP03].

> “…I tend to gravitate towards patients that may take more time just because I think that’s something [my] role can offer…” [HCP05].

HCPs understand the personal and professional benefits of working in the memory clinic with ADRD patients and their caregivers. They feel as though working in the memory clinic fits well with their personal traits and professional backgrounds. Receiving positive feedback from patients and caregivers for the work they have done is also a rewarding and fulfilling experience.

Overall, these main findings have allowed for the understanding of the HCP experiences supporting patients and caregivers, working in a team setting to provide support, and the personal and professional rewards of working with a complex population. Supporting patients and caregivers while maintaining patient dignity was found to be an important piece of HCPs’ experience with the patient and caregiver. HCPs feel responsible to provide the best support for these patients. HCPs understand the emotional aspects surrounding a diagnosis of ADRD, and try their best to support the patients and their caregivers going through this emotional journey. With the help of the team, HCPs find it easier to do their work. They value each role within the memory clinic team and feel connected to each member of the team. Being part of the memory clinic team allows HCPs to experience something different than a regular structure of a health team. Within the memory clinic, HCPs are able to work at the same time to provide care for the patient and caregiver. These experiences have been rewarding ones personally and professionally for HCPs.

ADRD is at times a complex disease to diagnose. Feeling motivated to find all of the important pieces of information in order to accurately diagnose ADRD is important for HCPs, and they enjoy working in a team to fit these pieces together. Having ongoing learning opportunities is also an important experience of working as part of the memory clinic team with ADRD patients. Feeling as though the type of work done in the memory clinic fits personally and professionally with them as people is another motivation to stay and support ADRD patients and their caregivers. These findings have captured the experience of the HCP working in a memory clinic team setting to support ADRD patients.

Chapter 5

Discussion and Conclusions

5.1 Discussion

This study is the first of its kind to examine the experiences of HCPs working in primary care memory clinic teams in Ontario, as these memory clinics were only recently established (approximately seven years ago). These HCPs reported that caring for persons with ADRD in a primary care memory clinic is an overall positive experience. They took pride in supporting patients and caregivers, and felt motivated in their roles knowing that they were “making a difference” and “doing good work.” The HCPs interviewed said they enjoyed working in close proximity with one another, respected their team members, and had the opportunity to learn from each other. Team members often motivated each other to continue to work on the memory clinic team.

5.1.1 Supporting patients with ADRD

When asked why HCPs chose to work with ADRD patients, their responses involved discussion around a desire to be a source of support for patients and their families. Consistent with other research(Nolan, 2006; Borbasi et al., 2006), maintaining the patient’s dignity and identity is an important aspect of this process. Other studies exploring patient experiences after early-onset ADRD diagnosis found that patients wanted to maintain a sense of their original identity prior to diagnosis (Harman and Clare, 2006; Pearce, Clare & Pistrang, 2002). Many organizations also stress the importance of maintaining a respectful demeanor towards persons with ADRD by reaffirming their sense of self and identity after diagnosis, as well as providing HCPs and caregivers with information and advice on how to do so (Alzheimer Society of Canada, 2011; Alzheimer's Society of the United Kingdom, 2010; Alzheimer's Association, 2011). Remaining flexible in responding to the person's needs, being a good listener, talking to them directly and using their first name during conversations are just a few simple ways that make a patient with ADRD feel respected and maintain their sense of self. Placing oneself in the position of the person with ADRD also assists with understanding the importance of maintaining dignity and identity.

HCPs described the emotional journey they take with patients and caregivers and the need to remain a responsible HCP. They described how their personal feelings during the diagnosis of ADRD would often depend on the patient's and caregiver's reaction to the diagnosis. Their negative feelings and emotional reactions to a diagnosis is difficult for HCPs. Other researchers have found similar results. In a survey completed by oncologists, Baile and colleagues (2000) found that an average of 67.3% were "not very comfortable" or "uncomfortable" when dealing with the emotions of cancer patients after breaking difficult news. Emotions such as sorrow and guilt are often experienced when delivering difficult news to patients (Fallowfield & Jenkins, 2004). As reported by others (Salas et al., 2008; Teamwork and Communication Working Group, 2011), this study found that having a team to discuss and debrief with post-diagnosis or after a tough visit was very important to how HCPs coped with their own emotions.

Being a responsible HCP during memory clinic includes obtaining necessary information in order to properly diagnose ADRD. During memory clinic appointments, patients are always asked to bring a family member or close friend. HCPs described the importance of family members and the information they provide during a memory clinic appointment. Family members provide pieces of evidence which may be missed if it were only the memory clinic team members collaborating with a patient. These findings are consistent in McColl and colleagues' (2008) study, which explored the experiences of physicians working with persons with disabilities. Interestingly, Pimlott and colleagues (2009b) found that physicians felt the same way about the role family members play during dementia care. When a relationship with a family member is strong with the patient, it enables proper dementia care as they are able to notice behavioural changes and report their concerns to the physician (Pimlott et al., 2009b). Consequently, physicians stressed how denial from family members and lack of information could prohibit a proper ADRD diagnosis and treatment plan for the patient (Pimlott et al., 2009b). The current study found similar experiences of HCPs, as having a caregiver providing proper information is a key factor to enhancing ADRD care.

Rapoport and colleagues (2007) discussed physicians' responsibilities after diagnosing patients with ADRD. Their study described the importance of recognizing that an ADRD diagnosis may pose risks to patients, hence physicians should take the responsibility of revoking a patient's license when the time is right. The current study found that not only did the physician feel responsible for revoking licenses, but other members of the team felt that they also played an important role in ensuring patient safety. Goldman and colleagues (2010) discussed the importance of shared responsibility when working in a team environment, as sharing these various responsibilities pertaining to patient care is noted as an important aspect of efficient teamwork. The current study found that members of the team felt that they were connected and work well together to provide support for ADRD patients.

5.1.2 Primary care team experiences

HCPs reported feeling valued in their role. Feeling valued and connected to team members is an important component of proper interprofessional collaboration. Feelings of connectedness have also been shown to be associated with job satisfaction, since not feeling valued is associated with higher rates of emotional exhaustion and feelings of stress (Edwards et al., 2004; Evans et al., 2006; Orchard, Curran & Kabene, 2005).

Disconnects between members of multidisciplinary teams has the potential to affect proper care for patients with chronic disease (Fallowfield & Jenkins, 2004; Jenkins, Fallowfield, Poole, 2001). Fallowfield and Jenkins (2004) describe the importance of communicating and understanding the roles of each team member when caring together for patients with chronic disease. In addition, Goldman and colleagues (2010) found that family health team members appreciated the collaboration with HCPs from other areas of expertise. In the current study, HCPs described the importance and value of each role within their team.

HCPs in this study stressed the importance of having a level playing field when collaborating with each other, and being able to discuss various perspectives and differing opinions. Personal comfort within team settings is important, as a comfortable team environment allows team members to speak freely, and not fear their superiors on the team (Salas et al., 2008). Respecting all team members is an enabler of effective interprofessional collaboration (Orchard, Curran & Kabene, 2005). Differing perspectives have the potential to hinder effective teamwork (Orchard, Curran & Kabene, 2005). This consequence was felt by HCPs as a potential issue that could arise. Understanding how team members collaborate with each other is important for learning how to communicate effectively. Clear communication was found to be a main theme from HCP interviews in

Moore and colleagues' (2012) study looking at the perspectives of family physicians and nurses who work in a primary care-based program for seniors. Clear communication allows HCPs to stay up-to-date on the patient's care plan (Moore et al., 2012).

In the current study, HCPs described feeling valued in their role and comfortable stating their opinion during a team consultation. Digging deeper into this finding is important, as the number of HCPs working in teams continues to grow in primary care (Health Council of Canada, 2009). Collier (2011) describes the importance of building trusting relationships with team members, and understanding the role and perspective each member brings to the team, stressing that this process could take years to establish. Lo (2011) conducted a literature review for the Canadian Patient Safety Institute exploring teamwork and communication strategies. Structured communication techniques that assist in achieving better communication among team members include using common language, being an active listener among teammates, and utilizing techniques such as SBAR (situation, background, assessment, recommendation) or DESC (describe the situation, explain any concerns, suggest alternatives, state the consequences) during team consultations (Teamwork and Communication Working Group, 2011).

When describing their memory clinic team, key words such as "family," "connected" and "support" were used. HCPs outlined many rewards associated with working in a "tight-knit" memory clinic team setting for patients with ADRD. They also described the difference between working in a memory clinic versus other team settings, explaining how teams in other settings were more disconnected, and how working in close proximity to other HCPs was more beneficial for this population. In a memory clinic team setting, HCPs are present, in real time, collaborating and setting up a treatment plan for patients. Longer periods of time to assess and follow-up with patients and caregivers are an important component of the memory clinic. HCPs described how appointments are typically not as lengthy in the regular structure of primary care. Pimlott and colleagues (2009b) and Connell and colleagues (2004) found time pressure to be a factor when HCPs attempted to diagnose ADRD. In the current study, HCPs described how the memory clinic structure allowed for more comprehensive assessments to be made, which enabled them to appropriately test for ADRD, discuss changes family members have seen with the patient, and work collaboratively with team members.

Researchers have stressed the importance of collaborative team models to address the needs of individuals with complex issues. When teams work properly to support those with complex chronic issues, the quality of care is enhanced (Boorsma et al., 2011; Callahan et al., 2006). It is believed that one of the components of providing patient care is mixing interdisciplinary and transdisciplinary collaboration. Morgan and colleagues (2009) use Foley's (1990) definitions to outline the importance of achieving transdisciplinary care when working together to provide care for patients with ADRD. Transdisciplinary approaches to care involve simultaneous assessments by HCPs during the diagnosis of ADRD as well as involving the family member during the care process, while in the interdisciplinary model of care, HCPs assess the patient individually and then meet to discuss their perspectives. Morgan and colleagues (2009) believe that both models of care should be adopted when providing care for patients with ADRD. Vyt (2008) stresses that transdisciplinary team models should not diminish the role of each HCP; rather, using each role to enhance the care of patients is an important component. In the current study, team members described the importance of seeing the patient simultaneously, meeting with all members of the team to discuss a diagnosis and care plan, and involving the family during the assessments. Their reflections on their experiences providing care in the memory clinic indicate they see these as different from working in a family health team setting. In the family health team setting, HCPs would typically see patients at different times and less collaboration would take place, at times losing pieces of valuable information.

The current study found that being able to provide various resources for ADRD patients was an important part of working in the memory clinic. Though this is the case, many HCPs expressed frustrations with navigating the system, and the long waitlists associated with some community resources for patients. McColl and colleagues (2008) found similar experiences of family physicians working with persons with disabilities, as shortages and longer waitlists impeded proper access to beneficial services for their patients. Rapoport and colleagues (2007) stressed the importance of recognizing the burden of having a license revoked and the need for better access to resources such as transportation services to assist with mobility. Accessing such services and support from various organizations such as the Alzheimer Society assists in decreasing distress for patients and their families (Downs & Bowers, 2008).

5.1.3 Personal and professional rewards

The HCPs in this study enjoyed their experience working with a more complex patient population. One participant response of “it never gets old” was a key reason why many HCPs enter the field of geriatrics after graduating from a health care provider degree. Feeling that they are solving a mystery is a thrilling part of working in the memory clinic, as HCPs must gather pieces of information from various sources and clinical tests and collaborate with teammates to come up with a treatment plan.

Often times, aggressive behaviours were noted as a challenging component of working with patients with ADRD. HCPs understood that the behaviours patients presented were part of their diagnosis. Nolan (2006) also found that challenging behaviours were seen by nurses in acute care environments as part of the dementia pathology and not of the patient him or herself. In the current study, behavioural symptoms of the diagnosis challenged HCPs to work together to develop creative strategies to alleviate ADRD symptoms. Callahan and colleagues (2006) found that receiving collaborative care was associated with improvements in patients' behavioural and psychological ADRD symptoms.

Cravens, Campbell and Mehr, (2000) explored the aspects that attracted HCPs to enter the field of geriatrics. Those who pursue a career in the field of geriatrics are interested in the challenges of patients' complexities and enjoy working in a multidisciplinary team setting. These findings are consistent with the current study's findings, as HCPs discussed their preference for working in a team setting to care for more complex patients, as well as their interest in the ongoing learning opportunities when addressing the complexities of the patients themselves.

Low interest in entering geriatric medicine may stem from the lack of exposure during education (Briggs, Atkins, Playfer, & Corrado, 2006). In a survey conducted by Briggs and colleagues (2006), 26.2% of specialists who chose to pursue a career in geriatric medicine were influenced by a senior or department. The current study found previous educational and work experiences inspired them to pursue their career in geriatrics and thus become interested working in the memory clinic.

Working with a more complex population was seen as an opportunity for professional and personal growth. For example, HCPs described feeling more comfortable diagnosing ADRD then they did previously in other settings. Uncertainties diagnosing dementia is common among primary care physicians (Pimlott et al., 2009b, Van Hout et al., 2000; Wilkins et al., 2007; Lee et al., 2010). In this study, team members, whether or not they were physicians, described the benefits of the learning experience through the memory clinic training program, as well as generally feeling more comfortable being part of an accurate ADRD diagnosis.

HCPs felt motivated by their teammates to stay and work in the memory clinic. HCPs saw the importance of each role and the value each HCP brought to the team. HCPs felt that each role provided a unique learning experience, allowing them to understand the responsibility of each role during ADRD care. Further, HCPs felt that they were able to transfer the knowledge they had gained from working with other disciplines within the memory clinic to other settings of practice. Goldman and colleagues (2010) stressed the importance of understanding the responsibility of each role in effectively working in a health team setting. Moore and colleagues (2012) found that when roles were not clearly defined in a team setting, proper communication was hindered and team members became confused. HCPs working in the memory clinic felt that their role was clearly defined and valued by others. These experiences of feeling valued in their role and understanding and valuing each other’s role may assist in the opportunity to excel in a team environment.

HCPs feel their work in the memory clinic is rewarding and satisfying. Bhatnagar and Srivastava (2012) describe how according to Werner (2001), job satisfaction is determined by five main factors. These factors involve: the person's responsibilities, their interest in the field, and the opportunity for growth and having social harmony and feeling respected by coworkers. HCPs felt personally and professionally fulfilled doing meaningful and good work. Working in the memory clinic felt like a "good fit" for their personal traits and career roles and responsibilities.

5.1.4 Importance of current research

As the prevalence of ADRD continues to rise, as well as the number of patients who will remain in the community to receive care (Alzheimer Society of Canada, 2010), it is crucial to explore primary care strategies for these patients. Exploring these strategies should involve examining the experiences of those working in primary care, as developing guidelines without an understanding the experiences of those who practice there may introduce challenges (Pimlott et al., 2009a). Working in a primary care memory clinic has been an overall positive experience, and this model can potentially inform other primary care settings in building a more effective model of care in their current settings.

This study stressed the importance of working with ADRD patients and families. Maintaining the patient's dignity while assessing and treating the patient is important for HCPs. Delivering a diagnosis is at times challenging, but a crucial component of working in the memory clinic. It is important to understand the experiences HCPs face when caring for a complex population, as the challenges (such as revoking a driver's license) are essential points to consider when developing strategies on how to remain a responsible HCP. Feeling professionally fulfilled by the care opportunities a more complex population has to offer is a key finding of this study. HCPs are intrigued by the complexities of the patients seen in the memory clinic, and these patients offer an enhanced learning opportunity. Gaining a deeper understanding on what motivates these HCPs to work in the field of geriatrics has the potential to influence strategies which may motivate current students to become more interested in caring for this patient population.

It is important to understand how HCPs of various backgrounds can effectively work together to provide proper care for complex patients. Primary care memory clinic teams allow researchers a unique opportunity to examine an interprofessional team dynamic. Looking at the experiences of primary care memory clinic staff provides further insight into the benefits and challenges of working with a complex patient population and also a collaborative team setting to provide care for those patients. This study stresses the importance of continuing to look at which team models best suit the needs of patients with complex chronic issues. Working in a mixed model of interdisciplinary and transdisciplinary care is stressed in the literature as an important method of enhancing care for patients with complex needs (Morgan et al., 2009). As team approaches in primary care continue to increase (Health Council of Canada, 2009), it is important to consider the most valuable and effective team approach to care for the patient. When HCPs have the opportunity to work simultaneously together to provide care to a patient, it may lessen the amount of repetitive information exchanged by the patient and family, allowing care to be an easier process for all parties involved.

5.1.5 Limitations and Strengths of Study

A number of strengths and limitations were presented during data collection and analysis. One researcher completed the coding and analysis of the data. Having only one coder could lessen reliability of the analysis. The researcher attempted to overcome this limitation by scheduling and meeting with committee members and colleagues to review the codes and the participant transcripts. The researcher also worked to diminish any biases from having only one coder analyze the data by engaging in member-checking with participants once the data was analyzed.

Selection biases may have occurred due to the sampling approach that was taken to recruit teams. Teams were chosen based on a criterion sampling approach. Contacting the Directors of the memory clinic instead of the participants themselves may have increased coercion. The researcher attempted to lessen this bias by asking the Director to only forward the information which was provided to the members of the team. If team members were interested in participating in the study, they were to contact the researcher privately. Further, the team members who participated in the study may have been more motivated than other HCPs working in a primary care memory clinic.

Teams who participated in the current study may have been higher functioning, and more established and thus transferability of these findings may be limited to newly established memory clinic teams. Though the teams were running for a number of years, some participants were not as experienced in the memory clinic as others, as experience ranged from approximately one year to approximately seven years. This range of experience did not seem to affect participants' perspectives and experiences, as the themes and subthemes describing their experience stemmed from all interviews that were completed. Having a range of experiences assists in understanding the shared experience of those working in the clinic. As teams develop over time, it is common for teams to hire newly trained HCPs to work with those who have been part of the team for longer. Therefore, it is important to address all experiences working in the team setting. Major differences between newer and older team members were not seen within this study. Saturation was reached after approximately six to seven interviews and the researcher kept collecting data until 12 interviews were completed to ensure that a full range of HCPs who worked as part of memory clinic teams were included in the study. The researcher attempted to strengthen the transferability of the findings of this study by engaging one urban and one rural memory clinic team. Recruiting HCPs from both urban and rural settings to participate in this study allows for a broader range of representativeness, alleviating as much as possible any biases of their experiences related to location.

Although various HCP roles within the team may have different experiences and perspectives, common themes still emerged from all 12 interviews that were completed. Understanding the shared experience of working in a team was the goal of this study. At times, HCPs would provide specific examples pertaining to their role in the team when discussing a rewarding, motivating or challenging experience, but the essence and main idea of those experiences were similar.

When asked about the challenges working in a team setting, some participants stated that they could not think of any. Participants may not have felt comfortable enough to speak to the challenges of working in team settings. The researcher attempted to lessen this bias by providing the participants with an information letter outlining the purpose of the study, explaining that the study will not have an effect on employment. In addition, before each interview took place, the researcher reminded the participants of the confidentiality measures being taken. It was also verbalized that if any names or identifying information was used during interviews, it would be deleted during transcription. Furthermore, the researcher ensured each participant had her contact information in case there were any further questions or concerns after the interview process.

In phenomenological studies, interviews are typically longer in length (approximately one hour) (Creswell, 2007). Due to timing constraints and the nature of their work, it was difficult for participants to commit for a full-hour interview. Alternatively, participants were interviewed for a maximum length of half an hour. Although this may have limited the researcher's opportunity to include additional probes to ask further questions, this length of time for the interviews still allowed for sufficient findings, and the researcher was able to probe questions to gain additional insight to participants' answers. Furthermore, the researcher was still able to reach saturation during the data collection process, which assists in justifying the decreased length of interview time.

A full experience of being involved in primary care memory clinics was not captured due to the study question focusing solely on the experiences of HCPs. Patient and caregiver experiences are important to explore when determining the quality of care that is received. Though this was not within the scope of the current study, it is acknowledged that future research looking at the experiences in enhanced models of care such as the memory clinic should include the patients and caregiver experiences.

5.1.6 Next Steps

The current study provides context to HCP experiences in working with complex populations in interprofessional team settings. Future research should focus on the outcomes of these clinics by exploring patient and caregiver experiences with specialized primary care teams, as it is important to gain their experiences to enhance care practices for these individuals. Though it was beyond this current study's scope, gaining patient and caregiver experiences may provide more insight to the full experience of the memory clinic as a whole, allowing for a deeper understanding of the benefits and challenges of the care setting from all perspectives involved. Examining how patient and caregiver experiences align with the positive experiences of HCPs will assist in enhancing the current model, and potentially inform future primary health care strategies.

Additionally, investigating the cost-effectiveness of caring for ADRD patients in a team setting is an important future research opportunity, as the demand for primary care strategies to care for ADRD patients is increasing. Examining whether providing ADRD support though memory clinics lessens physician visits and decreases hospitalizations are research questions that will allow investigators and policy planners to better understand the best practice strategies for these patients. According to Health Council of Canada (2009) these questions have not yet been answered.

It is important to note that patients with ADRD typically present with other chronic conditions (Schubert et al., 2005; Sanderson et al., 2002). Patients who present with more than one chronic condition are seen as a more complex population to manage (Sevick et al., 2007). Persons with multiple chronic diseases may not be well-served by many current models of primary care practice due to restricted length of time during consultations and improper coordination of care services, which may impede proper information exchange (Muntinga et al., 2012). The memory clinic model in primary care has been implemented to assist in solving the issue around improper ADRD diagnosis and treatment. This model is a first step of attempting to use enhanced models of team-based care to focus on a patient's complexity. Expanding this model to fit the full complex nature of these patients may strengthen the role of primary care teams in supporting these patients.

5.2 Conclusions

The findings of this thesis research project provide more context in understanding how to motivate future HCPs to work with complex populations. Primary care memory clinics are potentially one step closer in achieving better care for older patients with ADRD. The positive experience of all HCPs who are involved in providing care in these clinics shows the potential for primary care models such as the memory clinic to give care where HCPs feel they are making a difference and helping in any way they can. As the number of health care providers working in team settings continue to grow in Canada, as well as the number of patients diagnosed with ADRD, it is important to dig deeper into enhanced models of primary care practice and to reflect on the experiences of those providing and receiving care. Understanding the experiences of individuals involved in enhanced models of care may assist in improving and tailoring these models to better suit the needs of the patients they serve.

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Appendix A

Interview Guide

Section 1: GENERAL BACKGROUND INFORMATION (Adapted from Toscan et al., 2012[1])

*** These are "comfort-building" questions to assist in allowing the participant feel more relaxed with the interviewing environment and the interviewer. The answers provided will be used as probes when discussing questions based on Interprofessional Teams*

1. Please describe your position here at [INSERT LOCATION]?
    - **Probe: What is your role?
2. How many years have you been employed in this position at this family health team?
    - **Probe: how long have you worked in this memory clinic?
3. Overall, how many years of experience do you have as an [INSERT POSITION]?
    - ** Probe: in other health care settings, when did you graduate, etc.
4. Have you worked in a family health team setting before?
5. IF YES: How long did you work there?
6. How many individuals work with you on the health team?
7. Can you describe your team?

    **Probe: Their roles and backgrounds?

    **Probe: Could you provide more detail about your specific role within the health team?

    **Probe: How do you work together as a team?

*** The main question and probes (Section 2 & 3) have been adapted from Moustakas' (1994)[2] questions. These questions will involve probes (outlined by*

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[1] Toscan J, Mairs K, Hilton S, Stolee P. Integrated transitional care: patient, informal caregiver and health care provider perspectives on care transitions for older persons with hip fracture. International Journal of Integrated Care 2012;12(13): 1- 14.

an arrow symbol). General probes asking participants to clarify, give examples of, and expand on thoughts, ideas and discussion will also be made during the interview.

Section 2: Experiences working with ADRD patients

1. As a [Insert Position] could you describe your experience working with Alzheimer's disease and related dementia (ADRD) patients in this clinic?
    - ➢ What experiences have motivated or influenced you to work with ADRD patients?
        - ➢ What are some of the things about your job that you like?
        - ➢ Could you provide an example of a time/situation where you felt motivated to work with this population? What motivates you to work here?
    - ➢ What experiences have felt rewarding or valuable to you?
        - ➢ Could you provide an example of such an experience?
            - **Probe: With patients/families
            - **Probe: For you personally
            - How did that make you feel?
    - ➢ What experiences have been challenging working with ADRD patients?
        - ➢ Could you provide an example of a time you felt challenged/felt it was challenging to work with such a population?
            - **Probe: With patients/families
            - **Probe: For you personally
            - **Probe: How did that make you feel?
    - ➢ What motivates you to stay and work with ADRD patients?
        - ➢ Could you provide an example of a time you felt motivated to work/continue to work with this population of patients?
            - How did that make you feel?
    - ➢ OTHER PROBES:
        - ➢ Could you describe a good day?
        - ➢ Why is this work important to you?

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[2] Moustakas, C. (1994). *Phenomenological research methods.* Thousand Oaks, CA: Sage Publications, Inc.

    - ➢ At the end of the day, what makes you feel like you have contributed/impactful?
        - Is it patients?
        - Is it families?
        - Or is it really difficult to try and enjoy the good moments?
        - Can you describe the feeling?

Section 3: Experiences working in a family health team Memory Clinic

2 As a [Insert Position] could you describe your experience working in a Family Health Team based Memory Clinic? What is it about working as a team that you like?

- ➢ What experiences have motivated or influenced you to work in a Memory Clinic team?
    - ➢ How does your team come together to work interprofessionally and motivate each other?
    - ➢ Could you provide an example of a time where you felt motivated to work in a team such as this one?
        - How did that make you feel?
- ➢ What experiences have felt rewarding or valuable to you?
    - ➢ Could you provide an example of such an experience?
        - **Probe: Is there a time/situation where there was a positive outcome of working as a team?
        - **Probe: How did that make you feel?
- ➢ What experiences have been challenging working in a Memory Clinic team?
- ➢ How does your team come together to work interprofessionally in a situation?
    - ➢ Could you provide an example of a time/situation you felt challenged/felt it was challenging to work with such a team/interprofessionally?
        - **Probe: With your team
        - **Probe: How did that make you feel?
- ➢ What motivates you to stay and work in a team-based Memory Clinic?
    - ➢ Could you provide an example of a time/situation you felt motivated to work/continue to work with this team?

Appendix B

Information Letter Sent to Potential Participants of Study

Date: July 2013
Study Name: The experiences of health care providers working with persons with dementia in a primary care memory clinic
Researchers:

Paul Stolee, PhD
Associate Professor
University of Waterloo
200 University Ave W, Waterloo, ON N2L 3G1
Phone: 519-888-4567 ext 35879 **Email:** stolee@uwaterloo.ca

Linda Sheiban, MSc candidate
University of Waterloo
200 University Ave West, Waterloo, ON N2L 3G1
Phone: 519-888-4567 ext 35879 **Email:** lsheiban@uwaterloo.ca

Introduction:

You are being asked to give your permission to participate in a research study called "The experiences of health care providers working with persons with dementia in a primary care memory clinic" conducted by two researchers: Dr. Paul Stolee, and Linda Sheiban.

Your participation in this study is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent letter will tell you about the study. It will explain why the research is being done; what specifically you are being asked to do; and the possible benefits, risks and discomforts.

Please take time to read the following information carefully.

Who is conducting the study?

This study is being conducted by two researchers: Dr. Paul Stolee and Linda Sheiban, both who are from the School of Public Health and Health Systems at the University of Waterloo.

Background

What is the purpose of the study?

The proposed study will explore the essence of the experiences of health care providers who provide care to patients with Alzheimer's Disease and Related Dementia (ADRD) in primary care memory clinics family health team settings in Ontario. Previous literature has looked at health care providers' experiences working with dementia patients, to gain an understanding of working with older ADRD patients in an acute hospital or long-term care settings (Nolan et al., 2006; Rasmussen & Hellzen, 2013). Other studies have looked at physician’s experiences working with dementia patients in primary care (Pimlott et al., 2006). It is still not very well understood, however, the experiences of health care teams who work together to provide care to this population. This proposed study will build on research that has looked at experiences of those who work with ADRD patients, but will expand the knowledge necessary to gain the experiences of those who provide care in a primary care family health team memory clinic model. Understanding experiences, such as motivations and challenges when working in a team setting and with a complex population (dementia patients) will assist in informing policy and educational strategies, which will be useful to primary health care. As the prevalence of ADRD is expected to continue to rise, more diagnosed individuals will remain in the community, after diagnosis and will receive community-based care as their primary source of care service (Alzheimer Society of Canada, 2010). It is important to look at the experiences of health care providers who have worked with ADRD patients in team-based settings, as more models of support for ADRD patients will be needed. Understanding how a team of different professions can work together to provide care for a complex population will give the knowledge necessary to improve and expand these services.

What am I being asked to do?

You are being invited to participate in an interview conducted by Linda Sheiban, which will include an overview of the research project.

Afterwards, I will ask you to help address the research question by sharing your opinions and experiences in providing care to Alzheimer’s Disease and Related Dementia (ADRD) patients in a team setting. I would like your help in order to gain a deeper understanding on the reasons why some health care providers choose to have a career centred around caring for those with complex chronic conditions. By providing insights on your experiences, it will assist in the understanding of this research topic. This conversation will take place as an individual interview, which will be scheduled at your convenience. The conversation will be led in-person by one researcher, and will last for approximately 30 to 45 minutes. With your permission, the interview will be audio-recorded.

What are the Risks and Discomforts?

We believe that there are no risks or discomforts from your participation in this study.

What are the benefits of the research and benefits to you?

It is not clear if you will benefit from this study. There may or may not be direct benefits to you from taking part in this study.

Remuneration

Upon completion of an interview (whether it ends through self-initiated withdrawal or full completion of questions), you will receive a $10.00 gift card to your choice of Chapters or Tim Hortons for your participation in the study. The amount received is taxable. It is your responsibility to report the amount for income tax purposes.

Voluntary Participation

Your participation in the study is completely voluntary and you may choose to withdraw from participating at any time. Your decision whether or not to participate has no effect on your employment with the Family Health Team now or in the future. You can decline to participate in the study without penalty. If you agree to participate, you will be able to talk about whatever you are comfortable with. If there is an interview question you do not want to answer, you may say, “I don’t want to answer that question.”

Withdrawal from the Study

You can stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, has no effect on your employment now or in the future. If you decide to leave the study, all of the data collected from you will be immediately destroyed wherever possible.

Confidentiality and Data Security:

All information you give during the research will be held in confidence. Your data will be kept in a locked filing cabinet at the University of Waterloo, School of Public Health and Health Systems, and will be accessible only by the members of the research team. Your name will not appear on any of the data. Only the project team will have access to entire interviews. With your permission, anonymous quotations may be used in the following way:

- in teaching and demonstration materials,
- in scholarly papers, articles and other publications, and
- in presentations at academic, health care conferences

You will be explicitly asked for consent for the use of audio data for the purpose of reporting the study’s findings. If consent is granted, these data will be used only for the purposes associated with teaching, scientific presentations, publications, and/or sharing with other researchers and you will not be identified by name.

Confidentiality will be provided to the fullest extent possible by law.

All data and participant information will be stored in a secured and locked cabinet located at the University of Waterloo. Electronic files containing study data will be password-protected, and will be destroyed after 5 years. Audiotapes, transcriptions, questionnaires and data files will remain anonymous. An identification number will be used to organize the data, as each participant in the study will be assigned an identification number. There are no conditions under which the confidentiality of data cannot be guaranteed. In manuscripts for publication, individuals will not be named while explaining the study results, and any quotations used will be given pseudonyms to protect participants.

Questions about the Research? If you have questions about the research in general or about your role in the study, please feel free to contact Dr. Paul Stolee either by telephone at (519) 888 4567 x

35879 or by e-mail (stolee@uwaterloo.ca) or Linda Sheiban either by telephone at (519) 888 4567 x 35879 or by e-mail (lsheiban@uwaterloo.ca).

This research has received clearance through a University of Waterloo Research Ethics Committee. If you have any questions about this process or about your rights as a participant in the study, please contact Dr. Maureen Nummelin, Director, Office of Research Ethics, University of Waterloo at 519-888-4567 ext. 36005 or maureen.nummelin@uwaterloo.ca.

Conclusion

We are excited about this study and look forward to gaining your insight on your personal experience as a healthcare provider. We sincerely hope that you will consider participating.

Appendix C

Participant Consent Form

CONSENT FORM

By signing this consent form, you are not waiving your legal rights or releasing the investigator(s) or involved institution(s) from their legal and professional responsibilities.

I have read the information presented in the information letter about a study being conducted by Paul Stolee and Linda Sheiban from the School of Public Health and Health Systems at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

I understand that there is no guarantee that this study will provide any benefits to me.

This project has been reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.

☐YES ☐NO

I agree to have my interview audio recorded.

☐YES ☐NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.

☐YES ☐NO

I agree to let audio clips be used for presentations of the research results.

☐YES ☐NO

Participant Name: ___________________________ (Please print)

Participant Signature: ___________________________

Witness Name: _______________________________ (Please print)

Witness Signature: _____________________________

Date: ___________________________

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

☐YES, please e-mail me a summary of results. My e-mail address is:

____

☐YES, please mail me a summary of results. My mailing address is:

☐NO, I do not wish to receive a summary of results

Appendix D

Feedback Letter

UNIVERSITY OF
WATERLOO

inforehab
CIHR IRSC
Canadian Institutes of Health Research
Instituts de recherche en santé du Canada

November 12, 2013

Dear ***(Insert Name of Participant),***

I would like to thank you for your participation in this study entitled “The experiences of health care providers working with persons with dementia in a primary care memory clinic.” As a reminder, the purpose of this study is to explore the experiences of health care providers who work in family health team memory clinics and provides care to those with Alzheimer’s Disease and Related Dementia (ADRD).

The data collected during interviews will contribute to a better understanding of health care providers’ experiences working in a team setting to care for a complex patient population. These findings will assist in informing policy and educational strategies, which will be useful to primary health care, as the number of health teams and enhanced models such as the memory clinic model are increasing in Ontario.

Please remember that any data pertaining to you as an individual participant will be kept confidential. I plan on sharing the information retrieved from data collection with the research community through seminars, conferences, presentations, and journal articles. If you have any questions about the study, please do not hesitate to contact me by email or telephone as noted below. As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through a University of Waterloo Research Ethics Committee. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Maureen Nummelin, the Director, Office of Research Ethics, at 1-519-888-4567, Ext. 36005 or maureen.nummelin@uwaterloo.ca.

Sincerely,

Linda Sheiban
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Website: www.inforehab.uwaterloo.ca