

Families' perspectives on access to primary healthcare services for relatives living with
dementia in Manitoba

by

Isaac Oppong

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Abstract

This study purports to find out from family members of persons living with dementia about primary healthcare services available, challenges faced by relatives living with dementia when accessing these services, and their responses on how to improve access to these services in Manitoba. A literature review was conducted to describe what other scholars have reported on this matter or field of study. The researcher adopted the social model of disability as the underlying concept for this study. As this model holds that social and attitudinal barriers affect persons living with disabilities, it is incumbent on society to provide all the essential accommodations for persons living with dementia to improve their health and well-being.

This study employed a qualitative methodology with a case study design. Through a working relationship with the Alzheimer Society of Manitoba, eight people who had relatives living with dementia were interviewed. Ethical procedures were followed and approval was given by the Joint-Faculty Research Ethics Board (JFREB). A consent form was given to each of the study participants who voluntarily agreed to engage in this project to sign. Based on the information shared by the family members, a case study approach was used to write their stories. The findings revealed that relatives living with dementia used various forms of primary healthcare services and other services such as specialists, home care, nursing homes, and personal care home services. In addition, relatives living with dementia faced difficulties when using primary healthcare and other services. As a result, the family caregivers made suggestions to improve access to primary healthcare and other services. Themes were created in order to discuss the results of this study. The researcher gave some recommendations that could be used to tackle dementia care and support for persons living with dementia in Manitoba and across Canada.

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Dedication

I would like to dedicate this project to the Almighty God, my grandmother, and my family for their love and support throughout my life.

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Chapter 1

1.1.0. Background of the study

This chapter gives background information on how Canada is experiencing an ageing population, as well as some scholars' definition of dementia. The researcher justifies why there was a need to undertake this project. The underlying factors or position that influenced this study are highlighted. This research project sought to obtain information from family members who have relatives living with dementia in Manitoba. As such, three research questions were designed for this purpose. Also, the overarching objective of this project is to describe families' perspectives on access to primary healthcare services for relatives living with dementia in Manitoba. Since the primary healthcare system is vital to dementia care and also serves as a beacon of hope for families who have concerns about relatives living with dementia, the significance of this study was to create an enabling environment that promotes access to primary healthcare for persons living with dementia, contribute to knowledge and fulfill some of the gaps existing in the literature, add to existing ones, and recommend measures that can be beneficial in our primary healthcare system for persons living with dementia.

There has been an increase in the life expectancy of people in our contemporary society due to the advancement of medicine. Old age comes along with some health consequences which can affect the well-being of older adults. In Canada, some studies have projected that the older population will increase significantly in the years ahead. Due to this, Canada would be experiencing an old age population epidemic. According to McQuigge (2015), the current information given by Statistics Canada three years ago, reveals that there is a slight increase in the percent of the aged as against the younger ones who are less than fifteen years old in Canada. As noted earlier, the more we grow, the higher our chances of being susceptible to certain health

conditions which can affect our lives. Launer et al.'s study (as cited in Exalto et al., 2012) state that "[i]n general, dementia is rare below the age of sixty to sixty-five, but from the age of sixty-five onwards, dementia incidence doubles with every five years of age" (p. 861). Therefore, age serves as a contributing factor to living with dementia in the later stages of life. Thus, with the increasing number of older adults in Canada, who are susceptible to living with dementia, there is a clarion call for all stakeholders involved in delivering primary healthcare services to the people to proactively plan on how to improve this healthcare system to prevent this population from falling through the cracks. Dementia is a mental health condition which causes some functional decline in individuals who are being affected. The Alzheimer Society of Canada (2010) describes dementia as a health condition which affects an individual's cognitive capabilities. Dementia is a word employed to explain a category of brain conditions capable of causing an adverse effect in the endeavours of a person (Walsh, 2006). Therefore, dementia has a negative consequence on the performance of the human brain. Like any other health condition requiring some attention, persons living with dementia also need primary healthcare services that will improve their quality of life and support. A lot of institutions have been successful in designing high standards of specialist dementia care in order to satisfy or fulfill the requirements of people identified as living with Alzheimer's disease or similar conditions (World Health Organization & Alzheimer's Disease International, 2012). But some gaps still exist in our healthcare system in tackling dementia.

The College of Family Physicians of Canada (2011) states that the majority of healthcare services are provided in the primary healthcare system. Starfield et al. (2005) acknowledge that healthcare systems which are functionally active have primary care as one of its pillars regarding the provision of services. According to McColl (2006), "[a]ccess to primary care includes the ability to find a family physician, to get an appointment, to enter and use the facilities of the

practice, and to receive high-quality care” (pp. 293–313). Therefore, if all these rubrics used by McColl (2006) to measure access to primary care are not being met for all people including persons living with dementia who access these services, then access to primary care has been comprised. Aminzadeh et al. (2012) point out that primary care is important in dementia management. Therefore, these revelations support the idea that improving access to primary healthcare can enhance well-being and promote healthy lifestyle choices for people living with dementia. Family members providing home support to their relatives living with dementia play an essential role that promotes quality of life. According to the Alzheimer’s Association (2015), families perform over seventy percent of long-term care for older people. Smetanin et al. (2009) assert that by 2038, the number of hours that would be spent on providing caregiving to individuals living with dementia in Manitoba will be more than double of the number of hours spent during the early part of the twenty-first century. As such, the knowledge and ideas that family members hold about their relatives living with dementia cannot be overlooked. This has led to the support for a family-centred approach to dementia care (Gaugler & Kane, 2015; National Academies of Science, Engineering, & Medicine, 2016).

A family-centred approach to care involves families in the planning of events such as financial management, investment, property and estate management, healthcare appointments, advance directive arrangements in the event of death, and others that inure to the benefits of relatives living with dementia. According to Moise et al.’s study (as cited in Morgan et al., 2015), “[c]ore principles underlying planning for dementia include delaying institutionalization by supporting caregivers in maintaining home-based care, local coordination of services, and matching services to need” (p. 138). To achieve these goals, the involvement of a family member of the person being supported becomes crucial. Therefore, this study which targets families to

share their experiences on accessing primary healthcare services for relatives living with dementia has the potential to influence change in policy and direction in this sector. Chronic diseases are conditions that persist for longer than others that are short-lived. Many mental health conditions are chronic conditions of which dementia is of no exception. Taylor (2002) states that more than thirty-three percent of the health expenditure in the latter part of the twentieth century was because of long-term health conditions such as cardiovascular health condition, cancer, diabetes, and respiratory health conditions, which together translates to more than forty-five billion dollars. Also, the Alzheimer Society of Canada (2010) reports that the overall expenditure for supporting persons living with dementia during the early part of the twenty-first century was estimated to be more than thirteen billion dollars and has been projected to increase to more than one hundred and fifty billion dollars in two thousand and thirty-eight. Although these expenditures show that chronic health conditions are expensive to manage but ensuring that resources allocated for healthcare are accounted for and used efficiently may promote continuity of care in the primary healthcare system for persons living with dementia and other chronic health conditions.

1.1.1. Statement of the problem

In Canada, federal and provincial governments have the legal responsibility to meet the healthcare needs of residents. Hogg (1998) states that:

Health is not a single matter assigned by the Canadian constitution exclusively to one level of government. Like inflation and the environment, health is an 'amorphous topic' which is distributed to the federal parliament or the provincial legislatures depending on the purpose and effect of the particular health measure at issue. (p. 445)

This means that both the federal and provincial governments may collaborate to address some issues in the healthcare system which are deemed appropriate under their jurisdiction. However, some studies suggest that the healthcare needs of persons living with disabilities have not been met. McColl et al. (2010) state that persons living with disabilities who are counted as part of the labour force are highly susceptible to having their health demands not being taken care of as opposed to their counterparts without disability in Canada. Moreover, family members providing care to their relatives living with dementia have also suffered the same fate. Less than half of dementia caregivers in primary care environment get caregivers support and counselling about how to take care of some behavioural signs (Belmin et al., 2012; Reuben et al., 2010). While this puts the lives of persons living with dementia at risk, there may be some challenges in finding physicians and other healthcare services for them. Therefore, this study which seeks to initiate a conversation around the views that families have on accessing primary healthcare for relatives living with dementia in Manitoba can help in improving our healthcare system.

1.1.2. Reflexivity/ the role of the researcher

According to Mann & Kelley's study (as cited in Hesse-Biber, 2017), reflexivity centers on the ideology that "all knowledge is affected by the social conditions under which it is produced; it is grounded in both the social location and social biography of the observer and the observed" (p. 45). In this regard, there might be some preoccupied ideas, experiences, and knowledge as to why a researcher is conducting a study on a subject matter. I was born in Ghana, where I have lived for over twenty years. My grandmother lived with glaucoma and other health conditions. As a result, I provided caregiving support to ensure her safety and well-being. I was assisting her in many ways such as attending to a doctor's appointment, getting some drugs prescribed by the doctor from the pharmacy shop, and helping her to go for other medical checkups (e.g., lab tests). I could observe

from her facial expression the pain and sorrow in which she was going through. Throughout my experience in assisting my grandmother, I noticed that our healthcare system had failed older adults and seniors living in Ghana. We do have a national health insurance system, but from my subjective view, there is more to be done to ensure that many people have access to a higher quality of healthcare. Due to this, the researcher was motivated to conduct this study to find out from the perspectives of families the types of primary healthcare services available for relatives living with dementia, challenges that their relatives face in accessing these services, and some responses that families perceive as beneficial to addressing these difficulties in the province of Manitoba.

1.1.3. Research questions

1. What types of primary healthcare services do families perceive as available for relatives living with dementia in Manitoba?
2. What are some of the challenges that families perceive their relatives living with dementia face when accessing primary healthcare services in Manitoba?
3. What are some of the responses or solutions that families perceive can help address the challenges encountered by relatives living with dementia when accessing primary healthcare services in Manitoba?

1.1.4. Principal Objective

To describe families' perspectives on access to primary healthcare services for relatives living with dementia in Manitoba.

1.1.5. Research objectives

1. To find out from families the types of primary healthcare services available for relatives living with dementia in Manitoba.

2. To describe families' perspectives on some of the challenges faced by relatives living with dementia when accessing primary healthcare services in Manitoba.
3. To know families' perspectives on some of the responses or solutions they perceive can help address the challenges encountered by relatives living with dementia when accessing primary healthcare services in Manitoba.

1.1.6. Significance of this study

This research study seeks to create awareness on issues relating to accessing primary healthcare services for persons living with dementia in Manitoba. The World Health Organization & Alzheimer's Disease International (2012) proclaim dementia worldwide as a health condition that needs the attention of society and tasked all parties involved to put measures in place to tackle this increasing health condition facing the health and well-being of the masses. As a result, this study purports to draw the attention of policymakers, government institutions, and other relevant organizations to create an enabling environment that promotes access to primary healthcare services for persons living with dementia. Since Canada is encountering a dementia epidemic, there is the need to encourage research studies which will help the country to take proactive measures in managing dementia.

There are few studies that exist on the views held by family caregivers regarding the use of primary healthcare services for relatives living with dementia. In addition, a few of them also report on how family caregivers are affected in the course of providing caregiving support to their care recipients. Moreover, the field of disability studies is a new academic discipline that is beginning to receive some attention from the global community. Therefore, this study will help in contributing to knowledge and fulfill some of the gaps existing in the literature, add to existing

ones, and come up with some measures that can be beneficial to our primary healthcare system for persons living with dementia. This research project is unique in the sense that it was examined through a disability lens. Also, this research paper will be made available to society through publication and other platforms such as seminars and conference presentations.

1.1.7. Overview of the Thesis

In Chapter 2, the researcher provides in-depth information on the work of other authors relating to this field of study. As background, it provides a brief historical account of the Canadian health system that led to the creation of universal healthcare coverage in Canada. Some achievements that have been made in the primary healthcare system are documented to provide insightful information on how this healthcare system has evolved over the years. The primary healthcare services available for persons living with dementia, the challenges encountered in using these services, and responses that can improve access to these services, among others, are reported in this section.

Chapter 3 of this paper provides the methodological framework for this project. The social model of disability, which examines the relationship between disability and the activities of society to interpret how certain actions may prevent persons living with disabilities in realizing their full potential, is used as the main idea underlying this study. The researcher used a qualitative methodology through a case study design to provide detailed information from family caregivers regarding relatives living with dementia. In addition, the author of this study employed a purposive sampling technique to select eight people and conducted face-to-face interviews with each of the study participants. Based on the stories shared by the family members, themes were created to discuss the results of this project. Informed consent, confidentiality, and privacy were some of the

ethical issues taken into consideration. All the procedures to obtain ethical approval from the Joint-Faculty Research Ethics Board (JFREB) were followed.

Chapter 4 documents the findings of this study. Adopting a case study design, the researcher reports on the stories told by the family caregivers concerning relatives living with dementia. This study found that relatives living with dementia used various forms of primary healthcare services such as the services of a family physician, pharmacist, physiotherapist, occupational therapist, and nurse. Aside from these services, relatives living with dementia used other services that included specialists, home care, personal care homes, nursing homes, and others. Also, relatives living with dementia faced difficulties in using primary healthcare services and some of the other services. As a result, the family caregivers offered some suggestions that could improve access to primary healthcare services and other services such as specialists and home care services. In addition, many of the study participants shared how they were affected in the course of providing caregiving support to relatives living with dementia.

Chapter 5 discusses the results of this study. Due to the stories given by the family caregivers, issues emanating from these accounts are discussed under the various themes created. These themes include demographic characteristics of the relatives living with dementia, behavioural signs showed by relatives living with dementia, past incidents in the lives of relatives living with dementia, other health conditions experienced by relatives living with dementia, physical health conditions that have affected relatives living with dementia, medications for relatives living with dementia, and others. In this regard, some issues existing in the literature are used to support these discussions.

Family members play a pivotal role in caring for relatives living with dementia. As such, a lot of studies have not been done to ask about their opinions and ideas on this topic. As a result, this study opens a new chapter for policymakers and other stakeholders working in the healthcare system to amass resources to tackle the discrepancies that may exist in access to primary healthcare services for persons living with dementia.

Chapter 6 of this project highlights the researcher's recommendations concerning dementia care and support for persons living with dementia in Manitoba and across Canada. These recommendations are based on the issues found in the literature as well as the stories shared by the family caregivers in relation to relatives living with dementia. These suggestions include creating a national dementia strategy, creating a national pharmacare program, and providing funding support to family doctors, nurses, and specialists interested in training programs for dementia care.

Chapter 2

2.1.0. Literature review

This section describes some of the scholarly works that have been done that relate to the researcher's study. A historical account of the Canadian healthcare system is given in order to inform readers about how this system has evolved over the years. Since the provision of healthcare delivery for residents is the sole responsibility of provincial and territorial governments, some of the reforms that have occurred under the primary healthcare sector with support from the federal government are documented.

Also, the different types of dementia that affect people are highlighted and epidemiological information of its occurrence among the Canadian population is given to confirm the epidemic nature of this health condition. Other topics such as types of primary healthcare services available for persons living with dementia, challenges that persons living with dementia face when using these services, and some responses that exist to address these difficulties are described in order to show what has been done in this area of study.

2.1.1. The Canadian Healthcare System

The Canadian healthcare system has been touted as one of the best among developed nations that have universal healthcare coverage for its people. A general survey which took place at the end of the twentieth century and early part of the twenty-first century reports that the people of Canada regarded the healthcare system as one of the priorities of this country (Pollara Research, 2006). As such, advocates consider healthcare as a right and not a privilege. Moreover, since rights and privileges come with responsibilities, so does the healthcare system which has stakeholders responsible for its administration and delivery of services to the people. In Canada, provincial and

territorial premiers have the oversight responsibility of managing the healthcare system as enshrined in the Supreme Court laws of this country (Health Canada, 2012). The province of Saskatchewan introduced a healthcare financing model which provided funding for hospital services during the latter half of the twentieth century (Health Canada, 1999; Health Canada, 2012). This model set the stage or served as the forerunner to the universal healthcare insurance system in Canada. Around that period, the federal authorities introduced the Hospital Insurance and Diagnostic Services Act which was funded by the federal and provincial authorities (Health Canada, 2012).

Considering these turn out of events, the idea of providing healthcare coverage for the people was conceived by the regions across the length and breadth of this country. By the beginning of the sixth decade of the twentieth century, the provinces had established healthcare coverage for themselves (Health Canada, 1999; Health Canada, 2012). Although physician services fell short of the healthcare funding models which existed at that time and therefore, the federal authorities in the mid-1960s introduced the Medical Care Act to take this service into account (Health Canada, 2012). This did not end there as another Act was introduced to override the Medical Care Act. According to Health Canada (2012), the Canada Health Act which was introduced in the 1980s succeeded the Medical Care Act. The rationale behind this Act as reported by Health Canada (1999, 2012) is to give health delivery considered important to people who are entitled, and able to meet their healthcare needs. However, for the provinces and territories to get transfer payments, they must abide by the rules and responsibilities of this statutory law. These rules according to Health Canada (1999, 2012), include public administration, comprehensiveness, universality, portability, and accessibility. Each of these statutory elements describes the duties and roles expected from the provinces. The federal authorities via the Canada Health Transfer give

more than thirteen percent of the overall health expenditure incurred by the provinces and territories (Health Canada, 2012; Sutcliffe, 2011). As such, the majority of the cost which is said to be more than eighty percent are born by both the provinces and territories through levies collected from its residents (Sutcliffe, 2011). Therefore, the federal, provincial, and territorial governments have a statutory obligation to provide healthcare for the people.

The Canadian Institute for Health Information (2011) states that the provincial and territorial authorities fund seventy percent of healthcare cost, while thirty percent comes from the individual establishment which takes into account drugs and auxiliary health arrangements comprising of physiotherapists, chiropractors, massage therapists, occupational therapists, podiatrists, naturopaths, and psychologists. Therefore, private or individual establishment plays an essential role in the healthcare system. More so, physiotherapists and occupational therapists form part of the primary healthcare system which is vital to the delivery of health services to the people. But it seems that the seventy and thirty percent funding of healthcare by governments and individual establishments respectively remain arguable or questionable. Naylor (1986) asserts that these two statutory laws namely, the Medical Care Act and the Hospital and Diagnostic Services Act that served as the underlying factor for the creation of the hospital insurance plan, strongly highlighted out-of-pocket as the governing operation of institutions including remuneration for medical doctors in Canada. The Canadian Institute for Health Information (2010c) states that more than fifty percent of general practitioners constitute the labour pool of medical doctors. To further deepen the point on out-of-pocket payment as the principal means of operations in Canada, the College of Family Physicians of Canada et al. (2007b) report that out of the more than fifty percent of general practitioners delivering their services, more than forty-seven percent of them receive more than eighty-eight percent of salaries through out-of-pocket, while the rest receive salaries via

other financial arrangement models. To put this issue to rest, the Canadian Institute for Health Information (2011) highlights that residents living in this country cater for more than fifty-two percent of healthcare services that do not fall under the provincial health plan by themselves and the rest of these services are taken care of by institutions which offer private health benefits. Therefore, one may describe fee-for-service as the means of payment prevailing in our healthcare system. One reason to account for this may be the autonomy that physicians in Canada have in deciding the stream (public & private) to offer their services and the incorporation of new health facilities and clinics providing specialist services.

2.1.2. Primary Healthcare in Canada

The primary healthcare system features in many of the existing health structures and arrangements around the world. This may be due to the attention it has received through the activities of the World Health Organization on the provision of healthcare services. The World Health Organization (1978) through a communiqué issued in Alma Ata adopted this model to provide healthcare for people from all walks of life. In Canada, the primary healthcare sector forms part of the current health system. It comprises of programs such as prevention, public health, and programs offered by other different forms of health professionals in various areas designed to put people first concerning the delivery of services (Canadian Institutes of Health Research, 2014). Other scholars have provided a positive outlook on the potentials of the primary healthcare system. According to Watson (2005), stakeholders in primary healthcare consider it as vital in tackling the demands of a growing number of adult residents, the accumulation of persons who face long-term conditions, health conditions that are complicated and interrelated either with these and others that restrict participation. Therefore, the primary healthcare system offers hope for persons living with dementia if access is improved and directed towards their demands. The citizens of this country

have occasionally been demanding for an improvement in the primary healthcare sector, higher standards of health delivery, and other additional programs of this model (Watson & Krueger, 2005; Pollara Research, 2006). As a result, this healthcare sector has experienced some massive reforms and had received the support of the federal government through the provision of funds.

One of such funds was the Primary Health Care Transition Fund, where the federal government committed to providing eight hundred million dollars for reform programs carried out by the provinces and territories. Aggarwal & Hutchison (2012) state that the motive behind this was to deal with or tackle the healthcare demands of the ageing epidemic facing this nation and the increasing impact of long-term health conditions. This initiative was a step in the right direction as older adults and seniors are susceptible to living with dementia and other long-term health conditions. Therefore, the success of this program means availability of more primary healthcare programs, adequate access to these programs, and a higher standard of care for older adults and seniors living with dementia and other long-term health conditions. Throughout these reforms plan, a remarkable number of achievements were made. The Canadian Institute for Health Information (2010c) states that there has been more than seven percent improvement in terms of the ratio of general practitioner compared to citizens due to the availability of vacancies in the health educational institutions and housemanship programs for doctors who are into family medicine during the early part of the twenty-first century. This in effect means that more general practitioners will be available to offer their services to people who access primary healthcare. Besides, the barriers involved in finding a family physician would be reduced. According to the Canadian Medical Association (2002) & the College of Family Physicians of Canada et al. (2007b), nationwide, the number of general practitioners getting more than eighty-five percent of salaries through out-of-pocket transfers reduced considerably to less than forty-nine percent during

the early part of the twenty-first century. Some of the reasons that could account for this is that more healthcare programs may have been introduced and a considerable number of people were having access to publicly insured services than the previous years.

The Canada Health Infoway & Health Council of Canada (2006) state that more than ninety percent of information registered about patients who go to see their doctors were kept in traditional formats and many of the drugs given under the authority of a medical doctor were provided in manual forms. Therefore, information technology and innovation in healthcare delivery were not fully embraced at that time. But according to Schoen et al. (2006, 2009), the data from the participants in Canada who engaged in a study conducted by the Commonwealth Fund on practitioners in primary care shows that there was a fourteen percent improvement in the adoption of modern technological forms of keeping health information during the early part of the twenty-first century. This showcase how efficiency and higher quality of healthcare delivery were promoted in the primary care sector. Although all these statements given about the achievements made in the primary healthcare system are not meant to paint a perfect picture about this sector, as there may be some challenges facing persons living with dementia who access primary healthcare services. Therefore, this is one of the reasons why this study was conducted to seek the views of families on access to primary healthcare services for relatives living with dementia in Manitoba.

2.1.3. Types of Dementia

There are different types of dementia that affects several people and mostly the geriatric population. These include Alzheimer's disease, Lewy body dementia, Frontotemporal dementia, vascular dementia and similar ones such as Parkinson's disease and Creutzfeldt-Jakob disease (Alzheimer Society of Canada, 2010). Some suggested risk factors for dementia are gender, low

educational background, family history, past head injuries, and others (Larson et al., 1992). Some studies have reported on the linkage of genes to Alzheimer's. Hollingworth et al. (2011) assert that a lot of these genes does not trigger this health condition to the extent of bringing about a greater vulnerability. The category E4 of the apolipoprotein gene is linked to a greater susceptibility of living with late-onset Alzheimer's disease (Verghese et al., 2011). However, this relates to sporadic or non-familial Alzheimer's disease. Dening & Babu Sandilyan (2014) state that "[a]part from these genes, having a first-degree relative with late-onset Alzheimer's disease increases one's chance of developing Alzheimer's disease only slightly" (p. 40). The Alzheimer Society of Canada (2010) states that Alzheimer's disease is the most dominant of all the types of dementia and next to it is vascular dementia. Vascular disease and Lewy body disease, many times, exist in tandem with Alzheimer's disease (Bachman et al., 1992; Collerton et al., 1996).

As a health condition which adversely affects language and cognition, persons living with dementia hitherto to having this health condition, in many circumstances, live with other diseases such as coronary artery disease, congestive heart failure, hypertension, and diabetes (Prince et al., 2011; Kurrle et al., 2012). Nabalamba & Patten (2010) assert that over eighteen percent of persons living with dementia have a mood disorder. In contrast, they state that less than six percent of their counterparts without dementia live with mood disorders (Nabalamba & Patten, 2010). This information supports the idea that persons living with dementia have diverse healthcare needs and therefore, a comprehensive primary healthcare structure for dementia care is needed to improve the quality of life, care, and support for them. The Alzheimer Society of Canada (2005) asserts that more than seventy percent of Alzheimer's diagnosis and over sixty percent of the other types of dementia affect women. This opens a new chapter for additional studies to be conducted to identify the reasons behind this gender disparity in dementia disease occurrence among the general

population. By so doing, specific programs (adopting healthy living lifestyles, education on dementia care for family members providing caregiving support, healthcare initiatives for the vulnerable population who are at risk of living with dementia, e.g., Down syndrome, etcetera) can be created to help the people often affected by this health condition.

2.1.4. Prevalence of Dementia in Canada

The world is facing a dementia epidemic, and the same trend seems to be happening in Canada. The World Health Organization (2016c) states that more than forty-seven million people around the world live with dementia, and more than seven million cases happen as the year unfolds. Information from other parts of the world confirms the global nature of this health condition. In Canada, dementia is one of the significant health conditions facing the geriatric population. According to the Canadian Nurses Association (2013), dementia has reached the threshold where it can be considered an epidemic. Therefore, the healthcare system should be proactive in tackling this issue. The Alzheimer Society of Canada (2005) states that nine percent of the population from age sixty-six and beyond lived with dementia.

Moreover, the Alzheimer Society of Canada (2006) asserts that more than four hundred thousand people from age sixty-six and beyond, and thirty-three percent of people from age eighty-six and above lived with Alzheimer's or other similar health conditions. The Alzheimer Society of Canada (2010) points out that more than four hundred and eighty thousand people in Canada lived with Alzheimer's or other similar types of dementia. They projected that more than one million people in Canada would live with dementia in two thousand and thirty-eight, which represents more than two-point-seven percent of the population (Alzheimer Society of Canada, 2010). A careful observation of this epidemiological information shows that the number of people affected

by this health condition continues to increase among the Canadian population. These phenomena have the potential to exert more pressure on the existing primary healthcare services. According to the Public Health Agency of Canada (2014), this trend will have a greater impact on the primary healthcare sector. Therefore, it would be prudent and efficient to allocate resources to manage this health condition. By so doing, early detection of dementia and cutting-edge innovation in the primary healthcare system will be encouraged.

2.1.5. Types of primary healthcare services available for persons living with dementia

A variety of health professionals provide primary healthcare services. These professionals include family physicians, pharmacists, occupational therapists, nurses, physiotherapists, and dietitians, among others. Family physicians make referrals, coordinate with other health professionals, and do follow-up services to give the best of care to people. The organization of events and activities in dementia care is usually the duty of the family physician, but there are other sources that can be used to supplement these activities to enhance the quality of care (Burns et al., 2003; Callahan et al., 2006). Regarding referrals, persons living with dementia may be referred by their family physicians to other specialists such as a neurologist, who might perform diagnostic imaging to confirm a case of dementia. Also, family physicians prescribe medication for people in their care. Family physicians are the initial point of contact for persons living with dementia who access community-based services, but concerning drug prescription, family physicians and other specialists perform this function separately (Hillmer et al., 2006; Jeschke et al., 2011). Therefore, effective regular communication should exist between family physicians and other specialists such as neurologists and psychiatrists in their delivery of services to persons living with dementia. According to Thind et al. (2009), lack of agreement among professionals can result in lower standards of healthcare delivery. This might account for some of the reasons why there has been a

call for a multi-disciplinary approach to dementia care where health professionals come together to work in teams to ensure a higher quality of care for people living with dementia. The Alzheimer Society of Canada has created a program called the First Link which helps family physicians to connect people under their care to society to assist them to find other services deemed essential to their healthcare needs. Frank et al. (2011) state that:

The First Link referral process begins when the family physician seeks permission from the patient and family to provide the Alzheimer Society with contact information and sends a simple referral sheet to the local chapter office. The Alzheimer Society proactively contacts the patient or caregiver to introduce the services available and to arrange follow-up contact. (p. 1389)

This initiative has the potential to help family physicians who sometimes find it difficult to refer people due to the limited number of specialists. Persons living with dementia need services that will help them to maintain their functional abilities to ensure independence. Occupational therapists are some of the health professionals that can be relied upon to achieve this objective. One of their duties is to enhance the quality of life and assist people to engage in activities of daily living (Occupational Therapy Australia, 2013). Occupational therapists provide services to persons living with dementia who live in their homes, hospitals, communities, long-term care facilities, and others (Bennett et al., 2011). They assist people living with dementia to engage in meaningful activities that enhance their functional abilities and work with their families to achieve these objectives. As such, they also work to ensure the safety of persons living with dementia. Wesson et al. (2013) report that persons living with dementia are highly susceptible to experience a fall as compared to others. Injuries as a result of a fall are some of the factors which lead to a decline in an individual's capacity to take care of him/herself and to engage in activities of daily living

(Tinetti & Kumar, 2010). Occupational therapists work to ensure that persons living with dementia transition smoothly to their new environment because of some adaptations that have been made. This helps to avoid falls and other injuries that would have occurred. Therefore, occupational therapists play an important role in maintaining the dignity and integrity of persons living with dementia.

Dietitians form part of the primary healthcare system. They play an essential role by ensuring that people adopt a healthy eating lifestyle. They also provide education on sources of food nutrients and supplements that promote the health and well-being of people. At some point in the transition period for persons living with dementia, the services of a dietitian may be needed to assist in developing a healthy food menu plan. This helps families supporting relatives living with dementia to have access to a healthy diet that can enhance their well-being. The Alzheimer's Disease International (2014) share that overall, the reduction in weight linked to malnutrition usually comes before the beginning of dementia and happens further as the condition continues to develop. As such, Droogsma et al. (2013) estimate that one percent shy of fifteen percent of persons living with dementia who live independently were susceptible to malnutrition. Therefore, engaging the services of a dietitian could help in responding to malnutrition among persons living with dementia thereby reducing the incidence of weight loss. Chang & Roberts (2008) share that assisting elderly people living with dementia to take in food is usually complicated, requires time and becomes challenging in the transition period of the condition.

In addition, Kai et al. (2015) state that over twenty percent shy of a hundred percent of persons living with Alzheimer's encounter eating and swallowing problems. This reveals how feeding can be a hard task for families supporting relatives living with dementia. Again, dietitians can provide education to families on how to make some food textures (e.g., soft minced, etc.) that

are easy to eat for relatives living with dementia. Another particular group of people that may need the services of a dietitian are persons living with dementia who also have diabetes. According to Cheng et al. (2012), a contemporary combination of the findings from various studies shows Diabetes Mellitus as a great underlying element or component for the various forms of dementia. The services of a dietitian would help to ensure that people living with these two health conditions (dementia & diabetes) have a regulated food menu or plan which promotes access to a healthy diet and other food nutrients. By so doing, their blood sugar levels can be monitored and kept at a reasonable level. Otherwise, this can affect their physical health and well-being and also create a burden for their caregivers.

Pharmacists are part of health professionals working in the primary healthcare system. As such, they can be very beneficial to families providing caregiving support to relatives living with dementia. As dementia is linked to health conditions that are visible, there is a higher chance for being on many medications thereby causing greater susceptibility to the harmful side complication of the use of medication (The King's Fund, 2013; Wise, 2013). Tannenbaum et al. (2012) state that this scenario especially put adults at risk of having their thinking and memory affected, which is caused by the influence of medication. Many people living with dementia rely on drugs to manage their health conditions. Devanand & Schultz (2011) & Bell et al. (2012) support the assertion that numerous medications have the potential to impact the ability to reason and understand. As a result of this situation, using the services of a pharmacist could ensure the safety and appropriate use of drugs for persons living with dementia. Pharmacists have the ability to evaluate drugs in order to find out if the drugs given under the authority of a health professional to persons living with dementia are beneficial, creating problems, and to establish that their use is vital (Blenkinsopp, Bond, & Raynor, 2012). Moreover, at the fourth stakeholders' seminar in

Canada, donepezil, galantamine, and rivastigmine were suggested as drugs for managing Alzheimer's and other dementia (Gauthier et al., 2012). A working relationship between families, physicians, and pharmacists may be needed to ensure that persons living with dementia who are using some of these drugs are getting the right dosage and reviewing them at some point to find out if they were helpful or not. Doug et al. (2017) point out that some of the regular harmful complications linked to the usage of the drugs above include nausea, vomiting, and diarrhea due to the higher presence of acetylcholine. Again, Doug et al. (2017) talk about encountering some challenges in sleeping, drowsiness, reduction in weight, and fainting as potential identifiable alternative complications that can happen and therefore, an observation is needed. As these medications suggested at the fourth seminar in Canada are drugs that affect the work of acetylcholinesterase on acetylcholine in the human brain, a study in the United Kingdom, state that close to fifty percent of individuals on these types of medications use other ones that fight against the attachment of acetylcholine to receptors in the brain as a result of having physical conditions (Carnahan et al., 2004; Modi et al., 2009). According to Modi et al. (2009), medications that stop the role of acetylcholine are linked to sedation, memory and thinking problems, and delirium, while Aizenberg et al. (2002) tie them to falls. Therefore, it becomes imperative for families and physicians to work closely with pharmacists to prevent any unforeseeable harmful complications of drug use for persons living with dementia.

Allied health professionals contribute to the delivery of services in the primary healthcare system. For persons living with dementia who stand the chance of receiving a higher quality of care through a multi-disciplinary team approach, the services of a physiotherapist would help in maintaining their dignity and independence. Blankevoort et al. (2010) report that being less active add up to the limited choices in life faced by persons living with dementia and are at risk of having

the state of their body and performance negatively affected thereby causing a decrease in independence and engagement in the regular or day-to-day routine. Therefore, encouraging persons living with dementia to engage in daily activities in the home (such as cleaning, brushing, and bathing) and community (walking at the park and meeting with friends) can improve in maintaining some basic skills. Again, Thuné-Boyle et al. (2012) & Winchester et al. (2013) identify the engagement in an activity as having the potential to promote the performance of day-to-day routine, sleep as well as a decrease in neuropsychiatric signs of dementia. Rolland et al. (2007) describe that being more active fights against some of the adverse effects connected to dementia, which includes susceptible to falls and broken bones, wasting of the muscle, and disruption in the performance of the heart and blood vessels. Therefore, accessing the services of a physiotherapist to develop a care plan with persons living with dementia to engage them in some physical activities can improve their independence, dignity, and well-being.

2.1.6. Challenges that persons living with dementia encounter in accessing primary healthcare services

Levesque et al.'s study (as cited in Woodgate et al., 2017) affirms that “[h]ealthcare services are expected to be approachable, acceptable, available, accommodative, affordable, and appropriate” (p. 2). Therefore, these various factors can be the measures for assessing the accessibility of primary healthcare services as many health services are offered in this sector. If these factors are not met when accessing a primary healthcare service, then there are certainly some challenges impeding their usage. Access to transportation helps people to travel from one place to another. In our modern society, the usage of transportation services has become an essential part of the daily activities of people. Without it, a lot of our schedules will be disrupted. We need access to transportation to go to school, work, attend a hospital appointment, and other services. But

sometimes persons living with dementia may encounter some difficulties in accessing transport services to see their doctor or visit to other specialist services. This might be the case for persons living with dementia who live in rural areas where access to transportation remains a challenge. One of the things to take note of is that Dandy & Bollman (2008) state that the majority of the number of people living in the countryside in Canada is made up of the elderly as against the number of people living in the city. With transportation being an issue in rural areas, the elderly people living with dementia are highly likely to be at the receiving end. In the United Kingdom, an evaluation of diagnoses and post-diagnostic management of dementia cases in remote communities reveal that access to specialist services and others become an obstacle as a result of the challenges involved in accessing transportation (Szymczyńska et al., 2011). This situation can cause some delays which may lead to missing a physician or specialist appointment for persons living with dementia in these areas.

Health professionals in the primary healthcare sector provide essential services to people living with dementia. More than eighty-five percent of people in Canada reported about having periodic access to a health service which is often a general practitioner (Canadian Institute for Health Information, 2009). But most often, persons living with dementia and their family members encounter some challenges in finding health professionals who will provide them with the needed healthcare services. Hogan (2001) reports that the number of specialists available is not sufficient to provide the necessary services for the increasing number of persons living with dementia and their families and friends. In many circumstances in the United Kingdom and Canada, it becomes difficult to have access to psychiatrists and social workers (Lester et al., 2005; National Physician Survey, 2007). This might be the case for individuals with dementia who live in rural areas where there are a limited number of health professionals delivering their services. As a result, many of

them have to travel a long distance to cities where there are more primary healthcare services and specialists. This affects their healthcare needs and finances as a considerable amount of money is spent on transportation.

Generally, if there are more family physicians available, then many people will have access to healthcare services. One indicator to check is the doctor-patient ratio which gives the balance between physicians and patients. The higher the number of patients per physicians, the greater the challenges in finding a family physician and a likelihood event of facing long wait times in accessing primary healthcare services and vice versa. Chan (2002) states that in our modern times, general practitioners perform various functions in relation to their counterparts of the past decade. This means that physicians in our contemporary society have incorporated more services in their practice as against their associates in the past. According to the College of Family Physicians of Canada et al. (2004), steadily, the pace of general practitioner performance in surgical, anesthesia, and obstetrics functions is decreasing, while a new study shows that more than ten percent have reported limiting their level of engagement in the period of forty-eight months ahead. General practitioners, in the case of limiting their level of engagement or functions, would mean that persons living with dementia might have to look elsewhere for some services that were previously provided by them. This scenario can pose a challenge to persons living with dementia when accessing primary healthcare services.

There are a lot of uncertainties surrounding the diagnosis of dementia. This situation can affect family members caring for relatives living with dementia as they might be worried as to where to seek the right diagnostic services. In North America, according to the National Institute of Health's study & Small et al.'s study (as cited in Linda et al., 1999), one of such protocols suggested by professionals in diagnosing dementia:

...include obtaining information from the patient and family members on the patient's history of difficulties in functioning due to cognitive problems; mental status testing using standardized instruments; and a standard battery of laboratory tests, including complete blood cell count, blood chemistries, liver function test, and determination of thyroid-stimulating hormone levels to rule out possible reversible forms of dementia. (p. 4)

Morris et al. (1988) assert that employing this protocol has been proven to be viable in dementia diagnoses. But the level of knowledge and skills possessed by physicians and specialists play a crucial role in diagnosing dementia. Several research studies show that there are irregularities as to how primary care physicians use these suggested protocols in diagnosing dementia (Fortinsky & Wasson, 1997; Glasser, 1993). On the one hand, in Canada, Aminzadeh et al. (2012) point out that “[a]lthough the majority of patients experiencing the first signs of dementia initially visit a primary care provider, many, if not most, appear to have their diagnosis confirmed by a specialist” (pp. 85-94). On the other hand, according to Drummond et al. (2016),

Reasons for dementia diagnoses occurring in specialist practices rather than primary care are multifaceted and include primary care providers having a lack of confidence in dementia knowledge and support resources; concern about misdiagnosis; perception of usefulness of diagnosis and treatment options; and lack or mistrust of screening tools. (p. 180)

This explanation from these authors supports the argument that there is an existing knowledge gap among primary care physicians in diagnosing dementia. As stated earlier, family members may be faced with caregiving challenges and might not be sure as to where to seek the right diagnostic services for their relatives living with dementia.

In our contemporary society, persons living with disabilities encounter a lot of discrimination in their life endeavours. Barnes (1992) & Pfeiffer (2003) report that in areas such as education, employment, and health. The mainstream culture perceives persons living with disabilities as weak and fragile. In this regard, they are considered as a burden to the public purse and as people who need welfare services to survive. Thomas (2007) points out that a person is considered capable and financially independent based on his/her capacity to contribute to economic development. These mainstream ideas have caused significant damage to the lives of persons living with disabilities. Academic papers and publications have been able to expose the discrimination and exclusion faced by persons living with dementia (Blackman et al., 2003; Dorenlot, 2005; Beattie et al., 2005b; Davis et al., 2009; Brittain et al., 2010). The negative attitudes and discrimination from health professionals and other service providers against persons living with dementia have the potential to deny them access to primary healthcare services. According to Health Canada's study (as cited in Bielska et al., 2012), "[t]he Canada Health Act stipulates that healthcare services are reasonably and uniformly accessible to all citizens without financial barriers or discrimination" (p. 52). Therefore, denying an eligible person access to healthcare based on his/her race, ethnicity, disability, gender, and financial status, among others, amounts to a breach of this statutory act.

However, another exciting information according to Fierlbeck (2011) is that the provinces cannot be held accountable when they breach the Canada Health Act because it's not inescapable on them; acting in a manner that goes above their powers and that of the federal mandate. Therefore, if a provincial government tasked to provide healthcare to all eligible residents including persons living with dementia fails to do so, where would it be appropriate to seek redress? Also, persons living with dementia who need access to primary healthcare to improve their health condition will be left in the loop and might not get the necessary healthcare services.

This grey area in the law may serve as an escape route for provincial governments to renege on their mandate in providing healthcare services that accommodate the needs of persons living with dementia.

Waitlist management continues to be one of the issues plaguing the Canadian healthcare system. The wait times involved to have access to a doctor can adversely affect the health and well-being of the person seeking care especially if it is taking longer to see one. As it can be a challenge when using this service, more than seventy percent of mature people in Canada, assess the standard of health service provided by general practitioners to be outstanding or remarkable (Canadian Institute for Health Information, 2009). Schoen et al. (2010) point out that more than thirty percent of the people in Canada say that in the most recent times when they got ill, it took more than five days for them to have access to a physician service. Persons living with dementia might suffer the same fate when accessing physician services. Therefore, the wait times involved to see a doctor may serve as a challenge to them as this can affect their health condition.

Another potential challenge that can affect persons living with dementia who access primary healthcare services is the cost of prescription drugs. The Canadian Institute for Health Information (2006) points out that next after hospital expenditures is pharmaceuticals, and thus, purchases for medications given under the authority of a physician and over-the-counter medicines considered as the most significant and swift moving enterprise in the health field, with the rate of progress stated to be more than four percent per annum. Some of the underlying factors to consider when debating on why the pharmaceutical industry is showing definite signs of financial profitability are the prevalence of chronic conditions among the population and the desire to engage in breakthrough cutting-edge research into new drug discoveries and its clinical effectiveness. This gives pharmaceutical companies the legal right to have patents for these new

drugs. Although governments have oversight responsibility through their agencies (e.g., Patented Medicines Prices Review Board- federal stage) or existing agreements (e.g., Product Listing Agreement- provincial stage) when it comes to drug pricing, but when these drugs after approval from Health Canada are advertised and prescribed continuously for people due to its safety and effectiveness, then sales may be improved thereby attracting more financial gains for the pharmaceutical industry.

From a subjective point of view, when there is a high prevalence of chronic diseases among the population, then more people may need prescription drugs to cure or manage their health condition. All other things being equal, the more people buy prescription drugs due to having some chronic diseases, then the higher the sales thereby drawing in more financial gains for this industry. There are some dynamics involved when it comes to prescription drug coverage. The Canadian Institute for Health Information (2011) & Paris & Docteur (2007) assert that medications prescribed in health institutions are taken care of by the health insurance services administered by governments. In contrast, according to Paris & Docteur (2007), when it comes to medication expenditures, medications that are given under the authority of a doctor, but not in a health institution area and those that are used without a doctor's permission are not taken care of by the health insurance services provided by governments. Again, Paris & Docteur's study (as cited in Bielska et al., 2012) state that "[p]ublic drug coverage ranges from providing drugs to financially disadvantaged populations like seniors, welfare recipients, and those individuals with medical or financial needs to universal eligibility" (p. 53). While this is a laudable idea for the underprivileged, seniors, and those on social intervention programs, the issue of sustainability, change in government, and a change in policy direction come into play. Besides, Canada does not have a national pharmaceutical drug insurance plan to ensure uniformity and orientation for

prescription drug coverage. In effect, some provinces have designed their own programs to respond to this situation. Therefore, a critical observation of this phenomenon makes the cost of prescription drugs a potential challenge to the healthcare system in general and can affect persons living with dementia who often need some prescription drugs to manage their health condition.

2.1.7. Responses or solutions that can help address the challenges faced by persons living with dementia when accessing primary healthcare services

Information technology and innovation in healthcare delivery have begun to gain grounds in the Canadian healthcare system. The federal government and some provincial governments have taken some initiatives to this effect. The Institute of Medicine (2003) reports that in the course of treatment having detailed health data of a person can prevent some oversights in the delivery of healthcare. One of such initiatives is the Alberta HealthLink program used by people who are searching for physicians via an information technology platform which is accessible at all times (Letourneau, 2009; Alberta Health Services, 2013). Another initiative in the same province is the Access improvement measures (AIM) program which guarantees access to healthcare services for people within the shortest possible time (Alberta AIM, 2013). These programs can help family members encountering problems in finding family physicians and other healthcare practitioners for their relatives living with dementia.

A multi-disciplinary approach to healthcare delivery is one of the strategies which promotes quality of life and support for people in need of healthcare. New studies recommend that the most exceptional results for people under the care of practitioners are obtained through the collaboration among health personnel in the performance of their duties and functions and coming up with new methods to advance the delivery of care (Borrill et al., 2001). As this statement

supports a multi-disciplinary strategy to healthcare delivery, Barret et al. (2007) report that health practitioners using this approach assists people receiving care in getting access to many forms of treatment and ensure that services are provided efficiently. Therefore, it was not surprising that this idea featured in the First Ministers' accord in 2004, which was geared towards improving healthcare for the people living in Canada. Health Canada (2004) asserts that this agreement aimed to ensure that half of the population can gain the use of health professionals from various backgrounds who are working together at any time at the beginning of the year before two thousand and twelve. This confirms why multi-disciplinary care is necessary and a strategy that can benefit persons living with dementia who access primary healthcare services. More so, primary healthcare services involve a lot of health professionals and therefore, adopting a multi-disciplinary care approach would be in line with the underlying values of this sector.

According to Hum et al. (2014), "a multi-disciplinary team approach is crucial in managing both patients' and caregivers' evolving health and social care needs, as dementia progresses" (p. 101). In this regard, persons living with dementia who, in many cases, live with other health conditions will benefit from this form of healthcare delivery approach. Since persons living with dementia have many diverse needs of care, it is most difficult to find services that meet their needs. This is in part, due to the new paradigm shift in the medical field which encourages specialization. Tepper (2004) states that "[o]f those students electing to pursue family medicine training, an increasing number are seeking further sub-specialization in areas such as sports medicine and emergency medicine" (p. 10). Therefore, a collaborative or multi-disciplinary approach where health practitioners work in teams can help persons living with dementia to have access to a lot of primary care services and other specialist services that they might find it difficult to access.

One of the significant challenges identified in the healthcare system for rural residents is the limited number of health practitioners in these areas. As a result, several initiatives have been taken in Canada to encourage health professionals to work in rural areas. One of such programs is by providing training to people who come from rural communities with the aim that they will return home to deliver their services to the people living in these areas. Bowen (2000) asserts that there is a higher probability for these people to take this step to serve their communities. But because of the status of people such as work, marriage, education, and others change over the course of time, it may be difficult to achieve this objective.

The number of available health facilities in a geographical area can have an impact on the residents living in that area. There is less pressure on existing health facilities when a considerable number of others also exist. In rural areas where there are few health facilities, people living with dementia may find it difficult to access primary healthcare and other hospital services. Relatives or friends providing care support in the countryside in Canada gave the information that there are fewer choices in terms of the delivery of care related to dementia support provided in their locality in relation to the ones in the city (Forbes et al., 2008). According to Hum et al. (2014), community-based primary care is the initial point of contact for people exhibiting signs of dementia and their support networks. The Canadian Nurses Association (2016) states that “[f]orecasts show that the fifty-five percent of persons with dementia (sixty-five and over) living in their own homes in 2008 will grow to sixty-two percent by 2038” (p. 7). Therefore, strengthening community-based practices is one of the best strategies to tackle this situation to improve access to primary healthcare services for many people living with dementia in their communities. Aminzadeh et al. (2012) recommend that strengthening community-based primary healthcare towards dementia need the effort of every locality to re-examine the materials at its disposable, single out disparities existing

in the discharge of functions, and design a line of action that optimally harmonize the utilization of the materials or opportunities available.

Canada does not have a national strategy on dementia. As a result, there has been a call for one in recent times. Nationwide, a usual point of attention on a plan of action for dementia is gaining the use of knowledge, care, and programs for persons living with dementia including their support networks at every point in the delivery of support (Alzheimer's Disease International & World Health Organization, 2012). According to Lowi-Young (2015), over eighty percent of Canadians support this idea. The Alzheimer Society of Canada (2015) asserts that looking at the magnitude and cost of dementia, none of the provinces can resolve this issue separately. Therefore, this organization supports the idea of a national dementia strategy, which they affirm that it can resolve the discrepancies existing in dementia care. This is a laudable initiative because there will be uniformity and policy direction towards dementia care. But this strategy might be difficult to implement as healthcare is the prerogative of the provincial and territorial governments. Also, some provinces might not consider this matter as one of their priorities because they may have other pressing issues such as housing, suicide management, waitlist management, and others that need some attention and resources.

An accessible environment does not provide convenience to persons living with disabilities alone, but people from all walks of life. An inaccessible environment denigrates the integrity and dignity of persons living with disabilities and older adults who have the desire to live an independent life. This is one of the reasons why the province of Manitoba has the Accessibility for Manitobans Act (2013) aimed at making the environment accessible for all. Physical environments that enhance the movement of older adults can assist in avoiding dementia (Alzheimer Society of Canada, 2010; Kennan, 2014). For example, the construction of pedestrian walkways and curb

cuts promote the movement of older adults who use a wheelchair in the community. Therefore, making the environment accessible to persons living with dementia is one of the strategies we can adopt if we want to promote quality of life and support.

Although family physicians and family members play an essential role in the care and management of dementia, the complexities surrounding dementia diagnosis and management show that more resources should be provided to improve the knowledge of healthcare providers on dementia care. The Canadian Nurses Association (2016) suggests that the federal government should invest in resources that will improve the competencies of health practitioners at all levels of dementia management. Providing resources that make health practitioners have comprehensive information and knowledge on dementia care can help physicians who coordinate with family members to come up with strategies that work best for persons living with dementia.

Conclusion

A literature review is conducted to look into scholarly works done by other writers or authors concerning a particular area of interest. This helps researchers to compare and contrast ideas shared by them and offer a critique around this subject. In this study, a literature review on the following areas such as Canadian healthcare system, types of dementia, prevalence of dementia in Canada, types of primary healthcare services available for persons living with dementia, challenges that persons living dementia encounter in accessing primary healthcare services, responses or solutions that can help address the challenges faced by persons living with dementia when accessing primary healthcare services, and others were examined. By so doing, the researcher gave a critique on these topics in order to provoke the thoughts of people interested in this field.

In the next chapter, the indices and model underpinning this study are reported in detail.

Chapter 3

3.1.0. Methodology

Under this section, the methodology used to conduct this research project is described in detail to demonstrate the ideology framework influencing this study. The Province of Manitoba was selected as the location of this study due to its closeness and convenience to the researcher. A qualitative methodology through a case study design was used in order to get in-depth information from family members on this topic. As this study is examined through a disability lens, the two main models (medical model & social model) that are essential to the field of disability are taken into account. The application of these two models in relation to dementia issues, their criticisms, and other views held by some authors is elaborated. The researcher used the social model of disability as the idea underlying this project because it champions the rights of persons living with disabilities, recognizes diversity, gives a voice to the vulnerable, and affirms disability as a problem of society if some measures are not put in place to ensure the full participation of persons living with disabilities, among others. In this sense, the primary healthcare system fails persons living with dementia if a reasonable accommodation is not provided to meet their healthcare needs.

Moreover, the study population involved family members who had relatives living with dementia. Through a working relationship with the Alzheimer Society of Manitoba, the researcher recruited eight people who had relatives living with dementia in Manitoba. An interview guide was developed and a total of eight face-to-face interviews were conducted with family members who agreed to participate in this study. After collecting the data, the services of a professional transcriber was used to transcribe them. The transcripts were transcribed verbatim. Each of the study participants received a copy of their transcript to review them. Some of them edited their

transcript, while others did not do so. The edited transcripts plus the ones that were not edited were used in writing the stories shared by the participants. After writing the stories shared by the family members who engaged in this study, issues coming out of these narratives were grouped into themes. This helped the researcher to discuss the results of this study. The informed consent of the family members was offered through writing. Also, the confidentiality of the study participants was ensured by using pseudonyms to hide their true identities. All of the needed procedures were followed to get ethical approval from the Joint-Faculty Research Ethics Board (JFREB). This study will be made available to society by publishing it in academic journals. In addition, it will be uploaded on the University of Manitoba research repository such as MSpace.

3.1.1. Research setting

The province of Manitoba is in the western part of Canada. The Manitoba Bureau of Statistics (2017) pegs the population of Manitoba at 1,343,000. This province was the research setting or area for this study. Some of the factors which made the researcher choose Manitoba is proximity and the convenience involved in reaching out to participants who live in the same geographical area as the researcher. That aside, the researcher is a graduate student at the University of Manitoba. Therefore, conducting this study in Manitoba could help to improve the primary healthcare system for people living with dementia in Manitoba.

3.1.2. Research approach or methodology

For this study, the researcher employed a qualitative research methodology. Qualitative studies describe events and ideologies shared by participants (Berg & Bruce, 2007). A researcher using a qualitative research methodology may be concerned with describing events or phenomena around a topic of interest. In addition, an author using this methodology commits him/herself in collecting

in-depth information from the participants. In other words, the researcher is fully engaged in many of the activities of the study. Creswell (2005) supports this argument. Therefore, this method was used to inform readers about the views that families have in regard to access to primary healthcare services for relatives living with dementia in Manitoba. According to Corbin & Strauss (2008), this method subjects researchers to unravel the aspect of the life endeavours of respondents which are more hidden, and to decode how ideas are formed based on their way of life or background. However, some researchers have criticized the use of this methodology. Sallee & Flood (2012) downplay the use of this methodology by stating that usually a group with a particular interest favours or prefer quantitative research methods when there is a need for a study to be conducted. In a rebuttal to this statement, Donmoyer (2012) states that this method has the potential to inform people in authority about best practices as it produces an in-depth account.

3.1.3. Research design

A case study approach is popular in research studies and cuts across both qualitative and quantitative methodologies. Case studies are a means to express, report, or investigate events (Alpi & Evans, 2019). A researcher using this method establishes a relationship with the study participants to know more about their experiences and ideas on a topic. Alpi & Evans (2019) list interviews, records, objects associated with historical importance, direct observations, among others, as areas that case studies can depend on for information. As a result, a researcher may draw from these avenues to describe an event occurring in society. While it is challenging to communicate the outcomes of research in a comprehensive way, it is the duty of the author to translate an intricate event into a style easily comprehensible for a person who has an interest in knowing more about the study (Baxter & Jack, 2008). Recommended means of describing a case study include giving an account in the form of narration to the audience, producing a hierarchical

account, or by responding individually to the topics under inquiry (Baxter & Jack (2008). In this study, the researcher adopted a case study design to report on the stories shared by the family caregivers regarding relatives living with dementia. Some scholars have pointed out the shortcomings of the use of a case study in research. Dooley (2002) states that “case studies provide very little basis for scientific generalization since they use a small number of subjects, some conducted with only one subject” (p. 5). However, Crowe et al. (2011) share that a case study is a strategy employed to produce a detailed, all-round interpretation of an intricate subject in a realistic circumstance. Therefore, it was a step in the right direction to use this research design to obtain a detailed information from family members regarding access to primary healthcare services for relatives living with dementia.

3.1.4. The model or concept underpinning this research project

The researcher used the social model of disability as the main concept underpinning this project, as it has contributed immensely to the plight of persons living with disabilities. It might sound utopian or project an essentialist idea to have a general definition of disability. The existing body of knowledge stipulates that it would be challenging to describe precisely the meaning of the word disability, as it can be observed from multiple sources (Areheart, 2008; Darcy, 2004; Oliver, 1996b). But there are two models (medical model & social model) that have influenced the course and path of this field (Fitzgerald, 2005; Oliver, 1996b). These two models have also shaped legislation, policies, and other issues around disability (Darcy, 2004; European Commission, 1996). The medical model examines disability from a medical perspective and considers matters around the impaired body and restoration of a lost function (rehabilitation). Therefore, it is a broken limb or a dysfunctional body part that causes disability. In contrast, the social model cites the unjust social and physical environment as the cause of disability. The Union of the Physically

Impaired Against Segregation's (UPIAS) study (as cited in Scullion, 2010) describes "disability as the disadvantage or restriction caused by a contemporary social organization which takes no or little account of people who have physical impairments and thus excludes them from mainstream social activities" (p. 701). In this sense, it is the disabling social environment that perpetuates disability.

3.1.5. Applying the Medical Model of Disability in Dementia

The lives and experiences of persons living with disabilities in the past have been documented in the medical journals because of disability being perceived as a health issue rather than a social one. The medical model considers living with disability as an unworthy life, and as such, the individual living with a disability is not considered 'normal.' The overarching idea of the medical model is to make professionals consider a dysfunctional body as one that needs to be treated (Barnes & Oliver, 1993; Fitzgerald, 2005). According to Llewellyn & Hogan (2000), the central idea evolves around normalization and how to fit into society. In this regard, the individual submits him/herself to the instructions given by the doctor to be cured. This in part, explains why many people living with mental health conditions were admitted into psychiatric institutions to be given the so-called treatment deemed appropriate. This model draws a line between the practitioner (the doctor who has the solution to a problem) and the patient (the individual who is seeking treatment). Therefore, applying the medical model in relation to access to healthcare for persons living with dementia focuses on issues such as whether the person has put in place some advance directives (e.g., medical assistance in dying) in case his/her condition gets worse, taking lab tests in order to find out if other health conditions exist due to having dementia, and undergoing a diagnostic imaging test upon the request of a specialist (e.g., neurologist) to find out the damage caused to the brain in order to know the plan of action to take.

3.1.6. Criticisms of the Medical Model of Disability

Scholars have raised some concerns regarding issues that the medical model has failed to address. According to Darcy (2002), Oliver (1996b), & UPIAS (1976), the medical model does not address how society causes disability. This model considers disability as a misfortune or a personal tragedy. The person's individual condition has rendered the person disabled, and not society. Oliver (1996b) asserts that the medical model focuses on how to fix a person's impairment, as well as the notion that persons living with disabilities cannot engage in activities that are acceptable in the social environment. The disability right movement has criticized the medical model because they contend that inaccessible environment, negative perceptions, prejudices, and stereotypes that exist in the mainstream society about persons living with disabilities cause disability. Shakespeare's study (as cited in Scullion, 2010) identifies the medical model as a representative "for all that is wrong with traditional attitudes towards disability" (p. 699).

3.1.7. Applying the Social Model of Disability in Dementia

The social model came into existence due to the activities of the disability rights movement in the United Kingdom during the 1970s. Persons living with disabilities decided to demand equal rights and opportunities through activism. This model has contributed immensely to the lives of persons living with disabilities in many facets of life. Oliver & Barnes (2012) caution readers not to consider the social model as a theory or paradigm, but rather a political tool or instrument. As a political tool, it can influence change and remind policymakers and institutions of government to be critical in formulating policies and legislation around disability issues. As such, persons living with disabilities must be consulted when making decisions on their needs and welfare. In support of this is the famous adage, "Nothing About Us Without Us" (Charlton, 1998). According to Oliver (1996a), the social model does not treat disability as a medical issue but rather takes a collective

political and policy agenda in contrast with medicine and rehabilitation. This model pays attention to the limitations (physical, social, and psychological) that society puts on persons living with disabilities (Areheart, 2008; Burchardt, 2004). Thomas & Milligan (2017) state that “[i]n essence, applying the social model meant examining whether individuals who served as carers imposed any disablist social barriers upon those living with dementia, in everyday person-to-person interactions either in households or within institutions” (p. 5). These limitations or barriers perpetuate disabling conditions and can prevent persons living with dementia from participating fully in society. Therefore, the onus lies on society to remove all forms of barriers for persons living with dementia to realize their full potentials. Applying this model in access to primary healthcare services for persons living with dementia might evolve around issues which look at physical barriers that prevent them from accessing these services, negative attitudes of health professionals that may serve as a challenge in the delivery of primary healthcare services, and gaps that exist in the healthcare system that denies them from receiving a higher quality of care. As a result, if the tools needed to help persons living with dementia to fully access primary healthcare services are not provided, then society fails in this circumstance. This model serves as the theory influencing this study.

3.1.8. Criticisms of the Social Model of Disability

The social model has been criticized for not recognizing some issues of importance in this field. Chappell (1998) critiques that this model emphasizes physical impairment but neglects to address difference. Bury (1991) argues that illness can be described by its effects, its severity or magnitude on the daily life of a person, and its importance, and cultural meanings and beliefs around illness and disability. According to Crow (1996), “impairment in the form of chronic illness or pain may curtail activity and participation to the extent that ‘the restriction of the outside world becomes

irrelevant' and impairment will remain, yet without disabling barriers" (p. 209). From a subjective point of view, Crow (1996) downplays the idea that the limitations or obstacles faced by persons living with disabilities in society may not always be the cause of disability, but rather the health condition lived by the individual.

3.1.9. The study population

In this research project, the study population involved family members who had relatives living with dementia. This study population was essential to the researcher due to the wealth of knowledge possessed by families caring for relatives living with dementia.

3.2.0. The recruitment process of the study participants

The Alzheimer Society of Manitoba has been in existence for over thirty-five years. There was not much information about Alzheimer's disease at that time. Families who had relatives diagnosed with Alzheimer's disease were looking for information and resources that would help in providing the needed care and support. The search for help to support a person living with dementia brought together people from different backgrounds to form this organization. These people worked tirelessly to ensure the success of this new organization and embarked on fundraising and other activities. Membership in this organization is through donations. The Alzheimer Society of Manitoba seeks to achieve an accessible and friendly environment for persons living with dementia in Manitoba. In other words, this organization wants to ensure that the needs of persons living with dementia are taken into consideration in Manitoba. Some of their functions include awareness creation, education, and training for families and persons living with dementia in Manitoba. The Alzheimer Society of Manitoba provides some funds in the form of research grants to support researchers conducting studies in Manitoba. Besides, the Alzheimer Society of Manitoba provided

funding in the form of grants for this research study. The researcher through a working relationship with the Alzheimer Society of Manitoba recruited people from this organization for this project. The researcher decided to appear in-person at conferences and seminars organized by this organization to discuss this study and look for families who will be interested in participating. Although this did not happen during the recruitment process. Through a working relationship with the program director of the Alzheimer Society, the researcher used their platforms such as the website, Facebook, and the monthly e-newsletter to make this study known to the public.

3.2.1. Selection criteria for this study

In order to be eligible to engage in this project, the potential participant must be a close family member such as husband, wife, son, and daughter of the person living with dementia. He/she must be eighteen years and above. Moreover, the potential participant must at least have provided two years of caregiving support to his/her relative living with dementia. Besides, he/she should be able to communicate in English. These criteria were adopted because the researcher wanted to get people who have more knowledge and information about relatives living with dementia.

3.2.2. Sampling technique and sample size

There are different types of sampling techniques in research studies. These include convenience sampling, stratified sampling, snowball sampling, and purposive sampling, among others. In this study, the researcher used a purposive sampling technique in selecting the participants. This technique was adopted to select participants who had some knowledge and ideas about this topic. According to Tongco (2007), “the purposive sampling technique, also called judgment sampling, is the deliberate choice of an informant due to the qualities the informant possesses” (p. 147). One of the incentives derived from this technique is that the considerable amount of time and resources

involved in selecting the participants are used efficiently. As such, a total of eight family members (two wives, one son, and five daughters) of people living with dementia were selected purposively for this study. A research sample is the subset of the study population from which participants are drawn. As people living in different geographical locations may have different needs and experiences, the researcher conducted two interviews in Winnipeg and the rest in a small town in Manitoba. This exercise enriched the data that were collected, as the participants shared different information on accessing primary healthcare services for relatives living with dementia in Manitoba.

3.2.3. Research instrument

In this study, the researcher used interviews as a tool for data collection. According to Esterberg (2002), an interview exercise is an avenue where a respondent answers a question posed by an interviewer. In this situation, the researcher builds a rapport with the individual and initiate some conversations as well. The use of the interview in a qualitative case study is highly considered vital among the areas of information gathering (Creswell & Poth, 2018; Yin, 2009). For this study, the researcher used semi-structured interviews in collecting data from participants. Esterberg (2002) considers detailed interviews as semi-structured thereby defining it as a flexible activity which encourages a free-flow of ideas among an interviewer and a respondent compared to structured interviews. Corbetta (2003) defines semi-structured interviews as:

The order in which the various topics are dealt with and the wording of the questions are left to the interviewer's discretion. Within each topic, the interviewer is free to conduct the conversation as he thinks fit, to ask the questions he deems appropriate in the words he considers best, to give explanation and ask for clarification if the answer is not clear, to

prompt the respondent to elucidate further if necessary, and to establish his own style of conversation. (p. 270)

As such, an interview guide was designed for this purpose. The researcher used open-ended questions to get a wide range of knowledge and ideas that families living in Manitoba have on access to primary healthcare services for relatives living with dementia. Probing techniques were used to help the participants to elaborate further on questions posed to them.

3.2.4. Data collection procedures

Data collection procedure involves the steps used in getting information for any research study. It can be derived from different ways which include both primary and secondary sources. Heaton (2004) reveals that telephone interviews, field notes, focus groups, among others, are the various means in which information for a qualitative study can be gathered. O'Leary (2004) states that "[c]ollecting credible data is a tough task, and it is worth remembering that one method of data collection is not inherently better than another" (p. 150). A primary source of data collection was used for this research study. The researcher used an interview guide to conduct a single face-to-face interview with each of the participants in order to get detailed information on this topic. In total, eight face-to-face interviews were conducted. Two of the interviews were conducted in Winnipeg, while the rest were conducted in a small town in Manitoba. The researcher gave the study participants prior notice in writing and/or telephone conversation in order to agree with them in selecting the date and venue to conduct these interviews.

3.2.5. Trustworthiness or validity of this study

According to Creswell & John (2009), validity tests the truthfulness of the results of a study. Therefore, the integrity and truthfulness of any research study are put into question when there

seems to be a mismatch between the research objectives and the study results. This idea usually fits into a quantitative research methodology where data collected is subjected to a rigorous scientific form of data analyses. As a result, it is expected that the outcome of a study should be the same when it is subjected to the same format of scientific analyses by other researchers. But qualitative research studies digress from this rationale due to the complexities and subjective views held by research participants on a topic. In this regard, the researcher adopted a member checking procedure with the study participants. Where information is gathered and examined, there is a possibility for authors to decide to include member checking, which is a situation whereby the authors' explanation of the information gathered is made available to the subjects in order to give them the chance to debate and throw light on the explanation given, and offer other ideas on the topic being investigated (Baxter & Jack, 2008). In this study, the researcher sent the transcripts to the participants and informed them to cross-check to find out if what was written truly confirms what they said. They were informed that they have the right to edit the transcript if they wish to do so. All of the eight participants replied and confirmed that what was written represented what they said. Also, some of them edited their transcript. The edited transcripts plus the ones that were not edited by the other participants were used in analyzing the data gathered from them.

3.2.6. Analyses of data

In this study, the data collected from participants were given to a professional transcriber to transcribe them. The transcripts were transcribed verbatim. The transcriber signed a confidentiality agreement which states that "he/she shall keep all the audio recordings and transcripts relating to this project confidential." The researcher adopted a descriptive case study approach to write the stories of each of the family members regarding relatives living with dementia. Afterward, issues arising from these stories were grouped into themes to initiate some conversations that were

supported with empirical evidence from other scholarly works. This exercise or activity helped the researcher to discuss the results of this project based on the specific information shared by the study participants. Morse (2008) explains a theme as the vital concept emerging or originating from the information gathered. That aside, Saldana & Omasta (2017) point out that “[a]s with themes, the statements are arranged in an outlined format according to their evolving status as assertions and their constituent sub assertions, and revised as needed when any disconfirming evidence merits it” (p. 247).

3.2.7. Ethical considerations

Ethics in research studies are very crucial when conducting any study involving people. A lot of factors are taken into consideration to ensure the safety and welfare of participants. In this research project, some of the ethical issues that were considered included confidentiality, privacy, and informed consent. Emanuel et al.'s study (as cited in Liamputtong, 2007) describe informed consent as “the provision of information to participants, about the purpose of the research, its procedures, potential risks, benefits, and alternatives, so that the individual understands this information and can make a voluntary decision whether to enroll and continue to participate” (p. 5). The informed consent of participants was offered through writing. Each of the participants who engaged in this study voluntarily agreed and signed a consent form. The researcher kept a copy of this form and also each one of them (study participants) was given a copy to keep. The participants were told in writing that they have the right to withdraw from this study at any point in time if they wish to do so. If this situation happens, all the information shared by a participant would not be included in the findings of this project. Fortunately, in this study, this incident did not occur.

Christians' study (as cited in Liamputtong, 2007) states that “[c]onfidentiality aims to conceal the true identity of the participants” (p. 5). As such, the confidentiality of the participants was ensured by using pseudonyms to hide their identities. Also, the researcher decided to withhold the names of people and locations reported by the participants in quoting what they said. In writing the stories shared by the study participants, these were put into parenthesis. The researcher made sure that all data collected were kept in a locked cabinet and/or a password-protected computer. The author of this study was the only person who had access to this locked cabinet to avoid any breach of confidentiality. Furthermore, all protocols and procedures relating to ethical issues were followed to get approval for this project.

3.2.8. Dissemination

This study will be published in some journals (e.g., *Journal of Disability & Society*) and the University of Manitoba research repository platform such as MSpace. In addition, this study will be presented at the Centre on Aging Annual Spring Symposium. The researcher will provide both hard and soft copies of this research paper to the Department of Disability Studies and the Alzheimer Society of Manitoba for educational purposes. A copy of this paper (either hard or soft copy) will be sent to each of the study participants through a medium in which they wish to receive it. The information that will end up in the publication will be mostly the ones that answer the research questions of this study.

3.2.9. Limitations of this study

This study sought to get information from close family members who had relatives living with dementia in the province of Manitoba. All of the results and outcomes of this study were based on the opinions, ideas, and expressions of the study participants selected for this study. As such, all

of the information and discussions focused on families' perspectives on accessing primary healthcare services for relatives living with dementia in Manitoba. This study does not represent the views of persons living with dementia. Therefore, the researcher recommends further studies that will seek their experiences, knowledge, and ideas on this subject.

Conclusion

A research methodology is a strategy used in executing a project in order to achieve its objectives. This study used a qualitative method through a case study design to gather information from family members on access to primary healthcare services for relatives living with dementia in Manitoba. This research methodology was adopted because the researcher wanted to get in-depth information from family members on this subject. The social model of disability was employed as the main ideology influencing this project. Ethical approval was sought from the Joint-Faculty Research Ethics Board (JFREB). A purposive sampling method was used to select eight family members who had relatives living with dementia. The consent of the participants was sought through writing. A total of eight face-to-face interviews were conducted. Pseudonyms were used to hide the true identity of the study participants. A thematic content approach was used to discuss the results of this study.

The next chapter reports on the stories shared by the family caregivers regarding relatives living with dementia. A total of eight people talked about their experiences in providing caregiving support to their care recipients. These stories throw light on the primary healthcare services, specialist services, home care services, personal care home services, and others that have been used by their relatives living with dementia. The family caregivers provided information on the behaviours showed by their relatives living with dementia, challenges faced by their care recipients

in accessing some of these services, how they were affected in the course of providing caregiving support, attitudes of health professionals towards their relatives living with dementia, and concerns they had regarding the health condition of relatives living with dementia, among others. Due to this, many of them gave some recommendations that could be used to improve access to primary healthcare services, specialist services, and others.

Chapter 4

4.1.0. The findings of this study

The findings of a study constitute the information made available as a result of embarking on an area of interest. Its content is often influenced by the methodology used during the data collection process. In this chapter, a demographic overview of the family members who engaged in this study is documented. As such, their gender and the type of relationship with the individual living with dementia are elaborated. Based on the ideas and views shared by the family caregivers, a case study approach is used to write the story of each of them concerning relatives living with dementia. Pseudonyms were used to hide the real identities of the study participants. Also, the researcher decided to withhold the names of people and locations reported by the participants in quoting what they said. In writing the stories shared by them, these are put into parenthesis.

4.1.1. A demographic overview of the study participants

A total of eight people who had relatives living dementia were recruited for this study. Out of the eight people, seven of them were females, while the remaining one was a male. Moreover, out of the eight people who were interviewed, two of them reported that they were related as a wife of the individual living with dementia, five of them communicated that they were related as a daughter of the family member living with dementia, and one as a son of the person living with dementia. Thus, all of the study participants who shared their story concerning relatives living with dementia were close family members providing caregiving support to them. During the interview process with the participants, six of the interviews were conducted in a small town in Manitoba, while the remaining two were conducted in Winnipeg. As a result, many of the participants were recruited from a small town instead of the city.

4.1.2. The story of Andrew regarding his father who has not been medically diagnosed with dementia

Andrew provided caregiving support to his father who is over eighty years old now. His father has not been diagnosed with dementia, but he believed that that was the case. He reported that the whole process began during the beginning of the millennium year. He used to go to his father's place with his children to observe the New Year. However, his father seemed not interested in observing the New Year whenever they would go there to visit. Andrew thought that his father had missed his wife who passed away and did not think that there was something going on with him.

One day, he got a call from a doctor informing him that his father was at the emergency and due to be discharged. He enquired from the doctor what brought about this situation and was told that his father has been taking more of his medication than required. Talking about this incident, Andrew said:

It was January third of two thousand and sixteen, and an unknown number came up, and I have a habit of never answering unknown numbers. But I had a funny feeling and answered the phone. It was a doctor from (referring to a town), Manitoba, and he was saying that my dad was in the emergency, now basically to be released and of course, I said, 'What happened?' And what he said was that my dad was overdosing on his medicine because he couldn't distinguish or he's getting confused of the time of day. So, he would go to sleep in the light and he'd wake up at night and maybe think it was morning, and double up on his pills.

So, Andrew drove there with his mother-in-law and upon further conversation with the doctor, he took his father home. Andrew related that his father lived on his own. He found out that his father

had some challenges in keeping his place clean. Also, Andrew reported that his father was not able to cook. His father's landlord reported to him that he came to his father's place and found that the oven was left on and there was smoke. Sharing this account, he said:

...I talked to his landlord, and his landlord said, 'Well, it was about a year ago, I had to come in here because the oven was on and the smoke was in there, and I guess he forgot to turn the oven off or whatever.'

Discussing some health conditions that his father had, Andrew said that his father has been diagnosed with cancer and was going to CancerCare Manitoba for treatment. In addition, he had spinal and cholesterol problems, as well as diabetes. His father was facing some mobility challenges due to a hip problem. That aside, his father has been using anti-anxiety pills and blood thinners. Andrew reported that his father had some challenges in recognizing him and thought of him as a co-worker. He saw a decline in his father's condition when he was interviewed by a mental health coordinator. His father was in a nursing home, but he did not stay there for a longer period of time due to his condition. With the help of a health director, his father was sent to a hospital in a small town in Manitoba. Andrew said that his father's health condition improved. In addition, his father had a good relationship with the staff there. Later, he was sent to another hospital and eventually went to a personal care home.

Andrew reported that no health professional has been able to tell him exactly what was going on with his father's situation. On this, he said: "They haven't given me a diagnosis. That's what I'm telling you. It's not in black and white." His opinion about doctors was that you have to follow what they tell you to do because they have more knowledge. According to Andrew, the health professionals did not take it seriously if you have essential information to share and behaved

as if his father's condition was contagious. To him, his father's family doctor did not help much with his situation because she had every chance to ensure that he received the appropriate support, but she failed to do so. Although none of them had been able to give him a diagnosis of his father's health condition, he had his own suspicions about him. He made some observations about his father when he came to live with him for two months. His father slept a lot, put food in a wrapper, and in his pocket. These actions by his father helped clear the uncertainty he had about him. Sharing this account of his father's situation, he said:

Initially, the initial step, you know, well, I look at him, and I said, 'Yeah, he's got dementia,' you know, and as me being a layperson, you can tell when somebody's got dementia. It's pretty obvious, you know, if you're doubling-- and he's talking weird, you know, and when-- then when he came to stay with us for the two months or whatever, I was like, you know, gave him some Kentucky Fried Chicken or something, saves his food, and puts it in a wrapper, and takes it, and puts it in his pocket. You know, sleeps a lot and yeah, so initially right there, there was no doubt in my mind, you know, so.

He believed that his father's condition started about five or six years ago. Andrew shared that with the exception of his father, none of his family members lived with dementia. Also, he said that he had no idea if other relatives on his father's side lived with this health condition. Because his father was angry and there were challenges in providing support to him, he was assessed by a psychiatrist. His father was going to the family doctor because of hip pains, blood and cholesterol problems. In addition, he received all of his prescriptions from the family doctor. Since his father was a chef, he knew how to prepare a good meal. As such, he has not used the services of a dietitian. Although his father had some mobility challenges, he has not been using the services of a physiotherapist or an occupational therapist. Narrating the incident which led to this problem, Andrew reported that

when his father was young, he worked in a meat factory. Frozen meat fell on him and caused an injury to his vertebra. This incident also affected his hips. Also, his driver's licence was revoked and he got in trouble with the law. Andrew shared his story that he was the one who assisted his father to go to all of his healthcare appointments. Although he assisted him with a wheelchair, there were no accessibility issues. His father's greatest problem was not being accorded with the attention or caring that he needed. Andrew reported that his concern was to make sure that his father was treated with dignity. There were not a lot of health facilities in the area where his father was living. As a result, the cost of transportation from where he lived to Winnipeg was expensive. The reason for coming to Winnipeg was to provide some specialist services for him. Another problem they faced was to get an appointment with a doctor, which took some months to get one. Having to wait for a longer time in order to get a doctor's appointment had an effect on his father's health condition. To mitigate this problem, Andrew had the opinion that it would take a doctor who has more knowledge about how the healthcare system works in order to get you an early appointment somewhere else. Due to what his father had gone through, Andrew said that he was astonished that his father was not dead. On this matter, he said: "So, honestly and I'm not exaggerating to you, I'm surprised he's alive. I'm absolutely surprised."

Andrew related that all these experiences with his father did not affect his own health because he envisaged that to happen. But it made him learn more about Alzheimer's and other things. He had been in favour of euthanasia and these encounters with his father's condition have deepened his support for it. To him, it was like being in a situation where you cannot do so much to help yourself or voice out your concerns. Sharing how he felt about his father's condition, Andrew said:

So, you never know what's coming out or how he's going to behave, you know? Same thing when for instance if I take him for blood tests, you know, and the staff is very used to giving him a dose and all that stuff, right? And I felt really bad for the guy and like whether he's my dad or not, nobody should have to go through that. Nobody, just terrible. Like, what would it take for him to be diagnosed for a particular stage in between the stages of dementia?

Fortunately, Andrew was no longer working and that has been a game changer for supporting his father. If that was not the case, his father would have been on his own. Also, he said that supporting his father did not affect his relationship and support networks because he was not working. As such, Andrew related that he had more time to do other things. The health director has been his bedrock. She has been there for him in times of difficulties in searching for a place where they can get the needed support and care for his father. Based on his experiences and the challenges faced by his father when accessing healthcare services, Andrew recommended that family doctors should address health issues facing people under their care on time. Also, he suggested that health professionals should provide some guidelines and resources that can be used to support people who are receiving their services.

4.1.3. Angela's story concerning her husband who lived with Frontotemporal Dementia with secondary Alzheimer's

Angela provided caregiving support to her husband who lived with Frontotemporal Dementia with secondary Alzheimer's. Although she does not know how long he has been living with dementia, there were some changes that occurred before he was diagnosed with dementia. He was finding it difficult to remember the names of people which was unusual for him. Due to this, she became

suspicious that something might be going on with him. Narrating the process which led to his diagnosis of this health condition, she said that he was interviewed by a geriatrician, who informed her that he had a conviction that her husband was living with Frontotemporal Dementia and therefore the delivery of services for Alzheimer's disease would not be appropriate for him. He was using vitamin B12, coconut oil, and omega 3s with the aspiration that it might be beneficial to him. That aside, her husband did not have a family doctor because he was hesitant in going for a doctor's appointment. So, when it got to a crisis where they needed one, there was no personal doctor offering services to them. Also, they were moving from one family doctor to another because the ones they had moved to other places. Therefore, they were facing inconsistencies in having a family doctor. Talking about this issue, she said:

Well, the thing is that we had and then they'd move away. And then, we had, and then they'd move away. And then, I finally landed having a good doctor. I managed to find one, and he didn't need a doctor at the time, so we didn't pursue you know, making her my family doctor right away. And so, then it was always like the few times that he had to go for something which is minor, beside from now when it was dementia, he would just go and see a-- whoever would take him, right?

Moreover, they went for an appointment with a family doctor who was filling in for another doctor for a few months. This doctor requested a computerized tomography scan and magnetic resonance imaging for her husband's condition. She was informed that her husband was living with Frontotemporal with secondary Alzheimer's. Angela narrated that her husband was in his early sixties when he was diagnosed with dementia. Fortunately, in the process of assisting her daughter to go for an appointment, she got a new family doctor for herself. Later on, this doctor accepted her husband. She was very appreciative of the fact that their new family doctor was good,

supportive, and forthcoming. Her mother-in-law had fourteen children and also had Alzheimer's. But her husband happened to be the only child who had dementia and was often depressed. He was bringing up his pills after having a meal. As a result, he had to undergo a barium test because of swallowing problems. He had anxiety attacks which affected his chances of working. As such, they were facing financial problems. They had to stop engaging in independent hog farming because it was not financially viable for them. Angela reported that her husband performed activities such as running and walking, preparing breakfast, and mowing of the lawn. But he was engaging in dangerous activities. At one point, he had wanted to start-up a chainsaw by putting one of his feet on the blade. She had to assist in other activities such as cleaning of the eaves troughs, vacuuming, and cleaning of the bathroom. Her husband was facing difficulties in putting words together. On this issue, she said:

...he will substitute words constantly and I do a lot of guessing as to what he's trying to tell me because he uses 'thing' a lot to describe everything. And so, I've got to do a lot of guessing as to who-- try to figure a context, where he's pointing, etcetera.

Her husband asked so many questions and found it challenging to understand when she needed him to assist her. Angela related that she has been affected by this situation. As such, she has had some contact with home care and thought of using this service. But since her husband likes to run and go for a walk whenever the weather was good, she was not prepared to use personal care home services for him. Sharing this information, Angela said:

Especially when the weather is nice, he is running, he's walking, you know, and then he comes inside. And then, he goes outside again, goes for a run or walk around the yard. Then, he goes, comes in a bit, and then he goes out again, and goes hits golf balls in the

pasture and then he comes in. It's just in and out all the time, right? And so, to be put into a personal care home would be like putting him in a cage and throwing away the key. So, we're not ready for that.

According to Angela, it has been challenging for her in the course of providing caregiving support to him. It escalated her anxiety. She would have had to forfeit going to work in order to take him to appointments if she did not have a banked time at her place of work. In addition, it was not easy for her whenever they were in the community. Her husband did not like the fact that people were looking at him and he registered his displeasure. Talking about how it affected her relationship and support networks, Angela reported that she often invited her female friends around, so that her husband would not barge into their conversation. At family events, he would talk about things over and over again. Sharing this account, she said:

Well, I tend to not invite people down as couples very often. I will invite, you know, if I have friends down, I will invite mostly just the woman usually because that's what I'm comfortable with. And then, maybe he won't interfere with our conversation too much. Although he does even then but it's hard for men to interact with him because, you know, there's no real interaction. When I'm going out, he usually stays home, and I'll just go with my lady friends instead because it's too-- and I think they prefer it too because otherwise there's no meaningful conversation. When we are together even as our family-- at family gathering, he talks so much that others hardly have a chance to talk. And its repetitive things, but he has to talk about every single thing that he can think of. So, it just makes it awkward when he is—well, it's difficult because people don't get to visit amongst themselves when he's there usually.

They used the services of a psychiatrist, who had a thought that her husband was living with obsessive-compulsive disorder. She believed that it was definitely the case for her husband's condition. But her husband was not receiving treatment for anxiety, depression, and obsessive-compulsive disorder. During the first half of the year, mental health workers were coming on a regular basis to perform a mini-mental test with him. More so, she envisaged that her husband's restlessness at night might affect her if it reached a point where he would start wandering and had little time to sleep. Discussing one of the past incidents which happened to her husband, Angela said that many years ago, her husband was involved in an accident in a situation whereby his head came into contact with the windshield. As such, there was a glass in her husband's head, but she didn't see any serious signs during that period. Sharing this story, she said:

Yes, actually, there was one time that I'm aware of. He did have an accident, and this is back in the years when we didn't have to wear seatbelts yet. And so, his head hit the windshield, and it did dent the windshield. Didn't go through, but there was-- it was definitely cracked, and so he had glass in his head. So, they washed it out and stuff, but they didn't diagnose him as having a concussion, and I didn't notice any severe symptoms at the time. That was many years ago; I wasn't either aware of what symptoms to look for. But that's the only head injury that I'm aware of.

Also, based on a recommendation by the geriatrician, her husband lost his driver's licence. On this issue, she related that a letter was sent to the Manitoba Public Insurance, with a directive that her husband's licence should be revoked. Her husband was not happy with this decision. According to Angela, this was one of the reasons why her husband did not want to go to a doctor's appointment. When he lost his driver's licence, his brothers were taking him for coffee on a regular basis. Angela said that this has been one of his routines ever since she got to know him. This support

from his brothers was very important and beneficial. To her, people living with dementia who do not have this kind of support had limited engagement with their community. As such, she had the view that families can provide the support that meets the needs of people living with dementia. Angela narrated that they used a counselling service and speculated that it was done with a psychologist. They went there twice because that was what her coverage could take care of. However, it was challenging in assisting her husband to go for this appointment because he did not like going for a long drive. To her, the distance involved in going for specialist appointments was a problem as these services were in Winnipeg. As a result, she made the recommendation that it would be helpful to have these services in her community. In addition, another case which she thought stakeholders in the healthcare system might have to address regularly was early-onset dementia. According to her, financial assistance may be provided to families providing caregiving support to people living with dementia in the form of a subsidy.

4.1.4. Anna's story regarding her mother who lived with Alzheimer's disease

Anna provided assistance to her mother who was living in a different province. Her parents lived together and received support and care from her and her sister. Thus, Anna's sister was also involved in providing caregiving support. Her mother was seventy-two years when she was diagnosed with Alzheimer's. According to Anna, they noticed some changes such as a decline in her memory capability. At that time, she was around the age of sixty-eight. So, they asked her to discuss that with her family doctor. The doctor said that there was nothing going on with her and told them that it was as a result of being in her advanced years. They were not happy with the doctor's assertion which attributed her condition to elderliness. However, the family doctor referred her to the seniors' mental health team where some assessments were conducted. In addition, some specialists were involved in the process. Her mother went to see a neurologist for

a computerized tomography scan. Based on the information gathered, a case manager informed her mother that she was at the early stages of Alzheimer's. Relating some of the challenges that her mother faced when going for healthcare appointments, Anna related that her mother could not drive and was not in a good position to share the exact information with her doctor. As such, her mother had a lack of initiative and decision-making on her own health matters. Sharing this account, she said:

So, she wouldn't be able to drive herself there, she wouldn't be able to make the appointment herself, she wouldn't remember to go, she wouldn't know what questions to tell the doctor. Plus, she doesn't give the doctor accurate information, and she makes it sound like everything is okay when she goes to the doctor. Because she wants to impress him and she wants to make it sound like she's doing just fine, right? And so, those are some of the challenges and the fact that she lacks the ability to make healthcare decisions for herself.

Although the distance involved in going to see her family doctor was not a problem that of her specialist was definitely the case. In her mother's case, she had to take a flight to go for her specialist appointment. Anna shared that it was interesting to note that her grandmother had Alzheimer's at the age of seventy-two. Also, her mother was diagnosed with this health condition at the age of seventy-two. According to her, she would not be astonished if she was diagnosed with Alzheimer's disease because she was more susceptible to living with this condition than others. But she was not bothered about it because doing so would influence her chances of living with this health condition. On this, she said:

I absolutely will not be surprised if I get Alzheimer's as well. I'm doing what I can to improve my protective factors in my life. But, I absolutely know that the risk is a little bit higher for me than for the general population. I don't spend time worrying about it though.

Also, talking about how this would come into conflict with her faith, Anna said: "So, it just doesn't pay to worry and worry wouldn't be consistent with my spiritual values. And so, I try not to spend time worrying." Her mother performed some activities such as reading on her own, but she was anxious whenever she was left alone. Her mother had high cholesterol and lung cancer. She had the view that her mother might have gotten lung cancer because she lived with someone who was a smoker throughout her life endeavours. Narrating this story, she said: "Her mother was a smoker. My mother was not a smoker, but she lived with a smoker all her life so she breathed in second-hand smoke." Thus, Anna's grandmother was a smoker. Her mother was monitored by her family doctor, but they had not informed her about this condition based on the fact that it might cause her some discomfort. They made a decision that she would not seek healthcare services for lung cancer because they thought it would not be beneficial to her. Sharing this experience, Anna said:

We've told her that there is a concern about her lungs, and that's why she's going-- the doctor's watching her lungs, but we actually haven't even mentioned the word cancer to her because we feel even that itself is going to distress her. It's not going to be helpful for her and as her power of attorney's and her husband, we've all decided that it would be in her best interest not to pursue any kind of treatments for her lung cancer. So that's been the latest development that her G.P has helped with.

Also, her mother had a bladder infection and delirium. Anna related that her mother was taking statin medication, which she stopped using later on. Her mother used the services of a pharmacist

who has been very supportive of her in areas such as drug packaging and other matters relating to drug use. On this story, she said:

The pharmacist has been helpful in bubble packing the medication for them and also being an excellent resource in terms of asking questions about the medication that my mother is on and whether my sister should be asking the doctor about making changes to the medication. So, they have found that the pharmacist has been an excellent resource that way.

Anna related that her mother had been facing some mobility challenges due to lower back pain. As such, she had used the services of a physiotherapist who gave her some exercises to perform in order to improve her lower back pain. But she had problems following the instructions given to her. As a result, she needed somebody to be there to assist her in performing the exercises given by the physiotherapist. Reporting on this matter, she said:

Because the physiotherapist will give the instructions, but my mom can't follow them or remember to do them every day. And so, there still has to be someone every day for as many times a day as the exercises were prescribed to actually do them with my mom, you know, alongside of her so that she will do them. So, I'd say that's where the gap is.

Anna shared information that her mother had never used the services of a dietitian. Although it was one of the services that had never been suggested to her parents, they were lucky because her sister had ideas on how to plan a healthy diet. Sharing this information, she said:

You know, that is the one person that I don't think has been referred to them yet, and I think it would be helpful for both of them. But my sister is very knowledgeable when it comes to a healthy diet, and so they are very fortunate. They are fed very well.

That aside, her sister assisted her parents in doing their laundry, cleaning, meal preparation, and attending healthcare appointments. Her mother was also using home care services. A home care worker was coming in to provide respite care and assisted her with shower and medication. But the problem her parents had with this service was that different people were coming on different occasions to provide respite to them. As a result, her parents had a sense that their privacy had been compromised. Sharing this account, she said:

The only complaint that I heard them say about home care coming in was that it was a different person every time and they didn't-- they couldn't get to know the person that was coming into their home. And so, they felt like it was a little bit impersonal every time and they felt a little bit exposed. Like, there's a new person coming into our home, you know, coming into our bedroom, going into the bathroom, helping my mom with a shower. I think that that was hard for them.

Her parents stopped using this service because her father thought that it was expensive for them to afford. Anna shared that based on the fact that it was a different person coming on a regular basis to provide assistance to them, her father was not pleased with it. Again, since her father was receiving a special end-of-service package on a monthly basis, her parents were not eligible for government home care services. Later on, they arranged a private home care service which worked best for them. More so, they appreciated the fact that her mother was satisfied with the day program that she was attending. Anna shared her opinions about the hospital environment and family doctors. On family doctors, she shared her view that they had ideas about dementia, but their way of supporting people was the problem. That aside, expressing her view on the hospital environment, she explained that the signs were the greatest challenge as they should have been bigger. She elaborated that in some cases, it was difficult to comprehend what had been written on

them. Therefore, it would be beneficial if something could be done about this situation. Also, her sister had raised this issue based on an experience she had with her mother. Sharing her life experiences on how providing caregiving support to her mother affected her, Anna related that she had to use all of her vacation time from work in order to assist her parents. In this regard, she did not have some spare time from work to attend to other stuff. Narrating this story, she said:

Yeah, I would say for sure it was a sacrifice-- like for an example for me, I used up all three weeks of my holidays for this year, so that I could go and provide that care. So, my holidays are used up for this year. And so, it makes a difference in our family that now I don't have time to take holidays for other things. I know that maybe seems like a trivial thing, but it is stressful when you work all year and you look forward to a holiday and that holiday needs to be spent, you know, caring for my parents. I was willing to do that, but yeah, it was definitely a cost and a sacrifice I would say on my part.

Also, in some cases, it disrupted her work schedule because she had to fly to where her parents were living in order to attend to their needs. In addition, she did not have the opportunity to interact with people as her main point of attention was on providing support to her parents. On this account, she said:

Well, I think that we just have a lot less time to socialize ourselves because we are focused on caring for parents. But in terms of our own mental health and social life, I think we try to be careful to keep a good balance, but it's challenging. It's challenging when you have parents that you're caring for.

Anna reported that she had initiated the steps involved in using counselling services through her Employee Assistance Program. She decided to use this service in order to care for her father instead

of her mother. There were a lot of things involved regarding her decision to use this service. Anna explained that it was easy to care for her mother than her father. As a result, she opted to use this service in order to have some conversations with a counsellor. Anna gave some suggestions on some of the things that can be done to improve access to healthcare services for people living with dementia. First, she recommended that the provision of healthcare services should meet the needs of people living with dementia. This included areas such as how to talk to people living with dementia, making sure that they have an idea of what has been communicated to them, decision-making on their health issues, power of attorney, among others. Secondly, she suggested that more personal care homes and assisted living complexes should be provided for people living with dementia. On this issue, she said:

...I think that our biggest frustration is that, there aren't enough personal care homes services available or assisted living. And so, both of our mothers have ended up in hospital and really isn't a good place for people with dementia. They are trying their best to provide services, but they're an acute care facility, and they just are not set up to be a dementia-friendly environment. And it's terribly stressful for the person with dementia and for their caregiver to be waiting months and months and months in that kind of a setting. Day in and day out, without the kinds of services and supports that they need. So, I think for me that is one of the areas that I would say needs to change as soon as possible. People with dementia do not belong in hospitals; they belong in assisted living or a personal care home facilities.

Lastly, Anna suggested the creation of a medical program to tackle dementia care. Making this recommendation, she said:

The people that I talk to, the seniors that I talk to are actually more afraid of getting dementia than they are of cancer because they feel that they'll be better supported and that their quality of life and treatments are readily available for cancer. But when it comes to dementia, they feel like there's nothing. There's-- there's no treatment plan in place, there's no care support in place, we can barely get the home care services that we need to help people in their homes. We're so lacking in dementia care resources and programs and services. So, I definitely think that you know, technically whether they are going to put it under mental health or whatever they are going to put it on, under, I think that there needs to be a specific branch of medical-- or medical program that's gonna address dementia care. Yeah, the services definitely need to be more coordinated.

4.1.5. The story of Hannah concerning her mother who lived with Alzheimer's disease

Hannah supported her mother who lived with Alzheimer's disease. Sharing her story of her mother's life journey throughout this process, Hannah related that having her in personal care home made a huge difference in her life. She had her family, grandchildren, and a business to take care of. As a result, it was becoming difficult for her to provide some assistance to her mother. Again, this was the reason why home care services were considered as an option for her. Although she was not in favour of putting her mother in a personal care home, she had to do it in order to take care of other duties. Sharing this experience, she said:

It was absolutely painful and traumatic to even consider placing her in a care home because she was not of that frame of mind, she was not willing to go, and I know how much she might have felt hurt and betrayed. But I had to do this so that I wouldn't crash and be unable to care for her further or my family and whatever other responsibilities I had.

Prior to going into a personal care home, her mother was living on her own, but they relocated to live with her. During this time, she observed that her mother had a decline in her cognitive abilities. She used unpleasant words and that was not her nature. According to Hannah, she did not know that it was part of the process of experiencing a decline in cognition. Sharing this experience, Hannah said:

She had no filter; things came out of her mouth that were quite shocking. That I could say that was not her, but at the time these things were-- her behaviour that was the initial flag that came to mind. But we didn't really realize it was one of the beginning steps of her losing mental capacity, and it's upon backtracking that we could see the flags that we had missed.

Hannah related that her mother found it difficult to remember the things she taught her and it came to a climax where she had to be monitored throughout the day. Sharing this information, she said: "Things you would teach her one month on the computer, and she forgot the next month. Small things like that. But it quickly got to the point where she had to be supervised continuously, twenty-four hours." Her mother used to go for shopping, paying bills, preparing meals, and drove on her own. But things changed drastically and it reached a point where she had challenges in performing some of these activities. Based on this observation about her mother experiencing a decline in cognition, they brought it to the attention of her family doctor where some tests were performed. In the beginning, the family doctor diagnosed her with dementia. Later on, a psychiatrist and a mental health worker were involved. The mental health worker conducted a test to know the stage where she has reached, but Alzheimer's disease diagnosis came from the psychiatrist. Narrating this diagnostic process, she said:

The dementia diagnosis came in December two thousand and sixteen, by mom's family physician. A psychiatrist and mental health worker came to visit mom in at her home in April two thousand and seventeen and advised mom that her mental capacity had depreciated and was now diagnosed with Alzheimer's disease.

In addition, her mother was informed that her driver's licence would be revoked. This issue of losing her driver's licence had a tremendous impact on her. Hannah reported that her mother was seventy-two years when she was diagnosed with Alzheimer's disease. Her mother showed some behaviours such as being in a state of denial of living with dementia. Whenever she informed her about this health condition, she became surprised and also took a position that things were fine with her. She said: "I can tell her again today, 'Mom, you have Alzheimer's,' and she'd be shocked, utterly shocked. There's nothing wrong with her in her mind." There were times where she was angry and sometimes frightened. Although her mother had a cousin who had dementia, none of her close family members and brothers and sisters had dementia. In this regard, they were not familiar with this health condition. On this, Hannah said:

In our immediate circles with her siblings-- I know there's a cousin out there somewhere on mom's side somewhere that has dementia of some kind, but as for her own siblings and the immediate family, no. We've never seen anything like this, it's new to us.

Hannah related that her mother had other health conditions such as a pinched nerve in her back, benign lumps in the breasts, and marks on her body. She received treatment for the lumps and got rid of them. Also, she was given amitriptyline and gabapentin under the authority of her family doctor. Hannah speculated that her mother was taking a higher dosage of these medications. Discussing the harmful side effects of the drugs used by her mother, Hannah shared information

that her mother had gained weight and suspected that it was as a result of the use of amitriptyline. In this case, her family doctor took some steps in order to decrease her intake of this medication. Her mother was using this medication to manage her pains which sometimes affected her ability to walk. More so, she used the services of a physiotherapist, but it escalated her pains and she was advised to stop using this service. Her mother did not use the services of a dietitian because she took a healthy diet. She paid all of her medications on her own as she was not under any health insurance. This has been the case for her mother because she worked on her own. Hannah had the opinion that it was beneficial for her mother to buy her own medication instead of using insurance. Reporting on this matter, Hannah said:

She has no insurance plan. Well, she was always self-employed. She never did have a group insurance of any kind, and the amount of meds she has doesn't merit paying premiums for a group insurance. I just assessed all of that, and she's better off just paying for her own meds versus paying a premium for group insurance.

Moreover, her mother encountered some challenges in accessing healthcare services. Hannah reported that on one occasion, they had to wait three months in order to get a family doctor's appointment for her. This affected the delivery of healthcare services for her mother. As a result, they had to go to various places in order to seek treatment services. This included a visit to the emergency room. Another problem they faced was that her mother's family doctor was not available to sign some documents and this affected the panelling process for her to go into a personal care home. Hannah related that it was a helpless and discouraging moment for them. The other problem was the lack of proper communication between health professionals who were providing services to her. Her mother had a pharmacist in her area who looked into her medication. But there was a confusion between her family doctor, home care, and the pharmacist as to who

was responsible for taking certain actions in the delivery of care for her mother. As a result, Hannah said that she had to intervene in order to get these three health professionals to communicate among themselves. Sharing this story, she said:

It is cumbersome right now because one office believes that the other office should be notified and then that office feels no, the other-- the physician thinks the pharmacy and home care have to contact her, but then home care feels like, no, the physician should contact them. And it's just not my job, not my job, and I'm having to make these three talk to each other somehow.

Aside from using these services, her mother faced some difficulties in accessing specialist services. Hannah shared that it took one hour and thirty minutes to travel to Winnipeg in order to get a magnetic resonance imaging test for her mother. As such, the distance involved in using specialist services was one of the problems encountered by her mother. Sharing this experience, she said:

I picked her up for an MRI. So it's a half-hour to (referring to a town in Manitoba), to pick her up and then another hour to get her to (referring to a hospital in Winnipeg). And then, we went for breakfast, and I brought her back home. It exhausted her. She went straight to bed. I brought her in the suite, and she went straight to bed, but then any disruption to her day, any change of any kind is absolutely tiring to her.

Hannah related that the long wait times involved to get an appointment with a specialist was a challenge. There was one incident where they were informed by her mother's family physician that she has to wait for a year in order to get an appointment with a pain specialist. This discouraged them from doing so. More so, there was a case where they had to wait six months to access a magnetic resonance imaging service. Sharing these experiences, she said:

These specialists' offices are primarily in Winnipeg. Also, it takes months, sometimes years to even be able to see a specialist. Case in point, mom's family physician suggested she book mom to see a pain specialist. She told us there is a one-year waiting list to see them. We decided not to bother. Another case in point, there was a six-month wait to get even an MRI.

Talking about how she felt about her mother, Hannah said that it was painful to experience her mother's situation whereby she had an extraordinary feeling that something bad was going to happen to her. On this, she said: "It was watching a woman live out a nightmare that she could not get out of and that was utterly heart wrenching to watch somebody so dynamic, a human being going through this." In this regard, it was extremely sad for her to know about her mother's circumstances. However, the mental health worker was very helpful in situations where she needed some support for her mother. Hannah reported that the family doctor showed a positive attitude towards her mother, but that was not the case when she assisted her to go to the emergency room to seek treatment for her pinched nerve and pains. Sharing her views on the hospital environment, Hannah said that she had to assist her mother to go into the offices as the signs were not visible. In addition, she reiterated that she was not certain that her mother understood what these signs portrayed. Hannah related that she was affected in the course of providing caregiving support to her mother. She was stretched to the maximum, including some psychological effects on her well-being. Reporting on this issue, she said:

At the point where when we were at her house looking after her and the transition to moving her into a care home, I was at my limit there, absolute limit. It was exhausted, burnt out. Ranges of emotions between guilt and sorrow, grief. All kinds of emotions on the spectrum. It was a really tough time.

In addition, it affected her relations with friends. As such, she had the opinion that support groups were the appropriate setting to share experiences in providing support to a relative living with dementia. Talking about this matter, Hannah said:

... I've seen it with a group of girls I have coffee with twice a week, and I kept going on and on and venting about these things, and I was looking, and them and they're like, 'Okay, get over it,' because they're not there. So that's the one time I found a disconnect in my circles is when you're in the thick of it there dealing with the hard stages of caring-- being a caregiver, that I had to be more careful not to belabour these frustrations on to my friends, but instead go to these support groups. That is where you take those things rather where your friends out with these things. You can to a degree talk about it, but support groups is where it is.

Hannah related that providing caregiving support to her mother affected her, however, she did not use counselling services. She failed to ask for this service from the mental health worker because it escaped her mind. Hannah made some suggestions that could be used to address the challenges faced by her mother in accessing healthcare services. She recommended that there should be more family physicians and awareness of the health professionals that could be used by people living with dementia and their family members. To her, these moments are difficult times for family members dealing with this situation. On family physicians, Hannah said:

There again, I know it's hard to get physicians out this way. Again, but yeah, more physicians. The baby boomers are ageing, the system is getting loaded down and it's already too little too late for what there is now, but I mean, at least more physicians.

Sharing her view on the awareness of health professionals, she said:

At least more awareness of our healthcare workers that are available for families because the whole family goes through something traumatic when a parent or a loved one begins dementia. The whole family is off kilter and it's quite the journey, and they need support. And I mean, it's not just the parent or the individual with dementia, it's all of them around. The resources are needed for the family to be pulled together so that they know what they're doing and what they need. And they know they have support somewhere. That initially would help a lot.

Lastly, Hannah suggested that more personal care homes should be provided in order to help hospitals to find places for people who were due to go into personal home care. Giving this suggestion, she said:

I would recommend more facilities for personal home care facilities that hospitals are backlogged with people who are waiting to be placed in these places up to a year, which deteriorates their quality of health. Thankfully, my mother hasn't had to experience that kind of thing. Basically, that's it.

4.1.6. Jennifer's story of her husband who lived with early-onset Alzheimer's

Jennifer supported her husband who had been diagnosed with early-onset Alzheimer's disease. They had children who lived with them. Before he was diagnosed with early-onset Alzheimer's, there were some developments that occurred five years ago, but they had no knowledge about them. Narrating some of the changes that happened in her husband's case, she said:

You know, we used to go camping with friends of ours and we went for a walk one night and they both said to me, 'I think you need to see a doctor. This is-- he's repeating a lot of

the same stories and asking the same questions.' And they said, 'That's not normal. I think you should go to see a doctor.' And then, kind of hearing it from them, I thought that confirmed what I already knew, but wasn't seeing at the time.

Jennifer related that her husband has been living with this condition for four years. Sometimes he was angry and other times that was not the case. Her husband enjoyed watching hockey and spent a great deal of time watching television. He had inconsistencies in his sleeping pattern. Sometimes he went to sleep early and on other occasions, he went to bed late. Sharing this experience relating to her husband's sleeping pattern, she said:

Yeah, he probably sleeps a little more than he used to, but sometimes he stays up a little bit later, so I'm going to say some nights I think it's more to do with feeling lack of interest in anything. He just goes to bed early because he's bored and tired of watching TV all day. And there're some nights he's gone to bed at 8:30. Other nights, it's like 10:30 and that's kinda normal, and then when I get up and go to work, he does not usually get up with me.

According to Jennifer, her husband preferred to be by himself when engaging in some activities. As such, she gave him some space whenever he was performing those activities. He performed activities such as cleaning the floor, doing laundry, and spending time outside with the dog. In addition, he shovelled the snow, vacuumed, and mowed the lawn. Aside from these activities, he was also the leader of a community group and served as a volunteer. He attended to the needs of the people he served but lost interest in this group. Jennifer reported that her husband faced challenges in locating things in the home. Her husband noticed that he was experiencing a decline in cognition, which was irritating to him. On this, she said:

Sometimes things that, you know, where's a dish in the kitchen? Where do we keep it? And we've always kept it in the same spot for fifteen years, and now we don't know where it is. So what's funny is, he can forget that, but he doesn't forget that he forgets. So, it's a bit of a cruel thing that's going on, and he realizes that his memory is declining, and it's frustrating for him-- and in turn frustrating for everyone else because he's an angry person walking around this house.

Jennifer related that her husband did not feel comfortable in a noisy environment and this became clear to them on a family vacation. She explained that some children who were with them on this holiday trip were making some noise and her husband was not able to cope with it. Her husband often found it difficult to remember some of the things he was supposed to do. As such, during the time he was working with a company, he encountered some challenges at the workplace and was not able to perform certain duties which they expected from him. As a result, he was laid off from work. Jennifer related that there have been some changes in her husband and she felt that she has lost him. She said:

Now, I don't know if you can blame that on dementia or personality. And sometimes I think it's a combination of the two things. But he is a different person. His personality has changed. He is not the man I married by any stretch.

More so, his condition has created a big difference in her life. She shared that her husband was going to his family doctor for a physical examination. He was examined by his doctor and was directed to see a neurologist for further assessment. It took a while for them to have an appointment with this specialist. When they got in, she was given a questionnaire to fill. She found out that

some of the things in this paper was meant for people in their late stages of dementia and that was not the situation for her husband. Sharing this story, Jennifer said:

Yeah, with the neurologist, we went in umm, I filled out the sheet you know, they do an intake sheet, and I found that sheet pretty ridiculous because their questions were for advanced dementia. You know, do you have to help him dress? Do you have to-- and we were not at that point. We were early stage.

Jennifer shared that the neurologist directed her husband to go for a magnetic resonance imaging scan and informed them that there was a problem with his hippocampus. In the beginning, they were informed that he was living with mild cognitive impairment and later deemed it as early-onset Alzheimer's. He was given some advice by the neurologist to adopt a healthy living lifestyle. Also, the neurologist suggested to them to go to a clinical psychologist when they needed more insight into his health condition. The psychologist performed a cognitive assessment on him and also had a conversation with them on this examination. Her son was concerned that he was going to end up living with dementia because of his father's condition. As a result, he connected with a counsellor in order to seek guidance on this matter which was bothering him. On how her husband's situation has affected her son, Jennifer said:

...my one son was pretty worried that if my dad has this, I'm going to get this too, and it freaked him out for quite a while. And he did access a counsellor through (referring to the name of an organization) as well, and he talked a few things over. I don't know about what or everything, but it was helpful to him to verbalize some of his feelings and thoughts and to have that feedback.

Jennifer related that her husband was not using the services of a dietitian because they knew about a healthy diet. Therefore, she did not take this service into consideration. Responding to this issue, she said: "Well, we didn't utilize that. We know what good eating is, you know, so we didn't feel the need to go to a dietitian and draw up a new plan." In addition, she read about various dietary programs and eventually utilized the services provided by Weight Watchers. Her husband injured his shoulder and used the services of a physiotherapist. Talking about this issue, she said:

He hurt his shoulder once or something, and he went to see physio, and that was just a one visit, and they said, 'You know, do this exercise, and that should help you.' And then, so he did and then that was the end of it.

That aside, he lived with some other health conditions such as blood problems, high blood pressure, and had experienced a heart attack. Jennifer speculated that her husband had surgical treatment for a hernia as it happened hitherto to getting married to him. Therefore, she had little information on this matter. Her husband was using drugs which included Aricept, Imodium, Metoprolol, Atorvastatin, and Ramipril. Because she had an insurance package from her employer and a health expenditure account, the majority of the medications used by her husband were taken care of by her insurance. This was the situation because her husband was a beneficiary of her insurance coverage program. But there were some drugs and supplements that she bought them out-of-pocket. These included Imodium, vitamin B12, omega 3s, and baby aspirin. Her husband was affected by the negative side effects of the use of drugs. Jennifer reported that the Aricept caused some bowel problems for her husband and that was the reason why he was using Imodium, which was suggested by the neurologist. They had a pharmacist in their neighbourhood who was aware of the drugs used by him and offered services to them. Her husband enjoyed visiting this place and also had a good relationship with the pharmacist. Jennifer affirmed that it would be a great idea to

have this service in the communities in a situation whereby people would have a correspondence with a pharmacist. She shared that her husband's father lived with dementia, as well as her own father. So, in this case, she already knew some of the behaviours exhibited by her husband.

Jennifer reported that because of her job, she had access to counselling services offered by the Employee Assistance Program. She went for some counselling services and was also assisted by the counsellor in applying for a disability tax credit for her husband. The process involved in applying for this tax credit was cumbersome for her, but the counsellor was supportive in this area. She was going to a support group session regularly on a monthly basis and attended a conference gathering organized by the Alzheimer Society. Her aim of going to this meeting was to get some ideas concerning her husband's condition. Since she was interested in going to this program, she excused herself from work for a while and attended with her husband. Jennifer shared that she enjoyed this program, but her husband did not. Thus, she forced her husband to go to this program with her. Sharing this story, she said: "...I was kinda excited about that, and I took some time off of work to go there with him, but it was terrible. I dragged him there and I had more fun there visiting everybody than him."

Discussing the attitude of the health professionals towards her husband, she narrated that the clinical psychologist was kind to them. Also, her husband was assessed by Manitoba Public Insurance for the Drive Safe Program and was well received by the nurse who offered services to them. However, she was not happy with the neurologist based on some circumstances. Jennifer shared that people were concerned about her husband's driving and as a result, she contacted the neurologist on this matter. To her surprise, they received information from Manitoba Public Insurance informing them that her husband's licence had been revoked. Sharing this account, she said:

...through my umm, support group, they were, 'He's still driving,' and they would say that to me every time. And I'm like I'm a bit nervous about that. What if something happens, you know? So, I did phone the doctor, and I said, 'Is there some kind of test that we could have done to make sure we're safe?' And in response, we got a letter from MPI, in the mail two weeks later, 'Your licence is suspended, you're done, hand it in. What?! I just asked a question; I didn't say I thought he was a danger.' This is just something I wanted to manage before it became-- if it is going to be a problem. And no, he mailed a letter to MPI, telling them to take his licence away and that was a terrible blow, terrible.

Her husband was affected and frustrated about this decision. As a result, he associated the unpleasant things that had happened to him to this doctor. Jennifer reported that because of her husband's situation, it had some effects on them. She had to do a review of their mortgage agreement in order to have some funds available to take care of their needs. On this, she said:

Umm, what you thought was-- you know, saving for your retirement isn't happening. You thought your house would be paid off in a few years and because we knew things were going on when I did the mortgage again, I made it way longer because I wanted the payments to be less to free up more money to live month to month.

In addition, Jennifer related that she encountered some difficulties in searching for information as there were not a lot of resources for people living with early-onset Alzheimer's. Talking about this experience, she said:

We just need the guidance, and I was asking if there were some kind of programs out there and that was a difficult thing. And some of them were, 'Wow, we're not used to that, we

haven't had anyone like that. Oh, no, you gotta be age sixty-five or over to access this.' So they have an age barrier description or whatever on these services as well.

In this regard, she recommended that information should be provided at the very beginning so that people would have ideas and resources to inform their decision-making. Making her submission on this issue, she said:

Yeah, more information on the outset, make it available. Umm, you know, providing counselling services at the very beginning if people feel it necessary. You know, because it's a lot of it emotional and its hard stuff, it forces you to look at who you are and what you're made of and can I do this? How do I do this? How do I do this well? How do I not let this kill me and my family and everything? I don't know that I have the answers, but it's nice to have knowledge and information and then you can make choices.

4.1.7. The story of Megan regarding her mother who has been diagnosed with Alzheimer's and vascular dementia

Megan provided caregiving support to her mother who lived with Alzheimer's and vascular dementia. Having her mother accepted into a personal care home was a great relief for her. She was in a nursing home where she received some respite services. But that did not work out well, so she was now in a permanent place where there were a lot of activities for her to do. However, Megan was of the opinion that nothing significant would come out of it and felt that they were taking her mother to a personal care home to die, and this bothered her. On this issue, she said: "I kinda felt if we would put her in a home, it would-- it kinda felt like we were putting her there to die. I didn't like that." Also, in one of the places where her mother was receiving caregiving

support, she would get angry and swore at the staff. Giving an account of this behaviour showed by her mother, she said:

The first placement that she was for like a month and a half or whatever, it was maybe two months, I know her behaviour became challenging for them because she was exit-seeking. So, they had to keep a very close eye on her, and then if they would stop her, then she would get very angry and act in a very out-of-character way. Apparently, she swore at them which blows my mind because she would not do that in the past.

Megan shared that personal care home was considered as an option because they were not in a good position to provide the essential support and care for her. According to Megan, her mother has been living with dementia for four years. They noticed some changes in her mother and also had the habit of talking about things over and over again. Her mother would ask her a question and after responding to it, she would ask the same question minutes later. Sharing this story, Megan said:

So, it seemed very young to be repeating herself as often as she would. She'd ask, 'What's your son up to? What's he busy with today?' And I would tell her, and five minutes later, she'd ask me the same thing. For a while, she'd ask, 'Did I ask you that already?' And so, she was catching herself, but she'd do it again.

Her mother was in her early sixties when this started. She brought this to the attention of her mother's family doctor and asked him for his opinion. Whenever there was a doctor's appointment, in order not to embarrass her, she contacted the doctor ahead of time and gave out some information concerning her mother. This made the doctor know what to do before they would get there. Sharing this experience, she said:

I brought her in to see her doctor fairly regularly and said, 'This is what's going on, can you just let me know what you think?' Sometimes in order not to hurt my mom's feelings, I would contact the doctor ahead of time or write him a letter to read before he came into the room saying these are my concerns. And so, he would know what kind of questions to ask without me having to say it in front of my mom.

Megan said that her mother had a good relationship with her family doctor. Also, this doctor was a very good person. To her, the greatest problem they faced whenever they needed his service was the long wait times involved to see him. Usually, they had to wait for a month in order to have an appointment with the family doctor. Megan reported that personnel from seniors' mental health (A team or group of health professionals, which include specialists, primary healthcare practitioners, and social workers that offer diagnostic services and examinations to older people facing mental health problems) performed some tests with her mother. Based on this assessment, they were informed that her mother may be living with Alzheimer's and vascular dementia. Talking about this issue, she said:

...a gal from seniors' mental health, her name is (referring to a health professional). Umm, we were in contact with her, and then she would do some assessments of my mom again whenever we asked her to. And she was the one that told us mom probably was suffering from both Alzheimer's and vascular dementia.

Megan related that her grandmother had Alzheimer's disease, but she made sure not to worry about it. To her, it was terrible to live in this condition. Moreover, she did not feel stigmatized and was not bothered about what other people thought of them whenever they were in the community. She shared that her mother was more friendly to people. Her mother approached children in public

because she loved them and would try to take them from their parents. This was not an issue for many of the people because they understood that. On this, Megan said:

She's always loved children, and that became very pronounced. When you'd be out with her in public, and she'd see a child, she would approach anybody with a child. It got to the point where she was trying to take a child out of the mother's hands saying, 'Here, can I hold your child?' Or 'Come to me' and try and take him out of his parent's arms. Most people were incredibly understanding. Her sense of what is appropriate with strangers is gone, and so it made for some awkward situations.

Since her mother was finding it difficult to familiarize herself with the seasonal changes of the weather, she would put on sandals and a light jacket during winter time. As a result, Megan was helping her with what she needed to wear. Sharing this story, she said:

The last winter she was home she would go out in sandals and a light jacket. Even if we'd pick her up to bring her to our place to hang out with us or do something with us, I would say, 'Mom, it's winter outside, you have to wear boots or at least your runners.' And she would say, 'Oh, I'm fine, it's not that cold, it's beautiful outside.' Then, we'd step out the door, and she'd be like, 'Oh, it's cold out here.' So we got to the point we just said, 'Mom, you're not coming with us unless you put on your boots and a jacket.' Also, when the seasons changed, I went into her condo, and I took away all the out of season clothing, and for footwear, I only left her a pair of boots, so she had to wear her boots. She couldn't wear anything else; I took everything to my house so she couldn't find it.

According to Megan, her mother was finding it difficult to identify them as her children. One day, she went to visit her mother in the care home and she was delighted to see her. Her mother was in tears and thanked her for coming to pay her a visit. Sharing this account, she said:

She doesn't recognize us as her kids most of the time anymore, at least not by name. Occasionally, she might all of a sudden remember just for a moment or something, but it seems that if we don't tell her who we are, she might think we are a friend or her sister, or we might just be a nice person. So, physically she is okay, mentally she has gone down. She's still lonely sometimes even though there are other people there. I went to see her recently, and when she saw me, she just started crying. She was shocked to see me. She asked, 'You're here to see me?' I don't think she knew who I was really, but she was just so happy that I went to see her and she was crying and saying, 'You came! I'm so glad. Thank you for coming.' I don't know.

Also, in some cases, her mother refused to get help from them whenever they noticed that she needed help with something. Megan reported that they assisted in the planning of her mother's activities and she was able to follow through by documenting them on a calendar. Because of her health condition, it got to a point where she could not do this anymore. Her mother was in a state of denial and did not recognize that she lived with dementia. Talking about this issue, she said:

I don't think that she realized anymore that she had dementia. We had told her earlier. Sometimes she would say, you know, 'My brain isn't working very good,' but she also fought it. On one hand, she knew her brain wasn't working well, but on the other hand, she would say, 'I'm fine, I can do this by myself.' And so, she struggled with the idea of having dementia and fought about the help she needed to receive.

Her mother was facing challenges in performing household chores such as doing laundry, washing utensils, and keeping her place clean. Due to this, she broke her laundry and dishwashing machine.

Narrating this story, she said:

I know that one of her sisters would go visit her quite regularly, and I know she was doing some laundry and stuff. My mom would be putting dishwasher detergent into her washing machine, and she actually wrecked her clothes washer because she was using the wrong detergent. She also used the wrong detergent in her dishwasher and wrecked that as a result. She wasn't able to keep the condo really clean. I think in her mind she sort of thought she was, but I know her standards and the condo was definitely not kept up to those standards. She was just wasn't able to do it. I think it overwhelmed her.

Her mother was wandering and walking for a longer period of time and would get lost. Megan was told that some people were assisting her mother with transportation in order to get back to her place of abode. Megan narrated that the service of a pharmacist was used because a pill sorter they bought to assist her in taking medication did not work out well. So, the pharmacy introduced pill packs which worked for some time. Her mother was facing difficulties in taking her morning medications. She forgot to take them and eventually a home care worker was coming in regularly in the morning to assist her with it. Megan reported that her mother had some mini-stroke and issues with her heart. But through a stress test and observation, it was not too much of an issue to worry about. Her mother was using a pressure medication which caused her to cough. This coughing lingered on for a longer time and was reported to her family doctor. Upon doing research about the medications used by her, they found out that coughing can be a possible side effect of the use of blood pressure medication. As a result, they told her doctor to change this medication and give her another one. The doctor changed it and the cough went away. But when her mother

went into a personal care home and was given her previous blood pressure medication, her coughing came back. Narrating this story, she said:

In particular, the blood pressure medication that she was first on, she had a cough that would not go away. This was while she was still functioning on her own and so she'd go to the doctor and say, 'I have this cough, it doesn't go away.' It just took forever and didn't seem to get to the bottom of it. When our family was doing research on the medications that she was on, we learned that some blood pressure medications cause a cough, so that's why-- that's part of the reason we asked her family doctor to change her to a different one and then her cough was gone. Then, when they put her back on it-- on the blood pressure med in the home, she was coughing again.

Before her mother was accepted into a personal care home, she got involved in a fall incident. They did not know how this happened, but it affected her mother. This caused an injury to her back and she used the services of a chiropractor for some weeks. Talking about this incident, Megan said:

She would go for walks all over town, so I would say she was in really good shape. But when she fell, we think she may be landed on a door stop that was on the ground, and it did damage to her back. So, we had to take her to the chiropractor and massage for a number of weeks to try and get that fixed.

Her mother has never used the services of a physiotherapist and that of a dietitian. Megan said that she had not thought of the use of a dietitian and that was the reason why her mother has not accessed it. Megan discussed that she was affected in different circumstances in the course of providing caregiving support to her mother. She became emotional, stressed, and depressed. She

worked as a bookkeeper and was making errors that were unusual of her. She said: "I was a basket case. I'm a bookkeeper at my job, and yeah, I was making a lot of mistakes that I would have never made. I just I couldn't remember anything." Megan related that she had to forfeit going to work in order to assist her mother to go for her appointments. As such, it affected their finances. She managed to go through these circumstances because her supervisors accepted her situation. Narrating this experience, Megan said:

To take her to appointments, I would miss work so that would affect us financially. I was also the primary contact for the home to call if there were any issues with mom. So, I would get those calls while I was at work and depending on what the call was about, I'd sometimes be bawling at work which was so embarrassing. But I had really good bosses who were super-duper understanding. So I'm very fortunate, but yeah, I just wasn't coping very well. Yeah, sometimes I would have to leave work for different things.

Megan related that providing caregiving support to her mother affected her relationship and support networks. Visiting friends seemed like a task for her and she was not much involved with people. She opted to be at home without engaging in any activity. She was not accessing counselling services because she had friends whom she had communicated with them. More so, to be able to provide the needed support for her mother, she engaged in reading and accessed some online resources. Also, there was a family support group which had meetings on a monthly basis in her area. She got some ideas by having a conversation with family members who had been in this situation. Talking about this, she said:

I've read some stuff, just done some research online. There is a family support group that meets once a month here in town. That is more actually for me than for my mom. Yeah,

mostly just reading stuff online and then talking to other people who I know that have had family members who have gone through the same thing, and they just kind of compare experiences. Some of these friends have said, 'You know, (referring to herself), you need to do this or this is what my parent did.'

In addition, in order to manage the longer wait times faced by her mother in regard to going to see the family doctor, she had to plan ahead of time in scheduling an appointment for her. Sharing this story, she said:

I would just call when I needed to make an appointment and let them know. And I'm not a very pushy person, so I'm not very good at saying my mom needs to see him now. I would sometimes ask to be put on a waitlist if I felt that it was a really pressing matter. But basically, I'd just call and say, 'What's the earliest appointment I can have?' And then, take it. That's pretty much all I did.

According to Megan, the two things that could be done to improve access to healthcare services were providing more spaces in personal care homes and more physicians. Giving these two suggestions, she said:

I would say probably a bigger one would be more personal care home spots. I think that's a huge one. Anything else I think it's-- we're in a growing community and I guess there's only so and so many doctors for people and you just gotta wait your turn. I guess get more doctors that would be helpful. Yeah, more doctors, more personal care home beds. I think that would be probably my two biggest things.

4.1.8. Rebecca's story of her mother who has not been medically diagnosed with dementia

Rebecca assisted her mother whom she had a strong conviction that she had dementia. At the time her mother was living in an assisted living complex, she would go there to pay her a visit. She found that her mother was facing problems in keeping her place clean. This was what she observed about her mother from the beginning. Sharing this story, she said:

When she lived on her own, she lived in a senior's complex and the first thing we noticed was, we would come there, and she was no longer cleaning, and there were receipts on the floor, and there were Kleenexes on the floor.

Her mother was interested in doing puzzles, which they did together with her. Although she never sought treatment for her, because she had no idea that there was some assistance for dementia care. Her mother has not been medically diagnosed with dementia. According to Rebecca, this was the situation because it was never suggested to them to take this path. Later on, she found out that there was a chance for her mother to go through this process. Narrating this experience, she said: "It was never offered, and I think it's only later that I was aware that that was a possibility." But she believed that her mother had dementia. On this issue, she said: "I know it's dementia like, just by how she's acting..." She speculated that her mother has been living with this condition for six years, saying:

...I have to say this generally 'cause I know that I retired five years ago, and one of the reasons was that she was deteriorating, but she was still on her own. I just wanted to be there more often for her. So, I'm going to guess about six years.

Rebecca reported that she noticed some behavioural changes in her when she turned eighty. Also, based on a computerized tomography scan, it was found that her brain was declining and shrinking.

But she was not in favour of allowing her mother to go through some additional examinations. She said that none of her grandparents had dementia and therefore they were surprised to find out about her mother's situation. Her mother had problems in remembering what to do and at one point, they got home care services to assist in taking her drugs. Later on, her mother was transferred to supportive housing. Her mother felt hesitant to receive assistance from the staff and did not permit them to support her in taking her bath. But she permitted her family to assist her in this area. Also, she used to wander around during her time at supportive housing. Eventually, she went into a nursing home. During her early days at the nursing home, she wandered around, but her sleeping pattern was improved. In addition, things went on fine for her there. More so, she permitted the people working in the nursing home to assist her in performing some activities for her. Rebecca found the nursing home as a useful place, as they communicated with her whenever there were some issues with her mother.

Rebecca related that her mother had difficulties in walking, but she did not recognize that she was facing this problem. Her mother had osteoporosis and hip problems and as a result, she was going to her family doctor to seek treatment. Her mother's doctor helped them to get an x-ray for her when they needed one. Her mother was taking a medication for pain which was given under the authority of her doctor. She had a mini-stroke and was using Plavix. Also, she took aspirin and had medication for her high blood pressure. Rebecca narrated that her mother was affected by the harmful side effects of some of these medications. She observed that her mother's fingers were usually blue and cold. Her hands were either cold or warm. In the nursing home, they offered her another blood pressure medication to use and she got a rash and was itching. As a result, she brought this to the attention of the health professionals working in the nursing home, but they told her that it was due to dry weather. So, her mother was using a cream to manage this condition.

Rebecca was not happy that they did not inform her before offering her mother another blood pressure medication. Sharing this story, she said:

...I guess some problems with high blood pressure and they changed her medication. First, they took her off of it thinking she might not need it; then they gave her a different one which I believe caused her bad rash. I don't like that. I don't like the fact that they didn't talk to us first. I'd like to know why did you change the medication? She was doing fine on what she had, and I've-- I have come to them and said, 'Look, I think it's this is causing a rash, and a lot of itching,' and they seemed to control that with cream, and I got-- I guess we get tired and so I've left it.

Rebecca shared that in many cases, all of the drugs used by her mother was acquired out-of-pocket. Thus, she had to buy them on her own. On this issue, she said:

She had to pay all of it except there's a-- like the government does have a system that it's based on her income, right? So, then I think it was the last couple of months where she wouldn't have to pay, but most of the year she did.

Her mother was not talking more often. Rebecca believed that this situation was due to the degeneration of her mother's brain. In addition, her mother had a hearing problem and had some difficulties in hearing what was communicated to her by the doctor. In this case, family members had to be there in order to explain things to her. As a result, her mother was facing a communication problem and challenges in expressing her concerns whenever she went for her doctor's appointment. Narrating this experience, Rebecca said: "...she never was very good at verbalizing her needs as well, so that was a challenge for her." But there were no problems concerning the attitudes of the health professionals who provided services to her. Her mother was a wheelchair

user and fell on many occasions. Because of her mother's ambulatory problems, she was examined by an occupational therapist. But she had neither used the services of a physiotherapist nor that of a pharmacist. Rebecca had the idea that it would be beneficial to look into the use of the services of a pharmacist for her mother.

Sharing her story of how providing caregiving support to her mother affected her, Rebecca said that she had to forfeit going to work in order to support her mother. On financial matters, she explained that it was not much of a problem for her, but it was the case for her sister instead of her. Also, it affected her relationship and support networks such as companionship with people. Rebecca said: "The emotional care, the physical care, definitely it impacted friendships. Yeah, it's just reduced my energy to even want too." Although she was not overburdened in assisting her mother, it affected her emotions. Her husband and her two sisters have been there for her and that was the reason why she had never used counselling services. In addition, she was attending a support group session at the Alzheimer Society, which has been rewarding to her. Giving her recommendations on some of the things that could be adopted to improve access to healthcare services for people living with dementia, Rebecca suggested that there should be health professionals who had knowledge in dementia care. To her, it would be useful if there are doctors available in dementia care and management. As such, in her mother's case, this was a problem in the course of providing caregiving support. During the early stages of her mother's condition, they were not provided with resources that could be used to support her. According to Rebecca, she felt that it was a problem and discouraging for her. Based on this experience, she recommended that awareness of the availability of resources that could be used by families to support people living with dementia should be provided. Rebecca had the view that there was a gap in knowledge on the part of physicians on dementia care. As a result, she suggested that training on dementia care

should be provided to health professionals. In addition, she said that home care workers should be equipped with ideas that could help in providing the appropriate care and support for people living with dementia.

4.1.9. Sylvia's story regarding her father who has been diagnosed with Alzheimer's disease

Sylvia was the only daughter of her father who lived with Alzheimer's disease. She and her mother provided caregiving support to him. Her father was eighty-seven years old when he was diagnosed with Alzheimer's disease. Her father performed some activities such as going for a walk with his wife. Sylvia reported that her father's condition was not something which was new to her as some of her friends had been in similar situations with their parents. But her brothers had difficulties in facing the reality of his situation. Sharing this experience, she said:

Well, because we kinda knew already, it was just the finality. I have so many friends that have dealt with it with their parent, but it's not like, you know, somebody you know, and it was kinda like, 'Okay, it's in our family now.' It was a slow onset. It-- in the beginning, it seemed like we just have to take a day at a time. I can't say it was-- I've been really actually strong about it. It's bothered, my brothers. My brothers have had a harder time with it.

According to Sylvia, it all began about five years ago, when she noticed some changes about him. Discussing some of the changes she observed about his father, she said:

Like he would help me with a project and we'd go out together, measure something for sidewalk blocks and we'd come back and were putting these sidewalk blocks down and he'd look at me and say, 'What are you using these for? What do you need these for?' You

know, meanwhile like an hour ago, we had just-- we were working on this project. So, it was like little blips of information just gone.

Upon expressing some concerns to his doctor, an arrangement was made for him to undergo a psychiatric assessment. Based on the assessment by a psychiatrist, he was diagnosed with Alzheimer's. In addition, the psychiatrist suggested that his driver's licence should be revoked. Her father did not recognize that things were not going well with him. As such, he was in a state of denial of living with dementia. Sylvia said that she did not feel stigmatized about her father's condition. In this regard, she saw herself as someone who could be used to educate people. Because some people had been in this situation, there was a lot of support in their small community among families providing assistance to their relatives. Sylvia related that her father used to be a truck driver. As a result, he knew a lot of areas and locations in Winnipeg. But it got to a point where he began to ask questions about some places in the city and pretended that everything was okay. There were situations where he would get lost and seemed to be forgetful of his environment. Also, he talked about things that were not understandable to people. In this case, one of her friends enquired from her to find out if something bad was going on with her parents. Her father ate a lot, but he was losing weight. Although this had been the case, he has not used the services of a dietitian. He used to have asthma which he thought he might die from by way of an asthma attack. Her father had a brain aneurysm in his forties which really affected him. Narrating this past incident which happened to her father, she said:

He had in his forties, he had an aneurysm that was not fatal obviously, but it was like your blood vessel in your brain, it inflated. I remember as a kid when this happened, and he lost his balance, his sight, and part of his-- some paralysis. They took him to the hospital, and

they said they could do one of three things, either it would pop, and that would be death or it could seep. It could have a hole, and then there would be permanent brain damage.

As a result, her father had some speech problems which took some years to go away. He got anxious whenever he wanted to visit some places and would be looking at his watch and kept repeating that over and over again. Sylvia reported that her father was on anti-anxiety medication and was going to his family doctor whenever there was a health concern which needed some attention. As such, his doctor was the one who took care of the medications he used. She narrated that her father's family doctor was a very good person and someone who knew how to provide care and support to older people. Aside from going to see his family doctor, he has also been to an eye specialist due to some cataract problems. Again, he went to a urologist because of a tumour, but nothing significant was done about it. For most of these specialist appointments, she had to go to Winnipeg with her father. Sylvia said that on these occasions, parking, walking, and getting into buildings were some of the physical challenges that they faced.

Moreover, the distance involved in going to a specialist appointment was also a problem. She shared that there were not a lot of specialist services in her area. Also, before her father lost his driver's licence, he used to drive many of his friends to Winnipeg for their appointment. Sylvia recommended that transportation services should be provided in order to tackle this situation. In her opinion, specific days should be set aside for people to have access to transportation services for their appointment. Giving her suggestion on this matter, she said:

I think that a community this size should have a business, a transportation business like a shuttle, for-- from here to the key points 'cause it's the main clinic. Whether it's Winnipeg, Manitoba Clinic, Winnipeg Clinic, the hospitals, so they should have a shuttle. Whether

it's three times a week or like start it on some kind of a schedule that they can have pickup and drop off points and they could take all these people. So, that would be my thought.

In addition, Sylvia related that she would love to see some of these specialist services provided in her community. Because of her mother's health, they decided to opt for personal care home services for her father. She said that she was informed that before her father could be admitted into a personal care home, it would be a good idea for respite services to be provided for him. In this regard, the people at the personal care home would have the chance to get to know her father and also assess his needs. On this issue, Sylvia said:

Yeah, they do offer these week respites and I was told that before he gets placed permanently, they do encourage you to have at least one week of this respite and it gives the opportunity of the place that he's gonna be panelled for, to see him, to see what his needs are. It shows them how much the other caregiver is doing for him. So, they convinced me this was a good idea.

Eventually, her father was provided with free government home care services. Unfortunately, this did not work for him. Sylvia had the view that many people were in personal care homes. As such, it was not a good place for someone who was in the early stages of this condition. The difficulty which her father faced in using home care was the lack of consistency involved in staffing. Different people came on different occasions to provide caregiving support. As a result, there was a lack of privacy. Sharing this story, she said: "There's no consistency like, there's just way too many people. You don't have the communication that you do in a private situation." She kept repeating and giving information to the staff who were coming in to offer their services. Sylvia reported that some of the caregivers who provided support to her father were emotionally affected

as she arrived to see some of them in tears. To her, home care workers were good at handling the physical needs of people they support. But there seemed to be a gap when it comes to handling the emotional and psychological part of care. As a result, she recommended that home care workers should be trained in order to handle the emotional aspect of providing care to people living with dementia. On this, she said:

...we need home care workers for the psychological part of the disease. How to relate, and how to calm them, and how to encourage them, or how to distract them, or how to-- what are the things that they can do, what are their-- what's left that they can do, and then focus on how can I create an activity that uses whatever they have left. So, information like that, I don't think home care workers-- they don't, they don't have that. So, they should be better trained for when they are assigned to people that have less physical needs, but more emotional needs of the disease.

Also, she suggested that there should be training for a particular group of home care workers in order to deal with specific situations when the need arises. Another thing that she believed could help improve home care services was that driving services should be provided to people who use this service. Doing so would help them to have access to transportation for their appointments. Lastly, she suggested that it should be easy to do paperwork and funding for private family care as this can be a challenging task for some individuals who needed it. Sylvia shared that in the course of providing caregiving support to her father, she was affected in various ways. She had to press harder for a leave of absence at work in order to get time to assist him in areas where her assistance was required. Talking about this experience, she said: "...I have five absent days that I could take. That this would have qualified, but I had to fight for them at work. So, that added more stress to me." Sylvia narrated that she had children and grandchildren and was working full-time.

As such, it was stressful and challenging for her on some occasions. But she has not been using counselling services because she knew how to take care of stress and also has some friends that she can rely on. On this, she said:

I manage stress fairly well; I have all my life through different stressful situations. So, I haven't felt the need to go for any specialized counselling. I have a good network of friends that I can talk it out and I have a deep faith, and that certainly gives me strength. And so, I'm doing pretty good, overall.

Sylvia related that she attended some of the workshops organized by the Alzheimer Society. It was due to attending one of these workshops that her mother had a fair understanding of her father's condition. Her aim of going to these workshops was to obtain some skills to support her parents. Sylvia said that one of the things which could help in improving access to primary healthcare was that family doctors should provide information at the very beginning of the onset of dementia. In this regard, she used Glen Campbell's life experiences of living with dementia as an example where he (Glen Campbell) was monitored by health professionals in order for them to get an insight into the digression of his health condition. Sylvia considered Campbell's situation as an early assessment where proactive measures were taken to address issues that unfolded. To her, this could be beneficial to people living with dementia.

Conclusion

In this study, it was revealed that relatives living with dementia used many of the primary healthcare services available in Manitoba. That aside, specialist, personal care home, home care, and nursing home services were the other ones mainly used by them. The relatives living with dementia face challenges when accessing primary healthcare services, specialist, and home care

services. As such, family members who participated in this study gave some recommendations that could be adopted to improve access to these services. In addition, some of them shared their views on the hospital environment, attitudes of health professionals towards relatives living with dementia, the impact of providing caregiving support, and others.

In the next chapter, the issues coming out of the stories given the family members concerning relatives living with dementia are grouped into themes. This helps the author to discuss the findings of this study under the various themes created. By so doing, the work of other authors is used to support these discussions. The social model of disability as the main idea of this project is used to help readers to appreciate how this model interprets circumstances that relatives living with dementia found themselves in.

Chapter 5

5.1.0. Discussion of the results of the study

This chapter discusses in detail the findings of this study. Due to ideas coming out of the stories shared by the family members, the researcher developed some themes in order to initiate a conversation around this topic. Some of the themes created include a demographic overview of the study participants, demographic characteristics of the relatives living with dementia, behavioural signs showed by relatives living with dementia, past incidents in the lives of relatives living with dementia, other health conditions experienced by relatives living with dementia, and others. Many scholarly works or ideas from other authors are used to support the findings of this study. By so doing, a lot of essential information pertaining to this field is revealed in these discussions.

5.1.1. A demographic overview of the study participants

The demographic overview of the interviewees or study participants showed that many of the family caregivers were females. This finding supports information given by other studies that there is a higher propensity for women to provide caregiving support than men. Godfrey & Warshaw (2009) assert that in the global world, a traditional assumption exists about women to find themselves in performing care and support duties. However, Robinson et al.'s study (as cited in Erol et al., 2015) state that "[i]n many research studies on dementia caregivers, all or the majority of participants are women, reflecting the disproportionate extent to which they are relied upon as carers, although few of these look at gender as a specific issue" (p. 13). Also, in this project, many of the family members providing caregiving support were recruited from a small town in Manitoba. The researcher's observations as to why many people from a small town in Manitoba participated in this study was that the branch of the Alzheimer Society of Manitoba in this area is connected to

people who have relatives living with dementia. The participants had trust in the Alzheimer Society and were not bothered to share sensitive information by engaging in this project. Moreover, they were concerned about the welfare and well-being of their relatives living with dementia. Therefore, participating in this project was a means for them to advocate and voice out their concerns.

Another perspective that needs to be investigated is that according to Bollman (2008), the majority of the number of people living in the countryside in Canada is made up of the elderly as against the number of people living in the city. As dementia is more prevalent among older adults and seniors, further studies that highlight the geographic distribution of this health condition in Canada might confirm that many people living with dementia may be living in smaller communities instead of the city. Therefore, it would be of great interest to the general population and the academic community if such studies are conducted in order to priorities the delivering of services for people living with dementia in Manitoba and the whole of Canada.

5.1.2. Demographic characteristics of the relatives living with dementia

Gender has been identified as a key indicator of living with dementia. This is often tilted towards females as more likely to live with dementia than males. The Alzheimer Society of Canada (2005) asserts that more than seventy percent of Alzheimer's diagnosis and over sixty percent of the other types of dementia affect women. In this study, the findings showed that relatives living with dementia who were females were not more than the males reported to be living with dementia by family members. This revelation is essential to the demographic and epidemiological patterns of dementia disease occurrences among the population. While this may imply that many males are beginning to live with dementia in Manitoba, it might also be as a result of the methodology and research approach used in undertaking this research project. A qualitative study often involves a

small group of people compared to a quantitative study which uses a larger group of people as the study participants. Therefore, it may not be the case when dealing with a larger group of participants. In addition, the shortcomings of the use of case studies have been reported by some scholars. Dooley (2002) states that “case studies provide very little basis for scientific generalization since they use a small number of subjects, some conducted with only one subject” (p. 5). However, the main influence of a qualitative study is the ability to investigate a subject in detail (Carlsen & Glenton, 2011). Therefore, it was appropriate to use this approach because the researcher wanted to get in-depth information on the views that family members have concerning access to primary healthcare services for relatives living with dementia in Manitoba.

This study found out that Alzheimer's disease was the common health condition affecting many of the relatives living with dementia. The Alzheimer Society of Canada (2010) states that Alzheimer's disease is the most dominant of all the types of dementia and next to it is vascular dementia. Family caregivers providing caregiving support will be in a good position to assist relatives living with Alzheimer's disease if they have more knowledge and understanding of this health condition. Age has been reported in many studies as influential in living with dementia. Based on the information given by the family members who participated in this study, all of the relatives living with dementia were older adults at the time they were diagnosed with dementia. Launer et al.'s study (as cited in Exalto et al., 2012) state that “[i]n general, dementia is rare below the age of sixty to sixty-five, but from the age of sixty-five onwards, dementia incidence doubles with every five years of age” (p. 861). As they grow older, they may need the assistance of family members to help them to meet some of their care needs. According to the Alzheimer's Association (2015), families perform over seventy percent of long-term care for older people.

It can be challenging to get a diagnosis for a relative suspected of living with dementia. In some circumstances, family members may wait long periods of time before this can be carried out by a health professional. Some of the study participants reported that their relatives have not been diagnosed with dementia, but there was a strong conviction that they had dementia. According to Callahan, Hendrie, & Tierney (1995) & Valcour et al. (2000), percent wise, this is the case for thirty-three point three percent to more than fifty percent of people living with Alzheimer's disease. As noted earlier that Alzheimer's disease is a common form of dementia, many older adults may be facing this situation. Also, this adds to the caregiving stress and burden of family caregivers waiting for a medical diagnosis for relatives living with dementia.

Dementia is a health condition which can manifest for a longer period of time. As a chronic health condition, its impact can be catastrophic for people affected by it. Many of the participants revealed that their relatives have been living with dementia for some years. Therefore, continuity of care must be ensured to promote their health and well-being. With the increasing number of dementia cases in Canada, the primary healthcare system should be strengthened to respond to the diverse needs of persons living with dementia. Coming from a social model perspective, stakeholders in the primary healthcare system would be deemed to have failed if healthcare services that are considered essential in meeting their needs are not provided.

This study found that many of the relatives living with dementia had other family members who lived with dementia. Larson et al. (1992) report that some suggested risk factors for dementia are gender, low educational background, family history, past head injuries, and others. Dening & Babu Sandilyan (2014) state that "...having a first-degree relative with late-onset Alzheimer's disease increases one's chance of developing Alzheimer's disease only slightly" (p. 40). Norton et al. (2014) share that approximately around thirty-three point three percent of the masses being

vulnerable to Alzheimer's is probably due to habit or manner of living. People who have a family history of dementia may benefit from adopting healthy lifestyle choices in order to prevent or delay the possibility of living with dementia.

5.1.3. Behavioural signs showed by relatives living with dementia

Persons living with dementia exhibit some behaviours associated with dementia. In this study, it was revealed that all of the relatives living with dementia showed certain behaviours such as being anxious, angry, being in the state of denial of living with dementia, being forgetful about stuff, finding it difficult to locate things, wandering, among others. Finkel et al. (1996) list belligerence, roving, nervousness, stockpiling, distress, and others as the neuropsychiatric signs of dementia. Neuropsychiatric signs of dementia can be demanding for family members providing caregiving support (Donaldson, Tarrier, & Burns, 1998; Robinson, Adkisson, & Weinrich, 2001). As such, a certain amount of patience and understanding is required by family caregivers. Minimizing arguments and accepting the reality of individuals living with dementia foster trust and harmony between them and their family caregivers. Therefore, family members providing caregiving support should access resources that will help them to have more knowledge on how to manage or handle the behavioural aspect of dementia care.

5.1.4. Past incidents in the lives of relatives living with dementia

Knowing about some of the things that have happened to persons living with dementia can help other caregivers and physicians providing their services to them. This study found that some of the past incidents about the relatives living with dementia included falls, loss of employment, loss of driver's licence, injury to the backbone, and previous brain or head injury. According to Wesson et al. (2013), persons living with dementia are highly susceptible to experience a fall as compared

to others. A fall incident can adversely affect the mobility of older adults living with dementia in a situation whereby there is an injury to the hip or knee. As persons living with dementia progress through the stages of dementia, some modifications and adjustments may be needed for them to adapt to their home environment. Engaging the services of an occupational therapist can be very useful for them thereby reducing falls.

Dementia affects the ability of a person to discern and perform some duties. Being affected with dementia can lead to a loss of employment. Based on the findings of this study, this was the case for some of the relatives living with dementia. Persons living with disabilities face discrimination in employment due to the perceptions of employers. Barnes (1992) & Pfeiffer (2003) report that in areas such as education, employment, and health. Persons living with disabilities can perform their duties when reasonable accommodations are provided at the workplace. Therefore, employers should consider this for their employees living with dementia.

Driving promotes independence and easy movement of people. Losing the privilege to drive as a result of living with dementia can be heartbreaking for the affected person. This was the case for some of the relatives living with dementia. Berger et al. (2000) assert that people with visual problems or dementia including other health conditions can result in the loss or restriction of driving benefits. When this happens, relatives living with dementia often rely on family members to drive them to appointments and other social activities.

Being involved in a previous brain or head injury is one of the underlying indicators of living with dementia. Larson et al. (1992) support this assertion. As this was an incident reported by some of the study participants regarding relatives living with dementia, receiving ongoing

support from health professionals after being involved in this incident can help reduce some of the negative effects that follow afterwards.

5.1.5. Other health conditions experienced by relatives living with dementia

Some research studies support that persons living with dementia often lived with other health conditions. As a result, meeting their healthcare needs can be challenging to achieve. In this study, it was found that many of the relatives living with dementia had other health conditions. These included: obsessive-compulsive disorder, pinched nerve, depression, benign lumps, hernia, heart attack, high blood pressure, asthma, lung cancer, tumour, diabetes, osteoporosis, hearing impairment, mini-strokes, and high cholesterol, among others. As a health condition which adversely affects language and cognition, persons living with dementia hitherto to having this health condition, in many circumstances, live with other diseases such as coronary artery disease, congestive heart failure, hypertension, and diabetes (Prince et al., 2011; Kurrle et al., 2012). Adopting a multi-disciplinary approach to care can be beneficial to persons living with dementia who have other co-morbidities. Barret et al. (2007) report that health practitioners using this approach assists people receiving care in getting access to many forms of treatment and ensure that services are provided efficiently.

Also, it was found that a decline in cognition and speech and communication problems were some of the other health conditions that have affected relatives living with dementia. The Alzheimer Society of Canada (2010) describes dementia as a health condition which affects an individual's cognitive capabilities. Language problems are a common sign in persons living with dementia and possibly a sign pointing to dementia (Tang-Wai & Graham, 2008). Challenges linked to the ability to talk are part of the initial signs of dementia (Stanyon et al., 2016). According to

Banovic et al. (2018), “[t]he main characteristics of speech and language in people with Alzheimer’s dementia include: difficulties in finding words for objects, difficulties with naming, understanding difficulties, and a louder voice when speaking” (p. 222). As these conditions can have a significant impact on relatives living with dementia concerning their interactions with people, continue support and resources that can improve communication should be provided to them. Failure to do so may reduce their level of engagement and participation in many social activities. In the field of disability studies, inclusion and participation of persons living with disabilities in decision-making and discourse in society are very essential. As such, advocates of this model back these ideas. Therefore, society fails people living with dementia if they are not able to access resources (e.g., providing subtitles on television for people living with dementia who have hearing problems and using photos that depict both basic and instrumental activities for people living with dementia, who have challenges in putting words together to help them to communicate what they want to do, by pointing to these photos) that can promote their participation in meaningful activities due to having a decline in cognition, speech and communication problems.

5.1.6. Physical health conditions that have affected relatives living with dementia

Persons living with dementia may be faced with some physical health conditions that can be detrimental to their health and well-being. The findings of this study revealed that some of the physical health conditions that have affected relatives living with dementia included swallowing problems, weight loss, mobility challenges, and restless at night. Chang & Roberts (2008) share that assisting elderly people living with dementia to take in food is usually complicated, requires time and becomes challenging in the transition period of the condition. Also, Kai et al. (2015) state that over eighty percent of persons living with Alzheimer’s encounter eating and swallowing

problems. As such, family caregivers may need more time to assist relatives living with dementia who have eating and swallowing problems when taking in food. Weight loss affects some people living dementia as they transition through the stages of dementia. According to Alzheimer's Disease International (2014), overall, the reduction in weight linked to malnutrition usually comes before the beginning of dementia and happens further as the condition continues to develop. As such, Droogsma et al. (2013) estimate that fourteen percent of persons living with dementia who live independently were susceptible to malnutrition. The use of the services of a dietitian can be very helpful to relatives living with dementia and their family caregivers who are being faced with this situation.

5.1.7. Medications for relatives living with dementia

Persons living with dementia often use drugs to manage their health condition. In this study, it was found that many of the relatives living with dementia used various forms of drugs to cure or manage certain health conditions that have affected them. In addition, some of the relatives living with dementia were affected by the negative effects of the use of these medications. Since many drugs have side effects, it would be appropriate to use the services of a pharmacist in order to reduce or prevent unforeseeable harmful side effects of the use of drugs. As such, regular communication between family doctors, pharmacists, and specialists concerning drugs used by their care recipients living with dementia can be of great help in tackling this situation. Pharmacists have the ability to evaluate drugs in order to find out if the drugs given under the authority of a health professional to persons living with dementia are beneficial, creating problems, and to establish that their use is vital (Blenkinsopp, Bond, & Raynor, 2012).

Some of the study participants reported that certain drugs used by relatives living with dementia were acquired through out-of-pocket. This situation can affect the finances of family caregivers and their care recipients if many of the essential drugs are being paid by them or if there is no drug coverage plan in place. This may be one of the reasons why many people are advocating for a national pharmacare program in Canada. Also, there was an incident of doubling up on medication. According to the information given by one of the study participants (Andrew), this was as a result of the fact that the individual involved was having difficulties in differentiating between day and night time. Currently, there are some assistive technologies that exist in order to help reduce or prevent such incidents. With this technology, when the time for medication is due, an alert or a sound is produced to remind the individual to take his/her medication. However, people living with dementia who come from a low-income background may not be encouraged to use this technology, in many cases, if it is expensive for them to afford.

5.1.8. Activities performed by relatives living with dementia

Helping persons living with dementia to perform some activities by themselves can promote their independence and well-being. In this project, it was found that some of the relatives living with dementia performed certain activities which included cleaning the floor, laundry, reading, preparing breakfast, and others. Thuné-Boyle et al. (2012) & Winchester et al. (2013) identify the engagement in an activity as having the potential to promote the performance of day-to-day routine, sleep as well as a decrease in neuropsychiatric signs of dementia. Therefore, family caregivers should encourage relatives living with dementia to engage in meaningful activities in order to promote their independence, well-being, and dignity.

5.1.9. Activities that relatives living with dementia were not doing anymore

The level of engagement in activities for persons living with dementia can be reduced as they progress through the stages of the health condition. This study found that some relatives living with dementia were not performing certain activities anymore. These included meal preparation, cleaning, and following through on an upcoming event on a calendar, among others. Blankevoort et al. (2010) report that being less active add up to the limited choices in life faced by persons living with dementia and are at risk of having the state of their body and performance negatively affected thereby causing a decrease in independence and engagement in the regular or day-to-day routine. As such, finding ways that are simple and easy for relatives living with dementia to perform some activities can encourage them to have a desire to engage in those activities.

5.2.0. Primary healthcare services used by relatives living with dementia

The primary healthcare sector is one of the core structure of the Canadian healthcare system. The College of Family Physicians of Canada (2011) states that the majority of healthcare services are provided in the primary healthcare system. Starfield et al. (2005) acknowledge that healthcare systems which are functionally active have primary care as one of its pillars regarding the provision of services. It is a healthcare system which involves health professionals from different backgrounds. This study found that many of the relatives living with dementia used various forms of primary healthcare services. These included the services of a family doctor, occupational therapist, physiotherapist, nurse, and that of a pharmacist. Aminzadeh et al. (2012) point out that primary care is important in dementia management. It was revealed that all the relatives living with dementia had used the services of a family doctor. The Canadian Institute for Health Information (2009) states that more than eighty-five percent of people in Canada reported about

having periodic access to a health service which is often a general practitioner. As such, providing training on dementia care for family doctors will ensure a higher standard of care for persons living with dementia. Aside from the use of the services of a family doctor, the services of a pharmacist and that of a physiotherapist were the ones often used by relatives living with dementia respectively. Pharmacists have the ability to evaluate drugs in order to find out if the drugs given under the authority of a health professional to persons living with dementia are beneficial, creating problems, and to establish that their use is vital (Blenkinsopp, Bond, & Raynor, 2012). Physiotherapists may help persons living with dementia to do some exercise programs that can be beneficial to their health and well-being. Rolland et al. (2007) describe that being more active fights against some of the adverse effects connected to dementia, which includes susceptible to falls and broken bones, wasting of the muscle, and disruption in the performance of the heart and blood vessels. Also, proof exists about the possibility of physical activity being vital in serving as resistance to experiencing a slowdown in memory and thinking regarding individuals without dementia (Sofi et al., 2011).

5.2.1. Primary healthcare services that have not been used by relatives living with dementia

Some of the relatives living with dementia did not use the services of a physiotherapist and that of a pharmacist. This might be the fact that considering their current situation, these services were not needed for them. In addition, none of them were using the services of a dietitian. The services of a dietitian are very essential to persons living with dementia who have physical health conditions such as eating and swallowing problems, weight loss, and others. This may be due to the fact that more awareness of the importance of using this service for persons living with dementia has not been created. While it is not too late for many of them, more education in this area should be given to family caregivers and their care recipients.

5.2.2. The challenges faced by relatives living with dementia when accessing primary healthcare services

Some of the study participants shared information on the challenges that relatives living with dementia encountered when accessing primary healthcare services. These included long wait times involved to see a family doctor, delay in the delivery of care due to long wait times, lack of proper communication between health professionals, lack of initiative and decision-making on the part of care recipients in order to access healthcare services, and the inconsistency involved in having a family doctor, among others. Schoen et al. (2010) point out that more than thirty percent of the people in Canada say that in the most recent times when they got ill, it took more than five days for them to have access to a physician service. These challenges faced by relatives living with dementia could affect their health condition. Also, the health condition of their family caregivers can be at risk due to the stress and burden they may go through in seeking healthcare services for them.

5.2.3. Recommendations that could be used to address these difficulties and also improve access to primary healthcare services

As a result of the difficulties faced by relatives living with dementia when accessing primary healthcare services, some of the family caregivers gave some suggestions that could address the challenges and also promote access to these services. These included: providing more doctors, awareness of available resources, addressing health issues on time, getting health professionals who have knowledge on dementia care, providing information at the beginning of this health condition, creating more spaces in personal care homes, and others. There are five regional health authorities in Manitoba, with each region having a board of directors. To improve access to

primary healthcare services in each region for people living with dementia, it would be a good idea for each regional health authority to seek the views of family caregivers and their care recipients in order to implement programs that are tailored to their needs. This could help to reduce the challenges plaguing the primary healthcare system regarding its use for people living with dementia and their support networks such as friends and family members. In the field of disability studies, in support of this is the famous adage, "Nothing About Us Without Us" (Charlton, 1998).

5.2.4. Other services used by relatives living with dementia

This study found that other services used by relatives living with dementia included specialist services, home care, personal care home, nursing home services, mental health services, day program, counselling services, and disability tax credit program. Out of these services, specialist care, personal care home, home care, and nursing home services were the ones predominantly used by relatives living with dementia. The specialist services used by them included the services of a psychiatrist, neurologist, urologist, and geriatrician, among others. Under these services, the services of a psychiatrist and that of a neurologist were the ones often used by relatives living with dementia. Psychiatrists and neurologists may be involved in the diagnostic process of dementia because it falls under their specialty. Aminzadeh et al. (2012) point out that "[a]lthough the majority of patients experiencing the first signs of dementia initially visit a primary care provider, many, if not most, appear to have their diagnosis confirmed by a specialist" (pp. 85-94).

Also, it was found that some of the difficulties faced by relatives living with dementia in using specialist services included: the distance involved in accessing these services, long wait times involved in using these services, insufficient availability of specialist services in rural communities, and cost of transportation to a specialist appointment. Hogan (2001) reports that the

number of specialists available is not sufficient to provide the necessary services for the increasing number of persons living with dementia and their families and friends. As these challenges can adversely affect the health condition of persons living with dementia who need specialist care services, embarking on a periodic review as well as developing innovative means of how to improve access to this service could reduce some of these challenges.

Personal care homes can be used as a supplement to primary healthcare services for persons living with dementia in circumstances whereby they can have access to care and support services in a residential setting. This study found that many of the relatives living with dementia have used personal care homes. In the United Kingdom, dementia is considered to be among the greatest underlying factors for going into a personal care home for individuals who were sixty-six years and beyond (Alzheimer's Society, 2007). Considering the age of relatives living with dementia, a similar trend seems to be happening in Manitoba. With the increasing number of dementia cases in Canada coupled with an ageing population, it may be a necessity to expand personal care home and home care services in Manitoba and across Canada for persons living with dementia.

In this study, it was found that a common challenge involved in using home care was the situation whereby different employees were coming into the homes of the care recipients on several occasions to provide caregiving support to them. This may be as a result of the high turnover of employees in the home care sector. According to Turcotte (2014), Statistics Canada approximated that as there are over two million residents accessing home care, three percent shy of eighteen percent of them using this service shared that their demands have not been achieved. Also, some of the study participants gave some recommendations that could be used to improve home care services for relatives living with dementia. These included: training for a particular group of home care workers in order to deal with specific situations when the need arises, making it easy to do

paperwork and funding for private family care, and driving services for people who use this service. Since these family caregivers have first-hand experiences, taking their suggestions into consideration may provide some positive outcomes in the delivery of home care services for people living with dementia.

5.2.5. Feelings that family caregivers have concerning relatives living with dementia

Family members of persons living with dementia may have some feelings and concerns about the situation of their relatives living with dementia. According to Cronfalk et al. (2017), “[f]amily members that care for persons with dementia go through troublesome transitions: being a concerned relative, becoming a carer, a visitor at a nursing home and a grieving survivor” (p. 3520). In this study, many of the family caregivers expressed some feelings and concerns regarding their care recipients living with dementia in areas such as having a feeling of being susceptible to living with Alzheimer’s, a feeling of having lost a partner due to dementia, the state of the condition of a relative living with dementia, and others. As this can affect their emotional and psychological well-being, family members going through this situation may need guidance, counselling, and support in order to have a sound mind to provide caregiving support to relatives living with dementia.

5.2.6. Resources used by family caregivers with relatives living with dementia

Family caregivers often use some resources that can provide them with knowledge, idea, and skills in order to provide the needed support to relatives living with dementia. In this study, it was found that families providing caregiving used resources such as counselling services, support group sessions, and workshops, among others. Sinha’s study (as cited in National Institute on Ageing, 2018) state that “training, counselling services, and support groups, in addition to respite supports,

have been shown to positively influence the health and well-being of caregivers – but, the availability and access to these services varies considerably across the country and by location” (p. 33). The safety and well-being of relatives living with dementia are ensured when family caregivers have access to many resources for dementia care. Therefore, family caregivers should be encouraged to explore various kinds of resources in order to deepen their knowledge on providing caregiving support to their care recipients living with dementia.

5.2.7. Resources that have not been used by family caregivers of relatives living with dementia

Family caregivers providing caregiving support may not be using some of the resources that can help them to be in a position to support relatives living dementia better. This study found that some of the family caregivers were not using counselling services. Grossfeld-Schmitz et al. (2010) report that the underlying factor as to why there is less utilization of family counselling is that during the onset of this health condition, prediction on the growth of this health condition is not feasible, as well as insufficient knowledge on the resources at hand. According to Bruce & Paterson (2000) & Vetter et al. (1998), the effort to use counselling services is made mainly at the late level of the health condition. Therefore, providing education and creating more awareness of the resources that are accessible can improve the use of counselling services and other ones by family caregivers.

5.2.8. Family caregivers' opinions about physicians

In this study, the opinions of some of the family caregivers about physicians were documented. These included family doctors approach to care and mainstream ideas about physicians. Fortinsky (2001) reports that family or friends providing support to persons living with dementia have a thought that physicians do not handle signs associated with dementia and drugs for people under

their care who are living with dementia properly or give enough assistance during challenging moments and resources available for them. To change this perception, physicians should involve family caregivers in the provision of care in order to know what works best for them and their relatives living with dementia.

5.2.9. Family caregivers' views on the hospital environment

Creating an accessible hospital environment enhances the movement of people or users. Some of the study participants shared their views on the hospital environment. The common issue raised was on signs posted at hospital environments. They reported that the signs were not bigger and easy to see, and difficult to use. A statement made by one of the participants (Hannah) about the uncertainty of her mother's ability to discern what these signs stand for seems to support some of the reports given by the critics of the social model of disability. Crow (1996) asserts that "impairment in the form of chronic illness or pain may curtail activity and participation to the extent that 'the restriction of the outside world becomes irrelevant' and impairment will remain, yet without disabling barriers" (p. 209). While this should not be a legitimate reason in failing to provide an accessible hospital environment, frantic efforts should be made to include persons living with disabilities in decision-making in order to take their needs into consideration when building hospitals and other public spaces.

5.3.0. The attitudes of health professionals towards relatives living with dementia

The attitudes of health professionals towards people under their care can influence the level of trust and relationship between them and their care recipients. The people who use healthcare services are able to open up to their physicians if they feel welcomed and treated with respect. As persons living with disabilities may experience some form of discrimination, Barnes (1992) &

Pfeiffer (2003) report that in areas such as education, employment, and health. Academic papers and publications have been able to expose the discrimination and exclusion faced by persons living with dementia (Blackman et al., 2003; Dorenlot, 2005; Beattie et al., 2005b; Davis et al., 2009; Brittain et al., 2010). The findings of this study showed that while some health professionals exhibited positive attitudes towards relatives living with dementia, in some circumstances, this was certainly not the case for others. Therefore, creating awareness on disability issues among health professionals to recognize disability as a human diversity can help them to understand and embrace it as a part of life. This can promote positive attitudes and building of a relationship between health professionals and persons living with dementia who often use their services.

5.3.1. The impact of providing caregiving support to relatives living with dementia

Family caregivers of relatives living with dementia can be affected in various ways in the course of providing caregiving support. This study found that in areas such as their personal health, economic and livelihood, finances, planning ahead of time, relationship and support networks, and searching for information or resources. Sinha's study (as cited in National Institute on Ageing, 2018) state that "[i]n 2012, 20% of Canadian caregivers reported that their physical or emotional health had suffered in the past twelve months" (p. 22). The lives of relatives living with dementia are at risk when the health condition of their caregivers is affected. This may be one of the reasons why family caregivers use additional services such as home care to support relatives living with dementia. Keating et al. (2014) assert that there is a higher propensity for a decrease in the work output of people providing caregiving support, which has the potential to affect their general guarantee of employment. Sometimes family caregivers facing this situation may decide to make changes to their career goals and aspiration in order to meet the demands of their care recipients.

Fast, Williamson, & Keating (1999), Hayman et al. (2001), & White-Means & Rubin (2004) state that the financial situation of families or friends offering support can be impacted due to the regular expenditures associated with providing care. Often, family caregivers who find themselves in this circumstance may be left with no choice than to apply for funding and other social intervention programs in order to ensure the continuity of care and support for relatives living with dementia. Also, the challenges faced by family caregivers in searching for information and resources for relatives living with dementia can have a great impact and deter them from pursuing further. Smale & Dupuis (2004b) report that people providing support had challenges in using resources tailored to their demand at the right time, as well as resources that meet the targets of people they support.

Conclusion

The discussion of the results of a study is a platform for researchers to critique and initiate some conversations around the findings of their study from different perspectives. As such, the author of this study used the social model of disability and other existing literature in this field to support the discussion of some of the issues emanating from the stories shared by the family members.

The final chapter provides a conclusion and recommendations that could be employed to improve dementia care and management for persons living with dementia in Manitoba and across Canada. A total of eight recommendations are given by the researcher. These suggestions are based on issues found in the literature, as well as the stories shared by the family caregivers in relation to relatives living with dementia.

Chapter 6

6.1.0. Conclusion and recommendations of the study

In this final chapter, a conclusion is drawn and some recommendations are suggested that could help to improve access to primary healthcare services for persons living with dementia. These recommendations include: effective collaboration between family doctors, family caregivers, and other health professionals who provide services to relatives living dementia, providing funding support to family doctors, nurses, and specialists interested in training programs for dementia care, providing training programs for family caregivers to equip them with the knowledge and skills needed to support relatives living dementia, and providing many specialist services in rural communities to reduce pressure on existing ones in urban areas, among others.

6.1.1. Study recommendations

In this study, it was revealed that dementia as a health condition continues to affect older adults in Manitoba. It has been established in Canada that many women live with dementia than men. In this study, it might be the case that dementia is becoming more prevalent among men. Families providing support reported that relatives living with dementia show some behavioural signs or symptoms such as being anxious, angry, repeating stuff, forgetfulness of the environment, and wandering, among others. Also, many of the relatives living with dementia had other health conditions and were using various kinds of drugs to cure or manage these conditions. Some of them were affected by the harmful side effects of the use of these medications. In addition, some of these drugs used by them were paid through out-of-pocket. On the past incidents in the lives of relatives living with dementia, it became apparent that many of them had their driver's licence removed. This means that without the assistance of a family caregiver or other support services,

their engagement with their community may be limited. Family members of people living with dementia serve as a safety net in providing care and support and in many cases, assist them to access primary healthcare services. Relatives living with dementia encounter some challenges when using primary healthcare services available to them. As such, families providing caregiving support gave some suggestions that can help to improve the utilization of primary healthcare services for them. Aside from these services, relatives living with dementia used other services such as specialist services, personal care home, home care, mental health services, nursing home services, day program, and disability tax credit.

Moreover, specialist services, personal care home, home care, and nursing home services were the ones often used by relatives living with dementia. But they faced some difficulties when using specialist services and home care. Families providing support had some concerns or feelings about the health conditions of relatives living with dementia. As such, the services used by the families providing support were documented in this project. However, it was found that some of the families were not using counselling services. Furthermore, whereas some health professionals show a positive attitude towards relatives living with dementia, in some situations, it was definitely not the case as some families expressed their displeasures with such encounters. Lastly, Families providing caregiving support were affected in various ways such as their personal health, economic and livelihood, finances, relationship and support networks, and others. Based on the primary findings of this study and literature reviews, the researcher gave some recommendations that could be adopted to tackle dementia care in Manitoba and across Canada. These are as follows:

6.1.2. Effective collaboration between family doctors, family caregivers, and other health professionals who provide services to relatives living dementia

Persons living with dementia rely on families and friends to assist them to access services and other basic activities in the home. Families providing support to relatives living with dementia often have a lot of information concerning their health conditions. According to the Alzheimer's Association (2015), families perform over seventy percent of long-term care for older people. As such, family doctors and other health professionals such as a specialist may need the input of families to have accurate information about the family history of the person under their care. This information can help physicians in the diagnostic process for a relative suspected of living with dementia. In order to ensure the health and well-being of relatives living with dementia throughout the continuity of care, there should be an effective collaboration between family doctors, family caregivers, and other health professionals.

As the health condition of relatives living with dementia progresses, family doctors and other specialists (through a referral by the family doctor) delivering services may decide to review their existing care plan to conform to the changes that have occurred. These may include scheduling an appointment in order to re-examine them, reviewing the drugs used by them, and others. Also, when relatives living with dementia transition into palliative care, which basically involves providing comfort care and ensuring dignity, issues around property and investment, finances, funeral arrangement, and others need to be addressed. All these need the involvement of their family members. Therefore, effective collaboration between family doctors, family caregivers, and other health professionals are needed to ensure the safety and well-being of relatives living with dementia.

6.1.3. Providing funding support to family doctors, nurses, and specialists interested in training programs for dementia care

Sometimes it becomes a challenge in getting the right diagnosis for a relative suspected of living with dementia. As a result, some families might be left in the loop in taking this path. Family physicians are the first point of contact in our healthcare system. As such, many cases are brought to their attention before a specialist may be involved. In addition, nurses work with physicians and specialists to ensure that people under their care are receiving the right treatment. The Canadian Nurses Association (2016) suggests that the federal government should invest in resources that will improve the competencies of health practitioners at all levels of dementia management. Specialists such as neurologists and psychiatrists through a referral by a family physician may conduct further testing to confirm the existence of dementia. Therefore, providing funding support to family physicians, nurses, and specialists who are interested in learning more about dementia care and diagnosis will help in enhancing their knowledge, skills, and ideas. In the long run, this strategy can bring relief to families and people suspected of living with dementia who struggle to get the right diagnosis. Also, this strategy means that more physicians and specialists would be available to provide healthcare services to the increasing number of persons living with dementia in Manitoba and the whole of Canada.

6.1.4. Providing training programs for family caregivers to equip them with the knowledge and skills needed to support relatives living dementia

According to the Canadian Nurses Association (2013), dementia has reached the threshold where it can be considered an epidemic. This implies that many people in Canada are living with dementia. In many cases, family members are the first to provide caregiving support to relatives

living with dementia. Smetanin et al. (2009) assert that by two thousand and thirty-eight, the number of hours that would be spent on providing caregiving to individuals living with dementia in Manitoba will be more than double of the number of hours spent during the early part of the twenty-first century. As such, families of persons living with dementia will spend more of their time providing caregiving support during this period in Manitoba. The safety and well-being of relatives living with dementia depend on families or friends offering assistance and support. As a result, providing training programs for family members will equip them with knowledge, skills, and ideas needed to assist relatives living with dementia. The lives of relatives living with dementia are at risk when family caregivers do not have enough ideas and skills to support them. The Change Foundation (2016) reports that the people providing support require appropriate knowledge and skill in order to be in a position to support individuals receiving support from them. Therefore, providing training programs for family members on how to support relatives living with dementia can ensure their safety and well-being.

6.1.5. Providing many specialist services in rural communities to reduce pressure on existing ones in urban areas

In Manitoba, many of the existing specialist services are available in Winnipeg. As a result, persons living with dementia, who live in rural communities in Manitoba, travel a long distance to seek specialist services that are not available in their area. In this study, it was found that some of the challenges faced by relatives living with dementia in accessing specialist services included distance involved in accessing specialist services, cost of transportation, long wait times in using specialist services, and insufficient availability of specialist services in rural communities. These challenges can have a significant impact on their lives. Therefore, all stakeholders in the healthcare sector should create and promote programs that would make specialist services available in the

rural communities in Manitoba. By so doing, persons living with dementia and their families will save money on the cost of transportation and time involved in travelling a long distance to seek specialist care services.

6.1.6. Creating a national dementia strategy

Canada does not have a national dementia strategy. This means that the ten provinces and three territories would have to create their own programs to address dementia issues. The Alzheimer Society of Canada (2015) asserts that looking at the magnitude and cost of dementia, none of the provinces can resolve this issue separately. Establishing a national dementia strategy will ensure uniformity and a clear delegation of responsibility between the federal, provincial, and territorial government concerning dementia management across Canada. According to Lowi-Young (2015), over eighty percent of Canadians support this idea. There is a higher prevalence of dementia cases among older adults and seniors in Canada. From the researcher's subjective point of view, creating a national dementia strategy would address issues such as funding for dementia care, research and development, drug coverage plans, social intervention or support programs, and others for persons living with dementia. Therefore, all the needed support should be given in order to create a national dementia strategy program in Canada.

6.1.7. Creating a national pharmacare program

Canada does not have a national pharmacare program. In this regard, many people have championed the idea of moving towards this trajectory. In Canada, the cost of prescription drugs has been one of the challenges facing people from a low-income background who do not have the means to afford them. Paris & Docteur's study (as cited in Bielska et al., 2012) state that "[p]ublic drug coverage ranges from providing drugs to financially disadvantaged populations like seniors,

welfare recipients, and those individuals with medical or financial needs to universal eligibility” (p. 53). This idea is not sustainable due to unfavourable economic conditions that have the potential to force governments to cut-back on social intervention programs. Lexchin (2014) asserts that the Canada Health Act is unforthcoming regarding expenditure on medications given under the authority of a health professional. As such, instituting a national pharmacare program through an act of parliament can serve as a legal basis for people to demand answers from their government if they fail to perform their duties regarding drug coverage programs.

The Restrictive Trade Practices Commission, Royal Commission on Health Services, & Canada House of Commons' study (as cited in Lexchin, 2014) state that “[d]uring the 1960s, a series of three reports all pointed out that drug prices in Canada were among the highest in the world and all three reports identified patent protection as one of the major reasons for this situation” (p. 29). A table presentation from Industry Canada (2013) used in Lexchin's (2014, p. 28) study reveals that many of the drug manufacturing enterprises in Canada, selling medications under a patent were not owned by Canadians. In the past, compulsory licensing was a mechanism adopted with the aim of achieving a reduction in the cost of patented medications. According to Lexchin (2014), before the initial periods of the last decade of the twentieth century, this system was deployed in Canada to allow the outsourcing of the materials used in making medications from outside with the aim of causing a decrease in the cost of patented medicines. According to the data presented by the Commission of Inquiry on the Pharmaceutical Industry (1985), compulsory licensing was accountable for a decrease in a little over one-eighth of the overall medication expenditure of four hundred million dollars shy of two billion, whereas during the formative years of the last two decades of the twentieth century, less than four percent of the

domestic trade in pharmaceuticals were no longer in the hands of foreign-owned companies due to opposition from the trade in medications that do not have a trademark.

Product Listing Agreements are adopted by provincial governments in a situation whereby an agreement is made with a drug producing company in order to provide a coverage plan for certain medications. Also, it can be used by the authorities to achieve a decrease in the cost of medicines. Lexchin (2014) reports that persons who buy medications on their own and those under a special coverage plan does not gain from the decrease in the cost of medications brought about by the use of Product Listing Agreements. From two thousand and five to two thousand and ten, over seventy-five percent of the recent medications that have received permission from Health Canada to some extent were covered by an individual insurance program in regard to the over forty-five percent coverage by a provincial program (Canada Health Policy Institute, 2013). This means that private insurance companies are more likely to provide coverage for medications that are about to be used than the government. In addition, this may be one of the reasons why the cost of prescription drugs remains an issue for the less privileged in Canada.

Although instituting a national pharmacare program does not mean that all the issues concerning the cost of prescription drugs and coverage for residents by the government would be solved. But there are enormous benefits to be achieved under this program. Morgan, Law, Daw et al.'s study (as cited in Clement & Memedovich, 2018) state that “[n]ational pharmacare is defined as public coverage of medically necessary prescription drugs on universal terms and conditions across Canada, including limited patient co-payments and a basic list of medications available for all Canadians” (p. 150). This can be a safety net for persons living with dementia who have a limited source of income to fill their drug prescriptions. A new study revealed that this program has the capacity to decrease the amount incurred through the use of individual firms providing

coverage plans by over eight billion dollars and cause the amount incurred through provincial coverage programs to rise by five-folds of two hundred million dollars thereby saving over seven billions dollars of the overall drug expenditures (Morgan, Law, Daw et al., 2015). Therefore, creating a national pharmacare program would benefit persons living with dementia who often need drugs to manage their health condition.

6.1.8. Providing information to family caregivers on where to seek services and support for relatives living with dementia

Receiving information on services and resources available for dementia care and management at the early stages can be very helpful for relatives living with dementia and their family members. This idea was part of some of the suggestions made by some of the study participants. When family caregivers have information on services such as day programs, support group sessions, supported employment programs, and organizations providing training and resources, it allays their fears and uncertainty thereby assuring them that they are not alone in this journey of providing caregiving support to relatives living with dementia. Family doctors are usually the first to be contacted when family members have concerns about the changes in personality and behaviour of relatives suspected of living with dementia. Before the involvement of a specialist to confirm that a person is living with dementia, a referral has to be made by a family doctor. Therefore, family physicians play a distinguished role in the delivery of healthcare services to persons living with dementia. As a result, they should be in a position to know more about other services and resources that family caregivers can assist relatives living with dementia to use. To achieve this, family physicians should liaise with institutions providing training and resources to persons living with dementia and their family members. According to Holmes & Adler (2005), doctors are in a better position to

send people under their care and relatives to institutions that offer knowledge and resources for supporting persons living with dementia.

6.1.9. Creating an accessible environment in the communities and hospitals for persons living with dementia

The participation of persons living with dementia in the community is essential because there is a sense of belonging and togetherness when the necessary accommodation is created for this purpose. The mainstream ideas about disability have caused great harm to persons living with disabilities in areas such as health, education, employment, marriage and social life, and others. In this regard, the social model was adopted to fight all the wrongdoings of society against persons living with disabilities. The signatories to international conventions on disability issues acknowledge the removal of all forms of obstacles that prevent their participation in society.

The Canadian Nurses Association (2016) states that “[f]orecasts show that the fifty-five percent of persons with dementia (sixty-five and over) living in their own homes in 2008 will grow to sixty-two percent by 2038” (p. 7). This implies that there would be an increase in the number of persons living with dementia, who are dwelling in the communities in the years ahead. Therefore, all efforts must be made to ensure that the environments are accessible to persons living with disabilities. These include parks, malls, restaurants, school campuses, hospitals and clinics, public transportation, and bus stations, among others. The Alzheimer Society of Canada (2010) & Kennan (2014) report that physical environments that enhance the movement of older adults can assist in avoiding dementia. An accessible environment benefits all users and not persons living with disabilities alone. Adopting this strategy promotes the dignity, integrity, and independence for persons living with dementia, who may be experiencing some mobility challenges.

Dementia is a health condition facing many people living in Canada. As a result, the primary healthcare system should be positioned to respond to the foreseeable challenges that lie ahead. Moreover, families providing caregiving support can be useful in creating programs to help people living with dementia to achieve their healthcare needs due to the wealth of knowledge they have about their care recipients. In this regard, conducting this study was one of the means of creating awareness on dementia issues by reporting the views held by families on access to primary healthcare services for relatives living with dementia in Manitoba. Based on the stories shared by the family members, it was found that relatives living with dementia used various forms of primary healthcare and specialist services, home care, personal care home, nursing home services, and others. However, relatives living with dementia encountered difficulties when accessing some of these services. Therefore, implementing the recommendations given by the family members and that of the researcher could be beneficial in improving the primary healthcare system thereby promoting the quality of life and well-being of people living with dementia in Manitoba and the whole of Canada.

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Appendix A- Consent form

Research Project Title: Families' perspectives on access to primary healthcare services for relatives living with dementia in Manitoba.

Principal Investigator: Isaac Oppong (oppongi@myumanitoba.ca)

Research Advisor: Dr. Diane Driedger (Diane.Driedger@umanitoba.ca)

Sponsor: Alzheimer Society of Manitoba

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of this study: The purpose of this study is to find out from you the types of primary healthcare services available to your relative living with dementia, challenges that your relative encounter in accessing these services, and some responses that you perceive as beneficial to addressing these challenges in Manitoba.

Eligibility: You must be a close family member such as husband, wife, son, and daughter to the person living with dementia. You must at least have provided two (2) years of caregiving to your relative living with dementia. Also, you should be able to communicate in English and must be eighteen (18) years and above.

Procedures involving the participants: In this study, the researcher will use an interview guide to conduct a face-to-face interview with you. This session will last approximately 90 minutes.

However, you have the right to decide whether to sit in the interview for the 90 minutes duration or leave when you wish to do so.

Potential risks: The researcher anticipates that this study may have the potential to trigger some emotions as you will share some information about your close relative living with dementia. If such incident occurs, you have the right to discontinue this interview session. Also, please find attached, a document which gives an information on a counselling service available to you in case you may need one.

Potential Benefits: You will not benefit directly from this study. However, this study will help in contributing to knowledge in order to fulfill some of the gaps existing in the literature, add to existing ones, and also come up with some measures that will strengthen our primary healthcare system.

Role of the Alzheimer Society: The Society has provided funding for this project. In addition, the Society will assist in providing the researcher with an opportunity to make announcements at meetings, post on their website and newsletter in order to help recruit potential participants for this project. However, the role of the society in the recruitment process will have no bearing on the services and other benefits you receive from this organization should you decide to withdraw from this study.

Role of the researcher in the Alzheimer Society: Over the years, I have developed the passion of engaging in research studies that will help in tackling the problems faced by persons living with dementia and older adults in our society relating to the healthcare system. As a result, I applied for the Alzheimer Society Graduate Student Fellowship and was successful as the recipient of this award. It was through this award that made me establish a working relationship with the Society

as a student researcher. I do not hold any position and have never had any previous correspondence with this organization.

Recording devices to be used: Upon your permission, the researcher will use an audio-tape recorder to record the information given by you during this interview session. The recorded information will be given to a professional to transcribe them. The professional will sign a confidentiality agreement which states that he/she shall keep all the audio recordings and transcripts relating to this project confidential. Soft copies of your transcripts will be kept on a password-protected computer. Hard copies of your transcripts and audio-tape recordings will be kept in a locked cabinet.

Confidentiality: Identifying information such as your name and location shared with the researcher during this interview session would be confidential. As such, your privacy will be ensured by using pseudonyms to hide your identity. As stated earlier, the researcher will make sure that all data collected will be kept in a locked cabinet and/or a password-protected computer. The researcher will be the only person who has access to this locked cabinet in order to avoid any breach of confidentiality.

Remuneration: You will receive a \$50.00 gift card as an appreciation for your time after you have agreed and signed the consent form and will be reimbursed for parking fees.

Member checking: After the interview has been conducted, a copy of your transcript will be given to you. The aim of this exercise is to give you the time to go through it and correct any statement that you feel misrepresented. In addition, it will help you to correct any information that may reveal your identity.

Withdrawal: You have the right to withdraw from this study at any time, and after the interview has been conducted without any consequences. You may contact the researcher through email at oppongi@myumanitoba.ca if you want to withdraw from this study. When you withdraw from this study, the researcher will immediately destroy all audio recordings and transcripts collected from you. However, it will be impossible to exclude your data from this study when the researcher submits this work to the Faculty of Graduate Studies upon completion of all the Master's program requirements.

How and when participants will receive study results: The researcher will make soft and hard copies of the study results available to you within two (2) months (September 2018) after the collection of data. You have the right to choose the medium (mail and email) in which to receive a summary of the study results.

Destruction of confidential data: The researcher will destroy all confidential data and materials such as audio recordings, raw transcripts, and transcripts edited by you after the project has come to a complete end and submitted to the Faculty of Graduate Studies upon completion of the Master's program requirements. As such, cassettes containing audio recordings will be destroyed. Raw transcripts and transcripts edited by you will be shredded. Soft copies of transcripts stored on my password-protected computer will be deleted.

Dissemination: This study will be published in the University of Manitoba research repository platforms such as Mspace, Journal of Disability and Society, and presented at the Centre on Aging Annual Spring Symposium. Also, the researcher will provide both hard and soft copies to the Department of Disability Studies and the Alzheimer Society of Manitoba for educational purposes. The information that will end up in the publication will be mostly the ones that answer the research

questions of this study. This study will be a case study which gives an in-depth account of your views on accessing primary healthcare services with your relative living with dementia. As a case study design, the researcher will develop themes and give an account of the stories shared by you under the various headings created. The researcher will give a general statement on your account which includes a direct quotation. For example, "One of the participants living in rural Manitoba expressed some disappointments with transportation services."

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Joint-Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Coordinator at 204-474-7122 or through email at humanethics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

I give permission for this interview to be recorded: Yes No

Participant's Signature _____ Date _____

Researcher and/or Delegate's Signature _____ Date _____

Appendix B- Interview questions

1. Tell me how your life is going these days.
2. What is your relationship with the person living with dementia?
3. How is your relative doing?
4. Tell me how long your relative has been living with dementia.
5. Does any of your other relatives live with dementia?
6. Does your relative living with dementia have any other health condition?
7. Does your relative have a family doctor?
8. Tell me some of the healthcare services used by your relative.
9. Tell me any other services accessed by your relative.
10. How does assisting your relative in attending to his/her healthcare appointments and other services affect you?
11. Tell me some of the challenges that your relative encounter when helping him/her to access these healthcare appointments and other services.
12. Tell me how you are managing these challenges.
13. Tell me how these challenges can be addressed from your own perspective.

Appendix C- Probing questions used during the interview process

Probing question for Q1: What could account for that?

Probing question for Q2: Does your close relationship help in meeting the needs of your relative?

Probing question for Q3: What could account for that i.e. for your relative doing great or bad?

Probing question for Q4: Tell me how you got to know that your relative has dementia?

Probing question for Q5: How is he/she related to you?

Probing question for Q6: Is he /she receiving treatment for it or how is he/she managing this health condition?

Probing question for Q7: What kind of service/treatment does he/she usually go for, in terms of going to see the family doctor?

Probing question for Q8: Does your relative express some satisfaction with the treatment or service received? Does your relative utilize the services of a dietitian, pharmacist, and physiotherapist?

Probing question for Q9: Does these other services help in improving his/her quality of life and well-being?

Probing question for Q10:

a. In terms of your health, how does it affect you?

b. Economically, how does it affect your work and livelihood?

- c. In terms of your relationship with friends and other support network, how does it affect you?
- d. For your personal well-being, do you have access to counselling services?

Probing question for Q11:

- a. In terms of going to see the family doctor?
- b. Being referred to a specialist?
- c. In terms of the environment, how is the place accessible to your relative?
- d. In terms of the attitude of health professionals, how is your relative received or welcomed to the place?
- e. In terms of distance, does it serve as a challenge to your relative?

Probing question for Q12: Are these challenges having an impact on your relative? If yes, please in what ways?

Probing question for Q13: Please any other solution or response that you may have in mind?

Appendix D- Confidentiality agreement form

I.....shall keep all information, audio recordings and transcripts for the FAMILIES' PERSPECTIVES ON ACCESS TO PRIMARY HEALTHCARE SERVICES FOR RELATIVES LIVING WITH DEMENTIA IN MANITOBA project confidential. Upon completion of the project, I will delete all digital files and destroy any hard copies.

Transcriber

Date signed

Appendix E- Ethics approval certificate



UNIVERSITY
OF MANITOBA

Research Ethics
and Compliance

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Email: humanethics@umanitoba.ca

PROTOCOL APPROVAL

TO: Isaac Opong
Principal Investigator
(Advisor: Diane Driedger)

FROM: Kevin Russell, Chair
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol J2018:022 (HS21715)
**Families' perspectives on access to primary healthcare
services for relatives living with dementia in Manitoba**

Effective: May 28, 2018

Expiry: May 28, 2019

Joint-Faculty Research Ethics Board (JFREB) has reviewed and approved the above research. JFREB is constituted and operates in accordance with the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

1. Approval is granted only for the research and purposes described in the application.
2. Any modification to the research must be submitted to JFREB for approval before implementation.
3. Any deviations to the research or adverse events must be submitted to JFREB as soon as possible.

4. This approval is valid for one year only and a Renewal Request must be submitted and approved by the above expiry date.
5. A Study Closure form must be submitted to JFREB when the research is complete or terminated.
6. The University of Manitoba may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of *Manitoba Ethics of Research Involving Humans*.

Funded Protocols:

- **Please mail/e-mail a copy of this Approval, identifying the related UM Project Number, to the Research Grants Officer in ORS.**

Research Ethics and Compliance is a part of the Office of the Vice-President (Research and International) umanitoba.ca/research