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## 'I Honoured Him Until the End': Storytelling of Indigenous Female Caregivers and Care Providers Focused on Alzheimer's Disease and Other Dementias (ADOD)

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree in Anthropology

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## Abstract

Focused on the experiences of Indigenous female caregivers for a loved one diagnosed with Alzheimer's disease and other dementias (ADOD); this study uses Indigenous methodology of oral storytelling to examine systemic barriers of navigating the Canadian healthcare system. Non-Indigenous healthcare providers who care for families and individuals affected by dementia also share their experiences to give insight to culturally safe care and what institutional supports are needed for frontline staff to achieve this.

Indigenous caregivers were all Anishanaabe and Métis who share stories about caring for their male loved ones. Through their stories of strength and resiliency, the importance of family, intergenerational kinship and caregiving with minimal supports are discussed. Themes of jurisdictional barriers, continuity of care, cultural safety, discrimination, self-determination for community programming and funding are examined. Supports and services for seniors with regular substance use is a gap in healthcare that is discussed as a case study because healthcare providers are not addressing it because of ageism and a lack of education. This creates barriers for Indigenous and non-Indigenous seniors for accessing services and supports.

Throughout the study, recommendations are provided based on the stories of caregivers and health care providers to inform practice. This shifts the onus from caregivers to healthcare providers to have the knowledge, education and resources to support caregivers and their loved ones on their journey. This research contributes to the lack of existing research focused on Indigenous experiences of caring for a loved one with dementia and works from a social determinants of health framework. The audience for this research is health care providers, thus, resources to support Indigenous and non-Indigenous families affected by dementia are included throughout to improve their practice.

### *Lay Summary*

This research focuses on the story telling of female, Indigenous caregivers for a loved one with Alzheimer's disease and other dementias (ADOD). Healthcare providers also share their experiences of caregiving for Indigenous and non-Indigenous families affected by dementia.

Throughout the study, recommendations are provided based on the stories of caregivers and health care providers to inform practice. This shifts the onus from caregivers to care providers to have the knowledge, education and resources to support caregivers and their loved ones on their healthcare journey. This research contributes to the lack of existing research focused on Indigenous experiences of caring for a loved one with dementia and works from a social of determinants of health framework. Resources to support Indigenous and non-Indigenous families affected by dementia are included throughout along with resources for healthcare providers to improve their practice.

*Keywords*

Indigenous, First Nations, Métis, Inuit, dementia, Anishanaabe, Alzheimer's disease (AD), Alzheimer's disease and other dementias (ADOD), alcohol-related dementia (ARD), caregivers, caregiving, female caregivers, kinship, family, health care providers, culturally safe care, jurisdictional barriers, continuity of care, relationship centred care, stigma, story telling, oral story telling, social determinants of health, colonization, health disparities, dementia resources, navigating, navigation.

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Chi migwetch to my friends and family for supporting and encouraging me when I needed it most. To my sister 'Nelly', you have checked in on me and our conversations was always a reprieve to laugh and catch up. To Amanda, your faith in me kept me going.

I owe so much to my supervisors, Dr. Lloy Wylie and Dr. Regna Darnell. I appreciate all your teachings throughout this journey. The two of you have impacted my life in so many ways to help shape the path I have taken to focus on Indigenous health and as a healthcare provider in Indigenous health. My gratitude will never be enough to show how much I appreciate your time, energy, unending support and making sure I maintained balance in the many facets of my life.

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This research is dedicated to my Dad who has taught me to live in the moment, that I am stronger than I think, and that humour can make any situation better.

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# 1 Introduction and the Importance of Storytelling

## 1.1 Introduction

Before embarking on sharing my research, it is always important to situate myself and share who I am. I am Anishanaabe kwe and a member of the Chippewas of Rama First Nation which is located 90 minutes north of Toronto. Another important aspect of my identity and why I focus on the stories of female Indigenous caregivers for a loved one with Alzheimer's disease and other dementias (ADOD) is because I am a caregiver myself. I have been caring for my Dad for the past 5 years and it has been the most difficult yet rewarding journey together. I focused my master's thesis on navigating the healthcare system as a First Nations family since we struggled to access supports and services, faced barriers of discrimination and a lack of options. I also connected it across three generations of our family to examine how structural violence because of colonialism affects the lived experiences of our Indigenous family and the interplay between the public and the private (Alcock, 2012). Through stories of my grandmother, Dad and I, I examined how colonialism is perpetuated and how colonial policies including residential school, the 60's scoop and gender discrimination impacted our lives. I also examined the larger issues that presented when we were trying to access services for my Dad who was diagnosed with alcohol-related dementia in his 50s, thus the added complexity of regular substance use and younger onset.

After completing my master's degree, I was fortunate to work as a research assistant focused on the development of the *First Nations Health Authority (FNHA)* in British Columbia where Indigenous health is being determined by and for Indigenous communities; a first of its kind in Canada. The *FNHA* was created in 2013, and

...is responsible for planning, management, service delivery and funding of health programs, in partnership with First Nations communities in BC. Guided by the

vision of embedding cultural safety and humility into health service delivery, the *FNHA* works to reform the way health care is delivered to BC First Nations through direct services, provincial partnership collaboration, and health systems innovation (FNHA, 2019).

Coinciding with the research project with the *FNHA*, I was also able to be a research assistant through Public Health at *Western University* examining culturally safe care and education of healthcare providers for Indigenous clients in Southwestern Ontario. Both of these roles contributed to my knowledge of the importance of systemic change for Indigenous communities and influenced this research. This includes Indigenous communities self-determining their health using culture and traditions and the importance of educating healthcare providers who work with Indigenous clients to support them to improve their knowledge, education and resources to provide better care. The importance of my academic, professional and personal experience has contributed to this research because, “Indigenous epistemologies, for example, almost always intrinsically connect knowledge with action” (Smylie, Olding and Ziegler 2014:17). Through sharing my experiences as a caregiver and what I have learned as a research assistant, I can use it to benefit others.

Research on dementia experiences within Indigenous communities in Canada is minimal and,

little is known about the prevalence and incidence of dementia in Aboriginal communities in Canada but, as is the case for the Canadian population, dementia in Aboriginal people is expected to be an increasing challenge for federal, provincial and community health care systems. The current lack of information makes planning for, and responding to, this emerging health issue difficult for program and policy planners and for those who need to provide services to this population (Jacklin, Walker and Shawande, 2013: e39).

Throughout, I use the terms dementia, Alzheimer’s disease and other dementias (ADOD), memory loss and in a case study, specifically the term alcohol-related dementia (ARD). I use dementia because,

[it] is an umbrella term encompassing a variety of symptoms related to a decline in memory, orientation, language, judgment, or reasoning which reduces the ability to

accomplish activities of daily living. Alzheimer's Disease (AD) is the most common cause of dementia accounting for approximately 70% of patients (Reitz et al., 2011). Vascular dementia, Lewy Body dementia, and frontotemporal dementia cause the majority of additional dementia cases (Warren et al., 2015:1959).

All of the caregivers and care providers I spoke to also used the terms dementia, Alzheimer's disease or alcohol-related dementia dependent on the diagnosis of their loved one or healthcare experiences. Language connected to medical diagnosis is important because it shapes the experience of the illness through your personal understanding of it and your experiences caregiving for a loved one.

For my PhD, I wanted to focus on other female Indigenous caregivers' experiences because there is only one article specific to Indigenous informal caregivers' experiences in Canada (Bourassa et al., 2019:111). There is minimal research focused on Canadian women's experiences of caregiving for a loved one with dementia and there is nothing from Indigenous caregivers' perspectives. Focusing on women's stories are integral because their voices have been excluded from the knowledge production process and through focusing on their lives; it situates their experiences within their social context (Sefa Dei, Hall and Rosenberg, 2000:55). The Indigenous female caregivers I spoke to provided the best care they could without accessing a lot of supports and the added complexity that, "these women are often the sole support of families with a poverty-level income, and that they have the potential for increased exposure to sexism and racism in society" (in Iwasaki et al., 2009:979) which differentiates their experiences from non-Indigenous female caregivers. The inclusion of non-Indigenous healthcare providers' stories is important as well because they have taken the onus and responsibility to learn from Indigenous peoples and communities in a respectful way (Muller, 2014:195). The perspectives and stories of healthcare providers for improving dementia care is missing from literature of the systemic barriers they experience and what they view as deterring or stopping clients from seeking supports for themselves and their families.

Throughout, I provide recommendations and resources for healthcare providers to improve their care and support for Indigenous families affected by Alzheimer's disease

and other dementias (ADOD). Practical solutions are valuable since healthcare providers who want to be culturally safe often do not know where to access information or resources and often are not supported to institute long term change within the healthcare systems they work in (Hoffman, Bennett and Del Mar, 2013). Culturally safe care,

is a broad and complex concept developed originally in the 1980s by Indigenous Māori nurses in New Zealand. Cultural safety analyzes power imbalances in health care and the larger society. It addresses institutional discrimination, colonization, and relationships with colonizers as they apply to health care, and it requires an examination of how personal biases, authority, privilege, and territorial history can influence the relationships between health care providers and Indigenous Peoples. Cultural safety relies on both the self-reflection of researchers and the incorporation of critical reflection into the research project through the questions, data analysis, and reporting. A key element of culturally safe practice is establishing trust with the patients or research participants, and culturally safe care empowers people because it reinforces the idea that each person's knowledge and reality is valid and valuable (Brascoupe and Waters, 2009 in Dieter et al., 2018:4).

I also situate the experiences of healthcare providers and caregivers within larger structural changes that are needed within healthcare because colonialism continues to be a social determinant of health for Indigenous peoples on Turtle Island. Turtle Island refers to North America and there are many Creation stories that tell how Turtle Island was created. An Anishanaabe Elder from Neyaashiinigiing First Nation, Basil Johnson's,

...version of the story talks about Sky-Woman (the original human) who survives and comes to rest on the back of a great turtle. The following excerpt is from Basil Johnson's account of the Creation story:

*Gladly, all the animals tried to serve the spirit woman. The beaver was the first to plunge into the depths. He soon surfaced out of breath and without the precious soil. The fisher tried, but he too failed. The marten went down, came up empty handed, reporting the water was too deep. The loon tried. Although he remained out of sight for a long time, he too emerged, gasping for air. He said that it was too dark. All tried to fulfill the spirit women's request. All failed. All were ashamed.*

*Finally, the least of the water creatures, the muskrat, volunteered to dive. At this announcement the other water creatures laughed in scorn, because they doubted this little creature's strength and endurance. Had not they, who were strong and able, been unable to grasp the soil from the bottom of the sea? How could he, the muskrat, the most humble among them, succeed when they could not?*



*Nevertheless, the little muskrat volunteered to dive. Undaunted, he disappeared into the waves. The onlookers smiled. They waited for the muskrat to emerge as empty handed as they had done. Time passed. Smiles turned to worried frowns. The small hope that each had nurtured for the success of the muskrat turned into despair. When the waiting creatures had given up, the muskrat floated to the surface more dead than alive, but he clutched in his paws a small morsel of soil. Where the great had failed, the small succeeded (Johnson, 1976:4 in Manitowabi, 2018).*

I use the term Turtle Island throughout this thesis in order to reflect the Anishanaabe cultural, social and geographic knowledge where my research is situated.

In the final chapter I examine systemic changes needed. I also provide a resource guide for memory loss in London and surrounding area. For using the term memory loss, it is a culturally reflective term as opposed to Alzheimer's disease and dementia because, "...many ethnocultural and Indigenous communities, [dementia] may not exist or hold any meaning in their language, or it may have uniformly negative connotations" (Hulko, Wilson and Balterry 2019:7). I use memory loss for the resource guide created for London and surrounding area in hopes to be more appealing for Indigenous families to use.

The resource guide is specific to London and area based on social and health organizations I am familiar with, especially Indigenous organizations. The lens I bring to the experiences of Indigenous female caregivers is that I can relate and understand their experiences, but I also connect to health care providers. For the past 3 years, I have worked with Indigenous seniors (age 55+) and as an Aboriginal patient navigator in the hospitals in London providing support for ages 0-90+. In my roles, I see the systemic barriers Indigenous clients, especially seniors, trying to access supports because of discrimination and racism. But I also see the benefits of providing culturally specific healthcare supports and the importance of a patient navigator if you are not familiar with the processes and procedures of the hospital system. Most importantly, I can attest to the benefits of support that is relational and not just medical. In order to enact change for Indigenous families affected by Alzheimer's disease and other dementias, overall changes to healthcare need to be made. The healthcare system is not reflective of

Indigenous approaches or beliefs about well-being focused on holism and not just individual health, but the health of a family and community. The biggest take away I aim to provide is that in order to increase support and resources focused on dementia, colonialism needs to be examined and how it continues to be perpetuated within healthcare. I also emphasize that cultural safety is integral to positive change along with supporting healthcare providers to improve their practice.

The methodology of storytelling with Indigenous female caregivers for a loved one with dementia and non-Indigenous healthcare providers will be discussed. I provide an overview of the importance of storytelling as a tool for educating healthcare providers using a two eyed seeing approach and the importance of emotions to connect to heart knowledge to enact change. I also discuss the importance of storytelling for intergenerational knowledge, the importance of lived experiences for teaching about barriers in healthcare and that humour is healing and laughter is medicine.

## 1.2 Caregivers and Care Providers

All the wonderful people I was honoured to speak with were Indigenous caregivers for a loved one with dementia or a non-Indigenous healthcare provider with experiences or speciality caring for Indigenous and non-Indigenous families and individuals affected by ADOD. I use the term caregiver throughout, but none of the caregivers referred to themselves as such. They told stories from the first person to recount their memories and thus did not call themselves caregivers. Healthcare providers rarely used the term caregiver, mostly referencing the relationship to the loved one with ADOD such as son, daughter, wife, husband, partner when discussing familial support systems from their experiences. Healthcare providers also reference individuals with ADOD based on their gender when recounting stories. Healthcare providers also spoke from the first person when sharing, so did not refer to themselves as healthcare providers or care providers.

In order to find individuals interested in sharing their stories with me, the process was snowball interviewing. I met Jason, a geriatrician at a Geriatric Refresher Day where he shared research specifically on regular substance use for seniors. I approached him after

his presentation because my research was originally focused on alcohol-related dementia. I shifted my research to focus on ADOD because I was not sure anyone caring for a loved one with ARD would be interested in speaking with me because of the stigma of dementia and regular substance use. When I chatted with Jason, I described my PhD research focused on ARD and the experiences of Indigenous female caregivers and asked if we could meet to talk about his experiences as a healthcare provider and he agreed. Before Jason and I met, I shared the Letter of Information (LOI) and requested to audio record our discussion so I could review it later. I audio recorded all discussions because, “while ears enable us to hear, to ‘be all ears’ is more than just perceiving sound; it means to give your audience your full, sympathetic and thoughtful attention. To be all ears is the capacity to attend to others with full awareness, and to give due consideration to that which is being heard” (Chambers, 2004:7) When I met with Jason, my initial question was to tell me about himself and his role and it led to many stories of caring for seniors as a geriatrician who receives referrals for potential diagnoses of dementia. Based on my initial research interest in ARD, he shared stories about caring for predominantly non-Indigenous seniors with regular substance use and the barriers he sees for families and practitioners.

Amanda, a public outreach coordinator at an *Alzheimer’s Society* was someone I had previous contact with, and I knew she had several years of experience providing care to Indigenous and non-Indigenous families impacted by ADOD. When we sat down to chat, I initiated our conversation by asking about her role and what that entails. For conversations with caregivers and healthcare providers, I asked minimal questions and based them on the stories or experiences they shared. Using story telling as a methodology the storyteller decides what they want to share, what they deem to be important and the role of myself was to be the listener (Strega and Brown, 2015:186). I also asked questions pertaining to the current discussion, thus it was a reciprocal discussion since I shared my own stories and experiences.

Amanda was instrumental to connecting me to other people because of her social and professional connections. She connected me to two Anishanaabe caregivers who were a spouse (Kathleen) and a granddaughter (Michelle). Amanda met Michelle at a conference

where Michelle shared her story about her grandfather who had Alzheimer's disease. Amanda spoke with Michelle afterwards and told her about my research focused on the stories of Indigenous female caregivers and Michelle agreed to being virtually introduced since she is from Northern Ontario. Amanda also connected me to a social worker (Richard) in person whom she thought I should talk to because of his experience providing care to Indigenous clients. Amanda also recommended I contact a psychologist (Ali). I emailed Ali and shared my updated LOI focused on Indigenous female caregivers for a loved one with ADOD and when we met, I also started the conversation by asking her to tell me about her role. Through speaking with Ali, she has experience providing care for seniors with substance use disorder which I knew prior to meeting, so I asked questions pertaining to this topic. Another Anishanaabe caregiver, Annie, I contacted from her involvement in a provincial research report I read where she shared her story as a caregiver for her father to educate healthcare providers and influence policy makers in Ontario. I contacted Annie via email to chat over the phone since we are a few hours from one another, and she agreed. The Métis caregiver, Annette I knew from previous contact as well and thus knew she was also a caregiver for her Dad. In total, I interviewed 8 individuals; 4 were caregivers and 4 were healthcare providers.

Listed below are the pseudonyms I used for the caregivers and care providers excluding Annie who wanted her name and community to be shared:

**Jason:** Geriatrician with experience providing support to seniors with regular substance use

**Richard:** Social worker with experience providing care to families affected by ADOD including Indigenous families

**Annette:** Métis caregiver for her father diagnosed with alcohol-related dementia (ARD), mother and advocate

**Annie:** Anishanaabe kwe Elder from Kitigan Zibi First Nation, caregiver for her father who was affected by dementia and advocate

**Amanda:** Public outreach coordinator at an *Alzheimer's Society*

**Ali:** Psychologist with a speciality in seniors with regular substance use

**Michelle:** Anishanaabe granddaughter and mother from Northern Ontario whose grandfather was diagnosed with Alzheimer's disease, advocate

**Kathleen:** Anishanaabe wife, mother and grandmother from Northern Ontario whose husband was diagnosed with Alzheimer's disease

For conducting interviews, I had a phone interview with the granddaughter and grandmother at the same time which was a wonderful experience to hear both of their loving memories of their husband and grandfather and their different perspectives based on their relationship with him. I conducted phone interviews with Annie as well and we have talked several times throughout the process of writing. I met with Annette for an in-person interview sharing experiences as caregivers over bowls of her homemade three sister's soup and coffee. Annette and I have met many times to discuss further and provide her insight and knowledge to help shape what I should focus on and what to include. Annie was instrumental as well for telling me what was important to focus on and what parts of her story need to be included to educate healthcare providers to improve their care. For healthcare providers, I was able to conduct interviews in person at a location that worked best for them. All interviewees are in Ontario.

Each interview ranged from a minimum of an hour and 10 minutes to just under 2 hours. They were conducted between April 2018 until June 2019. After each interview was completed, I transcribed them verbatim to keep the flow and style of each of our ways of speaking and included laughter which is an important part of sharing stories. Everyone who took the time to share their stories with me was provided with a copy of their interview via mail, email or in person to give feedback for changes, exclusions or errors. Each caregiver was provided an honorarium each time we spoke to show the value for their time and knowledge, along with a gift and tobacco to say chi migwetch (thank you very much) for sharing their experiences. For healthcare providers, I provided gifts and tobacco as well and made donations to the *Alzheimer's Society* to show appreciation for their time, energy and sharing the good work they do since champion healthcare providers are key through leading by example.

## 1.3 Qualitative Thematic Analysis

I went through each interview and used *Nvivo 12* to code with keywords. I coded large sections of texts in order to maintain the context of the story being told. It was also important in order to keep the style, emotion and impact of the story on behalf of the teller. After I coded each interview, I went through them again to code based on themes that were apparent such as ‘caregiver experiences’, ‘issues in long term care’, ‘healthcare providers’ experiences’, ‘alcohol-related dementia’ and ‘systemic changes’. The larger themes are called top level nodes in *NVivo* with the correlated themes attached to them as child nodes. Each of the top level nodes can be seen as the trunk of a tree and the child nodes are the roots and the branches, all intersecting and connected to one another. Qualitative thematic analysis was used by Lanting et al. for their research with a Grandmother’s Advisory group to learn about Indigenous experiences of caregiving, dementia and creating a culturally specific assessment tool. I also chose this approach because, “it directly represents an individual’s personal point of view and ‘descriptions of experiences, beliefs, and perceptions’ (Luborsky 1994:190), and because it is able to provide an in-depth description of preliminary themes related to Aboriginal perceptions of dementia and care practices for dementia” (2011:109). Thematic analysis is integral since female caregiving experiences and perceptions are often missing in literature as Indigenous women (Crosato, Ward-Griffin and Leipert, 2007:2). It also allowed larger issues to become apparent for offering recommendations for change to healthcare practices and what should be included to improve experiences of caregiving. As discussed by Webkamigad, member checking is also important to research with Indigenous peoples to ensure accuracy of interviews and to discuss themes. Member checking is, “...a test to identify if the researcher’s account of the information shared is true to the participants’ recollections (Jaffe and Miller, 1994). Therefore, it is imperative that their accounts are correct in all ways and the intent of their voice is heard” (2017:37). Transcripts and chapters were shared with the caregivers and healthcare providers to see if any thematic topics were missing, needed to be improved or excluded. I excluded what was requested on behalf of caregivers to honour their loved ones. I also did not include a focus on the challenges of personal care for their loved ones, but more systemic

challenges. Caregivers were instrumental in shaping what I should focus on or include based on our discussions. Long term care issues were a topic that became apparent from the experiences of all caregivers who provided advice of improvements and what to focus on. Annie is an Elder whose stories had energy of their own, showed me that stories are powerful to make you feel and think and as a way to connect and educate healthcare providers. Member checking contributed to relationship building with caregivers and healthcare providers where it was not a one-time interview, but several discussions as time went on and meeting in person when possible to discuss the research and catch up on our lives.

## 1.4 Gendered Voices

Throughout the research journey, all the caregivers were women who shared stories about caring for a male loved one who was a husband, father or grandfather. Speaking with healthcare providers, most of their stories focused on the impacts of dementia diagnoses for men. It was discussed by healthcare providers that women accept support services more often than men, but there are shifts they have seen in their practices. The experiences of female Indigenous caregivers are especially important in dementia research because,

...existing studies on Aboriginal health have failed to adequately focus on the unique health needs of women (Young, 2003). How Aboriginal women and men provide care to seniors from a distance, or how they face the significant challenges associated with balancing the demands of work with the needs of family are important topics that need to be explored further (Parrack and Joseph, 2007:109).

All of the caregivers are amazing women who balanced working, caring for their children and providing excellent care to their spouse, father or grandfather. Their love and care were shown through all of them keeping their loved ones at home surrounded by their family for as long as they could. Two of the caregivers discussed honouring their loved ones until they passed (Annette and Annie), which is reflective of all the caregivers.

## 1.5 Importance of the Personal for Change

Using qualitative methods focused on storytelling is a way to connect head and heart knowledge because the stories of caregivers and healthcare providers were the merging of the two; caring for a loved one and for healthcare providers who love what they do and care for their clients. There are multitudes of statistics on the impacts of caregiving such as, “26 hours [is the] average number of hours that family/friend caregivers spend per week supporting a person with dementia, \$8.3 billion [is the] total health care costs and out-of-pocket caregiver costs of dementia in Canada in 2011 [and] \$16.6 billion [is the] projected total health care costs and out-of-pocket caregiver costs of dementia in Canada by 2031” (Canada Public Health Agency, 2019:8). The rates of dementia are rising for Indigenous peoples in Canada and we need more data. But,

...the importance of qualitative research for the understanding and interpretation of caregivers’ lived experience can hardly be overstated. While census and survey data are necessary to grasp the prevalence and incidence of various kinds of caregiving, and its association with a range of demographic, social and economic issues, it is essential to supplement this understanding with the more in-depth understanding that only qualitative approaches can provide (Gahagan et al., 2004:70).

Storytelling has a broader benefit of positively impacting healthcare providers. Instead of being told what they are doing wrong, hearing someone’s story can make a personal connection, to feel compassion and empathize with their experiences to integrate better practices.

Each woman shared stories of resiliency within their caregiving experiences, horrific experiences and stories of hope that there is change happening within healthcare to provide culturally safe care for Indigenous families. The stories of healthcare providers show that they are trying to enact change through their practice with educational outreach, compassion and being flexible. Stories are powerful entities and, “they are vehicles by which isolated subjects invite others to *imagine themselves* into their experience” (Doerfler, Sinclair and Stark, 2013:69). It is not dealing with healthcare in only a clinical manner, but it helps healthcare providers to remember how they felt when they hear stories and how it stays with you because it is heart knowledge to inform



practice. Stories are also tools for those who hear or read them to take responsibility to use what they learn into their practice (McCall, 2011:126).

## 1.6 Storytelling is Powerful

Through sharing their stories of caring, advocating and navigating the Canadian health care system, “although the individual families who participated in this research may not have benefited directly, this research would benefit the [Indigenous] community as a whole because it was being used to identify changes that were needed for current health care” (Hampton et al., 2009:30). Their voices and stories inform healthcare practice changes for cultural safety, the importance of self-determination in community for programming and the importance of love and compassion for caregivers on their journey. By analyzing their stories, the,

wider recognition of the role that historical trauma has played in shaping the lives of Aboriginal people provides a social context that allows individuals and communities to tell their stories in ways that can begin the process of personal and collective transformation from helpless victim, through courageous survivor, to creative thriver (Kirmayer et al., 2009:456).

The caregivers’ lived experiences are valuable and integral for change because their stories exemplify that Indigenous female caregivers are doing amazing jobs amidst healthcare barriers.

Using the stories of caregivers for loved ones diagnosed with dementia can be a tool to teach healthcare providers because, “storytelling is a non-directive, non-confrontational way of linking actions to consequences” (Chansonneuve, 2007, 43). Examples of real interactions can inform improvements or showcase how the provider contributed to the experience being positive or negative. According to Smith et al., practical tools can be developed where the,

care provider undertakes to consider the things that make clients unique, and to provide care that takes account of differences. This requires care providers to reflect on their own cultural identity and on their relative power as providers of care. Cultural safety is achieved when the recipients of care deem the care to be meeting their cultural needs (2011:11).

This is a shift for the care provider to be aware of their implicit biases and to treat each individual and their families as unique with their own specific needs and expectations. It is also a way to shift the onus from being on the caregiver to teach the healthcare provider about their cultural background in order to receive culturally safe care.

## 1.7 Indigenous Methodologies

For healthcare, it is important to understand how people perceive themselves and their world around them and the importance of narrative as a tool to do so. The, "...lessons of stories and the lifeblood of narrative for Indigenous peoples, ...genealogical stories are material and ontological forces by which Indigenous people knew and know place, relationality, and each other as individuals and communities" (de Leeuw, Lindsay and Greenwood, 2015: xxv). Stories are powerful because they make up most of people's lives, their experiences and ties and, "as fundamentally interpersonal beings, we are, paradoxically, creating our personal story in a context that is larger than our individual selves..." (Kenyon, Clark and de Vries, 2001:4). Stories are important to Indigenous health and well-being because they can enact change by evoking emotion and lets people take what they want from the learning to apply to their own lives. Stories can provide contextual understanding of someone's life and can show the complexity that illness is not just a biomedical diagnosis but is tied to someone being out of balance. It can also aid to help healthcare providers and people who have misconceptions and stereotypes about Indigenous populations and ill health. It is a way to emotionally connect with people who do not understand or empathize with someone's experience connected to their health in terms of regular substance use, structural violence or intergenerational trauma. Thus, storytelling is healing not only for the teller, but the listener because, "stories about real events first grab the heart, then the heart sticks them in the mind" (Ross, 2014:242). Biomedical approaches are often strictly focused on intellectual interactions of finding solutions, using acquired medical knowledge and experience to treat an illness. Rarely are the emotional and spiritual aspects of an interaction addressed; storytelling can create empathy on behalf of healthcare providers who only address issues with Indigenous clients based on Western approaches of quantitative merit.

In health research, compassionate minds and love are elements missing which are inherent to Indigenous holism; doing the work with a good mind and heart are rarely discussed as being a part of the methodology, theory and applications. As discussed within research focused on memory loss with Hawaiians, heart knowledge is shared within the context of relationships, blood memory and feelings of being connected to where you are, your community and social support (Sefa Dei, Hall and Rosenberg, 2000:46). Health is attained and protected with familial love and community acceptance which is often not addressed in healthcare interactions and literature. Love and acceptance are aspects of resiliency and flipping the approaches to health to focus on what is working and understanding that health and well-being is knowing who you are, your story and where you come from. In order for knowledge to improve or contribute to health and well-being, “making good decisions requires understanding and respecting the past, being critically observant of the present, and striving for a better future” (Tagalik, 2015:27). Heart knowledge is not individualized and compartmentalized because, “sharing what one has learned is an important Indigenous tradition. This type of sharing can take the form of a story of personal life experience and is done with a compassionate mind and love for others” (Archibald, 2008:2). The act of sharing knowledge is not limited to the knowledge shared between humans, but what is learnt through our kinship ties with all other elements of the world and the recognition that the health and well-being of all of our kin is inextricably tied to our own health and well-being as humans (Turner, 2007, Sefa Dei, Hall and Rosenberg, 2000). Thus, research and health care need to share knowledge that will have applications to benefit all kin and do it in a good way to help others.

## 1.8 Two Eyed Seeing and the Two Row Wampum

Two eyed seeing<sup>1</sup> is an approach for equal inclusivity of Western and Indigenous ways of knowing. To go beyond the concept of two eyed seeing, the metaphor of the two row

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<sup>1</sup> “The concept of two-eyed seeing originated through in the work of Mi’kmaq Elders Murdena and Albert Marshall from Eskasoni First Nation, along with Dr. Cheryl Bartlett at Cape Breton University’s Institute for Integrative Science and Health/Toqwa’tu’kl Kjjijitaqnn (Iwama et al., 2009). Two-eyed seeing is expressed by Elder Marshall as: ‘To see from one eye with the strengths of Indigenous ways of knowing,

wampum<sup>2</sup> should be used since it is based on relationships and assisting one another. Integrating Western and Indigenous approaches is complex but reveals structural inequalities that address health disparities. Storytelling can be used to provide context for Indigenous clients accessing health services that is holistic, connects them intergenerationally and to their culture and community.

Within the literature, an argument I came across was that Indigenous methodology does not need to fit into the paradigms of quantitative, Western approaches of research because theory and methodology are already integrated. Within the discussion of applying two eyed seeing, it also became apparent that Indigenous ways of knowing are not singular in their definition. There are elements that are common, but each community and nation have their own knowledge based on their ties to the land and if they are still close to their traditional territory which has ramifications for health. Each community has its own approaches because it is founded on the ceremony, stories and language of that specific nation. Elders are integral to Indigenous approaches because they carry and pass on the theory and methods that are embedded in the language, ceremony and stories of a place not only physically and not limited by Western conceptions of time and spirituality. With two eyed seeing, another important foundational element is that colonialism needs to be addressed. It will not be easy but is necessary in order to move away from perpetuating the same mistakes of the past where colonialism is not a determinant of health (Archibald, 2008:36). Thus, two eyed seeing is a way to decolonize, but as a methodology, Indigenous approaches to health cannot be something tacked on but should be foundational especially for research and healthcare for and with Indigenous peoples and communities.

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and to see from the other eye with the strengths of Western ways of knowing, and to use both of these eyes together' (Bartlett, Marshall, M., and Marshall, A., 2012: 335 in Hall et al. 2015:1).

<sup>2</sup> "Two Row Wampum is a beaded belt describing a friendship treaty between the Dutch and the Iroquois. The rows of beads on the belt represent Dutch vessels and Iroquois canoes, traveling side by side down the 'river of life'. The paths of the two kinds of vessels remain separate, but the people on the two kinds of boats are meant to interact and assist one another as need be" (Doubleday 1993; McGregor 2004; Stevenson 2006 in Berkes, 2012:283)

With two eyed seeing, the issue of evidence-based practice is: whose evidence is valued and why? Evidence based practice is, “the integration of best research evidence with clinical expertise and patient values” (Norcross, Beutler and Levant, 2006:13). Evidence based practice is developing as a, “new gold standard for research and applications. But with the concept of evidence, no one has asked why now? Whose evidence counts? What kinds of evidence are being privileged? What are we not seeing?” (Strega and Brown, 2015:12). Evidence based practice can be exclusionary because those who are creating knowledge are the same people who were producing knowledge before evidence-based practice became a paradigm shift. What I mean by this, is that if evidence-based practice is the sole approach, then inequality would be perpetuated because knowledge is created without critiquing who is contributing to it. Two eyed seeing is a way to contest this because it is privileging Indigenous approaches to not only research, but how healthcare can be changed and valuing more than quantitative data that does not address colonialism, gender and racial discrimination and social inequity. If two eyed seeing is the inclusion of Indigenous knowledge that is locally specific, community focused and where culture, traditions and storytelling are foundational, two eyed seeing is an approach that can enhance knowledge production and applications for changing health and wellness because the issues being addressed are based on the community’s needs and are embedded in their ways of knowing instead of trying to fit into Western approaches.

The level of respect and reciprocity between Indigenous and Western approaches is not only beneficial for Indigenous people, but non-Indigenous populations as well. Working with a community based on the context of their lives and experiences has benefits for any community working towards or continuing to have healthy members. Indigenous approaches to health and well being can offer novel perspectives for health and wellness for non-Indigenous populations when two eyed seeing is used because it is an alternative perspective that can provide a better way of doing things (Marshall, Marshall and Bartlett, 2015:18). Two eyed seeing as a methodology provides opportunity that can be better for health and sharing knowledge which allows communities to learn from one another, appreciate each other’s knowledge base and recognition of the limitations of only one approach (Sefa Dei, Hall and Rosenberg, 2000:273; Knudston and Suzuki, 1992:10). If Indigenous ways of knowing are valued as equal and Western approaches are

used as needed or wanted, there is the opportunity to learn from different approaches which can enhance health research and the patient experience.

The metaphor of the two row wampum is similar to two eyed seeing, but I prefer it because it is founded on relationships and not just the knowledge created. The two row wampum is the best way to describe and practice a reciprocal relationship that respects, “the integrity of both ways of knowing while maintaining the opportunities for the two kinds of knowledge to enrich one another” (Berkes, 2012:283). The two row wampum maintains the uniqueness of each approach, but includes collaboration focused on the people who will be interacting, working together and/or sharing knowledge and best practices. With the two row wampum belt metaphor, it is an acknowledgment of difference without creating the binary (Indigenous knowledge vs. Western knowledge) sometimes attributed to two-eyed seeing (McCall, 2011:34). Relationships are foundational to collaboration between Indigenous and non-Indigenous peoples, so respect, honouring different approaches and the choice of what to use for enriching your own knowledge goes beyond two eyed seeing. Since my research focuses on Alzheimer’s disease and other dementias (ADOD) including alcohol-related dementia, improving health and wellbeing of individuals and families takes the relationship approach of the two row wampum. In a book by Lock, she focused on the paradigm shift of research focused on ADOD. The concluding chapter of the book presents emerging knowledge in both epigenetics and epidemiology, strongly suggesting that forms of prevention that take a public health approach. This includes lifestyle changes, reduced exposure to toxins, reductions in poverty, increased community support, and other variables to reduce the prevalence of dementia worldwide to a much greater extent than an approach confined to expensive molecular micro-medical management of segments of those population deemed to be at risk that happen to be located in wealthier countries (Lock, 2013:4). Within ADOD research, there still needs to be a view of the person as a whole and the context of their lives. This extends beyond the parameters of someone with ADOD’s body in terms of what they eat, where they live and lifestyle. Since the two row wampum in my perspective is based on relationships, respect and trust, I think this is important for the health provider and client relationship, not only with the individual, but their family

and that they are a part of a community. An important observation that resonated with me as discussed in literature focused on the experiences of people with ADOD, is that,

...illness narratives...are so often about ‘my illness and me’-whereas the illness stories I hear from people in the field, as well as from friends at home, usually take a different form: they deal much more with the person’s relationship to others and to her world. The stories I hear people tell about their illnesses are more inseparable from the ongoing stories of their lives (Mattingly and Garro, 2000:218).

As a healthcare provider, applying the methodology of the two row wampum assists one another; recognizing and respecting that the person you are interacting with bring their own knowledge and context of their lives and that their illness impacts their relationship to their lived experiences. Approaching healthcare based on relationships can improve the dynamics between providers and the people they are caring for, Indigenous and non-Indigenous.

## 1.9 Emotional and Spiritual Knowledge

Storytelling and narrative approaches are a way to alter the interaction between healthcare providers and clients to include emotional knowledge and spiritual knowledge. Since storytelling is integral to Indigenous identity, intergenerational transmission of knowledge and ties to ancestors, it is also medicine and can be used to heal. Storytelling is holistic because it, “...is a part of the mind, body, spirit, family and community connection that we are all craving right now in this time of technology and social isolation” (Van Camp, 2015:184). Storytelling is not only the narrative being shared, but the experiential learning and connection between the story teller and the audience to be a collective experience. It is a relationship being fostered and shared and is a way to work from a strength-based approach of transmitting cultural values and teachings. Storytelling thus is a way of, “...lifting the burden of colonialism by visioning new realities” (Simpson, 2011:34). It is healing to use storytelling in order to shift away from the negative narratives of health. The intergenerational oral transmission of cultural knowledge and values are often excluded from biomedical health research and policies. They do not recognize that for the next generation to be healthy and thrive, their ties to the previous generation and their ancestors are a way for children to grow up to be

healthy youth and then adults. Speaking with Annie, she has become an advocate for dementia and has shared her story to educate others. When talking about the end of her Dad's life, she reflected on her father's teachings:

*But maybe it's because my Dad, I had to go through this to be able to tell the story to you and to tell the story to the Minister; a part of it. Not all of it. A part of it. And it still hurts me. When I talk about it, I still hurt because it's our own, that's our own people doing that to our own and Dad didn't need to die like that you know. He was a cultural man, he taught culture, he taught language, he taught everything. He was a good man. He had his faults, but he was a good man. He taught love regardless. That was his big word. Respect woman and love. Respect woman and love. If you don't respect woman, if you don't love your mother then you don't love the Earth. That was his teachings. I use it now and I know what it meant now. If man don't respect woman and don't love their mothers, then they don't love mother Earth. It boils down to that is what he used to say. They won't be able to respect mother Earth if they don't respect anything else. That's my Dad's teachings you see. The strong teachings.*

Through Annie and the other caregivers and care providers sharing their stories, they are educating about the social, political and cultural interplay with the personal. For Annie and all the caregivers who are strong Indigenous women, they honoured the lives of their loved ones and Annie's father passed on his teachings to her.

The intergenerational knowledge Annie's father passed down to her, she will pass on to the next generation, so learning across ages and life spans is important to Indigenous health and well-being. What stories can teach is that removing barriers such as long distances to access services and care and being able to have support in community means that intergenerational learning and reciprocity can continue for the benefit of families, but also enable Indigenous communities to keep their seniors; their knowledge keepers and storytellers at home for as long as possible.

Biomedical approaches that focus on fixing the problem do not address the healing power of stories. Narrative is more than the words, but all that is embedded in the process is preventative to illness in the first place. But in order for children and youth to grow up to



be healthy adults, it is the previous generation that creates that. The loss of intergenerational storytelling because of colonialism contributes to illness, but reconnection or retention is a way for the next generation to have health that is holistic. Stories are a way to combat the shame and thus silencing of negative experiences stemming from colonialism for Indigenous populations because, “in the sharing in the reliving of a tragedy, this sense of communing in a common loss, that gives stories their power, not to forgive or redeem the past, but to unite the living in the simple affirmation that they exist, that they survived” (Jackson, 2013:112). The power of stories is therapeutic and healing because the act of telling stories is a way to reclaim power and that experiences do not have to be dealt with individually (Gonzales, 2012:226). The recognition of the impact of structural violence can remove blaming the individual for how they are coping with stress and trauma and storytelling exemplifies resiliency.

Life stories are powerful for healing in that the impacts of colonialism can be examined within personal histories and how they shaped a person’s opportunities and challenges. Life stories show cultural and social ties to maintain identity and connections to community and ancestors. Stories can show the next generation that healing can happen. The practicality of stories can be a way to change the policies and the medicalized approaches to humanize people which seems logical, but is not practiced in medicine or healthcare. Stories are a way to connect people because of their power to evoke emotions in the audience and to offer context and how colonialism impacts someone’s life.

Treating people who have complexity, history and connections seems obvious, but people are not treated as such. Thus, stories, “not only... engender and sustain a humane dimension of medical care but also incorporate critical elements of the medical consciousness into those policy and political debates that too often reproduce the instrumental rationality we seek to criticize” (Mattingly and Garro, 2000:67). For change to be enacted, policy has to be implemented with consequences for healthcare providers. There needs to be healthcare policies that reflect holism, respect and the metaphor of the two row wampum instead of unequal power imbalances. Stories can be used to make the connection of how policy has real life impact on people’s lives when racism and discrimination are perpetuated through them.

## 1.10 Emotions in Research

When interviewing Annie, the importance of empathy and the emotions that arise when sharing her stories was brought up:

*One thing I can tell you Danielle is yes when I come back to the moment with you because that's who I am, I come back to this hurtful moment and I permit it, to come back to that moment so that you can feel how I felt.*

Within Indigenous knowledge, emotions are central to storytelling and are reflective of the lived experiences of caregivers (Kovack, 2009). The power of the emotions from Annie's stories of caring for her Dad including wonderful, loving memories are important parts of storytelling because they connect to the heart of the listener. The power of stories is how they make people feel. For myself as a caregiver, I empathize with her pain, sadness and joy from her stories since I can relate to similar experiences. Sharing our emotions within the process of storytelling is healing because, "...to 'visualize the pain that [others were] going through in order for us to feel it. (...) true and genuine support for the patient and a sense of hope was possible after making this connection with the 'other's pain' (Barkwell, 2005). It was through this healing process that individuals were able to 'cope with the suffering in their experience' " (Haozous et al., 2011). With all of the caregivers and healthcare providers, their emotions were integral to storytelling, to connect and remember how experiences in healthcare made them feel and realize that we are not alone since someone else can relate. Emotions also show the strength of caregivers who provide amazing love, compassion and care although there are barriers within the healthcare system.

## 1.11 Humour is Healing

Throughout the interviews and sharing stories from their caregiving experiences, humour was foundational. Transcribing interviews, I included laughter and noted it throughout. Listed below is a text search inquiry of the word frequency to show the percentage it accounted for within interviews:

**Table 1 Word Frequency of Laughing**

Interview	Word frequency	Percentage (%)
Kathleen (spouse) and Michelle (granddaughter) (Anishanaabe caregivers)	28	71
Jason (Geriatrician)	2	4
Amanda (Public Outreach Coordinator)	5	11
Richard (Social Worker)	14	22
Annette (Métis caregiver)	25	34
Annie (Anishanaabe caregiver)	29	51
Ali (Psychologist)	3	7

Humour within storytelling is a vehicle for healing for not only the storyteller, but the audience because, "...those who have lived through very difficult circumstances and who can share some humorous aspect of the experience have achieved some emotional or spiritual healing" (Archibald, 2008:68). Through humour, it connects people through laughter in the experience (Jackson, 2013:183) in that experiences are not determined only by challenges or obstacles, but happiness and humour. Thus, laughter included in stories is healing because it is a holistic approach to health and well being where people can connect and learn from others who may have had similar experiences. We were able to share funny memories of our loved ones and teachings that came from those experiences. It was wonderful as a caregiver speaking with other caregivers to have similar stories to share. Humour was important to all the interviews and reflects Indigenous health. From the experiences of two First Nation men discussing coping with stress and being diabetic, they shared that, "laughter [i]s an important healer, which was

taught by their Elders: ‘Well, laughter is a big healer when you’re down and out. My grandparents, they’re gone now, and one of the things that they taught me is, when you have a problem you have to talk about it and also put a little bit of laughter in it. And it heals. Laughter is a big thing’ (Iwasaki et al., 2005:983). Humour is a way to cope with stress, connect with others and can be important for remembering. Through research focused on aging and memory loss with Elders in Manitoulin, humour was a part of the research process within the sharing circles and within talking about aging in a positive way (Hulko et al., 2010:326). All of the caregivers including myself shared funny stories about our loved ones when they had dementia and as a part of their personality. Annie shared that her Dad used to tease her:

*I’ve battled for my Dad a lot, I protected him. Anyhow, I’m a very petite woman. He said ‘thank goodness you’re petite’ he says ‘because if you were 400 pounds, I think a lot of people would be flying around. And a man’ (laughing). He would always tell me that. Anyways I protected my Dad.*

I was able to share funny memories as well and we were able to laugh with one another amidst some of the more difficult memories of caregiving as Indigenous women. With laughter, it is medicine because it is therapeutic to talk about our loved ones. With all the caregivers, their loved ones have passed, so it was an opportunity to talk about who they were, their lives and memories of them. Throughout our discussions, it was learning about their husband, grandfather or Dad, and how much they are loved, appreciated and missed.

On behalf of healthcare providers, we laughed a lot as well, sharing funny experiences that taught us lessons along the way. It was also shared that humour is important to caring for Indigenous clients. Richard shared the importance of humour for building trust and being humble:

*I use humour a lot. I use self-deprecating humor. In other words, I’m not here to tell you anything, I’m no smarter than you are. I’ll just start a conversation with them, and I’ll just be open, and you know how do you say... be genuine with them and they see that and it’s a process. It’s earning that trust first and then approaching them.*

Humour is a way to connect with people as healthcare providers when trying to provide support especially for families affected by dementia. Humour is a way to show compassion and caring to connect with people in a different way since laughter helps foster relationships.

## 1.12 Concluding Remarks

Stories provide insight to larger structural barriers for accessing healthcare. Thus, lived experiences needs to be a part of research focused on systemic change for Indigenous families impacted by ADOD. The stories of Elders and seniors are imperative to health as well since they show resilience from colonial policies and practices that were designed to remove culture, language and community. Thus, supporting Elders and seniors, has, “...an important role to play in bringing forward knowledge of the past and applying or bridging it to contemporary issues, thereby creating new understandings of dementia and other culturally appropriate teachings” (Hulko, Wilson and Kent, 2019:216). Story telling of caregivers and their loved ones show how they cope and provide the best care they can with minimal to non-existent supports. Healthcare providers’ stories are important as well to understand what supports they need to be culturally safe as well as exemplify good practices that can inform other healthcare providers’ education and approaches. Stories are foundational to Indigenous health because they facilitate connecting, sharing experiences and using humour to heal and laugh with one another.

## 1.13 Key Findings

- Storytelling from caregivers and healthcare providers are important to enact change because they reveal the lived experiences of existing systemic barriers
- Storytelling is integral to connecting head and heart knowledge where practice and education can be informed by how it made people feel and not just telling them what they need to change

- Doing work with a good mind and heart need to be taught in medical school and healthcare interactions where relationships are foundational between providers with clients
- Two eyed seeing or applying the metaphor of the two row wampum is beneficial to work in collaboration with settlers to have the expertise of Indigenous and non-Indigenous knowledge translation and exchange
- Stories are an Indigenous methodology that shows personal and collective resilience, strength and the importance of culture and intergenerational relationships
- Stories are healing, in that people are not alone in their experiences and provides a positive perspective of where change can be made
- Emotions and humour are important aspects of research and developing relationships for supporting Indigenous families affected by ADOD

## 2 Literature Review

### 2.1 Introduction

In this literature review, I will focus on the existing knowledge of the impact of dementia within Indigenous communities, specifically in Canada. The inclusion material was predominantly qualitative because the majority of research was community-based and used Indigenous approaches to health that are focused on collaboration and the use of story telling. Thus, clinical trials were excluded since they did not include the lived experiences of Indigenous families affected by dementia. Lived experiences are forms of expert knowledge because they provide insight to the barriers and improvements that are needed in our healthcare system to support caregivers and their families affected by dementia. Most literature on dementia excludes Indigenous populations or provide statistics on the population impacts. This can show that there is a rise in dementia within Indigenous communities, but fails to contextualize how families are coping, what resources they are accessing and what can be done systemically to make changes to provide support, education and resources.

### 2.2 Background

*What is known about this topic?*

The statistical knowledge of the impact of dementia for Indigenous populations in Canada all states that the rate is growing because the population is aging and there is an increase of life expectancy. The rates are the following that, "...the number of Aboriginal seniors is growing more rapidly than the non-Aboriginal senior population. By 2017, Statistics Canada projects that seniors will make up 6.5% of the total Aboriginal population, and 8% of the Métis population; 6% of the First Nation population; and 4% of the Inuit population" (Turcotte and Schellenberg 2007:223 in Beatty and Berdahl 2011:1). The majority of literature focuses on First Nations communities for dementia and little to no data focuses on Métis or Inuit rates of dementia. Overall, little is known about the experiences of individuals and their families impacted by dementia within First

Nations communities and there is even less Métis or Inuit experiences. There are 2 articles that include barriers for health services for Inuit populations focused on systemic barriers. But they lack the inclusion of their experiences and voices although they provide excellent insight to the issues of geographic barriers (Huot, 2019) of Inuit seniors being forced to move hundreds of kilometres away for long term care since none exist in or near their communities (Gao, 2019).

#### *What Does this Chapter Add?*

In this chapter, I will examine the barriers for accessing healthcare including geographic locality impacting access to services, culturally safe care and assessment tools that are Indigenous developed. Through the literature review, I examine points for further research including: the experiences of being diagnosed with dementia, being a caregiver for a loved one, existing dementia services and self-determination for Indigenous communities needs to be a priority for research and development. Most importantly research that is community led ensures culturally safe care because the development, programming and services are determined by those who require access to services. This ensures higher uptake since dementia programs are developed in collaboration with the community members, leaders and health organizations to ensure service needs are met.

#### *What are the Implications for Practitioners?*

In this literature review, I discuss themes for a better understanding of the barriers, perspectives and understandings of dementia within Indigenous communities through examining the current available data. Healthcare providers gain insight to the importance of culturally safety in their practice and that bringing services into a community can alleviate or remove the barriers of traveling for specialists and referrals. It also provides the context of the contemporary ongoing impacts of colonization in the form of funding, intergenerational trauma and jurisdictional barriers. Since the inclusion for literature is focused on Indigenous families and individuals' experiences of dementia and navigating the healthcare system, healthcare providers can learn from their experiences to inform their practice since families affected by dementia are the most knowledgeable about what changes are needed. Focusing on caregivers is Indigenous knowledge translation through



sharing stories and experiences to educate others and is culturally safe. Practitioners and researchers can learn the importance of honouring stories shared by Indigenous families, that their experiences are important and integral to making changes and understanding how health disparities are created and how they are sustained (Richmond and Ross, 2009: 405). Learning from families are the best form of knowledge translation for practice because their experiences reflect how health disparities affect their health journey.

## 2.3 Methodology

This literature review was done in three stages. The first stage was searching for sources using databases. In the end, there were a total of 26 articles that were included. The types of articles used were the following:

- **4 quantitative:** 1=research findings, 1= health information report, 1=systemic review, 1=cross-sectional study
- **22 qualitative:** 2=descriptive, 1=literature review, 1=report, 1=case study, 4=systemic review, 1=scoping review, 1=survey result, 2=focused on interviews, 5=research findings, 1= institutional review, 2=PhD dissertation (1=qualitative, 1=qualitative and quantitative) and 1=MA thesis (qualitative).

Conference material was excluded because it described what was presented but did not provide more in-depth information about the research. Some conference presenters' articles are included since I searched for their research to gain more knowledge about their findings. The sources that met the criteria for inclusion of the literature are listed in **Table 1** outlining the author, type of article, community-based research (if applicable), geographic location and key notes.

### Stage 1

The first stage of searching for relevant literature was using the term 'Indigenous+dementia' on *Scopus* which yielded 8 articles. The search criteria on *Scopus* was: Canada only, 2010-2019 and no restrictions on type of article or subject area and written in English only. From the 8 articles, after reading their abstracts and searching the

body for ‘Indigenous+dementia’, only 4 were eligible. I also conducted a search of ‘First Nations+dementia’ on *Scopus* from 2010-current, Canada specific, no restrictions on subject or type of article and written in English. This yielded 4 articles that met the criteria and were included. Using *PubMed*, I searched ‘Indigenous+dementia+Canada’ within the title and full body of the text for the last 10 years (March 2010-March 2019) which yielded 7 articles. Three articles were not focused on Canada and were excluded. Four articles were duplicates from the *Scopus* search.

Using the *Academic Search Complete Database* at Western University, the advanced search requirements were looking for ‘Indigenous+dementia+Canada’ in the full text or title of the articles. I focused on articles published between January 2009 to current (March 2019), that were peer reviewed, the geographic subset was Canada and written in English. This search yielded 611 articles. For duplicates from previous searches, 24 articles were excluded immediately. I searched again using the search words ‘dementia+Métis+Canada’ with the same search terms used the first time which yielded 0 articles. My final search was using the term ‘dementia+Inuit+Canada’ using the same search requirements which yielded 0 articles.

## **Stage 2**

The second stage was going through the titles and abstracts based on the following research questions:

1. What is known about dementia impacting Indigenous communities and Indigenous perspectives on dementia?
2. What are the barriers for accessing healthcare services and supports?
3. What recommendations for culturally safe care exist for healthcare providers?
4. Are any methodologies Indigenous and include cultural safety?

## **Stage 3**

After reading through the abstract and searching the entire body for terms such as ‘Indigenous’, ‘Inuit’, ‘Métis’, ‘First Nations’ and ‘dementia’, any sources that were not applicable were deleted leaving 26 articles. Although the searches did not yield specific

articles for dementia affecting Métis and Inuit communities, 2 articles were focused on ideas of aging for Métis seniors (Desmarais, 2016; Bartlett, 2012) and discussed dementia. Another article examined the barriers for accessing healthcare supports in the Circumpolar North that included Inuit seniors (Huot, 2019) and a systemic review of long term care for Sápmi and Nunavut populations (Gao, 2018).

**Table 2 Literature Review**

<i>Author and Date</i>	<i>Community Partnership</i>	<i>Key Points</i>
<p><b>1. Lanting et al. (2011)</b></p> <p>Qualitative research, descriptive</p>	Saskatoon Community Clinic, Grandmother Group	<ul style="list-style-type: none"> <li>• Provides an understanding of the cultural perceptions of aging, dementia and unique experiences in dementia caregiving</li> <li>• Gives an examination of existing assessment instruments for the purpose of developing culturally appropriate assessment protocols</li> </ul>
<p><b>2. First Nations Information Governance Centre and Jennifer D. Walker (2017)</b></p> <p>Quantitative, research findings</p>	National (on reserve and northern communities above the 60 <sup>th</sup> parallel)	<ul style="list-style-type: none"> <li>• The primary objective of the study described in this article was to apply a frailty index that was validated in the general Canadian older population to describe aging experiences in First Nations populations living on-reserve and in northern communities</li> </ul>
<p><b>3. Desmarais, Diedre (2016)</b></p> <p>Qualitative, PhD thesis dissertation</p>	13 Métis seniors, Saskatchewan	<ul style="list-style-type: none"> <li>• Examine contemporary impacts of colonialism on the health of Métis seniors who do not have access to rights under the <i>Indian Act</i>, who are forced to access mainstream services, but have the same health issues as other Indigenous peoples</li> </ul>
<p><b>4. Cabrera, Laura et al. (2015)</b></p> <p>Qualitative, descriptive</p>	8 people from the Tahltan First Nation, British Columbia	<ul style="list-style-type: none"> <li>• Explore the geneticization and medicalization impacting the understanding of early onset familial Alzheimer disease along with the cultural and traditional understandings of the illness</li> </ul>
<p><b>5. de Souza-Talarico, Juliana et al. (2016)</b></p> <p>Qualitative, systematic literature review</p>	Global, no community partnership	<ul style="list-style-type: none"> <li>• Literature review (13 articles) on cognitive impairment in Indigenous elderly populations</li> </ul>

<p><b>6. Lanting, Shawanda (2011)</b></p> <p>Qualitative and quantitative, PhD thesis</p>	<p>Cree speaking Indigenous peoples in Saskatchewan</p>	<ul style="list-style-type: none"> <li>Adapting cognitive testing assessment tools that are Cree specific</li> </ul>
<p><b>7. Webkamigad, Sharlene (2017)</b></p> <p>Qualitative, MA thesis</p>	<p>Partnership with the N'Swakamok Native Friendship Centre, Sudbury</p>	<ul style="list-style-type: none"> <li>Indigenous health promotion, cultural safety, and health literacy are shared with respect to improving the health of Indigenous peoples through culturally safe fact sheets</li> </ul>
<p><b>8. Pace, Jessica and Amanda Grenier (2017)</b></p> <p>Qualitative, systemic review</p>	<p>Canada and United States</p>	<ul style="list-style-type: none"> <li>The aim of the study is perceptions of Indigenous older peoples to identify the key elements of successful aging</li> </ul>
<p><b>9. Tonkin, Rochelle et al. (2018)</b></p> <p>Qualitative, survey results</p>	<p>Nak'azdli Health Centre and Elders, Northern British Columbia</p>	<ul style="list-style-type: none"> <li>Used a survey to determine what community-based activities Elders living in a rural community would want offered</li> <li>Elders should be a part of the planning and implementation of programming geared to them</li> </ul>
<p><b>10. Finkelstein, Sara, Dorothy Forbes and Chantelle Richmond (2012)</b></p> <p>Qualitative, interviews</p>	<p>Aboriginal Health Access Centre, Southwest Ontario</p>	<ul style="list-style-type: none"> <li>Outline the interactions health care providers have with First Nations patients/clients, their families, and other health care providers</li> <li>Identify barriers to care and identify successes in providing care</li> </ul>
<p><b>11. Butler, Rachel et al. (2011)</b></p> <p>Qualitative, findings of research process</p>	<p>The University of British Columbia Hospital Clinic for Alzheimer Disease and Related Disorders (UBCH-CARD)</p>	<ul style="list-style-type: none"> <li>Genetic counselling to a kindred First Nations family impacted by early onset familial Alzheimer disease (EOFAD)</li> <li>Challenges of knowledge exchange and continuity of care that was culturally specific and in a rural community</li> </ul>

<p><b>12. Beatty, Bonita and Loleen Berdahl (2011)</b></p> <p>Qualitative, systemic review</p>	<p>Regina and Winnipeg</p>	<ul style="list-style-type: none"> <li>• Discuss which policy approaches are needed to improve the health and well-being of urban Aboriginal seniors reflective of their needs and culture</li> </ul>
<p><b>13. Hout, S. et al. (2019)</b></p> <p>Qualitative, scoping review</p>	<p>Countries in the arctic and subarctic region that are either partially or completely located above 60°N, including Canada, Denmark (Greenland and Faroe Islands), Finland, Iceland, Norway, Russia, Sweden and the USA (Alaska)</p>	<ul style="list-style-type: none"> <li>• Identify factors that influence healthcare users and providers in the circumpolar North</li> <li>• Unique geographical and culture of Northern communities including language barriers, transportation and minimal resources</li> </ul>
<p><b>14. Petrusek MacDonald, Julia, Deborah Barnes and Laura Middleton (2015)</b></p> <p>Quantitative, systemic review</p>	<p>Canadian populations (Indigenous on reserve, Indigenous off reserve and non-Indigenous)</p>	<ul style="list-style-type: none"> <li>• Modifiable risk factors are responsible for the most Alzheimer’s Disease (AD) cases among Indigenous peoples in Canada</li> <li>• Reducing the prevalence of physical inactivity and smoking and increasing education may have the greatest impact on the prevalence of AD among Indigenous peoples in Canada</li> </ul>
<p><b>15. Morgan, Debra et al. (2009)</b></p> <p>Qualitative, research findings</p>	<p>13 rural and northern communities with provincial network sites and rural and remote seniors in Saskatchewan</p>	<ul style="list-style-type: none"> <li>• Describe the development, operation and evaluation of an interdisciplinary memory clinic aimed at improving access to diagnosis and management of early-stage dementia for individuals living in rural and remote communities</li> </ul>
<p><b>16. Gao, Grace I-An (2018)</b></p> <p>Qualitative, Institutional review</p>	<p>Sápmi and Nunavut populations</p>	<ul style="list-style-type: none"> <li>• Examines long term care homes for assessing the scope of Indigenous self-governance and the extent to which decolonization and efforts of successive governments willingly cede power to, and control over Indigenous resources</li> </ul>

<p><b>17. Jacklin, Kristin, Jessica Pace and Wayne Warry (2015)</b></p> <p>Qualitative, interviews</p>	<p>Partnership with 7 sites in Ontario: urban (Ottawa, Sudbury, Thunder Bay), peri-urban (Six Nations), rural (Wiwemikong Unceded Indian Reserve, United Chiefs and Council of Mniidoo Mnissing (Manitoulin Island), and remote (Moose Cree First Nation)</p>	<ul style="list-style-type: none"> <li>• Explore common caregiving experiences and patterns across diverse communities with the purpose of gaining insight into Indigenous models of care to better understand how to appropriately support families dealing with a dementia diagnosis</li> </ul>
<p><b>18. Stevenson, Shaun et al. (2013)</b></p> <p>Qualitative, case study</p>	<p>First Nation unnamed, British Columbia</p>	<ul style="list-style-type: none"> <li>• The case study presents some of the pragmatic and conceptual challenges of ensuring community confidentiality when conducting health research with a remote and dispersed First Nation population that is at risk for a familial neuro-degenerative disease</li> </ul>
<p><b>19. Fergenbaum, Jennifer et al. (2009)</b></p> <p>Quantitative, cross-sectional study</p>	<p>First Nation unnamed, Southern Manitoba</p>	<ul style="list-style-type: none"> <li>• Obesity and metabolic syndrome were associated with lowered cognitive performance highlighting the importance of studying the health effects of obesity beyond traditional disease endpoints, even in a relatively youthful population</li> </ul>
<p><b>20. Warren, Laura et al. (2015)</b></p> <p>Qualitative, systemic review</p>	<p>International (Canada, Australia, USA, Guam, Brazil)</p>	<ul style="list-style-type: none"> <li>• The objective of this systematic literature review was to determine the prevalence and incidence rates for dementia among Indigenous populations worldwide</li> </ul>
<p><b>21. Braun, Kathryn et al. (2013)</b></p> <p>Qualitative, systemic review</p>	<p>American Indians, Alaska Natives, and Native Hawaiians in the United States, First Nations people in Canada, Māori in Aotearoa (New Zealand), and Aboriginal peoples in Australia</p>	<ul style="list-style-type: none"> <li>• This study explores various approaches to research with Indigenous elders, drawing examples from Indigenous groups</li> </ul>

<p><b>22. Jacklin, Kristen, Jennifer Walker and Marjory Shawande (2013)</b></p> <p>Quantitative, health information report</p>	<p>Alberta</p>	<ul style="list-style-type: none"> <li>• Report on physician treated prevalence rates of dementia for First Nations people in Alberta between 1998-2009</li> </ul>
<p><b>23. Dieter, Jessica et al. (2018)</b></p> <p>Qualitative, research findings</p>	<p>11 First Nations communities in the File Hills Qu'Appelle Tribal Council (FHQTC), Treaty Four Territory in southern Saskatchewan</p>	<ul style="list-style-type: none"> <li>• The project goals are to provide community members with access to dementia information and supports through existing community-based health initiatives and gather input and information about community members' experiences through focus group discussions</li> </ul>
<p><b>24. Bourassa, Carrie et al. (2015)</b></p> <p>Qualitative, research findings</p>	<p>National, Native Women's Association of Canada</p>	<ul style="list-style-type: none"> <li>• This paper examines the physical, mental, emotional, and spiritual impacts of neurological conditions on Indigenous peoples, primarily women including recommendations to healthcare providers relevant to culturally safe care</li> </ul>
<p><b>25. Hulko, Wendy et al. (2010)</b></p> <p>Qualitative, research findings</p>	<p>Decision-makers from the local Health Authority and Elders from three First Nation communities in British Columbia</p>	<ul style="list-style-type: none"> <li>• This exploratory research sought to address gaps through a constructivist grounded theory project on the views of First Nation Elders on memory loss and memory care in later life</li> </ul>
<p><b>26. Bartlett, Judith et al. (2012)</b></p> <p>Qualitative, report</p>	<p>4 rural communities collaborating with 45 Métis seniors, Manitoba</p>	<ul style="list-style-type: none"> <li>• The overall goal of this research was for the Manitoba Métis Federation (MMF) and the University of Manitoba to develop an understanding of the experience of Métis seniors</li> </ul>

## 2.4 Findings Based on Themes

### 2.4.1 Aging Well

Within the literature, a theme on the idea of aging was that, “understandings of successful aging among Indigenous older people focus on a positive attitude and willingness to



adapt to the changes that accompany aging, rather than an absence of disease, disability, and decline” (Pace and Grenier, 2013:252). This connected to the idea that aging is a part of the life cycle and connects to responsibilities of families and community members to look after those who are seniors. The level of respect for seniors within Indigenous communities that was apparent within the articles showed that seniors play an important role because strong intergenerational relationships were linked to good brain health (Hulko et al., 2010:333). Seniors are the knowledge keepers and the story tellers, and these are integral to aging well, to have an important role within community where you contribute to the transmission of knowledge to the next generation. It also creates reciprocity for caregivers where seniors are able to be cared for not only by their immediate family and extended family but the kinship ties of a community providing support.

Aging well also has methodological implications for research where the definitions of aging are not standardized or based on successful aging, but defined on the life story of those sharing their histories and what aging well means to them. This approach is more culturally-based and strength-based, not depending on North American ideas of success based on those who have had a lifetime of advantage (Braun et al., 2014:123). When Indigenous seniors self-reported on their well-being, “they overall said they were happy and content most of the time and satisfied with life” (Tonkin et al., 2018:720). Working with Indigenous seniors to identify what aging well means to them is important since it is culturally-based on holism where, “...successful aging takes place at the intersection of individual, social, and cultural contexts across the life course, and against particular historical, economic, and political backdrops” (Pace and Grenier, 2016:250). Any project collaborating with Indigenous peoples will benefit from focusing on their ideas of aging from a positive perspective instead of an absence of disease model.

## 2.4.2 Social Determinants of Health

All 26 articles focused on the social determinants of health for Indigenous peoples in Canada and that, “dementia in Aboriginal groups is underscored by the current state of dementia services, which are limited in comparison to other health services; therefore, ethnic groups requiring dementia care represent an even more vulnerable subset of an

already marginalized group” (Lanting et al., 2011:104). Examining social determinants of health is a methodology to critically look at the interplay of external factors such as government funding for programming, the continued impacts of colonization through policies that create poverty, lack of opportunity and reduces access to health that create barriers for people accessing services and supports. For providing support to Indigenous families impacted by dementia, social determinants of health are integral since the findings within existing literature is that,

while not all Indigenous populations have experienced the same historical trauma, it is generally accepted that Indigenous populations worldwide have a lower socio-economic status, lower levels of education, and poorer overall health (including higher rates of cardiovascular disease, diabetes, and alcohol abuse), increasing their risk for the development of dementia (Warren et al., 2015:1960).

Most of the literature on dementia was collaborative with First Nations communities, but for Métis populations, their health and well-being are impacted because they do not have the same access to health care services whereas, “...many First Nations and Inuit governance institutions receive federal dollars that enable the creation of community driven and capacity building health care initiatives. The Métis are not treated as eligible for these benefits. This inequitable application of health care and access to services adversely affects the Métis population and their communities” (Desmarais, 2013:12). Métis families are also included in the statistical data on the rise of dementia for Indigenous communities but are excluded from accessing government supports and rely on the same provincial services as Canadians.

What can be learned from the literature is that social determinants of health need to be a part of any approach with, by and for Indigenous peoples especially focused on dementia. It provides the context of understanding that systemic barriers remove or reduce opportunities if there are no services in the community available. The ramifications for Métis peoples are that although they face health disparities because they continue to be affected by colonization, they do not have the same access to services as First Nations or Inuit populations. This in itself is an example of discriminative policy that has implications on their daily lives for individuals and their families.

### 2.4.3 Colonization

Colonization is a historical and structural barrier of health care access because of the lasting impacts of intergenerational trauma from residential schools and the 60's scoop, the direct impacts on trust with non-Indigenous healthcare providers and the erosion of traditional ways of being. I will examine these topics in greater detail since colonization was discussed in many articles as a determinant of health and healthcare providers need to be educated to have an understanding and context that colonialism is not in the past, but still occurring today and has ramifications on health experiences.

### 2.4.4 Residential Schools and the 60's Scoop

Many articles discussed the lasting impacts of residential schools for seniors who were forced to attend as children and youth as well as the impacts for those who were removed from their families and communities and placed with non-Indigenous caregivers because of the 60's scoop<sup>3</sup>. The connection to understanding dementia affecting Indigenous communities is that, "the literature on Indigenous people's health and well-being reflects a balance between risk and resilience. The existing literature outlines that Indigenous peoples are at high risk of poor health outcomes as they age as a result of historical and structural factors" (Pace and Grenier, 2017:249). In terms of accessing healthcare, one way the impact of colonization manifests itself is reflected in the lack of trust towards Canadian institutions including healthcare because of residential schools. Colonization created imbalance for Indigenous peoples, affecting their overall mental, spiritual, emotional and physical health which continues to be negatively affected. Historical trauma has long term impacts not only individually, but for families, community and connection to culture (Webkimagad 2017:52). The 60's scoop is the continuity of structural violence where families were destroyed along with long lasting impacts on

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<sup>3</sup> "The Sixties Scoop refers to a particular phase of a larger history, and not to an explicit government policy. Although the practice of removing Aboriginal children from their families and into state care existed before the 1960s (with the residential school system, for example), the drastic overrepresentation of Aboriginal children in the child welfare system accelerated in the 1960s, when Aboriginal children were seized and taken from their homes and placed, in most cases, into middle-class Euro-Canadian families. This overrepresentation continues today" (Hanson, 2009).

their communities for the loss not only of the next generation, but the severing of language, culture and connection to who they are. Jacklin, Pace and Warry discussed intergenerational trauma and that healing is important in order to provide support for those affected by dementia and to understand the mistrust of the Canadian medical system (2015:114). One caregiver they interviewed shared their understanding of the impacts for caregivers that if their parent is diagnosed with dementia, healing is needed if the caregiver was removed for many years and reunited with their parent. This can be emotionally daunting for the caregiver to have the new role of caregiving while coping with their own emotional and mental health because of being forcibly adopted (Jacklin, Pace and Warry, 2015:114).

For healthcare providers, dealing with the impacts of colonization and intergenerational trauma is complex and will be unique to the family for how they cope. Healthcare programs specific to dementia need to work from a healing framework. The fracturing of families because of colonial policies still impacts generations of families and this needs to be a factor for supporting caregivers who may have lost their kinship ties and cultural connection to their community. The application is that fragmentation of families because of colonial policies for the forced removal of children will mean that caregivers will need additional support for coping with their own trauma and that of their loved ones if they are reunited. The severing of connection to community is key as well to healing to reconnect to their culture, language and ways of knowing to be a positive coping tool. But this can only be achieved through community determined and developed programming based on the lived experiences of caregivers, care providers and loved ones with dementia.

## 2.4.5 Self-Determination

Geographic locality was a prominent theme that location directly impacts availability of services and the barrier of traveling to access services for dementia in distant locations that are often urban-based. The lack of available services within a community to support individuals affected by dementia and their families is an example of colonization connected to self-determination. All aspects of Indigenous people's lives are determined

by the *Indian Act* because, "...it includes several sections that define the identity of Indigenous peoples; the land upon which they can live, fish, hunt and harvest food; governance over community decision making; services and resources available to community members; and the political relationship they have with the Canadian state" (Reading, 2015:9). The lack of and minimal access to health services and dementia specific services for Indigenous populations in Canada is colonization because communities and nations do not determine their own services but are dependent on governance and funding from the federal government. This perpetuates a paternalistic relationship as opposed to a nation to nation interaction. If funding is determined by the federal government on reserve and provincially off reserve, accessing services and benefits are determined by your geographic locality and thus determine your eligibility based on the jurisdictional boundaries determined by the *Indian Act*. The exclusion of Métis peoples from accessing benefits means that their lives are also determined by the *Indian Act* through their exclusion from it, forcing them to access provincial services only. Healthcare providers need to understand the ramifications for services that are determined by these colonial policies and be familiar with the policies to improve navigation and support. Healthcare providers need to be able to advocate for clients through knowing the differences between on reserve and off reserve and knowing what services exist within a community. The relationship with Indigenous peoples is not reciprocal, and healthcare providers need to know how to work within the current system to support clients, especially in order to improve dementia services and support for Indigenous communities.

## 2.4.6 Education as a Risk Factor

The forcible removal of children into residential schools had impacts on the quality and level of education obtained since it was a removal from Indigenous ways of knowing and education focused on 'killing the Indian in the child'. The impacts extend across generations for those forced to attend residential schools is discussed as a health risk factor for developing dementia. Petrasek MacDonald et al., found within their research focused on risk factors for Alzheimer's disease is that,

differences in education between Indigenous and non-Indigenous groups are likely influenced by colonialism and forced assimilation of [Indigenous] peoples. The history of imposed education through the residential school system contributes to the high rates of dropout among Indigenous peoples in the present day. Furthermore, the trauma of the residential school system continues to affect [Indigenous] peoples' psychological health and wellbeing, taking the form of increased stress such as posttraumatic stress disorder. Research has shown low rates of education then contribute to high rates of unemployment and low socioeconomic status among Indigenous peoples in Canada, which in turn drive other AD risk factors such as smoking and obesity (2015:155).

In order to understand risk factors and barriers for accessing healthcare, colonization needs to be included within any research partnership with Indigenous communities because of the lasting effects of intergeneration trauma and policies for healthcare that do not allow self-determination of communities connected to social determinants of health. It also means protective factors to health is a connection to Indigenous ways of knowing, of being connected to land-based learning, transmission of intergenerational knowledge and the resurgence of our languages. The protective factors of culture, community and language can be applied to preventative ways of healing from the perpetual stress of forced acculturation and the lasting impact of historical trauma for many generations (Brant Castellano, 2015:36). Education connected to risk factors also provides context for the impacts of being forced to learn in way that is not holistic, community-centred and Indigenous.

## 2.4.7 Transportation Support

Independence for families impacted by dementia was discussed in that getting to healthcare services is difficult. The majority of articles discuss that affordable transportation from rural or First Nation reserve communities was non-existent, so people had to rely on private transportation. In connection to social determinants of health, if seniors are facing financial insecurity, the cost of private transportation through relying on family, friends or taxis is not an option (Bartlett et al., 2012:23). A research article discussing developing an assessment protocol to detect cognitive impairment for Cree seniors in a neuropsychological clinic found that, "although referrals of Aboriginal seniors are made to the clinic on a regular basis, travel costs and long distances result in a

greater proportion of Aboriginal compared to non-Aboriginal seniors declining offered appointments” (Lanting, 2011:80). For Indigenous communities that are only accessible dependent on weather conditions, families are unable to even safely travel to appointments which can be integral to diagnosis and support for dementia (Huot et al., 2019:2). An excellent method of reducing the barriers for transportation to access dementia services is to work with communities to bring specialists to families instead of them traveling out. In northern and rural Indigenous populations, not only is there the financial expense associated with traveling long distances, there is the, “...added stress of psychosocial effects of being removed from their supportive and familiar home environment” (Butler et al., 2011:139). If specialists and memory clinics can be coordinated to be offered in Indigenous communities, it can eliminate the needs for Indigenous families to travel to urban centres to access services in order to obtain a diagnosis and support services. Cabrera et al. partners with a First Nations community in Northern British Columbia to bring the memory clinic to them for early diagnosis and public education about early onset Alzheimer’s disease. This meant that people were able to gain genetic testing for determining their risk factors and for coordinating follow up appointments if needed (Cabrera et al., 2015). This exemplifies that services can be brought into community through partnership where specialist come to the people instead of vice versa.

## 2.5 Culturally Safe Care

A barrier for Indigenous peoples and their families not accessing dementia support services or healthcare for diagnosis is because of a lack of trust and fear of discrimination. Lanting’s PhD thesis focused on developing dementia health promotion material with an urban, First Nations community and found that, “... a group of caregivers of Indigenous people with dementia expressed an overwhelming and deep aversion to residential care facilities (nursing homes) and there is a deep reluctance by Indigenous caregivers to use mainstream services as there is a lack of culturally appropriate services or services in Indigenous languages” (Jacklin et al., 2015 in Lanting, 2017:9). Culturally safe resource material and services for Indigenous families is important since it is developed with, by and for the community founded on reflecting

their cultural values and perspectives. For creating dementia specific resources and services, “cultural safety is possible when health care providers acknowledge their own cultural background, perspectives, and personal biases and how these impact patient care, particularly, when the patient has a cultural background that differs from that of the practitioner” (Dieter et al., 2018:5). In an urban study focussed on informal dementia caregiving, Jacklin et al., “found at the urban sites, the participants were grateful for services provided by the local ‘native friendship centres’ for supportive services and cultural programming and the Indigenous health centers for medical care” (2015: 118). Through community-based research with Indigenous communities, the development of culturally safe material is important because it is created within the social and culturally specific context of the community and there is opportunity to partner with Friendship Centres and health access centres to meet needs.

Culturally safe care extends to the providers, especially for home care service where personal support workers (PSWs) and nurses are Indigenous themselves. An article on Métis experiences of aging found that an, “... informal caregiver expressed the importance of having Aboriginal or Métis home care workers care for her mother. She felt her mother was better able to connect to such workers and was happier with this type of culturally appropriate service. She had inquired in the past to see if this was possible” (Bartlett et al., 2012:78). Training Indigenous community members in the health fields is capacity building. Training and retaining Indigenous personal support workers, doctors, nurses and homecare workers will be beneficial for families affected by dementia since services are offered from people they know and reduces the barrier of relying on external agencies.

### 2.5.1 Culturally Specific Assessment Tools

Assessing for dementia was a barrier within the literature for Indigenous communities because they were not developed within an Indigenous context. Existing assessment tools are created based on the social and cultural context of Canadians and, “it is now widely accepted that standard cognitive assessment tools, such as the MMSE [min-mental state examination], which are based on the English language and western education systems



may not be appropriate for use in all populations” (Hatfield et al., 2009; LoGiudice et al., 2011 in Warren et al., 2015:1968). Assessment tools for dementia need to be created for Indigenous communities that are based on locality since there is wide variance within Indigenous populations. The benefits of creating assessment tools that are culturally specific is that, “the need for evidence in different regions of the world, especially in emerging countries, to overcome limitations related to the cultural adaptation of cognitive instruments is relevant to guiding treatment and prevention of Indigenous health problems in a scenario of aging populations and changing multimorbidity profiles” (de Souza et al., 2016:285). If assessment tools are created through collaboration with Indigenous communities, it reflects their worldviews, perspectives and can increase prevention for dementia. An example of an assessment tool being created with an Indigenous Grandmother’s Advisory Council from Saskatchewan,

the ‘Grasshoppers and Geese Test’ was developed as a culturally and geographically appropriate modification of the Pyramids and Palm Trees Test. In generating new triads, discussion of the stimuli often evoked stories about the stimuli and their role in Aboriginal culture or the geographical landscape. Thus, we anticipated that this instrument would also prompt conversation and relaxation in clinic patients who were completing this measure. The further modifications made...focused primarily on semantic changes to items, in order for the instrument to be more easily translated from English to Cree and to ensure ecological validity and appropriateness of items for individuals who were illiterate [in English]. The Grandmothers emphasized the need to modify or remove items that would assume or require any formal education or exposure to urban culture (Lanting et al., 2011:113).

This input from the advisory council created an assessment tool based not only on their language, but the importance of using local animals and creating a culturally safe interaction when the assessment tool is being used. This process can be used as an example to show the benefits of culturally specific tools and the important role of assessing and identifying individuals impacted by dementia that is more effective because it is based on locality.

It was found within the literature that more education is needed for primary care providers including nurse practitioners and family physicians to be more comfortable conducting assessments and diagnosing. Research has found that, “...one-third of general

practitioners surveyed expressed limited confidence in their diagnostic skills and two thirds lacked confidence in management of behavior and other problems in dementia” (Morgan et al., 2009:19; Warren et al., 2015:1969). This training is needed to support family practitioners to be able to assess, diagnose and manage dementia. But within an Indigenous community, education should also be focused on culturally safety since fear of racism and discrimination are a deterrent for families accessing help. Research on the experiences of Indigenous women diagnosed with neurological conditions, including dementia, “...spoke about institutional racism and stereotyping within the healthcare system and in medical school and to the need for more Indigenous-specific curricula and training given the growing health disparities between Aboriginal and non-Aboriginal people in Canada” (Bourassa, 2015:16). If Indigenous culturally safety is mandated into education at post-secondary institutions, it can foster a better environment for healthcare providers to be aware of their personal biases and, “they are more inclined to understand upstream factors (e.g., government policies, racism, historical legacies) and their connection to the downstream effects influencing the health and healing of populations at risk” (Bourassa, 2015:16). Supporting family practitioners to be more confident in dementia assessment and diagnosis can also reduce the need to travel outside the community and if healthcare providers are educated about cultural safe care early in their training, it can develop a life long journey for improving their care with Indigenous clients, especially those impacted by dementia.

Healthcare providers play an important role within communities because they are the first point or only point of contact for accessing health services. Within any research or development of dementia specific programming, resources and support, healthcare providers have knowledge that can be instrumental. Healthcare providers in communities already have an existing relationship with the aging population and within research focused on Métis seniors,

not only do they have knowledge with regard to what is available to these seniors, but they might also have heard feedback from the seniors themselves or directly observed the efficacy of, or challenges they might face in accessing, these services and supports. The service providers might also have ideas on how to adapt programs and services to better suit the needs of the aging Métis they serve (Bartlett et al., 2012:29).

Healthcare providers have the insight to understand what their needs are for improving care and the barriers they may experience for dementia specific services and thus more research is needed focused on their experiences as formal care providers. Thus, my research contributes to the lack of literature focused on care providers' experiences for support to Indigenous clients. Their experience, knowledge and expertise are still often missed in literature focused on dementia that is only quantitative and excludes storytelling. The stories of healthcare providers provide insight to systemic barriers they see and what education and institutional supports they need to continue to be Indigenous allies in health providing culturally safe care.

## 2.6 Community-Led Research

Out of the 26 articles included in the literature review, 17 collaborate with Indigenous communities. In these articles, partnerships were with First Nations communities except for 2 articles that conducted research with Métis families (Desmarais, 2016; Bartlett, 2012). None of the articles include partnerships with Inuit communities. All of the articles discuss the benefits of developing relationships with communities that includes leadership (Chief and council, clan mothers), healthcare providers and families, especially for creating resource materials that are dementia specific. Indigenous peoples have been extensively researched (Stevenson et al., 2013:3) and do not often benefit if the approach is a Western perspective. According to the National Aboriginal Health Organization, "Aboriginal peoples have been studied to death, and many are disillusioned by research reports published by people who don't know much about their lives and have little concern about the impact of the results on their community" (2005 in Desmarais, 2013:89). But, "through community-driven research approaches, First Nations people aging in First Nations communities can take these concepts and reframe them to better reflect their worldview and experiences" (First Nations Information Governance Centre and Walker, 2017:11). Through working with communities, culturally based resource material is produced, and knowledge sharing and uptake is increased. It is important that research is conducted specific to their nation's social and cultural context because, "communities are dynamic and fluid and their knowledge and perspectives on dementia have changed over the past century, which means that the causes attributed to dementia

and the community's responses to those affected are not static" (Dieter et al., 2018:4). Each community is unique and will have their own resources, strengths and priorities for research partnerships. Therefore, research based on what works for communities in the beginning and throughout is a positive shift towards, "culturally relevant changes in Indigenous health research, such as the inclusion of Indigenous-run organizations, the implementation of Indigenous knowledge and methodologies, the movement towards positive patient care, and the formation of reciprocal relationships between Indigenous communities and the health care system" (Macaulay, 2009 in Dieter et al., 2018:1). Indigenous research that is collaborative and based on community needs is a form of decolonization where the methodology, approach and relationship is focused on meaning and not measurement (Steinhauer and Lamouche, 2015:15). Collaborating with communities means relationship development, often long term and sharing the knowledge and expertise with those who will benefit from it, primarily community members. A lot of articles discussed that their research took time to develop trust and to create the research based on what was needed in community.

The benefits of community-based research focused on dementia within Indigenous communities is that the process can be adapted to support other communities for transferable knowledge. A systemic review of existing literature on decolonizing research with Indigenous seniors in North America found that, "findings have applications to other marginalized or minority groups, including new immigrants, nonmainstream religious groups, and individuals who are lesbian, gay, bisexual, transgendered, and intersex. There is evidence that these groups experience disparities, and as with Indigenous peoples, these disparities flow from isolation, discrimination, acculturation, and/ or lack of power" (Braun et al., 2013:124). Undergoing community-based research that is developed in partnership with Indigenous communities has benefits for other communities that also face discrimination within the healthcare system. Within speaking with female Indigenous caregivers and healthcare providers specifically for seniors and experience with dementia, the knowledge they share have parallels to support other minority caregivers and provide insight to the gendered caregiving of women.

## 2.6.1 Two Eyed Seeing

Using decolonizing methodologies for research with Indigenous communities about dementia, two eyed seeing was often cited. Two eyed seeing is, “understanding, acknowledging, and respecting a diversity of perspectives of the world ‘without perpetuating the dominance of one over the other’ ” (Martin, 2012:24 in Webkamigad, 2017:26). Through the inclusion of Indigenous and non-Indigenous approaches and perspectives to understanding dementia, it was important to the research methodology because, “decolonization in the context of research is possible through a meaningful collaboration between Indigenous people and descendants of White settlers, if we embrace the task of learning from one another rather than about the Indigenous person as the exotic Other” (Jones and Jenkins 2008 in Hulko et al., 2010:320). It is also a shift in ceding authority for research on behalf of expertise being based on Western conceptions and not based in Indigeneity, where expertise comes from connection to community, understanding of self and includes academic and lived experience. How dementia is understood, defined and experienced within Indigenous communities will be distinct based on many historical, cultural and social factors that will also have variance amongst families and individuals. Applying two eyed seeing to understandings of dementia was used in a project collaborating with the File Hills Qu’Appelle Tribal Council where,

many of the findings emerging from the focus groups highlighted the difference between Indigenous ways of framing dementia as a natural part of the aging process and the traditional Western medical view of the disease model. For this reason, our researchers were careful not to imply that the participants should reframe or shift their perspective to align with mainstream medicine. However, we were able to convey that the two approaches, although different, still focus on health, establishing a good quality of life, and providing medical or healing interventions when applicable. While many participants did not wish to be thought of as sick or diseased, but rather as moving through a natural life cycle, they still acknowledged that pain and suffering for both themselves and their families was not desirable or necessary. The researchers, therefore, did not attempt to change or alter the participants’ traditional beliefs or experiences; instead, participants were able to keep their beliefs while still accessing modern medical care and supports (Dieter et al, 2012:12).

Two eyed seeing is a way to include self-determination for Indigenous peoples in that non-Indigenous collaborators are not forcing their conceptions of dementia, but working together to offer the best of both worlds and services for coping. Two eyed seeing was also used for another research process for understanding dementia in Northern Ontario for resource materials. By using two eyed seeing, they found the benefits of, “bridging essential Western-based strategies such as billboards, binders, expert knowledge, and media with Indigenous modalities such as sharing circles and community and cultural events demonstrates cross-cultural considerations” (Webkamigad, 2017:86). The benefits of Indigenous and non-Indigenous approaches to dementia through research and developing supports and resources is that it creates more access to services since both worldviews are included and work together instead of in opposition. It also means that the development of resources, programming and material can use the strengths of Indigenous knowledge translation and Indigenous ways of knowing specific to the community to give the best of both approaches, thus an abundance of information and options.

## 2.6.2 Confidentiality

Maintaining confidentiality for research partners was a common ethical issue for academic collaborators with Indigenous communities for dementia research. For a project focused on diagnosing early onset familial Alzheimer’s disease (EOFAD), this issue arose connected to the location of hosting the clinic at the health centre. Since the health centre was in the middle of the community, everyone can see, “...individuals as they enter the clinic, thereby decreasing confidentiality of appointments. Furthermore, family members of the kindred are staff at the clinic, which again compromises confidentiality” (Butler et al., 2011:141). Within Indigenous communities where healthcare providers can be family, there is confidentiality issues that can arise, so research partners need to be cognizant of location for providing services. Confidentiality can be a barrier for people attending programming or testing, thus home visits can be an option. The stigma connected to dementia makes confidentiality importance because people do not want others to know that they or their loved one are impacted by dementia. This was discussed

often within my time spent with caregivers, and as a caregiver myself, although it is a huge part of my identity, I rarely share this information with others.

Further expanding on the issues faced offering a clinic for diagnosis of EOFAD,

the external challenges involve achieving comprehensive outreach to individuals at rural and dispersed regions of the country, varying biological and cultural definitions of family, and the interconnectedness of family, community, and Nation. Both the internal and external challenges are of scholarly and procedural importance to the research team and Nation, and of personal significance to the community members (Stevenson et al., 2013:1).

Family is culturally significant for research focused on dementia because of confidentiality in a community and should be revisited throughout the development, implementation and sharing of research to understand the priorities of the individual and their families.

## 2.7 Family and Community Support

Within the literature review, many of the articles discuss the importance of informal care providers for loved ones with dementia. Within existing research focused on Indigenous communities, a common theme was the importance of upholding cultural traditions of intergenerational support and care. Indigenous families are facing many barriers including transportation, healthcare that is not culturally safe and a lack of support services. There is extensive research that, “Canadians taking care of their elderly are having troubles balancing work and family responsibilities, with many caregivers experiencing mental, physical and financial problems” (Beatty et al., 2011:12).

Indigenous caregivers face added stress of systemic barriers for service supports, but also the rewards of reciprocating care for their loved one (Jacklin, Pace and Warry, 2015:106, Cabrera et al., 2015:5). The experiences of Indigenous caregivers are currently minimal and there is an opportunity to gain greater insight to their needs through community collaboration to develop supports and resource materials. Through the stories of the caregivers I spoke with, the love for their husband, father or grandfather came through memories and caring for them with the utmost compassion and care. Compassion and care are missing in healthcare research and I hope to contribute by sharing stories that

love that is foundational to caregiving for a loved one with dementia, along with compassion that healthcare providers I spoke to shared. Relationships are foundational to their work, going above the expectations of their job descriptions in a culturally safe way. The love of their jobs and the people they care for contributes to the good work they do, and more literature needs to focus on the importance of relationships and emotional connection for good healthcare that is reflective of Indigenous approaches. Compassionate healthcare also gives hope for change because it is a vision of a better system where caregivers and their loved ones feel comfort when interacting with doctors, nurses and social workers (Kēpa, 2019:141).

The existing literature focused on dementia includes a focus on informal caregivers and the importance of providers understanding the caregiver's role in coordinating services and health advocacy for their loved one. Informal caregivers do so,

by sharing information about their symptoms and needs, clients alerted health care providers to the need for cognitive assessments, changes in care needs, dementia care, and referrals to other health care professionals. Because PWD [people with dementia] sometimes failed to share information about symptoms or were in some instances unable to articulate changes in symptoms due to their cognitive status, informal care providers were important secondary sources of information about the health status and needs of a PWD (Finkelstein et al., 2012:267).

Caregivers are important to the overall well-being of their loved ones as they are able to articulate changes to healthcare providers. Shifting towards a family centred approach in health care is beneficial since caregivers provide integral health information about their loved one. But there is strain associated with caregiving that was noted within the literature. Caregivers discussed that early stage dementia were easier to manage, but, “as symptoms worsened and the person with dementia's abilities declined, caregivers described greater challenges and a higher level of strain. Hygiene and medical care needs were especially difficult to cope with” (Jacklin et al., 2015:111). Caregivers need support and more research is needed on the subject to tailor to their needs as they navigate minimal healthcare services that are not culturally safe while providing care to their loved ones. More research is needed on homecare supports and caregiver support is minimally discussed in the literature. Homecare support can alleviate the stress for caregivers to not



have to provide medical care on top of emotional, mental and spiritual care. Thus, more resources need to be accessible within communities regardless of whether families are living on reserve or off reserve.

## 2.8 Concluding Remarks

Existing literature focusing on dementia within Indigenous communities shows the importance of research methodologies that are collaborative, community-based and work within Indigenous approaches to health. These approaches are beneficial to creating support and resources to families because it is culturally and socially situated. There is vast improvement needed for understanding dementia from Métis and Inuit perspectives since research is currently minimal to non-existent. For any dementia research partnership with Indigenous communities, it is apparent within the existing literature that examining social determinants of health are important to gaining context. This includes barriers for healthcare that need to be addressed to understand why families are not accessing services in the first place, recommendations for infrastructure changes and an analysis of the long-lasting impacts of colonization. Most importantly, understanding dementia needs to come from those who require support and services to effect long term change. This not only applies to individuals and their families, but their communities who provide care throughout the journey for aging well.

## 2.9 Key Findings

- Colonization is perpetuated in healthcare and needs to be contextualized to understand how disparities are sustained in our healthcare system
- Social determinants of health contextualize the systemic barriers for healthcare including intergenerational trauma from residential school, transportation support and the importance of cultural safety
- Community partnership with Indigenous families and communities contributes to decolonizing methodologies because the development of programming is community specific and includes Indigenous approaches to health and research

- Culturally specific assessment tools are being created in collaboration with Indigenous communities to be reflective of their cultural, linguistic and geographically specific ways of knowing
- The voices and experiences of Indigenous caregivers and healthcare providers are still missing from literature, although their expertise and knowledge are imperative to developing programming, resources and supports
- Inuit and Métis experiences of dementia are missing from existing literature although they face the same health disparities and issues of leaving their community to access resources and support including long term care

## 3 Regular Substance Use and the Aging Population

### 3.1 Aging Factors

My research initially focused on alcohol-related dementia within Indigenous communities because it was a continuation from my master's thesis. I decided to shift the focus to Alzheimer's disease and other dementias (ADOD) for my PhD because I was unsure if alcohol-related dementia would come up in the research when I spoke to Indigenous caregivers and health care providers. I was surprised that regular substance use and aging developed in the process of interviewing and that populations of seniors with regular substance use do not receive treatment because of healthcare providers' ideas of aging, missed diagnosis and the disconnect between practice and research. The implications of this topic apply to Indigenous and Canadian seniors since both were discussed in interviews. The importance of regular substance use for aging populations in Canada is that it is a public health concern with high costs for the medical system. Research focused on the global implications of regular substance use has found that, "alcohol dependence and abuse are among the most costly health problems in the world from both social and economic points of view. Alcohol is considered a factor in diseases such as cancer, liver and heart disease and 20–40% of patients in large urban hospitals are there because of illnesses that have been caused or made worse by drinking" (Harper et al., 2003:951). I focus on the insight provided by healthcare providers and the experience of Indigenous caregivers that can be used to enhance health care practices for seniors with regular substance use. Globally and in Canada, no research exists on alcohol-related dementia focused on lived experiences. This research project is also distinct because no other research examines alcohol-related dementia within an Indigenous context. Thus, this research can be used as a model for research with Indigenous communities globally focused on the experiences of caregivers, for alcohol-related dementia or dementia.

Taking a social approach to examining alcohol-related dementia in turn helps the diagnosed loved ones because their caregivers provide primary care, coordinate all medical services and maintain the health of their loved one. Thus, supporting the caregiver and improving or maintaining their well-being is integral to their ability to care

for their loved ones' needs. This research also contributes by adding to the lack of literature focused on the experiences of illness connected to accessing informal and formal healthcare services (Pavalko and Willson, 2011:460).

### 3.2 What is Alcohol-Related Dementia?

The definition alcohol-related dementia is widely debated in literature. In basic terms, alcohol-related dementia is caused by excessive, long term alcoholism and can include physical and cognitive impairments (Powers, 2005:1). It is a complicated illness since excessive drinking can damage different parts of the brain, affecting people through their own unique complications. The impacts of regular substance use affecting people differently was discussed by Jason, the geriatrician:

*...and again, older persons with alcohol looks very different. The older we get the more, what alcohol-related dementia looks like can be very different; large, belligerent, 60 year-old man who is still drinking versus slightly frail, 75 year old men and women, many who are still drinking a lot but are clearly dysfunctional; they can't pull a straight anymore even when they're totally sobered up; they're still not all there. To 90-year-olds it's tiny amounts of alcohol, none of them are drinking large amounts... and when they get a drink or two, they're falling all over and impossible to manage their incontinence and they're aggressive and a lot of them are quietly demented like an Alzheimer's patient. But again, there's quite a range there which is what I was really trying to get at.*

There is little known about alcohol-related dementia since excessive drinkers may also pass away because of other health complications such as cirrhosis or vitamin deficiencies that can also cause brain damage (Harper et al., 2003:951). The only studies focused on alcohol-related dementia are biomedical and what does exist is predominantly conducted by neurologists (Harper 1983; Rourke and Grant 1999; Moriyama et al. 2006; Oslin et al. 1998; Oslin and Cary 2003; Harper et al., 2003) who dissect the brain tissue of corpses to confirm the diagnosis or lack thereof.

Some researchers argue that there are no correlations between regular substance use and dementia, while others have found that, "...alcohol-related dementia has been reported as

the second-most-common cause of dementia among institutionalized older people. Other alcohol neurotoxic effects have also been observed, including cerebellar disease and peripheral neuropathy” (Thomas and Rockwood, 2001:421). This correlates to recent research in that, “alcohol use is a leading risk factor for disease burden worldwide, accounting for nearly 10% of global deaths among populations aged 15–49 years, and poses dire ramifications for future population health in the absence of policy action today” (GBD 2016 Alcohol Collaborators, 2018:1026). Alcohol-related dementia is unique among other types, “including Alzheimer’s disease, vascular dementia, frontal-temporal dementia, Lewy Body dementia and Creutzfeldt-Jakob disease [which] are caused by progressive neurodegenerative diseases. These dementias are irreversible and cannot be cured” (Alzheimer Society, 2010 in Pace, 2010:7). Thus, what differentiates alcohol-related dementia from other types is the potential for reversibility if it is diagnosed early enough.

### 3.3 Reversibility of the Illness

The reversibility of alcohol-related dementia is important because it connects directly to timing and accessing health services early. This came up in discussion with Richard, a social worker when he had an Indigenous client whose health transformed:

*He actually improved. It's like almost like it's a reversal of dementia, but [it is] not because he still has done damage over the years but it's interesting to see that he has actually had some improvement and is doing better with his activities of daily living. It's amazing.*

The importance of intervention is integral to be able to reverse or interrupt the progression of the illness. But this also connects to the ability of healthcare practitioners to assess in the first place and for families to have the knowledge and support to access services. Those with regular substance use are often disconnected from friends and family and do not have caregiver support because of the impact regular substance use has had on their relationships in the past (Lintzeris et al., 2016:229). This was discussed on behalf of the geriatrician and psychologist:

*So, one is the socioeconomic and the personal isolation layer. So yes, people in their 60s, 70s and 80s with previous alcohol use are more likely to be estranged from friends and family absolutely, are more like to be malnourished and though the likelihood is that they're showing up with worse dementia but showing up later because there's no one to rat them out or family to concernedly say 'he's not doing well'. (Jason)*

*Well for a lot of older adults if you don't have family or supportive people in your life...you're just isolated at home. Add in substance abuse, you've most likely burned a lot of relationships so you're even further isolated and I know that...in the literature, older adults are more likely to drink at home. They're not likely to be caught in bars or out and about. For the most part they're drinking by themselves. And so, there is in that piece there of who is going to be the one that helps support this individual? Or who actually even identifies that there's a problem? (Ali)*

Early prevention by healthcare providers is important if there is no family support to intervene. Social support is an integral part of accessing care to have someone recognize the change in cognition and be an advocate to get supports. Annette, a Métis caregiver shared that her father was diagnosed with alcohol-related dementia and their family were able to get support by starting the process:

*...to get the assessment because we had to prove him, you know, we had to show [that he was] financially unfit because of the alcohol-related dementia, we had to prove that, and we did. Then we could you know get him in the stream for care for the nurses to come do his health and all those things he needed.*

This exemplifies the integral role of caregivers as the ones to make the initial steps for care support. Annette and her family were able to have home care for her Dad because she was his advocate. Family support is integral, especially for alcohol-related dementia, and those social connections are key to early intervention and prevention. If an individual does not have family support, their diagnosis can be delayed until a crisis or hospitalization which was discussed by Jason and Ali. Thus, social support is integral to health and should be a part of literature to contextualize the social determinants of health

within someone's life to include their social networks or to provide support from organizations to fill that role.

Another theme connected to the lack of minimal services for Indigenous populations for dementia care including alcohol-related dementia was that individuals were undiagnosed because of a lack of services. Since services for dementia specifically are non-existent in rural or reserve communities, within the Canadian context, the,

under diagnosis of dementia in the First Nations population is probable and often attributed to: reduced access to health services in remote reserve locations, especially to provincial health care services and long term care facilities; questions concerning the cultural validity of screening tools, general cross-cultural care barriers, and differing and diverse understandings of dementia (Jacklin, Walker and Shawande, 2013:43).

For alcohol-related dementia, it can be misdiagnosed because healthcare providers are unaware of the symptoms or are unable to distinguish from other illnesses and co-morbidities (Thomas and Rockwood, 2001:415). Discussed within the literature was that those who did receive a diagnosis of alcohol-related dementia had a history of hospitalization (Withall et al., 2014:1959; Hendrie et al., 1993:12). For regular substance use related falls or illnesses, "the Indigenous hospital admission rate peaks around the ages of the mid-thirties and then again around the mid-fifties as the main cause of admission" (Arkles et al, 2010:22). Screening for dementia is shown within the literature to not be conducted because there are no services for dementia care in Indigenous communities in the first place, let alone addressing regular substance use.

### 3.4 Lack of Existing Literature on Alcohol-Related Dementia

Connected to the heterogeneity of experiences within literature focused on dementia for Indigenous populations internationally, a common issue was accurate data collection because of access to services impacted by jurisdictional issues. Within articles focused on American Indians and Alaskan Natives (AI/AN), accurate data was divergent based on whether research was focused on urban, rural or reserve participants. Government data of service provisions are based on those who live on reserve since urban Indigenous peoples

in the United States do not use Indian Health Services (Jervis and Manson, 2002:90). The lack of accurate data collection is further impacted by inconsistent or sparse data on those who identify as Indigenous. Within research on dementia care in Canada, those who seek services may not disclose their Indigeneity, or healthcare professionals are not trained on how to ask in a culturally safe manner. This is further perpetuated within mental health services where people with dementia are excluded on national population health surveys (Jacklin, Walker and Shawande, 2013:40). This is also found in Australia where there is an,

...under-disclosure of Indigenous status by Indigenous clients when asked; inadequate data collection protocols and inconsistency in how data are captured across and within linked systems; as well as limited data on dementia prevalence, and lack of data on dementia incidence, to inform rates of dementia in the Indigenous population (Arkles et al.,2010: ii).

The lack of data focused on dementia in different Indigenous populations within Canada and internationally can be applied to alcohol-related dementia where no data exists on national rates and only in specific studies. Thus, there are improvements needed within data collection in order to have more accurate representations of prevalence and methods of asking these questions that do not deter individuals and their families from disclosing their Indigeneity.

Inaccurate data is further complicated by the exclusion of participants affected by dementia at a younger age because data typically focuses on those considered as elderly and are 60+ years old. This is a gap in the literature for rates of alcohol-related dementia and explains a methodological flaw within literature focused on dementia in Indigenous communities, “given the accelerated aging phenomenon so common among Natives (National Indian Council on Aging, 1981; Jervis and Manson, 1999), younger individuals may have poorer cognitive functioning than non-Natives of a comparable age” (Jervis and Manson, 2002:93). The exclusion of younger people affected by dementia as a methodological flaw is being adjusted in Australia where planning for aged populations has been decreased to 50 for Indigenous peoples compared to 70 for non-Indigenous peoples (LoGiudice, 2006:270). This connects to epidemiological studies that have found that alcohol-related dementia occurs at a younger age and individuals are often excluded



from dementia research because of perceived age restrictions of the illness affecting a population (Ridley et al., 2018:4). Lowering the age of inclusion for participants can be a methodological approach in order to include populations of people affected by early onset including alcohol-related dementia.

The early age of admission for alcohol-related illnesses and the lack of knowledge by healthcare providers, screening is not being used. It was apparent in the existing literature on alcohol-related dementia that no services currently exist to specifically deal with the complexity of the illness which can include mental, physical and behavioural issues. Within research focused on dementia care within Indigenous communities, it is evident that services for dementia are minimal or non-existent, “therefore, ethnic groups requiring dementia care represent an even more vulnerable subset of an already marginalized group” (Means et al. 2003 in Lanting et al., 2011:104). Differentiating types of dementia, especially alcohol-related dementia is an aspect of literature that needs to be explored. Since the impacts of alcohol-related dementia can be modified if diagnosed early enough, healthcare professionals being able to differentiate the etiology is imperative for the potential to deter, reverse or interrupt the impacts of alcohol-related dementia.

Talking with Annette as a caregiver for a loved one diagnosed with alcohol-related dementia, the topic of available data arose:

*A: I wonder what the numbers are for alcohol-related dementia in our Aboriginal community.*

*D: I tried; this is my research! Australia has a lot of research, a lot of numbers and I talked to someone whose speciality is dealing with the aging population and they even said that in long term care homes, generally it's one in six people. Nobody knows, because no one wants to talk about it.*

*A: Generally, that topic isn't well discussed! (laughing) I agree, I concur. But you know, education is everything. But we should be finding out what the numbers are. How are we going to assess the need for families if we don't know what we're dealing with here? The*

*population is aging right?*

This is insightful because change cannot occur if there is a lack of knowledge of how many people are affected and how they are coping, especially since alcohol-related dementia affects those who may face social isolation. The wider implication of more research on the subject is not only beneficial for Indigenous communities, but non-Indigenous communities in Canada as well since regular substance use and aging are factors for both populations.

Since there is a lack of public outreach geared to early onset dementia, which can include alcohol-related dementia, a diagnosis is often delayed. For dementia, only people with Alzheimer's Disease (AD) are often sent to a memory clinic to start the process of diagnosis and assistance, but many people do not exhibit textbook symptoms, or their families do not know what to look for. This is also applicable to healthcare providers since diagnosis is much later as a result. People do not access services because, "...many are often not diagnosed with dementia or referred to dementia specialists until 2-3 years after the onset of their symptoms" (Lipton and Marshall, 2013:7). It is usually when a crisis situation occurs that people are provided services in a timely manner instead of services focusing on prevention and offering specialist services when symptoms initially present. But more research is needed to focus on positive preventative measures for Alzheimer's disease and other dementias, especially in Indigenous communities since there is limited literature on the subject. Cations et al. conducted a systemic review of younger onset dementia (YOD) which showed,

...that modifiable environmental and lifestyle risk factors are probably relevant predictors for YOD, but the field overall lacks high quality evidence [so] that it is not possible to confirm this relationship. The contribution of modifiable factors, particularly in 'older' YOD groups, may be underestimated as the field is dominated by studies of genetic influences alone. People with YOD can provide insight into the most important risk factors for dementia at any age, but high-quality prospective research is required to better understand which factors are important and when exposure is detrimental (2016:123).

Prevention through modifiable lifestyle changes is key to reducing dementia especially when it comes to alcohol intake. But this subject is entirely missed because of age and

those who have a past history of regular substance use are excluded as research participants (Lock, 2013:126). This was discussed by Ali about the impacts on knowledge translation because of exclusion of people with regular substance use:

*They want pure groups right. They want pure untainted groups where you just have the one problem and that's it. Yeah but that's not life. So, it's that longitudinal research that will be more interesting because I think they're a little bit more inclusive because they just follow people through time.*

If regular substance use is not included within research in the first place, then more knowledge cannot be gained, and thus public outreach and awareness cannot be mounted effectively. It is also a shift in research to be more realistic of lived experiences, especially seniors with regular substance use where their social and medical history of who they are as a person is complex and needs to be factored into literature.

### 3.5 Changing Landscape of Research

For research on regular substance use and dementia, the literature is in constant flux. Past studies that discuss the health benefits of alcohol consumption are disproven by others that state zero alcohol intake contributes to reducing risks for dementia. The importance of literature for regular substance use and dementia is that it has an impact on the practice of healthcare providers' knowledge on the subject and their recommendations and treatment plans for clients. Healthcare providers need to keep up with the changing trends because this informs their daily interaction with clients. Jason discussed the ever-changing literature on prevention for dementia:

*All the time thinking, knowing that half of what I teach will be proven false in 10 years. That's how I know I'm at the cutting edge but also how I know then you have to be humble enough to say 'what I taught you then is wrong. We've had a better quality of evidence, a better standard, a higher standard that disproved a lower standard'.*

*That's just the nature of the beast and it makes it hard when you're at the clinical interface talking to patients and their families because you have to basically say is 'what*

*we do is practice' because if we really knew what we were doing, we would call it something else and that in the 1990's I was advising older women to drink a little red wine and to take a little estrogen to save their brain. Once the women's health initiative came out and showed that estrogen actually doubled dementia risk, I said no and went exactly the other way and now I've got off that bandwagon many years ago but now it's on the reverse bandwagon which is cutting down to essentially no alcohol intake to preserve cognition in older people. But it will take us a while to get there... both within as a profession but also society wide. That will take even longer.*

Prevention is key to alcohol-related dementia, but if there is a lack of available resources for healthcare providers, their practice cannot be an informed approach. There is also the interesting aspect that as there are changes based on research, it takes time for uptake with healthcare providers and with the general public. This was discussed by Ali, the psychologist to educate about regular substance use and the connection to the potential health effects:

*So, we're hoping that if we can disseminate that to the general population, they might be a little bit more mindful about the drinking. There's lots of people just don't realize how alcohol can affect their health because there's obviously spectrums of drinking. There's like abstinence and then there's alcohol use disorder. But there's so much in between that people can fall into this gray area where they might be affecting their health negatively with alcohol use. So, we're trying to capture more of those individuals with those guidelines. But hopefully the treatment guidelines will direct its non-pharmacological treatments as well as medications. But there are some medications that are covered by OHIP. We are going to hopefully advocate that OHIP as well as other provinces because this is Canada wide coverage. The medications that have been proven to be effective for older adults and so that's exciting.*

A study released in 2018 documented a shift that no alcohol use is the only way to not have a health loss (GBD 2016 Alcohol Collaborators, 2018:1015). Past research was focused on the protective factors of alcohol consumption for diseases including dementia, but, "...these studies were limited by small sample sizes, inadequate control for

confounders, and non-optimal choices of a reference category for calculating relative risks” (GBD 2016 Alcohol Collaborators, 2018:1025). Although abstinence is not an effective approach for harm reduction, education is important for public outreach. It will take time for uptake for this shift in societal ideals for knowledge translation from research into public discourse. Therefore, healthcare providers can be a point of contact for sharing this information since prevention is important for reducing the risks of alcohol consumption on all diseases including dementia.

### 3.6 Historical Trauma

If regular substance use is being used as a form of coping with historical trauma and structural violence, it is important for healthcare providers to understand how health is impacted by colonialism. Regular substance use can be used as a coping mechanism related to historical trauma, which is the direct consequence of centuries of colonizing practices. Historical trauma is the unintentional impact on the next generation of self-destructive behaviours used to deal with perpetual life stresses and the loss of cultural identity including language and traditions (Brave Heart, 2003:9). Research clearly shows that the colonization of Indigenous peoples in Canada manifests across generations through the transmission of historical trauma. Historical trauma is a consequence of residential school including regular substance use, violence and the loss of traditional language, culture and history. All these intersecting factors can be traced back several generations to understand the long term effects of colonialism and that it is still happening today.

From his experiences working with Indigenous families, intergenerational trauma was discussed by Richard:

*I'm dealing with [the] gamut when you're dealing with caregivers depending on the situation. When you're dealing with early stages it's fine because I give them some education. I can say lifestyle changes, you know you have exercise, you've got the three big things being remaining social, diet and exercise. Doing that education and for the most part the older generation is good. I don't know what the next generation will be when they reach it. It could be different because now diet and everything has changed*

*that way. But exercise and the social with the older is there in a sense until they reach that middle stage and then their apathy is coming in full-blown. Family members and caregivers burn out rather quickly right because you have all that resentment from their childhoods right of the parent who wasn't there for them or drank or you know abused them, you know. So now they're resenting. So, trying to work through all these issues right is difficult. So, you're dealing [with] a lot..., I wouldn't say it's any different sometimes. It's just more pronounced if that makes sense. Because I have caregivers who now have their own issues of alcohol as a coping mechanism and now of course as our parents age has become more pronounced and how do I deal with this? So, they go back to some other patterns and it's difficult. I've got some who have given up alcohol and have taken up marijuana as a coping mechanism. It's really interesting to see changes. It's harm reduction I guess in a sense, but we'll see what the studies show.*

There is a need for a cultural understanding of the ongoing impacts of colonialism in order to contextualize that, “the roots of addictive behaviours are found in the impacts of this mass psychological trauma and these human rights violations. Unexpressed and unhealed, these impacts have manifested in social disorders. Cultures that had never before seen youth suicide, addictive behaviours, substance abuse, or physical and sexual abuse began a spiral into tragedy” (Chansonneuve, 2007:17). An aspect of healthcare providers being culturally safe is being aware of historical trauma and how it can manifest in the form of low socio-economic status, low educational attainment, fractured families because of colonial policies such as residential schools and the ‘60’s scoop’ in Canada and higher risks of regular substance use.

A recommendation to address historical trauma is culturally safe care, a holistic approach to health that is focused on the spiritual, emotional, physical and social. Culturally safety, “...recognizes that health care providers need to be respectful of nationality, culture, age, sex, political and religious beliefs, and sexual orientation” (NAHO, 2008 in Pace, 2010:13). The importance of cultural safety connects to understanding the beliefs and conceptions of dementia which can be divergent based on each nation, community or family. It was argued within existing literature on dementia in Indigenous communities that some people view dementia as returning to the spirit world (Arkles et al, 2010:2;

Hulko et al., 2010:319), while others argued that dementia is a ‘white persons’ disease (Pollitt, 1997:155). The divergent dementia perceptions shape culturally safe care that is contextualized based on beliefs about aging. Culturally safe care founded on Indigenous perceptions of aging, memory loss and dementia are needed since, “not enough is known about how various Native groups conceptualize, recognize, or manage cognitive impairment. Of special importance is understanding what happens to dementia sufferers when family care is unavailable, substandard, or fails entirely” (Jervis and Manson, 2002:94). This is applicable to families affected by alcohol-related dementia because culturally safe care is needed to make people feel safe in order to access care.

A holistic approach as discussed for dementia care is looking at the entirety of the life of an individual to understand the context of their illness. What this means is that the diagnosis is not understood only as a snapshot of that particular moment in their lives (Quesnel-Vallée, Willson and Reiter-Campeau, 2015:487), but looking at the interaction of social and biological determinants, both proximal (early life) and distal (mid to later life), impacting on late-life risk for dementia (Arkles et al, 2010: iv). A practical example of a cognitive assessment that is culturally safe was developed in Western Australia for the Kimberly Indigenous community (Smith et al.,2011:89). This tool is also applied to collect information not only about the individual, but their caregiver including biographical data such as smoking and regular substance use, emotional and social well-being and daily activities (Smith et al., 2011:89). The benefit of this cognitive assessment tool is that it can be adapted for urban Indigenous populations based on their geographic locality along with divergence in language and education levels in comparisons to communities who are living in rural or remote areas (Radford et al., 2014:1034). Since the tool is based on the community context and administered by community members, it is culturally safe whereas other cognitive tools are predominantly based on Western assessments including pictures and concepts of time not grounded in Indigenous epistemologies.

## 3.7 Ageism

Speaking to healthcare providers and caregivers, ageism became apparent for those who are being missed within healthcare practice. It includes those who have early onset dementia which is shown to impact more Indigenous than non-Indigenous peoples before the age of 65 who thus are missing from literature and health studies. But ageism is occurring for regular substance use treatment for seniors in that supports are not provided because of their age and a diagnosis of dementia is labeled without getting to know the person in-depth. This means that people are being missed which presents an area of improvement where ageism needs to be addressed for dementia not based on age alone. Public outreach ties into this in that education of healthcare providers is not only necessary, but the general public as well needs to learn to recognize that certain symptoms are not an inevitable part of aging and that just because someone is younger does not mean that dementia cannot be a possibility. Jason, the geriatrician summed up the correlation of ageism and accessing support:

*But you're a lot more convinced they're not demented now and that's the other part is that societally and amongst healthcare [providers], there's a real push once someone is past the age of 80, if they have cognitive impairment to put on a diagnosis of dementia and put it on quickly. When old people... make your mistakes when you're young because when you're old, it's not forgiven. If you go out and park your car and get a little fender bender in a snow storm or miss a few bills. Our society will come down on you so hard and will try to push home care and to the family docs and the geriatrician and say 'oh it could be dementia' and as soon as you say it could be, a lot of doctors in training start jumping up and down and saying 'dementia, dementia, dementia!' every time that person comes to clinic or [is] admitted. I didn't say they were demented, I said they could be and I'm going to sort it out. Everyone else is quite happy to apply that label and put them in a box.*

Social expectations for aging means that any sign of cognition change means that it is dementia. With a diagnosis of dementia prematurely labeled, it alters the way the person is treated in health care and shapes the path for their access to treatment. Through



labeling someone with dementia outside the context of getting to know them or treating them as a complex person, it, "...restrict[s] a person's social identity to 'the patient' or 'the burdensome patient', [and] is to put them at risk of malignant positioning and the ensuing treatment, malignant social psychology, that leads to depersonalization and a loss of self-worth, whilst simultaneously obscuring the person's remaining intact cognitive and social abilities" (Hughes, Louw and Sabat, 2012:297). It can also limit other health issues from being investigated if a singular reasoning is given. The importance of the above statement is that time is needed to get to know the person in order to find out their needs, issues and expectations in partnership with the healthcare provider. Amanda discussed getting to know the person:

*I think that all of us, all of us from different health related organizations, recognizing that there is interplay, that again our human self is very complex and you know an analogy that I heard from a physiotherapist to say you might have a victim and you have a culprit and sometimes you focus on the victim, we're not looking at what else behind it, so looking at other contributing factors. So, a person living with dementia, it might be something else going on with their health, it might be their emotional health, it might be some of their safety needs. So, there is a whole lot of other factors rather than just looking at a person from a medical model.*

Jason and Amanda are great examples of non-Indigenous healthcare providers who work with the person they are meeting with to address them wholly as a person. They do not strictly focus on a diagnosis of dementia that comes with attached social perceptions and medical impacts not only for the person, but for their interaction with healthcare providers solely based on age. Amanda was discussing those with a diagnosis of dementia, but it does not mean that everything is defined by that for their health. Contributing factors that are not only medical, but social and emotional, needs to be included in healthcare and that so often is missed.

The lack of treatment based on healthcare providers conceptions of old age is a barrier for older adults being admitted to emergency departments. If regular substance use is not included in the education of healthcare providers and addressing these ideas of aging and

what regular substance use looks like, it can limit providing support (Sullivan and Levin, 2016:10). I was surprised by this finding that regular substance use for seniors is missed because of ideals of regular substance use for aging populations and that medical providers are not trained adequately to address this. In looking for literature on the subject of aging and regular substance use, there are minimal resources which is another gap that needs to be addressed.

### 3.8 Co-Morbidities

For seniors accessing healthcare, since regular substance use is not often checked, another factor is that other medical issues and co-morbidities are dealt with first. This is contextualized by Jason:

*The old ones get admitted, we find other things wrong with them because we always find other things wrong with them, 'oh you're dehydrated and you had a mild kidney failure, you need to be hydrated because you haven't been eating or drinking very well lately. We thought you might have pneumonia too but then we decided you didn't'. You fix the dehydration, you fix the renal failure, you decide against the pneumonia and you didn't even touch the alcohol because you weren't aware of it and you might bring another pill or two in and off you go with home care to check on them and make sure they get something to eat and maybe take your pills and we feel good about that when we do that. I mean that's not very accurate healthcare but that's common, at least for the first time or two or three.*

Ali discussed that screening for regular substance use should be a part of all interactions, but it needs to be done without judgement which contributes to stigmatizing the client:

*Whereas it should be standard care to ask those questions and then have a nonjudgmental approach because that's what you need to do when you're working with older adults or any person with regular substance use issues. Leave the judgment up somewhere else because it doesn't help that person who's sitting right in front of you get the care that they need because I think that if our system was more compassionate and open minded and less authoritarian like 'you must do this', 'you must do that', maybe*

*people will be more open to approaching treatment because they're not going to be stigmatized or judged. Then they can say 'oh well maybe there might be something going on' and you just need that flicker of that hope that there might be something better and that's what you have to grab on to as a clinician right. Sometimes finding that glimmer is very difficult though.*

It tends to be several visits before someone's regular substance use is addressed because co-morbidities are prioritized since they often require medication changes. Although one study in Australia found that, "diagnoses comorbid with a dementia diagnosis included psychiatric illness in 41 (46.4%), alcohol abuse occurred in 12 (13.6%) and traumatic brain injury in 4 (4.5%). Multiple dementia diagnoses occurred in 33 (37.5%) participants—27 had two, 5 had three and 1 had four different dementia diagnoses" (Draper et al., 2016: B). The treatment is often focused on what can be fixed immediately whereas regular substance use cannot be addressed in a single visit. The complexity of regular substance use is that it requires more time, energy and resources to provide support. It also depends on meeting the individual where they are, to not force abstinence, but offer harm reduction if they cannot or do not want to quit. This would be an expensive endeavor since it would require longer hospital stays, offering more resources including spiritual care, social work and mental health counselling along with treating physical symptoms. As stated by Jason, it is not until several visits to the emergency department where regular substance use is considered, discussed or dealt with.

With other presenting illnesses, these are often treated excluding dementia or regular substance use as a contributing factor even though, "dementia symptoms rarely occurred in isolation. There was agreement among reports from caregivers and key informants that a diagnosis of 'dementia only' is rare in the Aboriginal population on Manitoulin Island. People are most commonly dealing with concurrent diseases especially diabetes, amputations related to diabetes, arthritis, depression and cardiovascular disease" (Pace, 2013:21). This was consistent in talking to caregivers as well that all of their loved ones had other illnesses including a past history of cancer, diabetes and heart disease along with dementia. These are often treated first, and it is not until multiple admissions or visits to a health provider before regular substance uses or dementia are even addressed.

The impacts on families and especially Indigenous families who are providing care with minimal to no additional supports, means that the caregivers are doing their best coping with co-morbidities as well as dementia and/or regular substance use. This creates strain for caregivers whose health and well-being may be impacted.

### 3.9 Non-Existent Services

Within the literature, minimal or non-existent services was defined as the biggest barrier for dementia care. Many factors were identified as inhibiting or deterring Indigenous individuals and their families from accessing formal care. These included a, "...lack of awareness of dementia, difficulty in travel to specialized healthcare services, language barriers, and distrust of Western healthcare systems" (Lanting et al., 2011:104). For community members living in rural or reserve locations, their access is further restricted by services not existing in the community and needing to travel to receive care. It was also argued that the, "need was also greater than supply for the following service categories: home health care; social services; alcohol, drug, and mental health care; and legal services. All housing services, economic services, and two support services (adult day care and respite care) were rated as often needed but rarely to never available, meaning these needs were rarely met" (Jervis, Jackson and Manson, 2002:304). Since access to services for dementia care are non-existent or minimal, services for alcohol-related dementia are further complicated because of early onset and behavioural issues. Since most care programs are geared towards older populations, those affected by alcohol-related dementia at an earlier age do not meet the criteria for services (Withall et al., 2014:1956; Jervis, Jackson and Manson, 2002:296) and the burden is placed entirely on the caregivers. A lack of services for regular substance use support is a global issue and,

in Australia, there is a paucity of data about the quality of clinical care provided to this patient population. This is a result of lack of clarity in clinical guidelines, uncoordinated (or 'non-existent') clinical pathways between service providers and incomplete data capture and follow up. The health services specifically providing for ARD are few and fragmented, and there is a scarcity of supported residential accommodation (McPhail, McDonough and Ibrahim, 2013:C).

If caregivers are the ones facing the challenges of caregiving for loved ones with regular substance use or there are no friends or family because of social isolation, this creates two vulnerable populations of people that are being missed in research and accessing services; one is the individual and the other is the caregivers.

With caregivers not being able to access supports that are specific to alcohol-related dementia, mainstream services geared to dementia are utilized. With the caregiver taking on the additional role of coordinating the different services because of issues of jurisdiction and continuity of care, there is a high risk of the caregiver becoming a 'hidden patient' (Medalie, 1994: 64). Continuity of care is successful coordination of health services on reserve and off reserve that, "...encompasses all three of the identified types of continuity: informational, relational, and management" (Reid and McKendry in Tarlier et al., 2007:132). Since the caregiver is focused on meeting the needs of their loved one, their own health is neglected. Studies geared toward settler Canadian female dementia caregivers found that, "other caregiver characteristics that increase psychiatric morbidity include caregiver 'overload', perceived low life satisfaction, role captivity, and depression" (Yeager et al., 2010: 377). Since dementia requires care because of physical and mental diminishment, the stress of caregiving increases as the health of their loved ones deteriorates. With the lack of support for Indigenous dementia caregivers, there is even greater stress and health effects for alcohol-related dementia considering that there is minimal medical knowledge for prognosis, so caregivers are left in a perpetual state of uncertainty for the health journey of their loved one and themselves.

Within Canadian healthcare systems, therapies are usually singular and not integrated. This was discussed by Ali about the siloed system:

*I think what will end up happening is we will become even more siloed right because we will be trying to protect what funding we do have access to. And then we will try to prevent people from double dipping and we often have those services right, where if someone's being followed from substance use services then I won't be involved because otherwise that will be double dipping; they'll have two clinicians and it's actually probably not helpful having two clinicians doing similar work unless they're*

*communicating right? Without having to cross what they're doing. Yeah but that's the system we work in with 1 service to answer all the questions. So, [there's] a new referral system called the geriatric ambulatory access team and physicians send referrals to them. [The Behavioural Support Ontario] program accepts referrals from anybody so neighbors, family members, clients themselves and so they treat it and then they decide what service they get so that you can't double dip. Which is good except that with really complex individuals for instance people with physical health concerns, challenging behaviours because of their dementia or substance use or mental health issue and some other issue, they only get one service. So how do you do that? So, we try for those individuals. So, we've had some individuals with really physical health issues as well psychiatric issues. We will partner with the team and go out to people or teams to come out and do a full assessment individually doing an assessment but to put together to get a better picture and then figure out which team should be continuing with follow up that would be appropriate. But we have to instigate that because the system doesn't want you to access more than one service even if it might be helpful. Yeah which is difficult. So, if it's moderate or high-risk behaviors we usually get it because we can respond quickly. We have the mandate of getting out within 72 business hours. Yes, but that means that anyone who is urgent gets sent to us because they can't wait for the actual appropriate service, which is difficult because it straps our case managers, so I think we're making gains on how to better access the system. But it's still not great.*

For people who need services, they can only access one at a time instead of having multiple service providers who communicate and work with one another even if it is beneficial for the individual and their family to have additional supports. The siloed system means that people can only access one service and they might have complex needs as stated above that can be physical and mental. For people accessing health care, you are forced to visit multiple providers to deal with different parts of your mental or physical health, thus contributing to the body as the site of importance for health. The ramification for ADOD and especially alcohol-related dementia, is that diagnosis is delayed or missed because a diagnosis is needed to confirm a definitive labeling (Lock, 2013:3). For dementia connected to regular substance use, if families are concerned, their recognition of symptoms is not legitimized until a doctor gives the label. This has

implications for anyone with ADOD or ARD and their families that can mean not accessing services that can be preventative if early enough. For Indigenous families, services are often non-existent in their communities or extensive travel is required. This is also applicable to non-Indigenous families dealing with ADOD or ARD in rural areas, in that specialists' appointments are difficult to travel to and can take many months when services are not available nearby.

The lack of research on alcohol-related dementia has implications for healthcare provision because it means that there is a section of the population that is missed because of the, "...limited expertise to diagnose accurately, limited expertise in clinical care, limited investment in research, and limited establishment of policy relating to these disorders" (Dew and Matheson, 2008:119). Research is integral to practice in that it brings awareness to a subject and can mobilize funding for support and further education to improve the lives of those who are affected by it. The lived experiences of caregivers and their loved ones affected by alcohol-related dementia is continuing to provide care until a crisis occurs. Thus, the perpetuation of providing care after the fact instead of preventative or early intervention.

### 3.10 Healthcare Providers Conceptions of Regular Substance Use

Regular substance use is a difficult subject to research especially since it is not a simplistic diagnosis that can be fixed with medication or a singular lifestyle change. Accompanied are complexities of the person and their family that need to be factored in. If healthcare providers do not have knowledge about alcohol-related dementia, it can prolong the process of getting a diagnosis and support including homecare and nursing if necessary. This creates stress especially impacting caregivers who are often sent to many different specialists with their loved one without receiving a diagnosis (Withall et al., 2014:1960). The lack of services for dementia illuminates that the lack of service provisions is exacerbated for alcohol-related dementia because of age, co-morbidities and regular substance use. This is a huge gap in service provision that has impacts on the family level of individuals and caregivers. The disconnect of knowledge and practice

affects the health journey of families navigating a healthcare system that is siloed and isolating. It forces caregivers to be advocates to get the support needed for their loved ones whereas the onus should be on healthcare providers to ask pertinent questions including regular substance use and treating a person holistically. It was found in the literature that practitioners are uneducated about the symptoms of regular substance use and alcohol-related dementia which means that it often goes undiagnosed. As discussed by Ali:

*I think a lot of people don't get a lot of education about alcohol use. I know it's not covered very much even in med school. So even GP's aren't. I don't think they're as well equipped as they could be. I know that...I didn't get any education about addiction except in undergrad which I mean that's not part of the clinical program. That's just regular for anybody. But I sought out substance abuse training because I had an interest in it. So unfortunately only the people who get the training or experience are the ones that want to work in it and those aren't the individuals you need to catch, you need to catch the other individual because you will see it in any age group across all cultures, groups, races, any setting that you will encounter substance use. So that's been a challenge.*

An improvement is to include regular substance use in education of healthcare providers so that they have the training, knowledge and resources to be able to address regular substance use with their clients. If they do not have the training to know what the symptoms and signs are, how to ask in a non-judgmental approach and to know resources, then people will continue to be missed. Korsakoff syndrome was addressed within the experience of Richard where healthcare providers were unaware of it. Korsakoff syndrome is, “an acute neurologic syndrome caused by thiamine deficiency and prolonged heavy ingestion of alcohol” (Kessels and Kopelman, 2012). Richard shared:

*I just think too, I think though the health professionals don't address [it], when I talk about Korsakoff, when I say Korsakoff; it's really in a severe situation of dementia wise. They don't know it. With Korsakoff, I've had doctors ask me what it is. Well OK let me try to explain it in my laymen terms. But its huge damage caused by dementia and you get*



*to a point where you can't do nothing about it when it reaches, when it basically reaches is what is determined Korsakoff syndrome, there's nothing you can do. I ran across it a couple times.*

The treatment of seniors with regular substance uses was discussed by Jason, in that in their profession no services exist for seniors with regular substance use:

*Outreach for peer counselling... for people that have alcohol issues but there is no explicit standalone alcohol for the elderly program that I'm aware of. There wasn't then and there isn't now and again partly I think it's the societal acceptance; it's OK for them to drink, how else will they cope with the miseries of old age? That's ageism when we don't allow that in young people. That's not acceptable for people in their 40s or 50s. But we somehow say that's OK where actions imply that it's OK for old people. People over 65, you have alcohol intoxication to excess or whatever are indistinguishable from those that have benzo excess or gabapentin excess who are in emerg and are confused and sometimes we check the B2 levels of alcohol and it's high and sometimes we don't because they look just like my grandma and she wouldn't do that, she wouldn't drink like that.*

*So I've spent most of my career encouraging young doctors to check an alcohol level, check a benzo level, check a narcotic level and all of the confused people that have been admitted because you never know and they're not doing any better than they did 20 years ago. It works but it could be better so that something that tends to get missed, it's a bit of a blind spot. The notion of this little old frail person looks like my granny who is delirious could be related to drug intoxication or withdrawal or alcohol intoxication or withdrawal. It's hard to tell, to sort them out, to see the difference. We still miss that a lot.*

Healthcare providers conceptions of regular substance use have impacts on their practice if they are not checking alcohol or opioid levels in the first place because of the age of the admitting patient. Ageism connected to regular substance use based on the physician's ideas of regular substance use to cope with aging means that they remove treatment options. Seniors should have all options offered to them and not limited because of their

age. A lot of people with alcohol-related dementia are being missed as well because they do not access healthcare support in the first place. It is typically those who are admitted more often or have social support to bring them in to get checked out:

*But again that's a minority so at 80% relatively silent and a 10% to 20% it's more obvious, ...makes a lot of noise and it gets a lot more attention. Generally elderly alcohol problems are swept under the rug and kept generally quiet, under perceived and I'm not sure how fast it is really changing. (Jason)*

It is a vulnerable population for those who lack social support and do not gain medical attention until a crisis occurs. Ali discussed family doctors as point of contact:

*And if they're isolated that's for the most part family physicians, not a lot of them screen for alcohol misuse. They will only ask questions if someone presents with a problem and if they present with a problem then you're already ahead of the game.*

In order to address issues of regular substance use, it needs to be common practice to be a part of the interaction with any healthcare provider since it might be the only opportunity if someone is at a medical appointment. But it is not consistent across the medical profession, so work needs to be done at the education and training level of new practitioners to ask every time.

Since regular substance use is not usually a factor until several hospitalizations, research in Australia focused on older adults with substance abuse and accessing regular substance use specific services,

...the high rates of existing health service utilisation by most clients and the diversity of health and social problems suggests that a care coordination or case management approach may be better suited for many clients. This would entail coordinated care plans that identify the client's (D[rug] and A[lcohol], health and social) problems, clarifies client goals, documents proposed actions and plans, and coordinates and integrates different service providers involved in the client's care. Such an approach is consistent with the principles of chronic disease management (Lintzeris et al., 2016:229).

Ali views case management as a form of harm reduction and giving clients choices in their healthcare journey:

*So you become a case manager and...like it's not an regular substance uses counselor. You're a case manager helping people with their everyday life because in the end, if you don't take care of those needs first, you're not going to tackle the substance use part. Yeah, it's not going to happen. So, I mean that's the quintessential harm reduction approach, meet the client where they're at to help them with those challenging issues so that they can deal with the issue when they need to.*

The benefit of case management is a holistic approach to addressing all needs of the individual as well as combating social isolation. Those who do not have familial or social support can access services that can potentially fill this gap for improved follow up, more involved team members and addressing social needs. Since there is no research focused on regular substance use for those who are affected at younger ages or those who will not access health services often or at all, there are quantifiable numbers of people being affected and thus being missed from being given support. Coordinated care planning can be a holistic form of healthcare not only to address social needs but create relationships of support since it is integral for well-being to have someone care about your health and advocate on your behalf.

### 3.11 Gendered Diagnosis of Men

Within most research, Indigenous male participants were more likely to be diagnosed with dementia or memory loss than women or were argued as being at higher risk because of their social behaviours. These behaviours were gendered intersecting with, "...higher rates of head injury, heavy alcohol use, and prior prison/police custody and were more likely to have been in paid employment through their lifetime and to be currently married or in a de facto relationship" (Radford et al., 2015:274). Within articles that included alcohol and substance abuse as potential risk factors for dementia, it was found that men, "comprised a much greater proportion of the definite (72.5%) and questionable (72.4%) alcohol abuse diagnostic groups as compared with those diagnosed with no alcohol abuse history (30.9%)" (Thomas and Rockwood, 2001:417). The gendered diagnosis of men having higher rates of dementia and regular substance use were not often correlated in articles. Regular substance use was included as a risk factor

but was not discussed in greater detail. Within one article focused on dementia in First Nations communities in British Columbia, there are commonalities with studies in Australia focused on Aboriginal and Torres Strait Islanders where men are experiencing dementia at twice the rate of Indigenous women (Jacklin, Walker and Shawande, 2013:40). The gendered experience of dementia for men is a topic of research that requires more study.

Most articles that discuss the higher rates of dementia for Indigenous men compared to women and non-Indigenous populations were quantitative. Thus, there is the opportunity for study focused on the social implications of gender intersecting with other factors such as regular substance use, low education and head injury. Head injury is rarely accounted for within dementia research although in one study,

head injuries emerged as a significant cause of memory loss in our sample. Three individuals directly described head trauma as the cause of their symptoms. Others referenced people they had known who had lost their memory after an accident involving a head injury. Participants described cases where memory symptoms immediately followed a head trauma as well as delayed effects on memory linked to childhood head injuries (Pace, Jacklin and Warry, 2013: 30).

This connects to practice in that:

*...the other thing interlaced with alcohol is that heavy drinkers often bash their heads and don't remember. So, you got that interaction as well that we're probably not capturing. (Jason)*

The correlation of head injuries and memory loss in conjunction with regular substance use, especially among men needs to be addressed. The prevalence of men being diagnosed with dementia was typical within my discussion with caregivers and healthcare providers where all the caregivers were for a male loved one and many stories of care providers focused on men as well. One interesting aspect when discussing regular substance use for seniors with healthcare providers, it was more common for non-Indigenous women to have regular substance uses and Indigenous women were not seen in their practice. This connects to the gendered role of caregivers being women for a loved one with dementia including loved ones with alcohol-related dementia.

The findings of Indigenous female caregivers for a loved one with Alzheimer's disease and other dementias reflects the gendered findings existent within literature. All of the caregivers who shared their stories cared for a male loved one who was either a spouse, grandfather or a father to them. This reflects an important aspect to the gendered diagnosis of dementia within the literature. According to Jacklin, Walker and Shawande their research, "...suggests that more First Nations men than women are being diagnosed with dementia, despite higher rates of diabetes and hypertension in First Nations women. This indicates that co-morbidity alone likely does not account for the increased prevalence of dementia found in First Nations" (2013:43). When asked about reflecting on Indigenous clients within their practice, one healthcare provider has not had many Indigenous women throughout their practice and another shared that:

*I don't have any female Indigenous people in my practice going back at least 15 years who have had alcohol issues. It's always been men whereas in the non-Indigenous population it's more women. (Jason)*

This connects to the importance of public outreach and prevention that needs to be targeted to Indigenous men. It provides insight to those who are caregivers are mostly women in Indigenous communities. This means that there is opportunity for understanding gender dynamics for caregiving.

### 3.12 Regular Substance Use Across the Life Span

If regular substance use is a part of the healthcare interaction and is investigated, it is often focused on the person's current usage as opposed to factoring across the lifespan. Drinking for an extended period of time throughout their life can mean that, "the differing elements of drinking patterns (for example, duration and severity of abuse, binge, and withdrawal periods) as well as difficulties gaining an accurate self-report of past drinking have further complicated attempts to link drinking levels to later cognitive impairment" (Ridley, Draper and Withall, 2013:3). The onus needs to shift to educate healthcare providers of someone's life holistically to gain understanding of their social context and that regular substance use may have been used in the past and getting to know why it was

used. Several hours and many visits with clients are needed to develop trust to be able to have candid discussions. Time is an integral aspect of healthcare that is not prioritized. Time allows a patient and their family to get to know their health provider in-depth to have a reciprocal relationship and to feel comfortable to share their life-history free from judgement. This was discussed by Jason:

*The question being we're probably asking more than we did a few years ago, is: were you a heavy drinker for like 5 years? Or 10? Or 20? Or 30? Or 40 years when you were younger as well? Not now, but in your 20s, your 30s, your 60s? The disclosure is better, but I think we're still not very accurate about people that had heavy drinking for decades when they were adults. It's much more focused [on] their drinking now and over the past few years and even recognizing that a lot of people were heavy drinkers for whatever reason; bad marriage, bad job, bad etcetera in their 40s or 50s, you know.*

A deterrent for people disclosing their regular substance use in the past to a healthcare provider can be stigma and fear of judgement. Ali shared the systemic limitation of time:

*I think people expect me to fix people and I can't. I'm not a miracle worker. I get lots of referrals of people who are drinking who need therapy and then they sit across from me even if they don't have impairment, and there's complete ambivalence. They know they should stop. But there are plenty of reasons why they should keep going. And they're not in a place where they even want to consider quitting really and besides the fact, they hear from everybody that they should quit. They don't need some other healthcare provider telling them that they need to quit because they already know it. It's finding the reasons that they want to quit. That is the hard part and unfortunately with the health care system we have, we have such a long wait list. We can't keep people like that on our books just because. I mean it would be great to have developed strong rapport and get someone to get to the place where they need to be. But we just can't. We don't have the capacity.*

This applies to people with regular substance use where help is often conditional on abstinence or the lack of understanding why someone would intentionally harm themselves. Applying the concept of health as a lifelong journey reflects Indigenous,

...recognition that no one can ever claim to be meeting their responsibilities perfectly or to be perfectly healthy. The belief is that we can always think, do, and be better than we are now. In that sense, we are all engaged in healing, which is to say, that we are all on the same road together, trying to move closer to Creator's spirit in everything we do (Ross, 2014:271).

The existing policies and programs do not reflect lifelong journeys but are disjointed and only focus on 'fixing' the issue at hand. The relationship between provider and client are not based on longevity. It is often singular interactions to prescribe and only seeing or helping people when they are ill. A change needs to be made where interactions are lifelong, to maintain health, assisting one another instead of someone being ill and only returning when it is not getting better. This concept of lifelong health being a journey can be beneficial for all populations because it is focused on a strength-based approach to find what is working to help find balance in peoples' lives. For policy implications, it has financial gains since people would not be accessing healthcare repeatedly for the same issue or because of a lack of relationships with providers that are founded on distrust and judgement.

### 3.13 Chronic Pain Management

With addressing regular substance use across a lifespan, another aspect being missed for seniors is pain management. When seniors are accessing the healthcare system, doctors are quick to diagnose for dementia instead of spending time with the person to get to know their health and social history. Education for pain management assessment and treatment was reflected in a systemic review, "reporting that key educational needs related to pain management in older adults include pain assessment strategies, pharmacological and nonpharmacological treatments, and how to distinguish pain expression from other behaviors that are commonly observed in this population, particularly those who have dementia" (Kaasalainen et al., 2017:178). Treating pain can greatly reduce the symptoms connected to memory issues and regular substance use as a self-medicating tool. Chronic pain is treatable and can be connected to symptoms similar to dementia such as memory and mood shifts. Jason reflected on his professional experience that:

*... it's surprising how much better many older persons will get in terms of their memory once you fix their pain and their mood. I wasn't expecting that, and nobody told me it was going to be like that and literally that was the big theme of my clinical practice over the last 20 years and that's a really common presentation and how we've handled that has really changed a lot. And one of the reasons that people are less demented on average than 20 years ago. Without a cure for Alzheimer's and without a recognition of what kind of dementia it is these old people have, is that what you thought was a problem wasn't the problem and what we thought was the solution wasn't a solution. That wasn't, this was. So, it's been fun.*

Treating chronic pain connects to the misdiagnosis of dementia for seniors in that if the person is treated more holistically, the removal or reduction of pain can improve other aspects of their lives including their memory and well-being. The practical benefits of pain management can mean effective, faster treatment since it means that their diagnosis is not dementia or dementia on its own. Jason shared:

*So older ladies, treating depression, treating chronic pain with reasonably straight forward meds. Preventing them from having more strokes and they got better and their cognition got better and they clearly weren't demented anymore or in need of help. They were fine living alone and so then after a year or two, it's like 'well now what do I do?' You go away, you're 90, but you go away so sooner or later you might run into problems again with your memory and you can come back. I've done that hundreds of times. No one told me that's what my practice was going to be like. I was practicing pretty much in isolation and my colleagues... with a 2 year wait list to see people with bad memory who they always diagnosed with dementia and they always put on dementia pills.*

In a study focused on regular substance use for seniors, it was found that 50% of their cohorts reported chronic pain (Lintzeris et al., 2016:229). An interesting aspect of pain management discussed was prescribing medications as an alternative. The healthcare provider stated:



*so that's been good because it's been reducing narcotic use and alcohol used because you're saying, 'you know what, this pill is better than three fingers of scotch to go to bed so you don't wake up at three in the morning with pain'. (Jason)*

This holistic approach is beneficial for seniors because it is rare for it to be a singular diagnosis such as dementia and can reduce hospital visits and long waitlists for specialty clinics if a healthcare provider can address pain management. As discussed above, pain affects daily functioning such as sleeping through the night. Addressing pain and lowering the use of regular substance use to cope can have long term positive impacts on seniors especially since chronic pain is common in self-reporting. Taking pain management seriously and having a discussion of how it is being dealt with including regular substance use means that healthcare providers need to prioritize it.

### 3.14 Depression Treatment

Similar to pain management is the importance of treating depression in seniors especially because only 10% of them receive treatment since screening is not routinely done (Carson, Henderson and King, 2019:181). Regular substance use was discussed as a tool for coping and thus increasing the chances of developing dementia as a result. If regular substance use is being used to deal with depression, the role of the healthcare provider is to understand why it is being used and to offer support. Dr. Gabor Maté, a physician who has focused on studying regular substance use support in Canada and globally recommends an ecological approach to health care where, "...recovery from substance use does not mean a 'cure' for a disease, but a creation of new resources, internal and external, that can support different, healthy ways of satisfying one's genuine needs" (2008:340). Working with individuals to understand why regular substance use is for coping whether it is for pain management or depression can be a way to address the root cause. An issue that might come up when working with seniors was discussed by Ali that a barrier to treatment is the stigma of mental illness:

*A lot of people are in denial and it's also the older group with the stigma of sharing those dark secrets that they often hide with alcohol use and it's hard. We don't have a system*

*that really supports that. We have a system that supports individuals that are almost ready or are ready to change.*

Stigma of mental health is a barrier for addressing depression and taking medication instead of self-medicating using regular substance use and the importance of getting to know the person over multiple visits since it is not a one-time diagnosis. It is important for the development of relationships between healthcare providers and clients to be able to have candid conversations about regular substance use and the recognition that medication can be an alternative to coping with depression.

### 3.15 Harm Reduction

For regular substance use, harm reduction is important to healthcare treatment of seniors. Harm reduction is a long term solution to keep seniors at home and independent for longer. For harm reduction, it is more successful for long term treatment if regular substance use is reduced as opposed to abstinence. Through working with clients to focus on function, it, “can reduce disability and healthcare burden in patients who continue drinking” (McPhail, McDonough and Ibrahim, 2013:D). There is currently minimal to no research focused on harm reduction for aging populations globally. For healthcare providers, education is important to even check for regular substance use disorders in the first place. It can be a start to be able to offer care where all aspects of the person’s health are factored in including regular substance use especially since,

we are witnessing now the magnitude of the intersection of aging and substance use. For healthcare systems to adequately care for the complexity of aging, chronic medical conditions, and substance use among its aging populations, a framework that draws from both geriatric-based principles and from harm reduction is required. Such a framework for caring for patients with multimorbidity must recognize the unique psychosocial issues and stigmas related to both aging and substance use (Han, 2018:136).

Treating seniors is complex since regular substance use does not occur in isolation, but there are often multiple co-morbidities that need to be addressed and may include dementia. A relationship centred approach is harm reduction in that it does not focus on

blaming or preaching but working with the person to understand their needs and wants for their well-being and working with them to attain that. Jason shared that:

*... I generally don't ask old people that drink to stop. I ask them to cut down so it doesn't affect function. It's all about maintaining function and then you have to get back to the thing they want to maintain in terms of function. 'I want to keep living on my own, I don't want to live with other people'. We're just going to cut down to x number of drinks per day so that you can still do that. But it might only be 1 drink a day and it might be a small drink and I think that gets me some leeway or some social cash with them as well. Doing other stuff to reduce alcohol withdrawal and pain symptoms and stuff like that.*

The applications of harm reduction can also be used to educate caregivers. Ali shared an example of a harm reduction approach for a senior with regular substance use and cognitive impairment:

*But I think it's really hard for people especially caregivers to understand that harm reduction isn't the same as enabling. So, I just actually did a consultation a couple of months ago of an older gentleman living in retirement and he would walk across 6 lane traffic to the LCBO to buy himself his gin weekly and he would fall or get lost or he'd be locked out of the retirement home. And so, it was all about harm reduction because he had zero insight. He had very little short-term memory. He would repeat the same story within seconds. Not even like some people can hold it together for a minute or two and he just wasn't able to do that.*

*So, it was really working with the family to provide the alcohol and they were very resistant to that initially. But it's one of those things where you're going to feel guilty one way or another. Is it going to be guilt because he's been out crossing the street and gets hit by a car or he falls and loses consciousness and no one's there to help you? Or is it keeping him safe in his home while you provide the alcohol he was going to get anyway? And that is really difficult for a lot of people who don't understand the addiction field about what harm reduction is because the daughter keeps calling me and saying 'is this okay? Am I okay to do this or am I enabling?' But at this point with his level of cognitive impairment, abstinence isn't an option for him because he would go. He'd find a way.*

*He'd find a way because they're resourceful that way. Well they've got something on their mind and alcohol certainly was in his long-term memory as part of who he is. That's not going to change just because you don't want him to drink.*

A harm reduction approach with caregivers can also mean education and support from healthcare providers to understand why abstinence might not be an option and focus on safety. This story exemplifies that a harm reduction approach can deter or stop other safety concerns and working with the individual where they are. If someone does not have the cognition to understand the impacts of their regular substance use, then trying to force them to quit will not be an effective tool. This support from Ali also allowed the caregiver to check in and ask questions, which can be helpful when you are trying to provide the best care to your loved one.

### 3.16 Falls Prevention

In 2016-2017, falls were the most common cause of injury and visits to the emergency department requiring hospitalization. The cost of falls for the healthcare system for reported emergency department visits for Canada was \$2.33 billion (Canadian Institute for Health Information, 5 July 2018). If falls are the most common form of injury and the risk is higher for those with dementia since, “15% of ED visits by seniors with dementia are fall-related, compared with 9% by other seniors” (Canadian Institute for Health Information, 25 Feb 2019), then public outreach is paramount to well-being. But the general public including seniors are unaware of the importance of falls prevention. Falls are preventable, but more public outreach and education is needed. Richard discussed falls for a client he cared for who had dementia:

*I don't know but I think there is a lot of safety and high-risk issues too with dementia and with the aging population rate of falls. One woman I know who had dementia in the middle stage was starting to lose the gait as well. But the ability to see things like you know how you lose the ability like say a black tile will look like a hole right? And her carpeting was all the same and it looked almost like a ramp and she had falls. It was just those risk factors, and no one is educating.*

A great resource already exists that can be used by healthcare practitioners. November is *falls prevention month* and there is an entire website dedicated to information for programming, statistics and support material to share with older adults as well as caregivers<sup>4</sup>. There is a toolkit provided that offers a holistic approach to wellness where falls prevention is connected to activity, healthy eating and practical solutions in the home for mobility.

Falls prevention is also connected to regular substance use and is the main cause of isolated seniors being admitted to hospital (Withall, 2013:230; Linzeris et al., 2016:227). Harm reduction approach was discussed by Jason to allow an elderly woman to reduce falls and continue to live alone and be independent for daily activities:

*I remember a little old lady that was 90 years old and 90 pounds and she's about 5 foot three. She wore a good 3-inch heel that she wore her whole life and she was falling. She was falling like crazy and she was especially falling in the morning when she was doing her laundry at 4 o'clock in the morning. She lived in an apartment building and she did it at 4 o'clock in the morning because she didn't want anybody else's stuff touching her stuff when she was using the washer and dryer machines. Her B12 was low so I fixed her B12. She was in these big clunky heels, so I tried getting her in better footwear, but she still fell. She was on a bad seizure medicine that she had been on forever that she didn't need anymore. So, we stop that, and she still fell. I finally went to visit her at home and realize that her well-meaning friends who were much more able than her we're basically hauling in a case of rum every two months. So, her drink every night was a rum and Coke, 4 ounces of Coke and about 4 ounces of rum and she would have one of these with dinner and she was so small and old that it was still in her bloodstream when she was doing laundry the next morning. So, she was literally drunk the next morning and falling when she was doing laundry and going boom! So I couldn't get her to stop, so we cut down on rum until there's no longer rum in your bloodstream when you're doing your laundry at 4 o'clock in the morning and she got that and cut down and sure enough she*

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<sup>4</sup> <http://fallpreventionmonth.ca/about>

*kept the 3 inch heels, and literally just cutting down to an ounce of rum was all it took to make her [not fall] which was kind of neat.*

This approach was working with the client long term, going outside the medical office to visit them at home to gain insight to their daily life and it allowed Jason to help drastically reduce falls. This positively impacted her ability to continue to live independently and contributed to her overall well-being because living alone was important to her.

### 3.17 Concluding Remarks

Healthcare providers play an integral role for the well-being of Indigenous and non-Indigenous seniors. Education of regular substance use for treatment is important for healthcare providers since they have the privileged position of providing resources, referrals and access to services. By focusing on symptoms as opposed to age, it can reduce ageism and increase access to services for those impacted by alcohol-related dementia, especially since it's a reversible illness. Holism is an approach to be applied for interaction because it allows the inclusion of assessing pain management, depression and falls prevention. Since it takes longer for knowledge translation to reach public discourse, healthcare providers can be a resource for understanding the impacts of regular substance use and providing harm reduction practices.

### 3.18 Key Findings

- Alcohol-related dementia is reversible, thus early detection, education and support can reduce, interrupt or limit the progression of the disease
- It is important for healthcare providers to be up to date on regular substance use and dementia to provide public outreach and education to their clients and caregivers
- Dementia diagnosis should be based on symptoms and not age alone

- A holistic approach is essential for interactions with the aging population to address their emotional, physical, social and mental health needs
- Shift towards a coordinated care planning approach where all caregivers and healthcare providers are brought to the same table
- Check for chronic pain, depression and falls prevention
- Reduce the age of participants in dementia research to be inclusive of those affected by alcohol-related dementia or dementia earlier in life
- Do not exclude research participants because of a past history of regular substance use which excludes part of the affected population
- More research is needed for systemic changes to reduce barriers for accessing services including transportation, reducing multiple specialist visits and bringing resources to Indigenous and rural communities for continuity of care
- Support predominantly female caregivers who are often isolated since services do not exist for the earlier onset of alcohol-related dementia and accompanying behavioural issues

## 4 Caregiving Experiences

### 4.1 Introduction

In this chapter, I will focus on the experiences and barriers for Indigenous female caregivers for a loved one with dementia. Care provider experiences are also included since both offer insight to the existing gaps and offer recommendations for improvements.

### 4.2 Accessing Dementia Specific Support

Prominent within literature that focuses on caregivers for a loved one with dementia, a common theme was caregiving without additional supports. *Healthy Balance* was a research project focused on the caregiving experiences of mostly women in Nova Scotia. Within their findings, “many participants revealed that neither they, nor most members of their support networks, were aware of formal supports available to caregivers” (Gahagan et al., 2004:49). This was similar for the experiences of caregiving and care providers who shared their stories with me. When asking Annette:

*D: Did you access any supports through Alzheimer’s Society or anything like that?*

*A: No, I didn’t even know it existed.*

*D: Yeah, a lot of people don’t know...*

There is a gap in knowledge translation to reach caregivers, especially within Indigenous communities for services offered through organizations such as the *Alzheimer’s Society* where they offer a multitude of support programs. From speaking with Amanda, a care provider at an *Alzheimer’s Society*:

*Yeah even within our own small community we know that the needs of every single client that walks into our door is going to be unique. We don’t offer ‘here’s your package, this is what you do’. You know our social workers work with every client in a very person-*



*centred way and finding out what are your unique needs and looking to support that person and not to tell them what to do. But to say here are some options and helping them to navigate that.*

From her care providing experience, the *Alzheimer's Society* offers a relationship centred approach to support caregivers and their loved ones. If caregivers were aware of services that are family focused and not a streamlined approach, it can assist in supporting their role as a caregiver because it is based on their specific needs. Kathleen shared that she accessed external support for her husband and herself:

*So, I end up taking him to a non-native one[counsellor] and um but he knew that person only because... her husband was um a manager of our son's hockey team. That's how he knew him but he um, I had to stay with him. So eventually, oh now I know, I received counselling through her counselling him too. So that's how I uh, I was able to um I guess focus or cope. Yeah. So, I had to stay with him. Because if I didn't stay with him, he would walk all over looking for me.*

Through accessing counselling not only for herself, but her husband, Kathleen was able to cope, which is integral to the overall well-being of caregivers. Accessing support is shown to be excellent for caregivers to gain insight for, "behaviours and changes to a person with dementia's needs, coping strategies for dealing with the round-the-clock demands of dementia care-giving and avoiding burnout, what services are available nearby as far as home care, respite, activities for the person with dementia, support groups, etc." (Pace, Jacklin and Warry, 2013:42). But caregivers overall and Indigenous caregivers especially are still not accessing services because they do not know what exists. This was expanded on by Annette,

*Yes, so there were never any suggestions for help. I never asked. I think we were just too busy running. I didn't know there was anything! I might be absent minded, but I'm not stupid. No one pointed out to me and I never thought to ask.*

Knowledge of what currently exists is something that can be changed through creating resources that are accessible and based on each Indigenous community since variance

will exist depending on a multitude of factors, especially geographic location. Education of existing services can be a community approach where it is not just geared to aging populations, but all ages since everyone will be impacted by dementia at some point in their lives within their families or friends. This shift of knowledge translation can also mean that that community members are able to offer knowledge of existing services and supports which can ease the burden for caregivers. Amanda, who teaches about dementia shared the importance of public outreach:

*I also do education for healthcare professionals. So, variety of different types of programs, whether it be people who are working in community, people who are working in hospitals, long term care, retirement. Making sure those staff have the tools that they need in order to know how to best support people living with dementia in their environments and how to really recognize the people living with dementia have so many strengths and to really know that person and understand who they are and then support them where they are and not where they were six months ago, and that each person that you're going to encounter is going to be very different and you have to look at who that person is as a person and that dementia is a part of their reality, but it does not define them.*

The *Alzheimer's Society* offers public outreach which a lot of organizations can benefit from. Educating healthcare providers is a practical application to increase their understanding of dementia, the associated risks and being able to diagnose. The importance of healthcare providers having knowledge about dementia is that they can instigate a conversation for healthy aging as opposed to clients seeking support later. This is integral and was discussed in literature focused on caregiver experiences where it was found that their healthcare providers needed more training and skills to be able to, “alleviate stress resulting from uncertainty about what was happening and allow caregivers to access resources sooner” (Morgan et al., 2002:1140). This applies to the journey for memory loss in that a healthcare provider can be a resource for support since caregivers are typically overwhelmed mentally and emotionally and lack the time to seek out existing supports.

## 4.2.1 Late Intervention

Within the existing literature focused on dementia, for Indigenous and non-Indigenous caregivers, they did not seek help until the later stages of dementia. Many families do not know what to look for as discussed by Michelle:

*I think another challenge for my gram would be like not, not knowing what to look for, you know, not knowing what it was, like what was happening. I guess, the lack of awareness. Like I guess, you know? To know, ok that's a sign of Alzheimer's, that's a sign of dementia you know. They thought it was a result of uh a head injury. So, I think that would be a big one too; like a lack of awareness because we didn't know he had it.*

The general public does not typically know the symptoms of dementia and the difference with Alzheimer's disease, so this is an area where public education can reach all ages and not just caregivers. Caregivers reflected back on their roles and discussed seeing the signs in retrospect, but in the moment, you are focused on caring for them and adjusting as needed. Thus, families are able to cope with the early stages, but as the illness progresses, they need support for coping themselves as well as training for knowing the symptoms and what to expect (Pace, Jacklin and Warry, 2013:41). This was also a theme when talking to healthcare providers. When asked, "Do you find that people are waiting until the absolute last moment to get help?", Richard replied:

*Absolutely. But it's the same with anyone. I see so many people here that are now in the middle stage and now late stages before caregivers are even reaching out because 'we can handle this; we can do this'. They don't reach out for the support and the help they can get.*

Since late intervention is common for all caregivers, this points to a broader issue that they seek out supports once they experience a crisis or burnout as opposed to prevention. This means that more public outreach is needed to let caregivers know what resources exist so that can potentially access them sooner or at least provide options when they want to or need to. For caregivers and the general public, education about dementia, knowing the symptoms and understanding the progression is often after a loved one is

diagnosed. Public outreach can be through stories of caregivers to share their experiences with others since it is an Indigenous approach to knowledge transmission grounded in experience, emotion, memories and connection to kin. But the difficulty is that existing caregivers are overwhelmed with caregiving, so asking them to provide more of their valuable time to share their experiences might contribute to their stress. So, bringing resources to caregivers may be the initial necessary step in addition to resources being brought to them.

## 4.2.2 Home Care

An excellent recommendation for caring for the caregiver is educating home care providers who can assess the needs of the family and thus create regular contact with the healthcare system (Morgan et al., 2002:1139). If homecare such as nursing and personal support workers (PSWs) are used, it can allow earlier intervention as situations change at home for the caregiver to access supports. Time and funding are needed for PSWs to be able to gain knowledge and training to identify, recognize and offer supports for families. This connects to funding that is needed to prioritize dementia specific education. A resource that was created by the *Alzheimer's Society* in Toronto is [www.alzeducate.ca](http://www.alzeducate.ca) where there is online training, live webinars and the option for in person training. It would be great for this training to be adapted to also be culturally safe for Indigenous families. Trust is a big barrier for allowing someone to enter your home or the home of your loved one, but culturally safe care can mean that homecare support workers can begin their relationship with the knowledge that time and trust are needed. Culturally safe care can provide the context of why Indigenous families do not access care because of the ongoing, "...devaluation of Indigenous knowledge and traditions fostered by colonization as well as historically imposed colonial institutions contribut[ing] to high rates of withdrawal of Indigenous people from Canadian institutions including the medical system" (Petrasek McDonald, Barnes and Middleton, 2015:156). Culturally safe training is important because it shifts the relationship where the responsibility is on the healthcare provider to have knowledge and training when interacting with Indigenous clients, instead of Indigenous clients being the ones to educate.

Education and training for PSWs can contextualize why Indigenous families do not trust institutions. It is also a practical solution since they develop trust with families through frequent contact and can intervene to assess and assist with referrals for support to Indigenous community organizations as well as the *Alzheimer's Society*.

### 4.3 The Importance of Continuity of Care

Continuity of care is where services are not determined on where the person is located and is coordinated care where multiple services are offered in the home. Continuity of care reduces barriers for accessing healthcare for families affected by dementia. Focusing on the experiences of Alaskan Natives and American Indians, “ideally, such services would comprise a continuum of care, including home health care, day care programs, respite care, traditional healing, residential care facilities, and I[ndian] H[ealth] S[ervice] medical facilities (Jervis et al., 2002). In reality, many of these services are not available on reservations, and those that do exist are typically delivered by a variety of sources with no central mechanism for coordination” (Jervis, 2002: S93). Services can integrate Indigenous approaches to health that include traditional healing and medicines and approaches that are specific to the community and the individual’s conceptions of health. But many services that are needed are minimal or currently do not exist for Indigenous families. With all the caregivers I spoke to, their level of in-home support and access to Indigenous traditional wellness varied depending on the programs offered through their community, health centre or being forced to use provincial services if you are Métis. The variations in access to services are different depending on community location and siloed services where communication and coordination are lacking which can mean that families are falling through the cracks or not accessing the level of care they need.

Funding for homecare is integral to the health and well-being of aging populations. It has been proven to be preventive and cost saving for the health care system the longer that people are able to remain in their home. The caregivers I spoke with shared that they were able to cope well if they had home care support, nursing and respite care. It was discussed by Annette that there were medical needs for her Dad that their family could not do:

*Then we would could you know get him in the stream for care for the nurses to come do his health and all those things he needed right. Because again, there were things we couldn't do. We couldn't change his bag for him, we couldn't put in the catheter, his feet needed care...*

Remaining at home is beneficial for Indigenous and non-Indigenous families since rural communities face parallel issues of accessing home care services that include specific dementia training. The *Canadian Home Care Association* (CHCA) found that,

although there was a 55% increase in the number of people who accessed home care from 2008 to 2011, no province has followed through on its commitment to increase home care funding. The CHCA calls for a reallocation of funds to home care from acute care. Reallocated home care funding targeted to dementia care may ensure greater numbers of staff with specialized training in dementia care and knowledge translation skills. Home care nurses would be able to provide more preventive and maintenance services to better support family caregivers through the exchange of best available dementia care knowledge and not always be responding to crisis situations that require acute care services (Forbes et al., 2015:138).

Resources dedicated to educating homecare providers can mean that families are not waiting longer periods of time to access supports and professionals in the home can provide knowledge translation. Continuity of care also means that service gaps are minimized because there is coordination between health care services in the home where organizations are working together ensuring that needs are being met. Communication between organizations is integral especially if someone accesses services in their community and agencies such as the Local Health Integrated Network (LHIN) for PSW, nursing and specialists externally. It allows providers to coordinate with one another as opposed to the caregiver being the care manager solely.

### 4.3.1 Indigenous Home Care Workers

Literature from Australia discuss the benefit of having Indigenous care workers from the community to be the ones going into the home to help those with dementia. The program they developed is called the *Yuendumu Old People's Programme*. This program, "is based in the traditional values, skills base and worldview of Yapa. 'Hands on' services

are delivered primarily by local people who speak Warlpiri and are known to the client group. They function within local cultural protocols, and hence are uniquely positioned to understand and accommodate the day-to-day activities and concerns of the clients” (Smith, Grundy and Nelson, 2010:7). This program aids seniors to remain in their homes, communities and with their families until they pass even if they are frail and have complex medical needs. This is a great example of community-based programming where Indigenous members are the ones who are trained and provide the care to their seniors in the language they speak and following cultural protocols. The creation of this program was working with family members to give additional support so it still within the framework of family centred care. This model can be adapted to Indigenous communities on Turtle Island where culture, language and community are the foundation to the programming being created from within instead of externally. Within research on Manitoulin Island in Ontario, having community home care workers was viewed as excellent because, “the support that people with dementias and their families received from local home care services was perceived to be particularly beneficial. The ability to access home care services provided by caregivers with knowledge of local language and culture was perceived to be especially beneficial” (Pace, Jacklin and Warry, 2013:42). Being able to speak your language with someone else creates comfort and connection with home care workers and it removes barriers for educating external health care providers about the communities they are caring for if home care workers are members of the nation and community. Funding for home care training within communities creates continuity of care since coordination can be done through the community health centre (if one is available) and reduces wait times if support workers need to travel to rural or remote communities.

Kathleen shared that their community had additional supports and allowed her husband to remain at home much longer:

*Michelle: Yeah. So [she] was a PSW right under our reserve?*

*Kathleen: Yeah.*

*Michelle: A PSW from the reserve?*

*Kathleen: Yeah and then I had another person come in for respite for me in the evenings. That's not every evening, but at was least once a week...because I uh, I think I wanted to stay home with [him]. You know and uh because we had a lot of years together too and I didn't wanna just, you know up and leave him. He um... generally he was ok.*

Being able to keep your loved one at home as long as possible contributes to the well-being of the family. As stated by Kathleen, they were together for many years and she wanted to be able to look after him for as long as possible because of her love for him. Although caregiving is tough, it is the relationship that keeps people going and their connection to their loved one even if their cognition and memory changes. Community PSW support and respite care are fantastic since they provide a short break for a caregiver to run errands, visit with friends or family or to be able to take time for themselves. If this was available in all Indigenous communities and offered in urban centres, it would be a family centred approach. Richard shared that in his experiences, he has witnessed a positive shift where:

*...it's getting better because now First Nations are getting more education and are heading back home again. So that's working a lot better.*

In-home care workers and respite care can support caregivers so their loved one can stay in their homes with their family. Having care providers from the community eliminates many of the issues previously discussed and the benefits outweigh the fiscal costs. Respite care contributes to the well being of the caregivers since they can share some of their role with a care provider and prevent burnout. This was found amongst care providers to be a service often underutilized by caregivers since a lot of them did not know it existed or had information about what it entails (Morgan et al., 2002:1136). Knowledge of existing services is important in order to share the knowledge with caregivers to provide options they can access.

## 4.4 Gendered Caregiving

Written extensively in literature focused on caregiving for Indigenous and non-Indigenous families, women are predominantly the caregivers for loved ones with



dementia, typically for their spouse or parents. This applies to my interviews as well where all caregivers were women caring for a spouse, parent or grandparent and care providers also mostly discussed female caregivers for a male loved one. Jervis and Manson found that women were providing more than 8 hours of care to a loved one who was cognitively impaired and faced higher rates of role strain than care providers for other illnesses because of doubts in their ability to provide adequate care (2002:S92). The connection of gender and caregiving, "...reflects the reality that it is female family members who have traditionally taken on the majority of responsibility for family caregiving and continue to do so despite their increasing participation in the workforce" (Joseph and Hallman, 1998 in Morgan et al., 2002:1140). Female caregivers are balancing caring for a loved one with dementia, working and caring for their spouse and children. Additional in-home supports that are culturally safe are important to recognize health concerns for the caregiver since their health is paramount to the well-being of their loved one. According to findings by Parrack and Joseph,

Aboriginal women, including middle aged women who are more likely to be providing care to seniors, have high migration rates, as seen between 1996 and 2001 when 36% of Aboriginal women between the ages of 45 to 64 changed residence (O'Donnell et al., 2005). This means that a significant number of Aboriginal women may need to provide care to elderly family members from a distance. Yet very little is known about how Aboriginal caregivers provide and manage care to seniors when they live far away (2007:109).

Even residing in the same city or town has limitations for travel if the caregiver does not have a vehicle. Annette shared that they moved to be closer to her Dad:

*I would be the one to say, whatever had to be done and would stay until it was implemented. But I mean, I couldn't be with him 24/7. While he was there, I tried to get there as often as I could. Of course, I was there in a matter of emergency. We moved to this end of town just to help my Dad and it was then only 2 weeks after that, he was placed because we originally, we were driving from way in the, heck the other end of town. We would no sooner get home and have to go back and help him. So, coming here, he was so close...when he was placed, he was placed out of town still. It was still closer than prior. So, we would go, I would go in an instant to help him when I could.*

Proximity to a loved one is key so you can be able to be there as soon as possible if there is an emergency or you can provide support and answer questions when there is home care support or nursing. Caregivers shape their schedules to their loved ones to provide excellent care, especially for Indigenous seniors with dementia who have access to less supports in their community and their spouses and daughters provide the care they need. Reducing travel time allows more time for caregiving which is importance since many female caregivers have their own families to care for as well. Women are the unpaid caregivers for children and seniors while managing working (Gahagan et al., 2004: vii) and this applies to the Canadian population as well. Annie shared that she would have to cover the transportation and accommodations cost for traveling to see her Dad when he was placed in long term care at the end of his life:

*I had to have a ride in and I don't drive, I'm disabled myself. So, I didn't wanna bother my brother to take me to see my dad two, three times a day into Maniwaki. So, what I did, I rented a motel room every two weeks at my cost going up there. It would take about an hour to get there, but it takes two hours by bus which I rode by bus.*

Annie would go and visit every 2 weeks for extended periods of time since she was unable to drive there herself and had to rely on public transportation. The costs associated with this often falls on the caregiver. It is estimated that, “caregivers spend \$4,600 out-of-pocket annually for each person under their care who is living with dementia” (Public Health Agency of Canada, 2019:40) and the cost is higher for Indigenous and rural families who have to travel even greater distances.

If their loved one or the caregiver resides off reserve, they are unable to access financial support through non-insured health benefits (NIHB) paid federally since travel for compassionate reasons is excluded in the policy<sup>5</sup>. This is a colonial policy and systemic discrimination where loved ones are forced to leave their community because services are

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<sup>5</sup> “Certain types of travel, benefits and services will NOT be provided as benefits under the NIHB Program under any circumstances and are not subject to the NIHB appeal process. These include assistance with:

a. compassionate travel” (Government of Canada, 2019)

not available, and their caregivers have to travel extensive distances to provide care, support and connection. Compassion is missing in healthcare and is exemplified within the NIHB policy itself where legally, the federal government does not have responsibility for ensuring that families remain supported and connected. If seniors such as Annie's Dad have to leave their community, caregivers should not have to cover the cost themselves for transportation and accommodations. Associated costs can be expensive since, "informal caregivers often take on a large financial burden in addition to their regular responsibilities for family members" (Bartlett et al.,2012:86). For Inuit families, there are often no long term care homes in community, so they have to move hundreds of kilometres from home. Research focused on long term care for Sápmi and Nunavut peoples, "...described how a Nunavut elder had to travel 2,000 kilometres, from Rankin Inlet to Ottawa, to secure a long term care bed" (Minogue and Konek, 2016 in Gao, 2018:26). In Sweden, they have created an informal caregiver program where they are paid for their time by the government based on the needs of their loved one and receive a salary, pension credits for missed time at work and are given up to 60 paid days off work to provide support as needed (Beatty and Beardhal, 2011:11). All the caregivers I spoke with were still working and adjusted their schedules to attend medical appointments, provide groceries and visited their loved ones as often as they could if they did not live together. Indigenous caregivers are keeping their loved ones at home as long as they can which contributes to their well-being to remain in their familiar surroundings and community. All caregivers are under immense amounts of stress and trying to find balance. There needs to a shift in the approach to family centred care where caregiving is valued and where finances can be mitigated by subsidies or payment through the creation of a program similar to Sweden where a caregiver is not fiscally affected for the time and energy providing excellent care. Within existing literature in Indigenous communities, it is female family members providing most of the care because of reciprocity and love (Browne et al., 2014:144; Parrack and Joseph, 2007:109; Jacklin, Pace and Warry, 2015:110), so if they can be paid for the work they are already doing, it removes barriers for access since it is not relying on external agencies for everything to alleviate some of the stress.

Kathleen discussed transportation support from their community to programming for her husband:

*We have a program in our community, and it's called patient transportation. So, they come up and take him too, because I was working so they would pick him up and take him and they would bring him back home.*

Transportation support in First Nations communities is integral to being able to access support programs. With transportation support, her husband was able to attend programs at the closest *Alzheimer's Society* when she was at work. The benefits are that she was still able to work, and he was able to be social and take part in creative activities. Many communities do not have transportation support for members, and if family members do not have a personal vehicle, they cannot travel to the nearest city or town. Thus, bringing support in community can be an opportunity to increase programming, education and support.

## 4.5 Knowledge of Dementia

Dementia is highly stigmatized, and people do not typically access information or resources until someone they love or know is diagnosed and this was applicable with caregivers and healthcare providers I spoke with. A lack of existing knowledge about dementia can be a barrier for accessing health care for a later diagnosis (Hampton et al., 2009:25). This is applicable to Indigenous and non-Indigenous populations where families try to support their loved ones on their own until a crisis occurs. A theme for the caregivers and care providers who shared their stories with me, was that most people do not know about dementia until they had to, but gained as much information as they could to understand the disease and support their loved one. Michelle shared the knowledge she had of dementia that:

*It's like an umbrella, right? And Alzheimer's is a form of it. So, say like cancer for an example, is the umbrella, breast cancer, brain cancer is a form of cancer. So, dementia is the big umbrella and Alzheimer's is one form of dementia.*

Michelle has become an advocate sharing her experiences and stories to educate others about dementia. This shows that personal experience is a tool for educating since the emotional connection of storytelling resonates with the heart knowledge of the listener. Michelle shared a story about her grandparents where her grandmother Kathleen practiced living in the moment:

*So, an example that she told me was when he did laundry and he mixed the whites and the darks. Instead of pointing out that he had done that, she kinda just said oh good job! Thank you, you know? Let him know that what he did was good even though it was kinda wrong (laughing). But she didn't go against him.*

This is an amazing example of a strategy that works well for caregivers to be flexible and to not argue or go against their loved ones' ideas and understandings. This was discussed by Richard that is a part of education for caregivers to cope with the cognition changes of their loved one and that it can be emotionally and mentally difficult:

*...they don't want to strain that relationship. They find it very frustrating. They don't know how to relate to someone with dementia, you know sometimes are going to have irrational ideas, the person with dementia. So, say I'll give you an idea for it, is one gentleman he wanted to build a garage. He had no use for a garage, he couldn't drive anymore because he lost his license. He, his wife was awful strained with it, of how to relate to it...and he ended up getting it built because, fortunately he did have a good pension and they were well off. If it pleases him, I said if you're frustrated because he's focused on it all the time, 'when are we going to get this done'? Repeating that? Wouldn't it just be better to just build it? It might add to your property when the time comes right? She started to understand. But for like two years she was frustrated with this. It took two years of involvement to get to the point of education, don't argue with him OK, just go along with it. He's just telling you the same story, just go with it. Don't tell him you told me the same story two weeks ago. You don't want to shame him. Of course he gets his back up because he knew that something was wrong, same as anyone. They just feel it is and take the social cues and get it that when people are saying 'you told me this five minutes ago, what are you doing?' Or asking that question over and*

*over again. And it took two years and she finally came around and the family finally came around to accepting that this was a part of dementia.*

These two examples show that there is an opportunity for educating about dementia and positive coping strategies for the caregiver and their loved one. Both of these examples show that it takes time and having a supportive care provider such as Richard who worked with the family for 2 years to have a trusting relationship and continuity of care with the same provider. This connects to findings by Jacklin, Pace and Warry, that Indigenous caregivers they interviewed reported that,

*...they have limited knowledge about how to provide care and that they use trial and error to devise effective care strategies (Hennessy and John, 1996). The lack of access to knowledge combined with the lack of availability of formal programming for seniors creates significant challenges for Indigenous people caring for a person with dementia compared to non-Indigenous people (2015:116).*

Since most caregivers do not access supports, they are navigating in isolation trying to provide support for their loved one. If supports can be put in place within Indigenous communities, it can reduce the stress through sharing coping strategies and education about expectations as the illness progresses.

## 4.6 Dementia is a New Disease

The inclusion of traditional understandings of dementia and that it is a rising issue in Indigenous communities was a theme. Kathleen shared:

*I guess...from what I understand, that a long time ago, that Native people didn't uh, weren't affected with Alzheimer's because they lived off land eh? They lived you know, I guess all the wild animals, and the plants and the food off the land, uh, they had lots of vitamins and minerals, so uh that's what I understood.*

This connects to existing research focused on perceptions of dementia within First Nations communities where it is seen as a new disease and is connected to social determinants of health. Changes in lifestyle to traditional food and shifts in family dynamics where everyone cared for their aging community members account for the rise

of dementia. The impacts of access to traditional territory, hunting, foraging and food that is from your community have all shifted as effects of colonialism. As Pace, Jacklin and Warry note in their study,

many participants in this study perceived dementia to be a new or worsening problem in their community, and linked the emergence of dementia with changes in their overall lifestyle, such as a shift away from traditional extended family structures, changes in food procurement practices and diet, a more sedentary lifestyle, and changes in the roles of older people in their communities. These individuals noted that older people did not get dementia in the past because they had more social support and important roles in their families such as being responsible for keeping the fire or caring for grandchildren (2013:20).

Food is a part of balance that is often only discussed as nutrition. But food is medicine; it needs to be viewed as such. Food is not only healing for the body, but is medicine for, "...the soul, for the spiritual connection to history, ancestors and the land" (LaDuke, 2005:210). Food as medicine is important to health because the physical environment and access to healthy foods as well as the ceremonies and ability to grow and learn from the land contribute to well-being. The direct impact of not being able to eat the food around you affects your physical health, but the loss of the ability to collect food (fishing or hunting for example), the traditional and the cultural ceremonies and the social ties of experiential learning can have huge impacts on health. This is also the social ties of memory and physical landscape that not only intertwine, but merge as one (Hulan and Eigenbrod, 2008). Food as medicine is not the simplicity of the food that is procured to be eaten, but the process is just as important. Many Indigenous people no longer have access to their traditional foods and the intergenerational stories and education of their responsibility to care for the food that will nourish them wholly. Food when discussed in biomedical accounts focuses on healthy eating and reducing the rates of diabetes in First Nations communities specifically. But what is missed is that the, "nutritional aspects of the foods has risen to a more important level than the social ones. We often neglect the social, the people and their cultural models" (Salmón, 2012:80). The benefits of traditional foods are being recognized in clinical studies, but again tend to focus on the quantifiable data and excludes the other elements of the balance of a person for their

spiritual, mental and emotional health when they can grow, eat and/or access foods that hold the memories, ties and stories of their communities and who they are.

Connection of land for health which cannot be dissected from language is important for understanding Indigenous health. Within Anishanaabemowin, there are no words for land ownership and that, “we belong to the land by birth, by need and by affection. And no man may presume to own the land” (Johnston, 1982:170). The connection of the environment to health in terms of the impact of having clean drinking water, a home to live in and access to affordable and healthy food are factors for health. But what is often missed when only a biomedical approach is used is that without the connection to land there is no language or culture (Teegee, 2015:120; Johnston,2003; Sefa Dei, Hall and Rosenberg, 2000). Those ties are beyond the physical environment, but the spiritual connection of being tethered to a place not only as a place of residence, but the community there, the traditional language that teaches the importance of reciprocity with caring for the land and the responsibility that it holds. Thus, health needs the spiritual connection of land and language because culture cannot exist, and all are integral to the holistic well-being of an individual, community and nation.

The inclusion of Indigenous medicines and trying to care on your own was discussed by Richard:

*So he was in a middle range by the time I actually saw him and amazingly enough the daughter backed off in care and it was the son that took over his care and who moved back to take on the care and lived with him to look after him and then trying to help him cope with it. But for education about dementia, the son would not attend because ‘we can do this’. It’s a culture that is very steeped, well the son a little bit but the father certainly was steeped in the cultural traditions so this could be done through different medications and plants that could assist him.*

The recognition of the changes in Indigenous communities connected to using traditional medicines for treatment can create a space for families to be able to use their teachings and understandings in conjunction with education about dementia as an emerging illness connected to diet, exercise, social connections and maintaining balance. Connection to



cultural ceremonies and traditions is a part of spiritual health so often missed in healthcare including a focus on dementia. The best summation of this concept was shared by an Elder that, “it is not important to preserve our traditions, it is important to allow our traditions to preserve us” (Hampton, 1995:22 in Archibald, 2008:57). What is missing on behalf of some non-Indigenous researchers is that they work from an approach that a person’s connection to the land, their community and culture are distinguished from their health and well-being. Health is a narrow definition in practice. There is a paradigm shift that food, medicine, ceremony and connection to land needs to be a part of health because of the positive, sustainable impacts it has on an individual, their family and even on their community. It is a broader recognition of the interconnection of humans to the world around them and the perpetual interplay that every decision and every action affects the world around you and the other way around (Cajete, 1999:239). Not only in the physical sense, but spiritually as well.

The existing shift in healthcare towards holism is viewing a person’s mental, physical and emotional wellbeing, but still exclude spirituality. Spirituality for Indigenous populations seeking healthcare are facing services that do not have the inclusion of inward knowledge and the priority of the benefits of participating in prayer, ceremony and dreams (Kovack, 2009:50). Inward knowledge is currently not deemed valid and needs to be included as an aspect of health for Indigenous people accessing services. Health is also often limited to the individual and may extend to their family. This still excludes their connection and responsibility to their community and that kinship is more than just humans (LaDuke; 2005; Hedican, 2001). Many Indigenous people already know the merits of holism being applied to healthcare, but they are not the ones who need to be educated, trained and change their methods, approaches, discourse and perceptions. The providers who work within healthcare who are trying to be more culturally safe and holistic, are limited by systemic policies which are missing an opportunity to heal people in sustainable, long lasting ways. But in order for this to happen, colonialism needs to be addressed and that Indigenous epistemologies have value and can teach a lot.

## 4.7 Learning from Caregivers

Caregivers are at the forefront of dementia as they navigate the healthcare system for their loved one, provide in home support and maintain their relationship with their loved one. They provide a lot of insight to the needs of loved ones with dementia and their own journey for changes and opportunities to support Indigenous families.

### 4.7.1 Coping Strategies

Jervis and Manson found ‘passive forbearance’ as a coping strategy focused on accepting and adapting instead of trying to control the situation (2002:S92). Within their research with American Indians and Alaskans, it reflected similar findings that Indigenous caregivers focus on their familial role of caring and adjust to the situation. The experiences of caregivers to not focus on shaming their loved one for not being able to do the same things as before and changing their perspective is a coping strategy founded on love and accepting changes as they come. When asked what advice she had for other caregivers, Kathleen shared:

*The other thing...um is being patient. But you have to expect the unexpected too. You know um, I don't know like what the individual would do...like for me, like [he was] doing the window, when he was fixing the window and he missed the whole window and he put all the tape and covering on the bottom and didn't do from the top to the bottom and then the door. He did that and the laundry and, you know. He knew how to do laundry, but he had missed, did all that wrong.*

Patience and acceptance are exemplified here where it is focused on their loved one being able to still help at home and do tasks they have always done, even if it is not the same way that they used to. If experiences like this can be shared with other caregivers, it can be a tool for educating the types of changes that might happen and how to address it and cope in a positive way. Existing literature examines caregiving stress and burden which needs to be examined to offer support and solutions. But many of them miss the positive aspects of caregiving that focus on family and the value of caring for the aging population (Browne et al., 2017:1013). Annie, an Anishanaabe kwe caregiver shared her experience of caregiving even when you felt alone:

*But I honoured my dad to the end. I honoured him, to the end. There were times there when he was hospitalized, I was alone. My husband was home looking after the kids. I was alone going to the hospital every night after work. I would hang onto the statues and I would kneel to give me the strength to walk into that hospital. I was so exhausted and so tired. I was so, I found it hard, but I did it. I hung onto the statue of secretariat, I hung onto it, ... Jesus, I held onto it just to give me that strength every day. I smudged and I would be on the ground. But I did it, I did it.*

Caregiving is a balance of the stress and rewards and more literature should include the positive memories and teachings because it provides hope and insight to other caregivers and can inform the practice of providers. For Annie, she knew that she honoured her Dad's life and cared for him the way he did for her. Another positive aspect of caregiving is gaining education about dementia and the emotional and spiritual learnings of the role (Gahagan, 2004:37). Annette shared that being a caregiver was helpful for supporting the aging population:

*This is what I learnt from community living especially with so many seniors in the building. I will knock on doors if I haven't seen someone in a while and find a reason to go over there, things like that. Things I never thought about before. If it wasn't for my Dad and what he'd been through.*

From the caregiving experience, she does wellness checks on other seniors who live alone in her community to be a caregiver for them. Caregivers have knowledge and insight that is paramount to improving access and supports to dementia care for Indigenous peoples because of their lived experiences and the importance of community connection. From Annette's experience caring for her Dad with dementia, she gained understanding of social isolation and that seniors should be checked on. Within interviews with care providers, isolated seniors were discussed by Amanda:

*D: So, there is nobody that is recognizing that something is going on. So, I think that is a barrier in Indigenous communities too is that if someone does not have that family support, then nobody is going to be the person to advocate for them I guess.*

*A: Yeah that's a big challenge. In Indigenous communities and we know that there are a lot of particularly isolated seniors and they may have family and they may not. But demographically I read somewhere recently that the population of people without family, people may not have had children, that is going to be a much bigger demographic group. I don't know if we know yet what we're going to do about that. So that is an ongoing and future consideration and, in the present, it is going to be a bigger issue in the future.*

Isolated seniors are a prominent issue and often discussed in literature focused on aging for Indigenous and non-Indigenous populations because of the shifts in dynamics of families moving to urban settings to access job opportunities and resources. Lanting and her colleagues found in Saskatchewan working with an advisory council that, "...the Grandmothers emphasized the isolation in the experience of aging in current society. One Grandmother stated: lots of the Grandmothers I visit are loners—they say their grandchildren don't visit and they feel isolated—that's why I feel isolated" (2011:111). This was also discussed in literature that aging Indigenous seniors go into long term care because they live alone, their cognition and ability to perform their daily activities are declining and since they do not have family support and are socially isolated, long term care becomes the only option (Habjan et al., 2012:215). Seniors living alone was expanded on by Annie:

*The reserves are probably a little bit better, but they live alone. But still they're isolated like a community. I'm not saying all reserves, maybe they are different, other reserves. But mine is like the city and the youth don't care. I'm sorry but they don't. They say it but they don't care. They say it but they don't care and I'm not afraid to say it. I've been trying to teach the youth, but they don't care. Some do but a lot of them don't. They say they care for their Elders, care for their elderly. No, they don't care. They don't care! It's not true. I know. I see. Do you know who cares? The average person.*

Annie touches on the changes in First Nations communities and trying to engage youth to look after the aging population. For the impacts of intergenerational trauma, there is a missing connection of the past which is a part of Indigenous health; cultural and social beliefs of time crossing generations. What needs to be a factor as well is that each

community is unique and needs to be treated as such. For those who attended residential school, they were not only impacted as individuals, but for those left behind and for the next generations by:

disrupting families and communities; the transmission of explicit models and ideologies of parenting based on experiences in punitive institutional settings; patterns of emotional responding that reflect the lack of warmth and intimacy in childhood; repetition of physical and sexual abuse; loss of knowledge, language and tradition; systemic devaluing of Aboriginal identity; and, paradoxically, essentializing Aboriginal identity by treating it as something intrinsic to the person and thus static and incapable of change (Kirmayer and Valaskakis, 2009:19).

Health crosses generations in terms of teaching through example, passing on the language, culture and traditions that contribute to a person having balance in their life emotionally, mentally, physically and spiritually. Cultural and spiritual health is well-being which is integral to Indigenous approaches to health. It also includes the specific cultural and spiritual beliefs and practices of a person that is significant to where they are from, their past, present and the health of their future selves and how that connects to those around them.

The impacts of residential schools, the 60's scoop and the shift of respect for seniors is that intergenerational knowledge is being affected by the changes in family dynamics. Youth are moving to urban centres or seniors are living alone and not with their extended family which causes a diminishment of social and cognitive stimulation which is important for keeping a healthy brain (Pace, Jacklin and Warry, 2013:31). There is greater support needed for Indigenous and non-Indigenous seniors living in isolation and points to a change needed where, "caring for each other is a defining human trait and what society is ultimately for. We need to build a society with caregiving as a central value" (Gahagan, 2004: xvi). Annie brought up an excellent point that youth are needed for the role of caregiving because as they age and as do their loved ones, they become the caregivers themselves. There is opportunity to engage youth to support elderly people in their community whether it is on the reserve or in the city and be able to gain knowledge themselves through the support they provide.

To combat isolation for seniors and engage youth to be the ones to provide social support, a recommendation in the literature has been the development of a friendly visiting program (Pace, Warry and Jacklin, 2013:44), especially for people with dementia. There is going to be a greater need for support for seniors living on their own. A friendly visiting program can be a way to combat loneliness, have someone check in on them and notice when there is decline and the reciprocity of sharing knowledge is beneficial for the volunteers as well. The benefits for youth are that they can be educated about dementia and being dementia friendly which can be applied for lifelong learning for supporting others with dementia. Sitting with Indigenous seniors is a form of medicine (Geniusz, 2009:86) where the knowledge learned from being with them is insurmountable to the medicine a youth can provide through sharing a meal, time and humour. It is not only the traditional stories that can teach healing and strength, but seniors and, “Elders’ life stories can show how we, as Indigenous peoples, survived and how we can keep our cultural knowledge intact. Their life stories depict resilience and resistance to colonization” (Archibald, 2008:42-43). The generations before us have survived in order for the next generation to be here. That alone is strength and that policies focused on cultural and physical genocide were not successful. Life stories are also powerful for healing in that the impacts of colonialism can be examined within personal histories and how they shaped a person’s opportunities, challenges and how their cultural and social ties were able to maintain their identity and connections to their community and ancestors. Stories for people who have had similar experiences because colonization is a social determinant of health, can show the next generation through the lives of Elders that healing can happen. The application of a friendly visiting program can be adapted based on language, spiritual/religious beliefs and cultural backgrounds so it can be beneficial for all seniors who want to remain at home but might not have the familial support because of geographic and social shifts for families. The benefits for youth can be learning resilience, cultural strength and identity from spending time with aging community members.

## 4.8 Peer Support

Supporting one another in community also came up for peer support for caregivers. All of the women I spoke with are strong, amazing caregivers for their loved ones. They dedicated their love, time and compassion to support their loved one with dementia. Many of the women discussed the importance of having peer support to be able to cope well and it helps to know that you are not alone in the experience. The *Alzheimer's Society* across Canada work from the peer support approach where caregivers and their loved ones can access services and support based on storytelling and personal experience. Amanda shared the benefits she has seen on the lives of caregivers:

*Yeah I think that it helps. That not feeling alone I think is huge. It's true for anyone going through any disease to know that wow I can talk with you about this because you know, because you get it and I think that this allows people to let their guard down and to be open and just say 'these are the emotions that I'm feeling and I feel like, are these emotions OK? and I feel guilty for having these emotions' and people can say 'no I've had those same emotions and you're not alone. You're not wrong, you're not wrong for having those emotions'. So just that support and our social workers are great in providing that structure in that facilitation to allow people to come together and do that. So, they're not there to dictate what's going to happen. They're there to guide the process a little bit.*

Isolation can be a part of the caregiving experience for anyone since there is stigma of dementia and many caregivers try to do everyone on their own with limited support. If there is an increase of public education of the peer support services that exist, it can be helpful for Indigenous caregivers. Shifting the peer support programs to be culturally safe and potentially offered in community to combat transportation issues can assist caregivers so they can share their fears and concerns in a safe space.

Peer support is integral since they may lose some of it when they become caregivers for their loved ones and if friends and family do not offer support. Annette shared that friendships grew stronger and created positive boundaries for their relationships:

*It has been a learning experience for me, because I will now, I've told a few friends. People I have known for years. 'You know how I felt. Well whoa, wait a minute, I dropped everything for you over the years, no matter what was going on. I put you before family first sometimes you know. And yet, you don't have time for me. I'm feeling that, you're showing me that by your words and your actions and at that moment, and I'm not using past history, I'm using at that moment where it comes up again'. I called them on it and the friends that took that as a learning experience, have hung on and it's made our relationship better right and that's been a good thing because now they'll say, 'is it an ok time to talk? Or are you busy with your family? Or I'm sorry this conversation has been more one sided for me you know, I want give you equal time'. So, it's been a learning experience which is good, but...I mean, I come by this late. It's not like I was carrying this wonderful maturity at age 19 or anything (laughing) dang it!*

Social connection for caregivers also has positive impacts on their health and well-being especially since caregivers lose connections if friends or family cannot relate to their experiences (Bourassa, 2019:118). But they also gain insight for supportive relationships especially when they are caregivers and need support for socializing, laughing and having connections outside of their roles as caregivers. For Kathleen, she shared the support she had from family and friends:

*Michelle: She wants to know if you seeked any support from the Alzheimer's Society, after?*

*Kathleen: for myself? No.*

*Michelle: No.*

*Kathleen: I had friends though that I talked to.*

*Michelle: And your brother too right?*

*Kathleen: Yeah.*

*Danielle: So you had really good family support?*



*Michelle: Oh absolutely.*

Social support for women is beneficial and,

...women do have stronger support networks than do men, and these networks appear to enhance their well-being (Denton et al. 2004, Shye et al. 1995). Some studies indicate that women benefit more from social support than do men (Denton et al. 2004, Denton and Walters 1999, Forthofer et al. 2001, Umberson et al. 1996). However, the evidence on this point is not conclusive (see Elliott 2001, Neff and Karney 2005), as women are more involved in the health needs and behaviors of family, friends, and other social network members, and this higher involvement can result in additional strains and stresses that are harmful to health (Shye et al. 1995 in Read and Gorman, 2010:374).

The positive aspect of caregiver experiences is also learning from them and having relationships based on support and reciprocity since time becomes limited for caregivers. But the other side is that since women are more socially engaged, they are also caregivers to their friends and family more than their male counterparts which can be added strain. A lot can be learnt from caregiver experiences in regard to informal relationship support for themselves and what they learn about their own emotions and well-being through changing dynamics with those around them. Peer support can act as a resource for caregivers to relate to others in a similar situation and have an outlet to laugh and share, thus is healing overall.

## 4.9 Concluding Remarks

All of the caregivers are women who honoured their loved ones as stated by Annie. Their love, patience, understanding and dedication as their loved one was affected by dementia, shows the resiliency of these women and that caregiving is difficult, but also has many positive aspects of fulfilling kinship roles, learning about themselves and their strengths as well as gaining knowledge for navigating the health care system and being a caregiver to other members of their community. Caregiving is a social issue for everyone since we are all caregivers at one point in our lives. Hulko and her colleagues offered a perspective to shift the thinking and approaches to supporting caregiver and revamping the healthcare system. In their research,

if responding to memory loss is part of ‘supporting one another’, then assistance would be offered or given by other community members and health care providers and would not be sought by an Elder. With respect to decision-making, supporting one another calls for the inclusion of other community members beyond the individual and immediate members of their primary family. In Western health care ethics, there is a great deal of sensitivity paid to the privacy of health information gathered only from individuals (or their direct relations with permission) as the basis of care-planning. The involvement of non-related community members is not usual practice, although it may be more culturally safe (see Hulko and Stern 2009) (Hulko et al., 2010:335).

Supporting caregivers is not only waiting for them to seek help, but a shift for healthy communities where people support one another. As shown through the stories of Kathleen and Michelle, their community had these structures in place for transportation support, social visits and respite care. For others, there is a lack of these services if their loved one do not live on reserve or if their community does not have these services available. Inclusion of community is a change where everyone provides help when needed and offers support. This has been discussed in literature focused on dementia in First Nations communities where the perspective is that, “there’s more physical contact, there’s more nurturing. It’s not give them a pill and shut them down. [...] we take care of our elders, we don’t just pop them full of pills and stick them in a corner” (Participant 7, FG7 in Cabrera et al., 2015:5). The idea of supporting one another as opposed to help seeking means structural changes in community where healthcare providers have the resources, education and training needed to support people with dementia and where supports exist in community, so people do not have to leave to access healthcare. Many Indigenous communities and families are providing exceptional care already on the basis of respect and love for their seniors without many supports. If supports followed the person as opposed to being based on their geographic location for service access, healthy communities thrive and are able to provide exceptional care to their loved one with dementia.

## 4.10 Key Findings

- Indigenous caregivers are not accessing dementia specific supports since they often do not know they exist

- Public outreach and developing culturally safe programming is integral for communities to provide support to families affected by dementia
- Home care support workers are integral to the well-being of families since they have frontline contact and relationships with families
- Training and educating Indigenous community members can remove cultural barriers and bring services into communities
- Caregivers are resilient and provide exceptional care with minimal resources despite systemic barriers including a lack of continuity of care, jurisdictional funding issues and a lack of existing services such as transportation to services, respite and in-home support
- Caregivers have a lot of knowledge and experience that can inform systemic changes and should be included in the development of programming for support
- Peer support can be a great coping mechanism for Indigenous caregivers to be able to share and heal with other caregivers who have similar experiences
- Friendly visiting for isolated seniors can combat loneliness and has benefits of intergenerational knowledge translation for youth through the exchange of medicine through socializing, sharing a meal and learning from one another
- For caregivers for a loved one with dementia, there needs to be a shift of supporting one another instead of help-seeking and building communities that have resources and infrastructure because healthy communities means healthy families

## 5 Issues in Long Term Care

### 5.1 Introduction

All four caregivers interviewed placed their loved ones in long term care facilities until they passed. Health care providers shared their experiences helping families navigate the healthcare system and the issues that arose for placement in long term care such as waiting until a crisis arose, the lack of culturally safe care and the importance of being advocates.

### 5.2 Alcohol-Related Dementia in Long Term Care

Alcohol-related dementia (ARD) is discussed in literature focused on dementia because rates are recorded as higher in long term care homes than literature that focuses on different types of dementia. They are not being referred to neurology or memory clinics since ARD is reported as only accounting for 3-5% in literature on dementia rates, but they are being placed in long term care homes since data focused on alcohol-related dementia states that it accounts for 10-24% of the resident population (Ridley, Draper and Withall, 2013:4). This was reiterated within the practice of Jason:

*So, if you ask, if you look at the practice of neurologists and geriatricians, well less than 1% of the dementia diagnoses are alcohol-related dementia. When you look at people in dementia homes, it's about a 1/6 of everybody in a nursing home in Ontario today has a diagnosis of alcohol-related dementia.*

This discrepancy in public health data on ARD rates and within the experience of the geriatrician shows that those with regular substance use are not seeking earlier prevention or intervention medical support but are placed in long term care most likely once there is a crisis and full-time care is needed. The implications connected to Indigenous populations is that, “vascular/multi-infarct (mixed) and alcohol-related dementias have been found to be more prevalent amongst Indigenous people of North America than [Alzheimer’s Disease]” (Henderson and Henderson, 2002; Schubert et al., 2006; Hendrie

et al.,1993; Jervis et al. 2006 in Hulko et al., 2010:318). But all research focused on dementia has excluded alcohol-related dementia for inclusion criteria for research and the basis of age predominantly focused on those 60 or older. The impact is that huge portions of the population are being missed for developing resources, support and knowledge on the topic. It also shows that long term care homes are being used for accommodations which means that families are coping until they no longer can or individuals who are socially isolated are being placed by care providers. Thus, preventative care or reducing the impacts of ARD, a reversible illness is not being accessed until full time care is required. Since the majority of people affected by ARD are younger, this has implications for long term care homes since,

the lack of appropriate cultural and social stimulation in aged-care accommodation may exacerbate behavioural problems and lead to a deterioration in function and increased risk or severity of psychiatric complications such as depression or psychotic episodes. In Australia, patients with ARD are younger by a generation or more than residents in aged care, where the average age is 84.3 years (McPhail et al., 2013:C).

Long term care homes are not equipped to deal with younger residents and the recreational, social and health approaches are not geared to their inclusion. With a diagnosis of ARD, there are the additional intersectional issues of not only cognition change, but accompanying, “high rates of behavioural and psychological symptoms, largely due to the types of prevalent dementias. These behavioral disturbances are a leading challenge in providing long term care in younger-onset dementia” (Withall, 2013:230). Long term care homes are not equipped for dealing with behavioural issues which might be exacerbated because they are not designed to cater to younger residents.

### 5.3 ARD and Admission to Long Term Care

In order to move to long term care, the issue of sobriety in order to be accepted as a resident was discussed. This can be a barrier for being accepted to long term care if someone has regular substance use but requires full time support. Jason discussed sobriety as a requirement in his experiences:

*You shouldn't be allowed to discriminate against someone's alcohol intake as a reason for their admission to long term care. If someone is actively drinking a lot when they're coming into long term care, then yeah that can be a factor. Please remember that 20% of all acute care beds in Ontario right now are occupied by people waiting for long term care. So that's easy. You dry out in the hospital and then you're going dry from the hospital to the nursing home or one or two beers a day in the hospital. Given that there is 80 or 90 people at [hospitals] right now waiting for long term care. At least several of them are getting a beer or two a day. So just another route is a way to go around that.*

Harm reduction approaches are a practical solution for ARD because it is not forcing someone to stop drinking entirely but focuses on reduction or supporting them where they are. With long term care homes requiring that individuals be sober prior to admission, it works from a framework of regulating what behaviours are acceptable (Vrecko, 2010:47). Individuals with ARD are using emergency services in hospital when there is a crisis, they are assessed and the process for moving to long term care is waiting for a bed to become available. Beds being taken up by individuals with ARD, "...contributes to strain in the ED [emergency department] and high healthcare costs. ARD is a relatively common but frequently under-recognised condition that is disproportionately associated with delayed discharge, contributing to hospital 'bed block'" (MacPhail et al., 2013:A). The need to rely on long term care points to a broader issue of the lack of existing support for regular substance use for aging populations and that preventative or harm reduction approaches are missing in healthcare. There is a program that has been developed in England to cope with the rising demand of healthcare needs for individuals where, "a recently developed ARD rehabilitation service in England reported a reduction of 85% in acute care use. This service was developed within an existing service for younger-onset dementia at relatively low cost, and consisted of person-centred care planning, close follow up and collaborative, interdisciplinary care" (MacPhail et al., 2013:D). This program ensured that people were not falling through the cracks where they receive acute care, return home and end up back in emergency. It is an early intervention where services are wrap around for the person with multiple healthcare providers. If intervention is early enough, it can greatly reduce the wait times in hospital and can potentially keep people at home longer because they have support services in

place. Regular substance use should not mean that someone does not have access to support services for their health concerns and be discriminated against accessing long term care if it is needed. There is already harm reduction being done in hospital where people are being provided with alcohol. So, this can be continued in a long term care setting as well as opposed to denying access because of regular substance use.

For Annette, when her father was placed into long term care, they faced discrimination because of his regular substance use:

*D: Did you find, like I found a lot of difficulty once they would hear the diagnosis of alcohol-related dementia and that it would shift to be very judgemental to the treatment. I guess was that ever an experience for you guys?*

*A: Oh yes especially um well I noticed right from the get go, the care in the nursing home. Day one I was talking to the [manager] there. This was their plan;*

*'We're just going to put him on Ativan and then we're going to slowly withdrawal that'.*

*I'm like 'what? You're going to what with restraints? You're going to do what?'*

*'Well you know, were a nursing home, we're not rehab. It's not our responsibility to straighten out somebody's drinking problem. This should have been dealt with before he came here'.*

*That's the attitude I got.*

*'So, in our stream, what we're going to do is give him some Ativan and any other tranquilizers, should he need it. Dope him up and then wean him off the booze'.*

*I said 'well he's had a taste for alcohol all these years right? He has to have something that tastes like alcohol. I was told at the desk that we can have some stash here, just in case right?'*

*Then they said 'no, no, no stash. It has to be non-alcoholic. It can't'.*

*I had to buy near beer.*

There is still judgement within the healthcare system for regular substance use. As shared by Ali, people refrain from disclosing for fear of judgement:

*So, the person...actually lived with an addiction for a long time but also was caregiving a parent with the same addiction issues. So, she knows it from two perspectives how to navigate the health care system. But she said often times she knew not to be honest. Even from the get-go with a family doctor because she knew what the doctor would say and hiding it was better than not.*

The current treatment for regular substance use is not relationship centred where people feel comfortable discussing regular substance use without fear of judgement. Annette discussing the particular long term care home where her Dad lived shows it was not equipped to provide support nor allowed alcohol to be provided to her father once he lived there even though it was as an option when applying for long term care. This creates additional stress for the caregiver to worry about the mental health of their loved one if they are no longer allowed any alcohol after regular substance use for decades. This drastic zero tolerance in long term care also shows the lack of support for seniors in that a detox option does not exist. Discussed in literature focused on regular substance use for aging populations,

alcohol-related health problems among older people may be significantly under-attributed. This can occur because alcohol-related illness is difficult to distinguish from other chronic illnesses and from adverse reactions to medication; symptoms of alcohol problems may differ from those observed in younger patients; and older people show a greater reluctance than younger people to self-report alcohol abuse. As a result, alcohol-related morbidity in older people may go undetected—and thus untreated (Thomas and Rockwood, 2001:415).

Services are minimal for seniors with regular substance use because of ageism in healthcare practice. If seniors are not even being screened in the first place because of healthcare providers biases for age, then people cannot be properly diagnosed. There is a tool available for screening seniors for regular substance use called the **Senior Alcohol Misuse Indicator (SAMI) Tool** which is included below.

The SAMI is, “a brief, senior-specific screening tool with questions that are designed to



detect existing or potential alcohol problems in older adults without eliciting negative reactions, such as denial and defensiveness, from those being screened” (Purcell, Flower and Busto, 2003). This tool is excellent because any healthcare provider can use it including homecare support to intervene earlier and ask these questions in a non-judgemental approach. The amount of alcohol is adjusted in the screening tool which is an important factor for seniors which was discussed by healthcare providers:

*We're focusing on low risk drinking guidelines, specific for older adults which is lower than the lower stricter guidelines for the general population because one piece I think that older adults don't understand is why they need to cut down on their drinking because a lot of people think 'I've been drinking like this all my life so I'm fine. I don't need to cut down'. They don't acknowledge that there's lots of changes in their body that necessitate cutting down your drinking unless you're drinking very little to begin with and so what we're doing is we're cutting the drinking guidelines in half. (Ali)*

*An 80 year old lady that weighs a 100 lbs, her alcoholic drink is supposed to be 3 ounces of beer, maybe an ounce and a half of wine...um it never happens. You would never even think of serving an 80 year old lady a whiff of beer or a shot glass of wine. You just wouldn't do it. But that's what all the science says you should if you want her to get a good alcohol buzz for 6 hours, but not fall done right. (Jason)*

**1a. Have you recently (in the last few months) experienced problems with any of the following (if yes, please check box):**

Changes in sleep?       Changes in appetite or weight?       Dizziness?  
 Drowsiness?       Difficulty remembering things?       Poor balance?  
 Falls?

**1b. Have you recently (in the last few months) experienced problems with any of the following (if yes, please check box):**

Feelings of sadness?       Lack of interest in daily activities?       Feelings of worthlessness?  
 Loneliness?       Feelings of anxiety?

**2. Do you enjoy wine/beer/spirits? Which do you prefer?**

**3. As your life has changed, how has your use of [selected] wine/beer/spirits changed?**

**4. Do you find you enjoy [selected] wine/beer/spirits as much as you used to?**       Yes       No  
*(For clinical use. Not included in scoring.)*

**5. You mentioned that you have difficulties with  (from answers to questions 1a and b). I am wondering if you think that [selected] wine/beer/spirits might be connected?**       Yes       No

SCORING KEY	
<p><b>Single responses (a score of 1 for each response):</b></p> <p>Question 2 I enjoy <b>all three</b> of wine/beer/spirits OR I enjoy <b>a combination of any two</b> from wine/beer/spirits      <input type="checkbox"/></p> <p>Question 3 I have <b>increased</b> alcohol consumption from when I was younger      <input type="checkbox"/></p> <p>Question 5: <b>Yes</b>, there <b>may be</b> a connection between my alcohol use and health      <input type="checkbox"/></p> <p><b>SUBTOTAL 1 = <input type="text"/>/3</b></p>	<p><b>Multiple responses (a score of 1 for each combination of responses):</b></p> <p>Question 2 &amp; 3: <b>Yes</b>, I do enjoy alcohol There has been <b>no change</b> in alcohol consumption <u>=&gt; If both responses provided, check box =&gt;</u>      <input type="checkbox"/></p> <p>Question 1, 2 &amp; 3: <b>Yes</b>, I have experienced <b>5 or more</b> symptoms <b>Yes</b>, I do enjoy alcohol <b>Indicates any</b> current alcohol consumption (regardless of any change in pattern) <u>=&gt; If all three responses provided, check box =&gt;</u>      <input type="checkbox"/></p> <p><b>SUBTOTAL 2 = <input type="text"/>/2</b></p>
<p><b>TOTAL SCORE = SUBTOTAL 1 + SUBTOTAL 2 = <input type="text"/></b></p>	

**Figure 1 SAMI Assessment Tool**

It is further complicated in that services do not exist in the first place that offer harm reduction, detox or support to meet the individual where they are, so they are forced to access hospitals when they are really ill. If detox is required for accessing long term care,

then people will remain in hospital since it is the only way to be transferred to long term care to get the support they need. Using existing tools like the SAMI can be a method of prevention to work with seniors where they are using harm reduction approaches as opposed to abstinence which would be impossible if there are cognition changes as well.

## 5.4 Stigma of Regular Substance Use

When a loved one is placed in long term care who has regular substance use or a diagnosis of ARD, there is still discrimination. This was the experience of Annette once her father was placed and any time there were concerns with him, she would be contacted:

*But the staff would ridicule me and him when there were times he had reason to be upset because he was developing an infection, or something was going wrong and I would get a call from a nurse who would um sarcastically say, 'oh maybe I should just give him a beer and that will shut him up, what do you think?' That's the attitude I would get. Not good. So, there is a lot of work that needs to be done here.*

If the staff are not providing adequate care because of their biases of regular substance use, it negatively impacts the relationship with the caregiver because of imposed judgement. It also creates issues for level of care if there are legitimate health concerns that are being ignored because of regular substance use. This places the caregiver in a precarious position to be the advocate for their loved one to have their concerns investigated and creates fear for the level of care being provided. Annette further expanded on her experience when he was in long term care:

*It was non-stop, things that I never thought arise, arose. And the disrespect part was the most, that's why I wanted to speak to you today. I remember the sneers, the laughter, the sarcasm, the criticism from staff. Yeah it wasn't good.*

Staff being disrespectful to caregivers and their loved ones based on their judgements of regular substance use directly impact the care provided or perception of negative care being received when a caregiver is not present. If healthcare providers are blatantly being rude and disrespectful when caregivers are present or when coordinating services, it does

not foster a relationship of respect, reciprocity and care. There are improvements that need to be made in long term care based on rights and access to healthcare not determined on whether the person is deserving of excellent care because of regular substance use. Education is integral to shifting to compassionate care where caregivers and their loved ones are not stigmatized.

## 5.5 Caregiver Role When Their Loved One is in Long Term Care

Geographic location is imperative for caregivers to be able to visit as often as they like, to be able to provide support and advocate for their loved one's medical, social, emotional and spiritual needs. Even though her husband was placed outside of their First Nation community, Kathleen said:

*But I went quite a bit, I went almost every day to go and see him.*

Being able to see your spouse or parent daily or several times a week is important for their well-being since they are moved to an unfamiliar community. Caregiving by family maintains relationships of love and affection even if their loved one cannot remember them; the caregiver remembers. Loved ones are often placed far from their community which is often the case since, "a lack of basic dementia care resources was apparent in the reserve community: physician services, respite care, crisis support, emergency services, long term care, visiting nursing services, and medical transportation were all limited or absent" (Finkelstein, Forbes and Richmond, 2013:260). It can be a barrier for family to still provide the level of care they want to because of transportation. Annette discussed that she was taking her father to all his specialist appointments:

*What I found was a bigger problem was this; when we had appointments out of the nursing home, because they only have a doctor, an excellent doctor that would come in once a week right. But all of our family have specialist appointments in this stream or whatever, so I would bring [Dad] into these appointments. Often, I would have help because he would need his oxygen, he had a bag, and make sure he was ok and wasn't*

*getting stressed out about going somewhere new. So, you know parking of the car, getting [Dad] in, getting [Dad] to the doctor's, you know what that's like right?*

Once someone is placed in long term care, the responsibility for transportation and accompaniment falls on the family. This can be a barrier if they do not have access to a personal, accessible vehicle or have the financial means to pay for transportation services for medical appointments. If someone is residing outside of their community, they are not eligible to access financial support from Non-Insured Health Benefits (NIHB) through *Indian and Northern Affairs*. Since long term care homes do not exist in the majority of First Nations communities and are residing in nearby towns or cities, health access for benefits are not an option. For Métis families, they do not have the same health rights and benefits as First Nations or Inuit peoples, thus have no additional supports for transportation costs. For isolated seniors, Indigenous and non-Indigenous, once they move into long term care, if they do not have family support to take them to appointments outside their home, they have to rely on transportation service such as *Voyageur, Meals on Wheels* or *Victoria Order of Nurses (VON)*. The limitations for finances can mean that specialist appointments are missed or delayed which can cause health complications. Transportation is a huge barrier for accessing health care services and more financial supports are needed, especially for Indigenous communities that are forced to travel extensive distances because of forced displacement from their communities to be in long term care home because of colonial policies.

For Métis health, we currently have minimal to no data. As discussed by,

Indigenous scholar Janet Smylie (2010, 2)... [a] key challenge with respect to coverage is the absence or inconsistency of First Nations, Inuit, and Métis ethnic identifiers in vital registration systems, primary care and hospital administrative datasets, as well as acute and chronic disease surveillance systems. As a result, First Nations, Inuit, and Métis people are largely invisible in the majority of provincial and territorial health datasets (Andersen, 2016:78).

Without existing data, it is difficult to have accurate information to be able to access funding and make systemic changes for improvements to healthcare for Indigenous peoples. In terms of long term care, Indigenous peoples have to leave their community. Although there, “are currently over 630 First Nation communities in Canada, very few

First Nation communities have their own long term care facilities. According to information provided by ISC, only 53 long term care facilities are managed by First Nations across the country” (Report of the Standing Committee on Indigenous and Northern Affairs, 2018:26). Thus, there is no data on the number of Indigenous seniors in non-Indigenous long term care homes.

## 5.6 Advocacy as a Caregiver

Being an advocate for their loved one when they were placed in long term care was a common topic with caregivers. All of these amazing women ensured great care and would be a voice for their loved one when their health needs were not being met. Annie shared a horrific story that is common for a lot of Indigenous families of receiving care that had detrimental health effects. Annie shared this memory when her Dad was in long term care at the end of his life and she would travel 2 hours to see him:

*I saw Dad, I complained. He had such a big bed sore on his spine, his lower spine, his coccyx area...that I saw the bone. I saw the bone. I saw his skeleton. It freaked me out because I never saw it and I called the nurse and I said, 'I don't know what happened but it's a bedsore'. I said 'why is this happening? Is no one looking at his back?' And I said, 'why is this open that you can see the bone?' and they hurried up of course. If I wasn't there, he would've been like that, might've gotten bigger maybe....*

*I'm getting emotional because he was in pain and I had to turn him over and I saw a bone. When you see a bone of your father, it's hard. It's hard to look at especially in a place of care. So, I started to complain of that. I said 'get things going' so they put a plaster on him and got things going.*

Annette had similar concerns of the level of care if she did not show up often:

*When I come in; 'Oh my gosh, she's here. The family's here!' That's what they would say when they would see me coming. Like get your shit together, the family's here. Like they would call it when they see me coming off the elevator right because they didn't want me to see that he hasn't been fed or that his bag needs changing.*

When Annie was sharing the story of the bedsore she found on her father, she was emotionally reliving that moment and I can only convey in words the deep sadness she felt. No one should ever experience what Annie did and shows that health treatment for Indigenous seniors can be abominable in long term care. Annie and Annette were advocates and visited their Dads as much as they could in their new residence at long term care. The fear of mistreatment without their presence meant that they were always advocating and being hyper vigilant to ensure their Dads were treated well. Fear of how your loved one will be treated because you are an Indigenous family should never be a part of a caregiving experience and illustrate that we have vast improvements to make to ensure all families feel comfortable and trusting of the level of care being provided.

Annie expanded on her concerns when she was not able to be there constantly:

*Yeah and they're fearful and I don't blame them, and I still wonder to this day what they did with my Dad when I wasn't there. What did they do to him? I wonder many times because he was very quiet. He stopped talking. Why did he stop talking? From singing to not talking and never talked after. He just quiet, he shut his mouth. Even with me. I couldn't even get a word from him.*

*I would say 'are you OK?'*

*He would say 'yeah', nod his head.*

*I wonder to this day if they had threatened him.*

These memories exemplify why there is still distrust of the healthcare system rooted in the history of colonialism and that many families avoid long term care homes for as long as possible because of their fears of lesser than treatment (Webkamigad, 2017:9).

Everyone deserves excellent treatment especially for complex needs of loved ones with dementia and long term care homes do not have the infrastructure or staff to meet those needs, especially in a culturally safe way. Infrastructure changes that would be ideal are long term care homes in community, rooted in the culture and close to family, surrounded by everything and everyone they know and love. But if families still have to access homes outside of their community, cultural safety needs to be a priority to work towards

reconciling the legacy of mistrust because of so many stories similar to Annie and Annette.

## 5.7 Indigenous Perspectives on Aging

Since long term care homes become an option for a lot of families with a loved one with dementia, they need to be family centred because the, “benefits that relate to family care include that people with dementia have more access to emotional support and cognitive stimulation and benefit from being cared for by people who know their interests and history” (Pace, Jacklin and Warry, 2013:40). It is a shift towards a kinship approach to healthcare where seniors are treated like family members as opposed to clients. There are many seniors, Indigenous and non-Indigenous who live in long term care, but do not have family support or live in proximity to visit. They lose their social connections with those who know them best along with emotional connections. Annette showed affection and spent time with other seniors in the long term care home where her father lived when she would visit:

*People were always coming up to talk to me. I can't tell you how many clients at that nursing home would come up and tell me their life story and how much they missed their loved ones and all of that and I would always listen, and you know, they just need someone to talk to, someone to listen. I never said anything, I would listen and say oh and whatever I had to contribute to the conversation to make them feel better. There are so many people like that and yeah it breaks my heart because um, they're needy. They need family that don't come, they need interaction daily with people that listen to them.*

Long term care homes function from a medical model where health needs are met, but the emotional connection is missing of having someone to talk to and interact with. Long term care homes should be holistic and factor in the emotional connection for seniors. But this would require a shift in funding to no longer work from a model of medical based needs alone where frontline staff are working with minimal supports and low staff to resident ratios. Annette and I further expanded on the topic for the importance of physical touch for interaction as well:



*D: I went to a conference about long term care homes and even just touch that some people, they don't get hugs. The staff doesn't hug.*

*A: That is a human need. You know, that right? That in this modern, urban society that we have, we've had to adapt. That is a human need that is supposed to be met daily and then when it isn't, we fill that. We go out of our way to go to the same favourite grocery store for that checkout person that smiles like they might care or they might remember you or you go to that same teller at the bank, you go to that bank because that one teller takes the time, because they've seen you over so many years to strike up a conversation. That is taking place of that human need for touch, daily touch and it's been proven without daily touch and daily interaction, like plants, they die. You know, plants need water, sunlight, they need to be told that they're loved. People need hugs and food and shelter and told that they're loved, and they need to be held and those things aren't happening. And yeah, it's totally inappropriate for anyone to do that but family and that's where it's so hard and so many people aren't getting it and the seniors that are shut in.*

Isolated seniors who do not have family support in community or in long term care are missing social connections that is important to their well-being; to be heard, valued and respected. The inclusion of the emotional well-being of aging populations, especially those with dementia needs to be prioritized along with their mental, physical and spiritual health.

Seniors who are missing the social connection of family shows a cultural shift for Indigenous and non-Indigenous peoples. Through their interviews, Hulko et al. found that,

in 'them days', many generations were involved in caring for the older ones, including both adult children and grandchildren, as the following quote indicates: I guess she was pretty—really old and the kids were all lots of them, eh? And she was in a tent in the summertime and the parents would go picking, so my mom and all of them little kids were saying, 'look after her, look after her, your granny's very old' and they told them, 'You know she might die. Look after her, anything happens or if you think something happened to her come run and get us, call us' (interview 1, Feb 9, 09) (2010:333).

Intergenerational caregiving has shifted since people are leaving their communities to access resources, jobs and education if they are minimal to non-existent in some Indigenous communities. These changes have huge impacts on seniors because it is a move away from seniors being cared for by their extended family and seniors caring for the younger generation, which is integral for knowledge and cultural translation. The benefits for seniors as well are engaging in cognitively stimulating activities and contributing to their self-worth because of their involvement in teaching, taking part in ceremonies and their language (Pace et al., 2019:97).

Front line staff in long term care are not supported for relationship centred approaches where their time can be spent with each individual to socialize or focus on more than their medical needs. This is a systemic change that is needed to support the staff who are providing care to those with dementia. Amanda summed up the difficulties for staff:

*The folks who work on the front line with people with dementia, they have a big job and the pay is not great and the job's not glamorous. It can be really challenging and there's a lot of time factors and there's a lot of paperwork involved and so many different demands on time. I don't think people always feel empowered to get to know the person that they're connecting with. They feel like that's a luxury but it's sort of changing the conversation and I think it's just sort of a whole system change that if we start from knowing the person and that's the number one priority and the other elements will follow. So that's hard and I think it's just how the system is structured right now and it's not enabling people to do that in a way that is easy.*

Long term care homes are designed from a bio-medical approach where interactions are task orientated and overall focused on cost effectiveness as opposed to relationship centred care. There are constraints on all staff to ensure that medication is taken, and people are bathed as opposed to a focus on quality of life for residents (Ducak, Denton and Elliot, 2018). Staff must follow the regulations of the *Ministry of Long-Term Care* where recreational activities or the inclusion of residents' ideas of well-being are not included in the policy directives. It was summed up well by Amanda:

*We're not working with widgets for example. A lot of things now are very task focused and those tasks might have to be done but you're losing sight that you're working with a human being and not looking at it that way, sometimes we run into trouble.*

All Canadian health care can benefit from an Indigenous approach of holism for providing care that is based on relationships and not just being task orientated. Annie worked in long term care homes for years and brought a relationship approach to the care she provided:

*Each person I took good care of. I know I was. They told me I was slow because it was a quality, not quantity. I was taught that way to respect the elderly. I told them 'no, I'm taking care of her, you go take care somebody else'. But I had a whole floor to do. I got them all done in time, some needed more, some less.*

Annie exemplifies a cultural shift in the treatment of seniors in long term care where it is quality and not quantity of achieving the required tasks. It is care not only that is medical, but social and founded on respect for those that are aging and in the later stages of their life deserve to be treated with love from those caring for them.

## 5.8 Indigenous Culture in Long Term Care

Since all their loved ones were placed in long term care, we discussed if Indigenous culture was included in the homes. When speaking with Kathleen and Michelle if Indigenous culture was ever included in the home:

*M: Ah I'll ask my grandma. When he was in the nursing home, did they do anything to include Aboriginal people? Anything like specific or do you remember other Aboriginal people there?*

*K: No there wasn't any.*

*M: And they didn't do anything...?*

*K: No.*

This topic was a theme with all the caregivers I spoke with that there is no inclusion of Indigenous culture in long term care. When speaking with Annette, we discussed our experiences at the homes where our fathers lived:

*A: Do you find that um well what about for cultural encouragement? Cultural messaging? Is there anything where he is? Or does the family have to interject there?*

*D: No, they don't do anything at all. I know there are other people in there who are Indigenous, and they won't say anything. They won't tell the staff. They'll tell us, but they won't tell the staff.*

*A: Dad was noticeably First Nations, people there and we got, if that person needed something, they would you know you help them, or they ask you, you just did. So, 'hey sister, how are you doing? Is there anything you need?'*

*'Yeah, yeah'.*

*Because you knew they weren't getting the help they needed unless they hollered loudly right. So, I find, between the front door and getting upstairs to where my Dad was, yeah there were a few people in between.*

As an Indigenous family, Annette would take on the role of being a caregiver for other Indigenous seniors in the home since they knew they were a Métis family. Although there were Indigenous people living in the long term care home, there was still no culturally specific programming and other residents relied on Annette to fulfill a role as a helper when she was visiting her Dad. Within existing literature, there is no data that focuses on the numbers of Indigenous peoples in long term care although most people have to leave their communities to be placed. But families might not be comfortable disclosing their Indigeneity for fear of mistreatment. It is complex to be able to improve long term care without knowing the numbers, but if it is known that long term care is only available in a few communities, then long term care homes must have more Indigenous people than they are aware of. Thus, cultural safety should be mandatory in long term care and the inclusion of Indigenous culture for those who are removed not only geographically but socially and culturally from their communities and homes.

Long term care homes should also be providing the opportunity for loved ones to engage in activities in the home that interest them. In Australia, in a long term care home, Smith discussed the benefits of outings for residents and caregivers,

They mightn't be able to walk, but even just to sit down on the beach some of them just love it, it builds their morale up too make them feel good and gives that bit of, but even though when you do that you still need someone to give that extra support to the carer as well because, so that there's a bit of balance for the time for the person, the client having their own time as well as the carer having a little bit of time out for themselves as well (Carer 14) (2011:10).

Within improvements for Indigenous culture for long term care, they include place based activities for residents to spend time on the land. Long term care homes lack access to land based activities and often only include a garden as a place to connect with nature. Thus, all residents would benefit from place based activities to reconnect to the land. Literature focused on Métis seniors in long term care in Manitoba discussed the lack of cultural inclusions and the impact it can have on residents:

'So you move them out of [home and into] a more mixed nursing home where nobody speaks their language, nobody understands their culture necessarily...I mean what's important to us is totally not necessarily what's important to them...And they're a very strong people so. But I think that's the biggest, once they get old and there isn't family support, they know that the only place they're going to go is totally outside their community and their people' (Bartlett et al, 2012:65).

It must be alienating and lonely to not have the inclusion of anything that remind you of who you are, where you are from or your community, especially for loved ones affected by dementia. I am a member of the *Ontario Caring Advisory Council*<sup>6</sup>(OCAC), created in 2018 as a part of the *Centres for Learning, Research and Innovation in Long Term care*. OCAC is comprised of 10 Indigenous members from Northern and Southern Ontario to develop culturally appropriate resources to support Indigenous residents in long term care. This is a great resource for anyone involved in long term care including administrators, front line staff, residents and caregivers since education and tools are provided including the importance of place for Indigenous

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<sup>6</sup> <https://clri-ltc.ca/resource/supporting-indigenous-culture-in-long-term-care/>

families to spend time together. A Secwepemc Elder shared the importance of a, “spare room, it could be called a spiritual room. Just like the sema7 [white people] have a chapel at the hospital, we would like a room like that where we could have our privacy, play our drums, sing our spiritual songs, smudge and do our spiritual thing like the sema7 does his” (2019:21). Physical space and design can reflect culturally safety where there is a place for families to gather and for seniors to practice their culture.

Annette made a great analogy of what it might feel like if you think you are the only Indigenous person at a long term care home:

*A: Yeah, they're just left there bored out of their mind and their only excitement is going out for a smoke.*

*D: Yeah.*

*A: I feel sorry for them.*

*D: Yeah, there's a lot of people. There's room for improvement to put it mildly.*

*A: I don't know how they feel if they're rowing in their canoe alone. I don't know if they have the social network to realize that there might be other community members in the home.*

*D: Yeah because nobody talks about it.*

*A: No and they do these community outreach where they put people on a bus and drive them somewhere. They should be hooking up some of our people together in one destination to do something right?*

As shown by Annette who provided support to others when she visited her Dad, knowing other Indigenous families in the home is great. From research conducted with Indigenous caregivers for neurological conditions, including dementia, it was overwhelmingly stated by caregivers that they need peer support and counselling so they can meet other people going through relatable situations (Bourassa et al., 2019:120). It can create social

networks for caregivers to not feel alone and can aid with isolation of caregiving when a loved one is in long term care. It also contributes to the well being of families, since the caregivers' wellbeing positively contributes to their loved ones if they feel supported in their journey.

## 5.9 Positive Experiences in Long Term Care

What contributed to positive experiences for families with a loved one in long term care was excellent relationships with the staff and knowing that they were providing good care. Discussed in literature focused on caregivers in the East Coast of Canada, "caregivers often walked an interpersonal tightrope of diplomacy held together with a healthy measure of humility in order to secure resources for themselves, their families and/or their care recipient" (Gahagan et al., 2004:44). Relationships with the care providers enhance the feeling of assurance for a loved one with dementia in long term care. This was discussed by Kathleen:

*But I went quite a bit, I went almost every day to go and see him and uh what I did, how the workers, um well I didn't tell them but I told [him], I said 'well I'm coming back tomorrow, so I'll come and see you. But I don't know what time I'll be. I'll be here' and I wanted them to make sure that he was clean so in the morning, they would give him a bath and do whatever they do. So, by the time I'm there, like he had fresh clothes on, like he wasn't left. Because I saw some of the people, some um residents or patients there, that nobody go and visit them, so they don't bother them. So, then I made sure that at Easter, or Valentines and Christmas, we brought um a dozen doughnuts or a box of chocolates. We put on the card 'thank you for looking after my papa' and we put [the grandchildren's] name on it on it, signed you know on the card you know? Yeah but it was so that they know they're appreciated there. Yeah.*

*D: Do you think, is there is anything that long term care homes could do to I guess to give really good care to people with it?*

*M: Did you hear her? Is there anything you think that long term care homes could do to take better care of their residents?*

*K: Well, I would say, like he was in a good place because I know, I know the nurses, or the PSWs that we're working there, they looked after him really good and um but today, I haven't been there in a long time they say it changed and I don't know if um, they said it's not like how it used to be so I don't know what changed there. But other than that, I believe that he, that we got good care. I know that one of his PSWs said that they give them baths once a week eh. She said 'I'll give him another bath sometime this week' she said like they made sure that he was looked after.*

*D: Oh that's good.*

*K: Yeah, I think it's how you treat them, the staff too has a lot to do with it.*

*D: Yeah that's true. Timmies helps. The nurses are big fans of caffeine to keep them going.*

*K: Yeah.*

*M: But I also feel like you shouldn't have to do that to get good care. That's just my opinion.*

*D: Yeah I know. It's a double-edged sword.*

Kathleen and Michelle showed the different perspectives for caregiving to navigate their relationships with staff where they show their appreciation and visit often to ensure that their loved one is treated well and that everyone should be treated well regardless if their family checks in on them. The connection of care to the visiting of family members was also discussed by Annette:

*I know. Feel sorry for them, there just stuck there right. I don't know how many families come to see them. Like you think about these things and you wouldn't unless your family member was there. Or you volunteered at a place like that, or you worked there unless you're there. These are things; those out of sight, out of mind things. You know, you're thinking about these people, not just your family member, but other people when you're there and their needs.*



Relationships not only with the residents is important, but also reassures family members when they feel like staff are empathetic, compassionate and care about their family members. Relationship centred care has to be supported on all levels and can contribute to less staff turnover if they are able to work from an approach based on relationships as opposed to being task based. It also increases consistency for residents to have the same staff who know them well. PSWs are instrumental since they know residents' dislikes and likes, their schedules, what works for them, so keeping PSWs long term is supportive for other staff since they can provide the understanding of behaviours and what will benefit residents.

A shift of relationship centred care means enabling flexibility for care providers, families and especially residents. For Indigenous families, flexibility can aid with,

...overcoming barriers to culturally appropriate end of life care is the development of specific health care policies that accommodate the holistic needs of Aboriginal families. These policies need to be flexible in order to allow cultural practices to occur in health care settings. Additionally, efforts need to be made to make families aware of where culturally appropriate services are available, which can be addressed through networking families and community services (Hampton et al., 2009: 59).

For loved ones to move to long term care and be away from everyone and everything that is familiar, working with the family to bring in cultural safe care can make it an easier transition. Hulko and colleagues discussed the importance of tailoring cultural programming dependent on Nation:

The study directs the provision of culturally safe dementia care for First Nation Elders with memory loss by respectfully integrating specific knowledge of a particular Nation. For the Secwepemc Nation, this could mean including content on cultural traditions (e.g., respect for Elders), history (e.g. residential schools), and values (e.g. supporting one another) into direct care practices. Seeking ways of supporting culturally safe communication with Elders in clinical practice is an imperative as a result of this work (2010:334).

Through integrating culture that is specific to the person has been shown to be beneficial for aging Indigenous peoples with memory loss. It also ensures that a pan-Indigenous approach is not applied since there are more than 200 First Nations communities alone in British Columbia and the variance is increased between Inuit,

Métis and First Nations peoples. Through culturally programming, it is also an opportunity to get to know the resident and their life history.

## 5.10 Shift in Lifestyle for Caregivers

Once a loved one is placed in long term care, it is a drastic shift for their family and caregivers. Little research focuses on the caregivers' emotional experience of their loved one moving to long term care and how it changes their lives. Kathleen discussed that it has taken her years to adjust to living alone:

*D: Did anything happen, why you decided to put him in a home?*

*K: Ah well, I had someone come in to take an application to uh because eventually we were going to put him in a home, so I had someone come in to take an application. She just nicely sat on the chair and she said 'oh no, he can't stay by himself now'. She said 'you know, he um, he should go, I'll try to speed it go for him to go into the home'. I guess um... he was going ah, ah, I don't know how. He was going up, you go different levels right?*

*D: Yeah.*

*K: Going up the levels, so that's...and yeah. I thought he was really going to resist when uh when I told him. I just said 'you have to go to the hospital and I'll get you a tv and um and uh I'll come and visit you' and he said 'yeah ok'. He was easy going that way.*

*D: I guess how was the adjustment for you once he moved?*

*M: How was the adjustment for you once he moved?*

*K: It was terrible, no (laughing). I was really lonely. Yeah, I was really lonely and I was uh, I didn't want to stay home. I was always gone some place, or you know. I didn't really, it's just now that I'm starting to stay home more. We're at, what 13 years now that he passed away?*

The process for moving is quick once a bed becomes available from the top 5 long term care home choices and the family has 48 hours to decide and typically the move is within the same week. It is often a whirlwind to go from a loved one living with you to them moving to long term care. It was honest for Kathleen as a spouse to share that it was lonely, and she tried to keep busy and visit her husband every day while she was still working full time. It was similar for Annette that she looked after her Dad for more than a decade with no support before he lived on his own by choice for a few years before placement in long term care:

*D: For you as caregiver, what supports did you have through all of this?*

*A: None and he lived with me for years prior. In fact, we lived on a property where I lived in the basement and my father and my daughter lived on the main, that would have been, his Alzheimer's' was already distinctive and troublesome back in 2006. So, I went 12 years looking after him.*

For Annie, her father lived on his own in their community, Kitigan Zibi and would come to live with her family during the winter a few years before he was placed in long term care:

*The minute November came, I took him in for six months, so for six or seven months I took care of him. Not take care of him in a sense where I would serve him or anything. I would let him be autonomous in that time was very important for me to let him be so that he would not fall into childhood. So, he could find himself, he liked whatever we bought and this was a good time. It was not easy living with him, because the more he got older the more demanding he was. We respected that and my boys respected him, they loved their grandpa and so forth. So, grandpa was living with us. When we lost my mother, he started to come live partially at home and after that it grew into six or seven months during the winter season he would live at home.*

The common theme is that they provided amazing care and their loved ones lived from two generations when they resided with their children and grandchildren. From interviewing First Nations seniors about aging,

strong intergenerational relationships in the past were seen to be connected to brain health with one Elder noting that ‘to me, when the old folks looked after their grandchildren—they didn’t have time to lose their minds’. Elders spoke of an acceptance of growing older—a view that was fostered when many generations were involved in caring for the older ones— and suggested this not be hidden from the young, lest they grow up to follow the shémá [white] way, treating growing older as a negative part of life that is to be feared (Hulko et al., 2010:333).

All of their loved ones were cared for and surrounded by their extended family and grandchildren were caregivers as well. The change in family dynamics for their loved one to no longer live with them is a difficult transition. With the process being so fast to move into long term care, there is little room for emotional support for the family during this decision. Michelle shared her memories of always being at her grandparents’ home and that most of her memories of her grandfather was when he had Alzheimer’s disease:

*M: Oh, um well for me, I spent a lot of time with both of my grandparents growing up. So, uh most weekends and most evenings with my grandma and my papa. Um so for myself, I was very close to them. Actually, my papa was the first person in my life that I every lost.*

*D: Yeah.*

*M: Yeah, I was really young, but I remember um things such as, they would take me to McDonald’s a lot and I used to sleep over there all the time and they let me do whatever I want.*

*D: (Laughing)*

*M: (Laughing) Yeah, but that’s how I remember my Papa and then obviously um probably like half of my memories of my Papa is when he was sick because I was so young.*

It would be amazing for loved ones to be able to remain at home until they pass surrounded by their spouse, children and grandchildren. There needs to be support services in the community to have this as an option. A lot of families do the best they can

until their loved one needs full time care and they have to move to a long term care home. We have a long way to go to systemically change the healthcare system where there is transportation support, respite care, in home services such as nursing, PSWs and for caregivers to not be alone in their journey.

## 5.11 Jurisdictional Barriers

An issue that is often discussed in literature focused on care for Indigenous seniors is that most communities do not have long term care facilities as an option. This connects to jurisdictional barriers for funding through different regulations that apply for First Nations reserves where,

federal funding policies have not allowed for the building of long term care homes on reserves. Any initiatives undertaken by First Nation Bands are privately funded by First Nations, and because they do not have operational subsidies like the off-reserve long term care facilities, they face many challenges. This was the case of a 30-bed, long term care home on the Muskeg Lake Cree Nation, closed in August 2010 after four years of operation due to insufficient funding, among other reasons (Beatty and Berdahl, 2011:5)

If First Nations communities do not receive the same subsidies as mainstream long term care homes and are expected to cover the cost to sustain the home, it is not financially feasible. With all the caregivers I spoke with, as well as care providers, we discussed the benefits if someone can remain in community. Richard discussed that the process now is bringing external service workers into community:

*I think when you're dealing with dementia, that type of thing or any kind of physical health, we need to build more in their areas to help. It's not going to be an easy thing and you're just bringing our care partners trying to keep them in [community]. You just can't do it. Family builds resentment and then you get one against the other because 'you're not doing enough; I'm doing it all' and that type of thing.*

As a social worker, he has witnessed the impacts on caregivers because of the lack of services or a long term care home to keep loved ones with dementia in community. This is substantiated in literature that quality of life for Indigenous seniors and their family is impacted since people are forced to move to urban cities, and once moved to long term

care, they felt lonely, isolated and worried about not being treated well (Beatty and Weber-Beeds 2013:123). The ratio of available beds to need in long term care homes that are located in First Nations communities are low compared to non-Indigenous ratios where, "...there is only one nursing home bed for every 99 individuals in First Nations communities compared to one for every 22 individuals in the general population. Moreover, nursing homes for Aboriginal seniors are mainly located in Ontario and Manitoba, leaving seniors outside of those provinces without access" (Parrack and Joseph, 2007:108). Therefore, even if there is a long term care home in community, it means there is a waitlist and that the person might not be living in their own nation. There are currently no Métis long term care homes and they have to rely on placement closest to their home since they do not have the same recognition for health treaty rights as First Nations and Inuit peoples. For Inuit peoples, they are forced to move to Ontario because, "there are 27 long term care beds in Nunavut, including three designated for respite or end of life care. No facilities in the territory provide care for dementia. That means a growing number of elders are sent to residential care facilities in the south, like Embassy West in Ottawa" (Sponagle, 2017). If there are no beds, especially for dementia care and minimal to no existing services in communities, families are coping as long as they possible can before their loved ones are moved hundreds of kilometres away from home. Seniors in Indigenous communities are the keepers of language, culture and history and removing them from community is a loss of all of those and has long lasting impacts for them, their families and communities.

Annie was unable to place her father in the long term care facility in Kitigan Zibi because they were not able to provide the care he needed:

*They have an old age home on reserve, but they were not equipped you see. They were not equipped for him. He needed special care. Now they're ringing up to have one because they know that I spoke and I'm not afraid to speak up believe me because it hurt me so much.*

The discrepancy in funding for long term care homes on reserve and off reserve is a form of systemic racism where funding, structural barriers and forcing people to leave their

communities because the services do not exist or are not enough to provide the care needed. If there are subsidies for long term care homes in the provinces, the different treatment for Indigenous peoples shows that treaty rights are not being upheld and this distinction is proof of systemic discrimination. Métis populations have to rely on mainstream services and Northern First Nations and Inuit communities are working with what is available if mainstream services are not an option dependent on geographic locality to a town or city. Even if urban Indigenous peoples have access to a physician, they still face systemic barriers and do not see their physician as often as non-Indigenous populations (Walker and Jacklin, 2019:29). Even accessing a physician on a regular basis is not an option since, “rural communities have limited access to health services in Canada, as distance to urban settings to seek medical assistance is a major logistical and financial barrier. More than two-thirds of residents in northern and remote regions in Canada live more than 100 km from a physician” (Ministerial Advisory Council 2002; Romanow 2002; Statistics Canada 2003 in Butler et al., 2011:139). With the *Truth and Reconciliation Commission*, there are calls to action for health. One of them is addressing that the rights to health are not being upheld although they are legally binding in treaty rights:

we call upon the federal, provincial, territorial, and Aboriginal governments to acknowledge that the current state of Aboriginal health in Canada is a direct result of previous Canadian government policies, including residential schools, and to recognize and implement the health-care rights of Aboriginal people as identified in international law, constitutional law, and under the Treaties (Truth and Reconciliation Commission of Canada, 2012).

Within the treaties that were made, health was a large component where Indigenous nations agreed to share the land and resources and the reciprocity was the inclusion of health rights considering,

Indian nations and tribes that signed the treaties did not relinquish their sovereignty to the British sovereign nor to Canada. Nor did the Indian nations and tribes that signed the treaties relinquish their traditional health regimes to the British sovereign or the Government of Canada. No textual evidence exists of such relinquishment. Evidence does not exist that suggests that the Crown intended to limit Aboriginal rights to health. Moreover, a limitation of Aboriginal rights to health would violate the sovereign’s promise of protection (Boyer, 2003:9).

The current barriers based on legal determinants of who is Indigenous and based on whether you live on or off reserve is a violation of the treaty rights that have been in place since Indigenous peoples agreed to share the land and resources with settlers on Turtle Island.

Within speaking with caregivers, there were massive ramifications on their ability to care for their loved one because of the barriers of jurisdictional rules. Annie was an advocate and caregiver for her Dad throughout his life since he had many hospital admissions for co-morbidities before dementia in later life. She shared a story about a hospital that wanted to return him home before he was well:

*There was another time when he, I don't know what happened and he was going to surgery. Again, in the hospital, he came down from Maniwaki by ambulance and they operated [on] him and he hadn't eaten, he wasn't eating and that was early on in his life.*

*They called me and they said 'we're bringing him back up'.*

*and I said, 'how come you're bringing him back up?'*

*They said, 'he has to go back up'.*

*'He's weak, he's not eating, he didn't eat yet, he's not walking'.*

*The nurse came up and...she said, 'he's going'.*

*and I said, 'oh yeah?'*

*and I held onto the elevators and I put my hand across the elevator and*

*she said, 'move'.*

*and I said, 'no, he's not going anywhere'. I was holding onto the elevators (laughing)*

*and I said, 'he's not going anywhere'. I really had to fight for my Dad that time and then*

*I looked at her and I said, 'who signed that document?'*

*'He's going'.*



*I said, 'let's go take a look at that paper together, come on. Let's see who signed that document' because I took him in. So, she took out his document and I said, 'who is that name marked on it?'*

*She looked up at me: 'You?'*

*I said, 'yes'. I said, 'now, Madame, if he dies on the way, who do I sue here? You?' I had to go to that limit. 'Do I sue you? Do I sue the institution here, or the doctors? Who do I sue? You know what I'll sue everyone including you if he dies on the way'. She called the ambulance and called it off and*

*Said, 'he's going to stay for a few extra weeks'.*

*That's how rough I had to get. That's what they do, they send them home. If I wasn't there, would he have made it? Probably not. He was too weak; he was very weak and I had the signing authority and there is no way he was getting out of there. They had to call it off. They had to keep him for three weeks until he was strong enough and they asked me, 'is he good now?'*

*I said, 'yeah he's strong enough, he's walking and he looks good. Now you can transfer him'. That's the battles I had to fight, many of them, many of them. A lot. That's how I had a fight because he never spoke.*

Sending her father back to their community before he was well could have had dire consequences. Annie fought to make sure he was kept in the provincially funded hospital and not sent back to community before he was strong enough. But there are seniors without family support, and families should not have to advocate for their loved ones to remain in hospital in the first place. Jurisdictional boundaries should never determine access to health services, but for Indigenous families, this is constant in our health care journey navigating the system of who provides funding and eligibility requirements dependent on where you live.

For Métis and non-status Indians under the *Indian Act*, they are not federally recognized as eligible for rights and thus rely on the provincial programming. For example,

although provinces and territories provide health care services, the federal government is responsible to pay for status Indian and Inuit health care. Despite being declared Aboriginal under the Constitution Act, 1982, to date Métis and non-status peoples are not recognized as a federal responsibility. Thus Métis and non-status Indian peoples receive the same provincial benefits as all other Canadians (Beatty and Berdahl, 2011:7).

This includes thousands of Indigenous peoples who are not receiving healthcare services they are legally entitled to because of federal and provincial arguments of who is responsible. For Indigenous families coping with providing care and support for their loved one with dementia, trying to navigate what services you are entitled to should not be a part of the healthcare journey and changes need to be made that are relationship centred and not determined by fictional boundaries created by the Canadian government.

## 5.12 End of Life Care

One important topic that was discussed by Annette was end of life care when her Dad was living in long term care. During the admission process, DNR (do not resuscitate) is discussed along with transporting to the hospital. For Annette, she was surprised to hear that most families do not consent to additional medical supports:

*Oh and there's another thing. The nursing home said to us, me as the family, because I said 'look, if there is an issue, I want him to get care, medical care'.*

*'Oh well most of our families don't ask for that'.*

*I was like 'what are you talking about?' They had to spell it out to me because I didn't really get it at first.*

*They basically explained, 'most people don't ask for medical care, they are just here to die'.*

*D: What?*

*A: And I said, 'I want care for my father. He doesn't want to go anywhere. He wants to be here with us and his family. So, you better make sure he gets that care or there's hell to pay'. But this is my interpretation; the care was good, don't get me wrong. But for me,*

*it was more of what I saw outside the stream with the uh specialists and medical doctors that did raise an eyebrow.*

Within literature focused on palliative care and experiences of end of life, there is minimal research focused on Indigenous families (Duggleby et al., 2015:1722). End of life care is important for those living in a long term care home with dementia. The interaction she had with the nurse at admission is a snapshot that there needs to be changes in long term care homes where they are not places to die, but a place that feels like home until someone passes. The discourse around long term care homes as a place to die was also discussed within the experiences of Richard as a deterrent for Indigenous and non-Indigenous clients avoiding moving:

*...that age group is hugely against long term care.*

*'You know I'm going to die in my house and they're going to carry me out'.*

*It's not a question of that, it's a question of quality-of-life...and your safety. To no avail,*

*'it's where they went to die. That's where you go to die right and that and I'm not going there'.*

This public discourse around long term care shapes the perceptions of healthcare providers as well. It could represent that long term care homes need to change to be more focused on supporting life in a good way for Indigenous and non-Indigenous seniors with their loved ones there, with adequate support staff and being able to continue to do what they love. The existing approach is that,

...people living with dementia are less likely to be referred to palliative care teams, are prescribed fewer palliative care medications, and have more difficulty accessing end-of-life care than those diagnosed with other life-limiting illnesses. This could be due to difficulties assessing needs as dementia progresses, limited access to palliative care programs, poor communication between care providers, and the mistaken view that palliative care is not relevant to dementia among some families, patients, and health professionals (Canada Public Health Agency, 2019:36).

The best option would be for loved ones to be able to remain at home supported by family with enough care to provide respite, nursing and personal care. But long term care

homes are still being used and should shift to a holistic approach to end of life care instead of just medical. Annette expanded on her reflections of her father in long term care and that he became very social while there:

*He got the best care of where he was, and they really worked hard to make sure that everything was put in place for his appointments out of the home and at home he was looked after. He was well fed, he loved it there. For the man that never socialized or did anything, he was going to the penny auctions, he was playing bingo, he made friends for the first time in his life when he was sober. He actually developed empathy and a conscience. I finally got my father after 88 years. I had this little snippet of time with the man my mom loved and married. It was beautiful. That was worth it, but we went through hell to get there. Especially with the diagnosis of alcohol-related dementia.*

Although Annette's family faced many challenges navigating the healthcare system, there were great memories of her Dad in the home and these should be included in research as well. Positive impacts of long term care homes should be included when great care is received and can be a way to educate other homes for what works. Since there is little literature on the experiences of Indigenous families and the process and transition to long term care, good memories should be included since they provide key insights to care.

Kathleen shared a memory about a nurse in the long term care home discussing Alzheimer's disease since her husband was on a dementia specific floor:

*K: It affected me more when I was told he had Alzheimer's because uh I knew that he didn't have that much time with us and he's going to forget us.*

*D: Yeah.*

*K: And that's exactly what happened. Yeah. So, we ended up admitting him to a home and...and...he stayed on the floor, on the same floor where people with Alzheimer's so it was kinda hard, like to see all of them and how they, how they interact. But the nurse explained to me that uh she said that 'he's ok, because uh he's in his own world' and that um, and she said, she told me that 'if anything ever happens to me, I hope that I have*

*Alzheimer's. She said look at how happy they are. She said they are in their own world she says and uh they don't have no worries eh?' That's exactly what happened.*

The nurse providing her perspective on memory and Alzheimer's disease helped Kathleen to see it differently. It is a perspective of hope and happiness as well as the recognition of the impacts on caregivers. As Kathleen stated, she took it harder with the diagnosis because she knew he would forget them. The nurses' perspective shows compassion for the visiting loved one as well who might struggle with watching their loved one be affected by dementia. I think long term care homes should be places where support for caregivers is through patience, compassion and kindness.

Another component of end of life where changes can be implemented to be culturally safe is the inclusion of Indigenous space for families to gather and grieve. It has been identified as a need within medical settings such as hospitals and long term care homes since,

often there is no place available for gathering in hospitals and when there is such a space available it is often unknown to family members or inaccessible. One family member reflected on how although the hospital where their loved one passed away did have a space for Aboriginal family members to gather together, they were unaware of this at the time. Had knowledge of this space been made available, this family member says it would have been helpful, 'I was hoping to be with the other family members and I don't know this room existed. I would have liked to have sat, just think and talk and just have coffee with the family and maybe have a pastor come in and talk. ...we need to come together with us and talk and cry and cry and talk' (Hampton et al., 2009: 27).

Having a physical space for families to gather, to be able to access spiritual care whether it is a pastor or an Elder is important for the end of life journey and allows the family to be with them and to follow protocols and ceremonies for preparing their loved one to pass. Hospitals and long term care homes are often not accommodating for large families to gather and healthcare providers are unaware of the importance of extended family for Indigenous end of life care (Gahagan, 2014:56). Most medical settings do not have a space to accommodate Indigenous families where they can smudge as well if that is what they practice. By providing space that can allow for extended family to gather, it can

contribute to families feeling safe to enter the medical institutions since their culture can be supported and practiced.

### 5.13 Concluding Remarks

Current literature on the experiences of Indigenous families moving to long term care homes is minimal and speaking with caregivers sharing stories of their experiences provides insight to changes that are needed for long term care homes to be culturally safe. The best solution would be preventative support services in community and at home to support families and their loved ones. If loved ones with dementia could remain at home, their holistic well being would benefit from being connected to their community, family and history of who they are. If caregivers are supported with respite care, in home support services such as PSW and nursing on a regular basis, it can maintain their health and wellness. But jurisdictional barriers impact the ability for loved ones to remain at home and families have to access long term care homes to get the support their loved ones needs. Structural changes are necessary in order for improvements to be made for end of life care, including funding and training for care providers to be able to focus on relationship centred care as opposed to the existing model of being task based.

### 5.14 Key Findings

- ARD is common in long term care homes and there is stigma of regular substance use on behalf of staff. Thus, training is needed on regular substance use for aging populations since the rate is 1 in 6 people in long term care for Indigenous and non-Indigenous peoples
- Indigenous caregivers are advocates for their loved ones in long term care homes and fear mistreatment for their loved one. Therefore, training and infrastructure is needed to provide culturally safe, relationship centred care
- Indigenous culture is not included in long term care and more resources are needed. An existing resource is the *Ontario Caring Advisory Council* that is developing culturally based resources

- Positive experiences for Indigenous families in long term care need to be included in research as well because they offer teaching opportunities
- More research is needed focused on the transition and emotional impacts for caregivers when a loved one is moved to long term care and they need continuous mental and emotional support
- Jurisdictional barriers based on geography instead of needs and following the person has serious impacts on the well-being of Indigenous families caring for a loved one with dementia forcing them to move far from home into non-Indigenous long term care
- Long term care homes need to shift the dialogue and care to end of life instead of a place where people go to die and provide physical space for families to gather

## 6 Systemic Changes That are Needed

### 6.1 Introduction

Systemic level changes are necessary to improve navigation through the Canadian health system. Existing healthcare services for Indigenous peoples in Canada have systemic flaws including jurisdictional barriers and policies that are not culturally safe and prevent people from accessing care in a timely manner. I will address the systemic barriers which

include a lack of holism in healthcare approaches, the need for collaboration and self-determination with Indigenous communities and the importance of intergenerational health and decolonization. I will provide recommendations for improvements based on the experiences of caregivers and care providers supported by extensive literature focused on healthcare delivery for Indigenous populations globally and more specifically in Canada. These recommendations have positive applications for non-Indigenous populations, especially newcomers and community members located in rural areas who face parallel geographic barriers that determine access to services.

## 6.2 Siloed System

The current healthcare system is designed in siloes where body parts are designated to different specialists and services provide only certain things such as nursing or PSW support. This existing system comes with communication breakdowns since most specialists, primary care, PSWs and nursing support do not interact or discuss with one another to ensure there are no gaps in care. For dementia care, the siloed system applies as well. This sectioning of body parts based on specialty was discussed by Ali:

*We have one individual we've been consulting who drinks excessively. The wife provides it and willingly provides it and he came in for surgery because he had liver disease, ... liver cancer. I'm pretty sure. And so, our clinician contact[s] the surgeon says 'this is a major issue. I don't think he's candidly capable of consenting to this because he doesn't even acknowledge that he has issues regarding his alcohol use'. And the surgeon just brushed it off and said 'he's fine. I saw him. He consented to the surgery we're going to have the surgery' not even thinking about what might happen after he returns home and the recovery and the withdrawal even during surgery. And so, we can only do so much. But the system has to be there to support the individual. Because my colleague tried hard with letters and emails and you know they don't get it because they're there to do their job and if they don't see a red flag right away in the 15 minute consultation that they have, and often it takes a little bit longer to really see the problem. Like for instance, that guy forgot until the day he was being checked in or pre-registered that he actually had cancer. He didn't remember and that wasn't a red flag for them which is shocking to me right? If he forgot, why then there might be some other issues going on cognitively, then*



*you should be considerate. But again, it's the blinders. Yeah and that's the system we work in right now. It's all about the blinders. Yeah, I will attend to this particular body part, that body part, that body part belongs to someone else and the thing is with substance use, that's the whole body.*

This exemplifies that the current system is not holistic, treating the person entirely instead of depending on medical diagnoses. Communication is a part of shifting towards holistic care where healthcare providers work together. Ali's colleague tried to advocate for the senior prior to surgery, but the specialist ignored their concerns since they were only focused on the surgery for cancer. For Indigenous health to improve overall, there need to be systemic changes to the current approach to health. The biggest learning from female Indigenous caregivers is that the entire system needs to be altered to be culturally safe for Indigenous families with dementia. The benefits are not only for families affected by dementia, but all Indigenous clients and Canadians since the current system is segmented and not always working for them either. The entire healthcare system needs to be altered and,

with this approach, instead of fixing one component of the system, a system innovation is created. Changes reached in this way are more sustainable, and we can thereby prevent short-term solutions by avoiding a focus on symptoms only (Naaldenberg et al., 2009). Likewise, the Medicine Wheel emphasizes connectedness: that all parts must interact harmoniously (Chansonneuve, 2007; McCormick, 1995). If we fragment the experiences of First Nations communities and focus on solving only one issue, without any attempt to understand the whole system, we will not produce a meaningful change in the care of the elderly who live in rural and remote communities (Habjan, Prince and Kelley, 2012:220).

If an Indigenous community has the infrastructure to provide the supports needed for families, it has a reciprocal impact to have a healthy aging population because they can remain with their loved ones for intergenerational caregiving. My research shows this is not normative in healthcare considering negative experiences are still common for Indigenous families because of systemic barriers including racism, discrimination and a lack of available and accessible resources. In order to work towards sustainable change focused on holistic health within institutions including hospitals and long term

care homes, cultural safety needs to be mandatory. Working with Indigenous families and communities,

ultimately, it can be seen from practical experience that, to achieve optimal outcomes, cultural safety and cultural competence are both simultaneously necessary to the relationship: awareness and knowledge of Aboriginal culture and history, cultural self-knowledge by service provider, and a mutual and respectful relationship that focuses not only on specific service delivery but also on the aspirations and broader well-being of the client. Cultural competence and cultural safety are not mutually exclusive and may be the optimal combination to affect social improvement (Brascoupe and Waters, 2009:17).

Cultural competency training is offered online through the *San'yas Indigenous Cultural Safety Training*<sup>7</sup> and free online modules offered through *Cancer Care Ontario*<sup>8</sup>. Each provide an excellent starting point to learn about First Nations, Métis and Inuit peoples and cultures to enhance practice in healthcare if you do not have much knowledge. But as stated by Brascoupe and Waters, cultural competency and cultural safety are both needed to work towards removing discrimination, bias and racism in interactions with Indigenous clients. In order for healthcare providers to work in a culturally safe environment, they need to be supported at the institutional level. This includes working from an interdisciplinary model to support families by sharing skills and knowledge with one another and the families they support instead of working independently (Kothari et al., 2011:6). Interdisciplinary care was discussed by Amanda:

*So, looking at the communication, looking at tools that are easier to understand and easier to use and just showing that everyone on the team has a role and things are very siloed. So, a group of people in one department might have excellent information but no one else in the organization knows it, so it's not helpful. So, looking at it, how we communicate across organizations and I think it goes back to when I spoke about*

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<sup>7</sup> <http://www.sanyas.ca/>

<sup>8</sup> <https://elearning.cancercare.on.ca/course/index.php?categoryid=2>

*dementia friendliness and that we all have a role to play and it goes back to human rights again. (Amanda)*

A dementia friendly community,

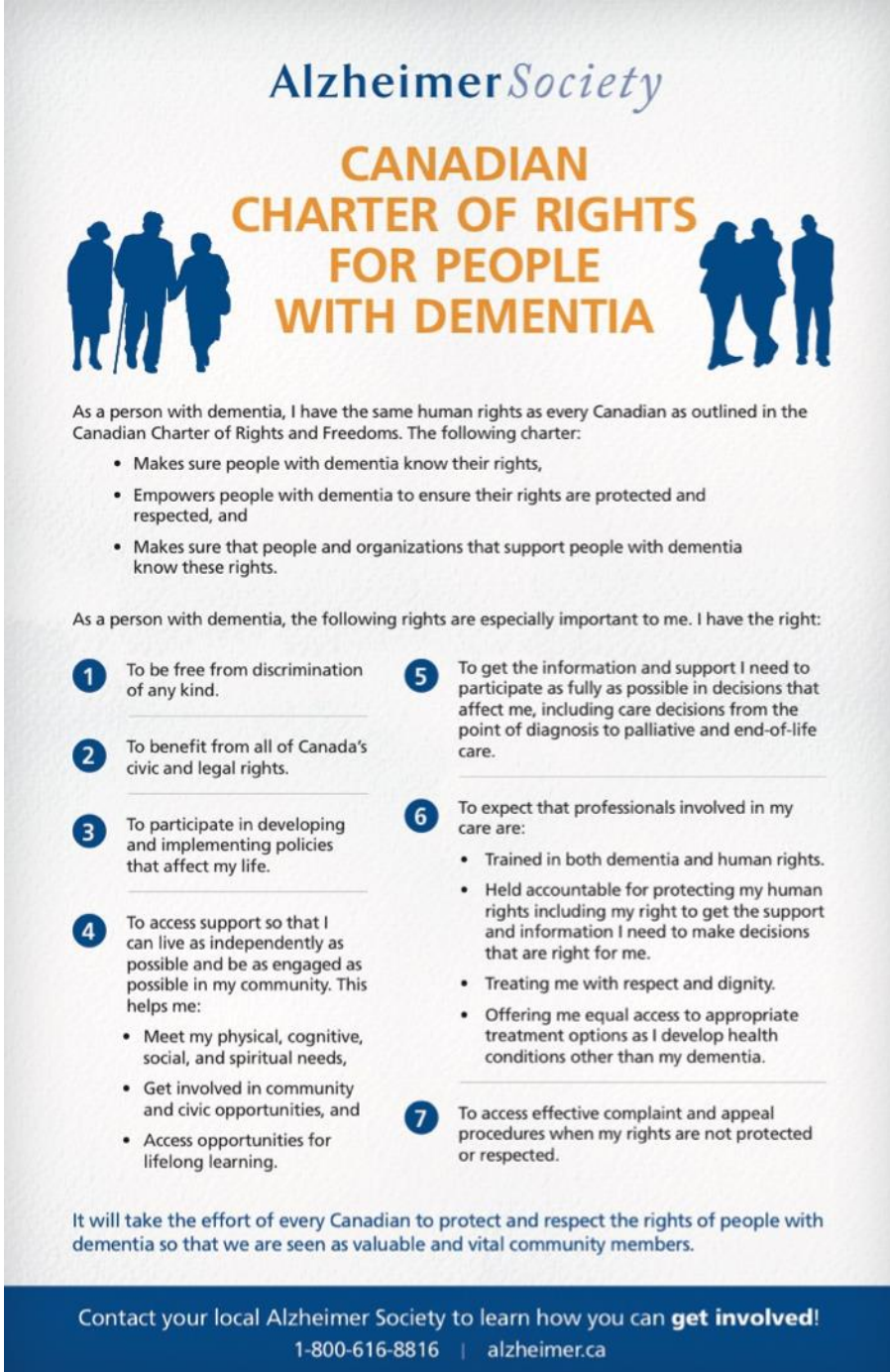
is a place where people living with dementia are understood, respected and supported; an environment where people living with dementia will be confident that they can contribute to community life. In a Dementia Friendly Community, people will be aware of and understand dementia, and people living with dementia will be included and have choice and control over their day-to-day lives and level of engagement (Alzheimer's Society, 03 May 2019).

The *Alzheimer's Society* will assist an organization or business to customize training needs, develop in person training and provide long term support to help become dementia friendly<sup>9</sup>. This is an excellent resource to gain knowledge, training and expertise to be

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<sup>9</sup> <https://alzheimer.ca/en/on/We-can-help/Dementia-Friendly-Communities-Ontario/Building-Dementia-Friendly-Communities>

supportive for those living with dementia and can inform care approaches. The discussion



The poster features the Alzheimer Society logo at the top, followed by the title 'CANADIAN CHARTER OF RIGHTS FOR PEOPLE WITH DEMENTIA' in large, bold, orange letters. Silhouettes of people are shown on either side of the title. Below the title, there is a paragraph stating that people with dementia have the same human rights as every Canadian. This is followed by a bulleted list of three points: making sure people know their rights, empowering them to ensure rights are protected, and making sure support organizations know these rights. Another paragraph states that certain rights are especially important to people with dementia. These are listed in seven numbered points (1-7), each with a horizontal line below it. Point 1: To be free from discrimination of any kind. Point 2: To benefit from all of Canada's civic and legal rights. Point 3: To participate in developing and implementing policies that affect my life. Point 4: To access support so that I can live as independently as possible and be as engaged as possible in my community. This helps me: (bulleted list: Meet my physical, cognitive, social, and spiritual needs; Get involved in community and civic opportunities, and; Access opportunities for lifelong learning.) Point 5: To get the information and support I need to participate as fully as possible in decisions that affect me, including care decisions from the point of diagnosis to palliative and end-of-life care. Point 6: To expect that professionals involved in my care are: (bulleted list: Trained in both dementia and human rights; Held accountable for protecting my human rights including my right to get the support and information I need to make decisions that are right for me; Treating me with respect and dignity; Offering me equal access to appropriate treatment options as I develop health conditions other than my dementia.) Point 7: To access effective complaint and appeal procedures when my rights are not protected or respected. At the bottom, a paragraph states that it will take the effort of every Canadian to protect and respect the rights of people with dementia. The footer contains contact information for the local Alzheimer Society.

Alzheimer Society

## CANADIAN CHARTER OF RIGHTS FOR PEOPLE WITH DEMENTIA

As a person with dementia, I have the same human rights as every Canadian as outlined in the Canadian Charter of Rights and Freedoms. The following charter:

- Makes sure people with dementia know their rights,
- Empowers people with dementia to ensure their rights are protected and respected, and
- Makes sure that people and organizations that support people with dementia know these rights.

As a person with dementia, the following rights are especially important to me. I have the right:

- 1 To be free from discrimination of any kind.
- 2 To benefit from all of Canada's civic and legal rights.
- 3 To participate in developing and implementing policies that affect my life.
- 4 To access support so that I can live as independently as possible and be as engaged as possible in my community. This helps me:
  - Meet my physical, cognitive, social, and spiritual needs,
  - Get involved in community and civic opportunities, and
  - Access opportunities for lifelong learning.
- 5 To get the information and support I need to participate as fully as possible in decisions that affect me, including care decisions from the point of diagnosis to palliative and end-of-life care.
- 6 To expect that professionals involved in my care are:
  - Trained in both dementia and human rights.
  - Held accountable for protecting my human rights including my right to get the support and information I need to make decisions that are right for me.
  - Treating me with respect and dignity.
  - Offering me equal access to appropriate treatment options as I develop health conditions other than my dementia.
- 7 To access effective complaint and appeal procedures when my rights are not protected or respected.

It will take the effort of every Canadian to protect and respect the rights of people with dementia so that we are seen as valuable and vital community members.

Contact your local Alzheimer Society to learn how you can **get involved!**  
1-800-616-8816 | [alzheimer.ca](http://alzheimer.ca)

Figure Error! Main Document Only. **Canadian Charter of Rights for People with Dementia**

on the human rights relates to the *Canadian Charter of Rights for People with Dementia*. It was created in 2018 so that people affected by dementia are treated the same as other Canadians and are empowered and supported in their healthcare journey.

Addressing dementia as a human right for equal and holistic treatment is a way to hold healthcare providers accountable for ensuring that their care is relationship centred and working with the individual and their families to meet their needs. Amanda discussed the benefits of the charter for individuals affected by dementia:

*It was released a few weeks ago and it's just right over there, the new Canadian charter of rights for people with dementia. So that is exciting and I think really fits with what we're doing and make sure we're respecting that charter and it really is a tool that allows us to empower our clients to say, you do you have rights just like any other person in Canada. You have the right to live well in your community and just giving them that extra encouragement and that extra bit of faith in themselves to advocate for their rights. So that's a wonderful tool and things around disability. There's a lot of focus on physical disability but understanding that a cognitive change is also a disability and there are rights attached to that and looking at making our community is more accessible for people living with dementia. So, I'm using words like accessibility and dementia friendliness in the context of dementia is really important.*

For Indigenous families impacted by dementia, there is the added issue of dealing with healthcare providers who need more education, training, support, accountability or repercussions for the biases and racism they practice. Change is slow and when reflecting on their practice as a social worker, Richard has witnessed little change over the last 20 years:

*Next generation, I don't know. I still see those same issues and underlying things and dealing with caregivers for, as the ones who are now younger than I am, in their 40s and 50s who were going to be that next generation who might be entering into that dementia era. Because I don't think there's, that's where I think we need now to do a whole lot better in getting information and teaching and doing better and setting up supports now for that next generation or we're going to be doing the same thing. You and I are gonna*

*be talking in another 40 years, I will be 90 but you know what I mean right? You know there's going to be us talking in 80 years about the same thing again because nothing's going to change quickly that I can see. We've been fighting the same system for I don't know how long now. I think for the last, since I would say 1996, and I've seen very little change to now in how the medical system deals with First Nations. Even and I'm talking dementia here even. They're saying, we made progress but very little. But they're still dealing with, 'Well if you stop drinking you would not have these problems'. Really? I keep saying that but it's so true because that is what they are still getting right?*

With biases such as stereotypes of alcoholism from healthcare providers, it changes the dynamics with Indigenous clients and affects the ability to develop trust. The biases on behalf of healthcare providers shows that change is needed systemically, that institutions like medical offices and hospitals need to ensure that their staff are educated, trained and supported long-term to provide good care and challenge the stereotypes they carry into their practice. It also means repercussions are needed to deal with healthcare providers who are racist in their practice and continue to do so without any consequences for change.

### 6.3 Storytelling as a Tool to Educate

Within existing health care delivery, there needs to be a distinction between disease and illness and the importance of the perspective of the person who is experiencing sickness. For Indigenous health, holism reflects well-being, not the absence of illness which is reflected in, "...current biomedical/technological health models [which] are firmly grounded in Cartesian thought in which there is a separation of mind and body and the body functions as a machine of many parts" (Sefa Dei, Hall and Rosenberg, 2000:139). This division of personhood from bodies is the perpetuation of a disease-based model which is from the perspective of the practitioner whereas illness is from the person who is experiencing it (Mattingly and Garro, 2000:9). Illness focused on the experience and stories of the person includes a holistic approach because their environment, not only physically, but historically and socially affects their well-being. Although there are, "...thousands of research papers published in leading scientific and medical journals, countless monographs and conference documents and several outstanding academic

books on the subject, the role of the environment in brain development isn't taught in many medical schools" (Maté, 2008:180). Environment cannot only be examined in terms of the physical space, but also listening to the stories of the client which uses a life course approach. Existing services for dementia prevention and resources tend to segment social and biological risk factors as though there is a strict boundary between the two and not a perpetual interplay because of social, political and environmental factors that shape a person's life (Henderson, Carson and King, 2019:45). Thus, including illness experience in healthcare is more holistic because it is the focus on the person, their stories, understandings and that they are more than their bodies alone (Leibing and Cohen, 2006:249). Applicable to Indigenous families affected by alcohol-related dementia and ADOD, people who are diagnosed or experiencing symptoms are often reduced to their disease. Their personhood is often defined by their memory loss and their life stories are not heard during interactions with healthcare providers. The inclusion of their stories and experience of their illness needs to be included that they, "...are far from being passive victims, are active agents in their lives, actively seeking meaning, responding, and attempting to act on their world" (Sabat and Harré 1994; Sabat; 2001 in Hughes, Louw and Sabat, 2012:245).

Annette shared that she got to hear stories of her father's life:

*Thanks for bringing that up because the long-term memory is still there, so there is that chance for bonding, for story sharing and learning about things he can remember from his childhood and from the community. You know, it was a chance to talk about those things and I experienced that with my Dad.*

Reminiscing for Indigenous seniors is oral storytelling and promotes social connection and, "during such exchanges, people with dementia can sometimes recount stories about their past, which, even if fragmented, give carers valuable insights into their unique history and personhood" (Fels and Astell, 2011 in Purves and Hulko 2019:197). Their experiences matter and need to be listened to. Their memory needs to be situated within their life course and that their personhood is beyond their memory loss. A relationship

centred approach needs to be a change for healthcare interactions where disease is not the basis of who they are.

Applicable to individuals and families affected by Alzheimer's disease and other dementias, the breakdown of a person into the dualistic mind and body split, or even an attempt to integrate science and social effects impacts the interactions with healthcare providers. Discussed within the literature, there is a paradigm shift in ADOD research that there are internal factors such as nutrition, immune system or endocrinology along with external factors such as stress, trauma or infection that can create imbalance in the neurology of a person, and the biological and social are not exclusive from one another (Lock, 2013:128). Although it is a step towards a more balanced perspective of a person's health, it is still biomedical because it is trying to find the cause that affects the brain, still reducing someone to their neurological functioning. It also focuses on empirically validated data of truth in terms of what is the direct link or correlations of factors that cause or contribute to ADOD (Leibing and Cohen, 2006:175). A focus of proof invalidates the experience of the person with ADOD and their family because their explanations and understanding of their illness cannot always be corroborated with empirical evidence. Their truth of who they are and what they think is often dismissed and excluded from the interaction perpetuating the divide of the healthcare provider being the expert alone. The disregard or removal of the experiences of those with ADOD is silencing them and, "...prevent them from speaking, and above all, when they do speak, pretend they haven't said a thing" (Deleuze and Guattari, 1987:38). The applications of holism can be beneficial to ADOD research and programming because a person is not just the impacts on their brain, but their lives as whole, looking at their lives intergenerationally when they seek support from healthcare providers.

## 6.4 Colonialism as a Social Determinant of Health

Not only does a relationship centred approach improve health care delivery, systems and policies but what also needs to be shifted in healthcare is colonialism as a social determinant of health. For Indigenous populations globally, "within political and social domains, colonialism has yet to be fully and consistently accounted for as a significant



determinant of health” (de Leeuw, Lindsay and Greenwood, 2015: xi). Colonialism is often discussed as historical and no longer applicable. But the legacy is still intergenerational and has contemporary impacts on the lives of Indigenous peoples in Canada. Colonialism is ongoing and, “an Indigenous [social determinants of health] framework demonstrates that settler ideologies, interactions and imposed systems are a significant cause of the causes of Indigenous ill-health, then settlers need to confront the persistence of racist attitudes and with this, society’s role, along with the state and its institutions, at contributing to poor health outcomes” (Czyzewski, 2011:10 in MacLeod, 2019:62). A non-Indigenous social determinant of health approach, “...often excludes or marginalize other types of determinants not typically considered to fall under the category of the ‘social’-for example, spirituality, relationship to the land, geography, history, culture, language, and knowledge systems” (de Leeuw, Lindsay and Greenwood, 2015: xii). Indigenous social determinants of health, “depicts life stages, socio-political contexts and social determinants as nested spheres of origin, influence and impact; each affecting the other in temporally and contextually dynamic and integrated ways” (Loppie and Wien, 2009:25). Within the context of dementia resources and support, colonialism impacts the lives of those affected and needs to be contextualized. The resilience of those who survive colonialism is a testament to their strength that their existence contributes to the survival of the next generation, not only genealogical, but culturally and socially.

Changes may seem daunting to systemically alter healthcare. But a change within hospital systems suggested by Richard is freedom and flexibility:

*Yeah same with hospitals and I think some of that especially for the seniors and even some of the others what plays in a little bit with them because it is so restrictive right. I've got, I've seen some younger people with health issues, not dementia but are against going to have anything taken care of at the hospital. So, they end up, they'll turn down an ambulance coming, but they like the freedom. I guess we all do, but they like to be out on the land. If you're at the hospital and you're in there any length of time you're not allowed to do anything and that's important to them. It's mother, Mother Earth. It's nature and it's just important to them. I worked in a hospital and I understand sometimes it's hard, but sometimes I think it would also benefit to the person to at least try to help*

*them to get out to have gardens or somewhere they can go out. I don't know. I guess I'm pretty naive when it comes to that kind of stuff, but I think it would help. I think anything that you can do that can be person centred, in our case client centred is better. Listen to what they have to say and what they want. It will help with the healing and it will help build bridges again right. It's not going to seem as bad. You do have a little bit of freedom in hospital you do have a little bit of this, you can do that, you know. If I want cornbread or corn soup, they should have that provided.*

These are other types of determinants that are affected by contemporary colonialism and have a direct impact on the emotional, social, physical and mental health of a person and can put someone out of balance. It is the ability to be outdoors, connected to the land, to have access to your traditional food (Pace et al., 2019:92) and how those connections can contribute to healing for the individual, but for relationship building with healthcare institutions and providers. A solution suggested by Annette for long term care is to take people out on the land:

*A: No and they do these community outreach where they put people on a bus and drive them somewhere. They should be hooking up some of our people together in one destination to do something right?*

*D: Yeah like a friendship centre that has awesome programming for doing a bus trip out. I'm sure lots of people, it would be nice for people to go do stuff like that.*

*A: Yeah if there's one day they came to one place, you know because those bus trips happen often. I know a lot of money went into the pot to make that happen. So, you would have a cultural day; Indigenous and non-Indigenous. Round them up, throw them on a bus and bring them in. That would be good. That would be a lot of talking at the nursing home.*

Bus tours are often organized, and this can be done to take seniors out to the land. They can also bring in Elders to provide ceremony and teachings to residents as a part of programming that is offered. For those who are unable to leave the home or have mobility issues, virtual reality is a great option. It is already being done through, “Virtual

Reality Elder Care, a joint project of Kluane First Nation and Yukon Health and Social Services, [which] reconnects home-bound and bedbound Elders to the land, their community and their culturally significant activities. Yukon believes that providing on-the-land experiences through virtual reality can improve the quality of life for Elders” (Public Health Agency of Canada, 2019:74). It has been suggested by an Elder to take seniors with memory loss to sweats at a lodge or better yet, build a sweat lodge outside the long term care to give people the chance to thank the Creator for caring for people (Secwepemc Elder<sup>10</sup>, 2019:21).

When connected to health and alcohol-related dementia, especially within Indigenous communities, there is a focus on the behaviour and usually trying to educate the person on the impacts of their self-destructive decisions. But,

the precursor to regular substance use is dislocation, according to Bruce Alexander, professor of psychology at *Simon Fraser University*. By dislocation, he means the loss of psychological, social and economic integration into family and culture; a sense of exclusion, isolation and powerlessness. ‘Only chronically and severely dislocated people are vulnerable to regular substance use’ (Maté, 2008:261).

Structural violence is not always transparent and easy to pinpoint. It is the subtleties that oppress and impact at the personal level affecting families and individuals (Sefa Dei, Hall and Rosenberg, 2000:250-251). As healthcare providers, instead of preaching, there needs to be understanding and contextualizing peoples’ lived experiences of regular substance use. Jason discussed that looking at a life course model is beneficial for all doctors:

*D: One thing I was I was wondering if you have any recommendations for other healthcare providers dealing with anybody affected by alcohol-related dementia?*

*J: The main thing is to look more widely. Why you drink doesn’t usually come up and it’s more looking globally. If the person drinks, is it alone or socially for a reason? There’s a reason why it’s become problematic or may become problematic. It really is the context and the flipside is don’t expect them to stop. All you can expect to do is get them to cut*

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<sup>10</sup> The Elder wishes to remain anonymous

*down so doesn't affect function. That's all you ever say is that we're going to cut down on this while we're doing this and this and this and try to get it to where you're not falling down anymore and you're not losing weight so that you can actually keep your weight up, not fall down and stay at your own place . So those are the main frameworks for approaching alcohol misuse in older people and even the whole notion of capturing how much alcohol they are really ingesting. (Jason)*

Each person will be different, yet all Indigenous people are affected by colonialism to varying degrees including resisting through retention of their language, culture and community. The most accurate summation of a recipe for destroying a person is the following: “destroy the material basis of a culture; force the people into an environment which provides little means for economic activity; foster the culture of poverty and dependency by means of minimal handouts; make ignorant and racist attacks on the structure and superstructure of what remains of the culture; as the adults disintegrate from these shocks, experiment blindly with their children” (Stevenson, 1999:306 in McPherson and Rabb, 2011:85). Residential school, not honouring treaties, policies that determine if and when you can practice your culture and creating First Nation reserves on Turtle Island are all elements that are often missed that can contribute or affect health and well-being. Instead of only focusing on the illness or illness because of regular substance use, healthcare providers need education that is lifelong learning about colonialism and its ties to health and why disparities exist.

Within the experiences of female Indigenous caregivers, they faced negative experiences within the healthcare system. Annette shared the lack of respect toward her father when he had a specialist appointment:

*We get to the doctor's appointments and we're seen first by an intern, as you know, or a doctor that's training with the physicians, the specialists. There were doctors that talked down to my Dad, talked about my Dad like he wasn't even alive and the man was sitting right there in the room. Total disrespect. So, I would call the secretary of the doctor and tell them that in our community, an elder is a precious gift; just as precious as a child. An elder in fact is revered and I would have to tell them everything. Not only, our*

*understanding of what an elder is and how we would never talk down to an elder, say anything bad about them, ever especially when they're in in the room, like they're not even there! Dementia doesn't change anything in my opinion right. So...because there were examples when my father was... 'well he's old. What do you want me to do? He's got dementia'. Well he's not dead yet, he's right here. You can talk to him yourself. He understands. That kind of a thing would go on all the time and it was total disrespect. So I would be on the blower to the doctor's office telling them you know why this is so wrong, why on so many levels, that we respect our elders and even though my father isn't Indigenous, I am, my mother is, my family is and my Dad lived with us and he understands what that respect is supposed to be about and he is respectful to other people too. So, this is how we do things, and you can't at least do that, then you shouldn't be taking clients because everyone wants to be treated equally anyways. You're falling short because this person has a diagnosis of dementia. So that was my experience repeatedly.*

Their experience shows the lack of cultural safety intersecting with the diagnosis of alcohol-related dementia where her father was spoken to as though he has not in the room and that nothing can be done for him because he had a diagnosis of dementia. It became Annette's role to educate healthcare providers and to be an advocate. Annette also expanded that she had to reinforce cultural safety with staff at the long term care home where her father lived:

*This is the issue at hand that has to be dealt with. This is what I found was always coming out of my mouth, taking it back to 'this is the issue here. How are we going to fix this? What are we going to do to work together to make this right?' So that became my job, just like you and so many of us are facing. And the whole cultural component, uh, no clue! There is no understanding and sometimes you don't know if you should even bother explaining anything.*

*D: Yeah, it becomes the caregiver's extra job to educate.*

*A: Yes, and not just that, you get all the staff running up to you and telling you, 'oh my brother in law's wife is a Cherokee princess, her family is a Cherokee and there was a*

*time we went to the blah, blah blah' and meanwhile, I mean you have to be polite and this is their idea of helping, is telling you their story which is usually not connected. But sometimes, it is. I can't say it's black and white. So, it comes down to their interpretation of our culture which has nothing to do with anything. It's not about you! It's about our family that we're trying to look after you know? We have to bring it back to that all the time and after you've dealt with the other external ignorance right and its difficult right?*

Educating medical professionals needs to be mandatory within the curriculum so they will, “understand the cultural contexts of their local communities so that new graduates can be prepared to serve the community effectively upon graduation” (Woolley et al., 2013:90). Experiences such as Annette's puts the onus on the care recipient to educate whereas situations like this could be avoided with education and training of nursing and medical students early enough in their careers to be culturally safe.

The health impacts of colonialism,

...is kinesthetic wounding. Kinesthetic wounding is the health disparities that have physical impacts. The removal or lack of cultural and social ties is the wounding of the spirit, an element of interacting with patients that is limited, but beginning to be recognized as a priority. Violence is not an intellectual knowledge, but rather one that is known because of damage done to our skin, flesh, muscles, bones and spirits (Hulan and Eigenbrod, 2008:155).

Structural violence is perpetuated through and by people. This includes healthcare providers who continue to practice in ways that are racist, discriminatory and are not culturally safe for Indigenous clients. Annie shared a story through tears and with anger and sadness in her voice of a time when she visited her father in long term care:

*But my dad has long hair you know and they put pig tails on him and he would look at me, he was not gone gone and he would shake his head and laugh but I know he didn't like it. So, I would take his hair down immediately and braid it. I would say 'don't put pigtails on him, pony tails, that's not him'. So I would leave his hair down. But these are things that they did, they made him look like a lady. These are insulting things.*

*But you know, then I thought to myself how many of our elderly people are going through that? They didn't say anything like a mouse. He tolerated the pigtails. How many times*

*did they put pigtails on him? He was not a girl. He had a bib and he didn't like it, he told me 'take that thing off'. He had a bib and a high chair like and he didn't like it, he told me to move it off. I know they have to do it for security reasons, but they didn't have to put a bib on him you know. He ate well. He wasn't dribbling.*

*D: They weren't respecting him.*

*A: No.*

The lack of respect and understanding of the importance of hair for Indigenous communities is an example of racism within long term care where the staff lacked the knowledge of why their mistreatment not only affected the care of her father, but Annie because she was impacted by this discriminatory act. Hair has different cultural meanings for Indigenous communities. It is the connection to the Creator and ancestors and is cut for mourning of a loved one. Cutting the hair of residential school children was a form of assault on their culture; using their bodies as sites of inscribing civility and taking before and after photos to show evidence of successful transformation of 'heathens' (de Leeuw, 2007). For Indigenous seniors who may have been survivors of residential school, the lack of respect and culturally understanding of an act of putting an Anishanaabe man's hair in pigtails shows that vast improvements are needed since this act re-inflicts trauma. There needs to be more work done within institutions such as hospitals and long term care where racism continues in gerontology settings (Beatty and Berdahl, 2011:7) and the impacts on the health and well-being of Indigenous residents and their caregivers.

Respect should be foundational to all interactions with seniors and a lack of culturally safety within the interactions shared by Indigenous caregivers shows that there are vast improvements that need to be made at the institutional level. According to Browne et al., from their interviews with Hawaiian seniors and their caregivers, they voiced similar experiences and avoid using medical services such as hospital and long term care as they age because of their experiences of insensitivity and disrespect (2014:143). The direct impacts mean the continuation of an underutilization of services on behalf of Indigenous clients because of the perpetual racist experiences they face in medical settings. This means families will continue to provide care as best as they can without accessing

services because of a fear of mistreatment which is actualized through past interactions. Institutions need to focus on how they are allowing racism and discrimination to continue and what barriers they have created and continue that allows interactions to be negative. Simply adding education and training for staff does not address how the entire process with healthcare systems begin with exclusion and barriers.

Within literature focused on the impacts of accessing services for dementia, transportation is a prominent issue. For Kathleen, their diagnosis took time because they had to travel to Toronto:

*Because it took a while before we uh were told he had Alzheimer's because uh I took him to a psychiatrist, we went for counselling and uh, but the psychiatrist referred him to a doctor in Toronto and she dealt with, I guess head injuries or brain. But his family physician also was, I guess he was a teacher before he became a doctor and he said 'I know her, I taught her'. He helped a lot by sending a letter to, uh for them to see [him] and uh when we got to Toronto and had that appointment, that's when we were told he had Alzheimer's and [my husband] told me (laughing) not to tell anybody and I said uh OK. I went right to my son when we got home and I said to him, my son, I said I feel as though I lost your Dad already, I said...because I know he's not going to be the same eh? Then um, but I kept him home for ...uh for a while because I didn't know exactly when his Alzheimer's start because uh I never been around anybody with Alzheimer's before.*

Rural communities have similar barriers of accessing specialist services at great distances (Morgan et al., 2002:113; Gahagan et al., 2004: xiii; Habjan et al., 2012:212). The financial costs are placed on the families whereas training physician and nurses to diagnose for ADOD and bringing specialist services to communities can aid with reducing the extensive travel to obtain a diagnosis and receive support.

## 6.5 Public Education and Outreach

With all the Indigenous caregivers, including myself, I did not know the symptoms or recognize them until the formal diagnosis. This was also discussed by Mere Kēpa, a Maori caregiver that no one recognizes the signs until they reflect back since they did not



know what the symptoms are (2019:138). For Kathleen, reflecting back on their journey together, she sees the signs now:

*But I noticed there was different things. Like when I look back, there was different things he did. He uh doesn't normally do uh, he said he fixed the screen door, but I don't think he fixed the screen door. He thought he was fixing the screen door and then he thought he was putting plastic on the window, and he missed the whole window. He put all the plastic on the bottom and also when he did the laundry, he did the laundry wrong too and he mixed all the clothes together so the whites and the dark and uh those kinds of things. I didn't know like and uh when my son, our son went to visit him, all the elements were on the stove, so you know, we like at that point, we still didn't know that he had Alzheimer's there.*

Annette shared that caring for aging loved ones is focused on helping them and honouring them, so discussing ADOD is not a focus of caregiving to maintain respect:

*There is a lot of denial going on too especially about our elders because we don't want to say, because we honour them. Our parents or otherwise. So, it's so easy to get in the mode of helping them and not really talking about the situation or dealing with the big elephant in the room per se. But knowing it's there because we played that game for a while with our family, with our Dad. Oh yeah. Until we realized it wasn't working. But um, yeah so, I, you know then there's this whole concept that when people age, they do get forgetful you know. So how, where is the line of understanding that ok, this is normal with age and no, we're maybe on the onset of diagnosis here. The average Joe has no clue of what would follow what side of the line.*

Within existing research on dementia impacts within Indigenous communities, the common theme for systemic change is that, “awareness campaigns are useful only when supportive services are in place and adequate to meet community needs” (Bourassa et al., 2019:124). This connects to developing meaningful information and programming by working with communities, including Elders and caregivers and that education needs to come from qualified trained frontline staff who are Indigenous members of the community or are trusted allies (Goldberg et al., 2018:1). Education can not only be

focused on aging populations and caregivers, but the general public as well so that the knowledge is shared among all ages and not just when you are personally impacted.

Amanda as a public outreach coordinator shared that public knowledge is improving:

*There's a lot of myths around the disease and that's not unique to the Indigenous community. It's really getting better over the years; I've been here nine years. It's better, it's getting better for sure, in the broader community. People are much more aware. But I'm still always shocked by some of the pervasive myths that are out there. Even the just not understanding the difference between terminologies. So, people thinking that Alzheimer's and dementia are completely unrelated things or thinking that gosh, I have dementia at least I don't have Alzheimer's or I have Alzheimer's and not dementia. So just the basic semantics or terminology are not always understood and is not specific to Indigenous communities. So, we still have a lot of work to do and the stigma again is present in all communities. I think like mental anything related to your head like mental health has a huge, a lot of stigma.*

Through public awareness, it can aid to reduce stigma if more people are educated about signs and symptoms and understanding the different types to know what to expect and to alleviate stress by having knowledge about the illness. For working with Indigenous communities especially in remote locations, program development and support,

...needs to be mindful of the appropriate people and groups to approach and be cognizant of the contextual features of remote communities. Finally, health professionals, including remote area nurses, must become skilled in the early identification of clients with dementia to optimise quality of life for those impacted with this growing disease burden and to facilitate appropriate access to and collaboration with relevant services (Lindeman et al., 2012:193).

Each family and community are going to be distinct culturally, linguistically and spiritually. Factoring in the impacts of geographic locality is needed for understanding the availability of services, but also the importance of connection within community and traditional ecological knowledge where connection to the land, ancestors and medicines can be a part of the education on ADOD.

The impacts of later diagnosis because of a lack of existing knowledge of ADOD is also applicable to care providers. Connected to this is public education since another research study conducted by Bourassa et al. found that caregivers thought their loved one's memory loss was a part of aging. It was not until the symptoms worsened that they started researching and looking for support (2019:118). But more research is needed to focus on positive preventative measures for ADOD, especially in Indigenous communities since there is limited literature on the subject.

Education for healthcare providers is integral as well especially if loved ones are admitted to hospital. Annette had a horrific experience when her Dad was admitted to the hospital and she was not notified although he had dementia:

*Well, I remember the time, I couldn't get a hold of [Dad] and I was quite concerned. But sometimes he would go on these little I'm busy episodes and this was before he was placed. So um, two days pass and I say something is going on to my husband and he's not answering his phone. Maybe the phone's not plugged in. Went over there, banged on the door, made sure he didn't fall asleep with his headphones on because normally the door is unlocked and we can just get in. Of course this is night and the manager is nowhere to be found. I don't know what's going on, I can't get an answer and it's the weekend, of course. So, I don't know what's going on in there. If he's dead and rotting or he wandered off, his phone is bugged up. So, um I in the morning, I get a call from the hospital.*

*'Hi, we just want your permission to put your father in restraints'.*

*I'm like 'who the hell is calling me? What's going on?'*

*'Oh, your father's been admitted for 3 days'.*

*I'm like why didn't you call me? He's got dementia and I've been worried sick; I've been calling him and I haven't been able to get an answer. Oh well, he had just sorta fell through the system and we didn't get a call. Well, did I ever raise hell on that. You know, and then, they were just back on the issue,*

*'Well he's going into withdrawals and we gotta restrain him. Is that ok?'*

*'No, it's not ok. I don't want my father restrained, why is he in the hospital?'*

*'Well we can't tell you that'.*

*'What do you mean you can't tell me that. What hospital?'*

*Well that did it, I got off the phone and I remember I hadn't slept and it was one of those crazy days. No sleep and driving to the hospital. By this time, its almost 2 o'clock in the morning and trying to find what floor he was on, where he's admitted, and I was not a happy camper. At least he was safe, and I had to come to the conclusion. At least he's safe, at least he's where he needed to be. He never thought to call me with his dementia. He called 911 which is good. The ambulance guys came and took him away and he had the sense to remember to lock the door.*

This experience shows that education is needed for first responders as well as emergency staff to do an assessment and be aware of symptoms of ADOD. This experience also happened to Annie when her father was hospitalized in his early 80s for pneumonia. He was hospitalized close to her in Gatineau, Quebec:

*He scared me one day, I went in and he was not in his bed. Nobody told me and they had my number. That's a whole thing about the hospitals I'm getting to you now. Nobody told me they released him.*

*D: No! They didn't tell you?*

*A: No. They didn't notify me and they had my home number and my work number and everything at the time. So, I got there and I thought he died.*

*I said, 'where is my Dad?'*

*They said, 'he's gone'.*

*'Gone where?'*

*'He's released'.*

*'Oh, ok but where is he?'*

*Nobody knew and they said, 'oh he took a cab'.*

*Took off if they inquired. I said oh he's not home where could he be? Of course I knew only one place he could've been was at the casino. My Dad (laughing). My Dad was at the casino. So, the people at the casino got to know me quite well when I was looking for him.*

Communication is key for family members to be notified when their loved one is admitted to hospital and can ensure that trust is developed between caregivers and the providers. Through literature focused on the experiences of Indigenous caregivers in Australia, “a key service issue emphasised by caregivers, service providers and community workers was the need for improved communication and coordination among service providers, and among service providers, communities and caregivers” (Smith et al., 2011:8). If healthcare providers are not educated on being dementia friendly and working with patients to notify their families, caregivers will continue to not be contacted and can ruin the development of relationships if there is no communication in the first place. Caregivers can provide the medical and social history as advocates for their loved ones.

## 6.6 Health is a Lifelong Journey

Since I chose to focus on Indigenous authors or researchers who have been doing community-based research with Indigenous communities, the same argument was made repeatedly that healthcare providers and researchers are missing the benefits of holistic health approaches (Matè, 2003). If a person's emotionality, spirituality, mentality and physicality are working harmoniously, they are able to be healthy which is a lifelong journey (Marshall, Marshall and Bartlett, 2015:17). This is missing within existing healthcare systems in that the removal of an illness does not mean a person has achieved health. It is a lifelong process of finding balance. Healthcare interactions are so focused

on the specific ailment and not the entirety of someone's past and future. Holistic health approaches are preventative and protective and there are financial gains (Hoffman, Bennett and Del Mar, 2013:330), not only for individuals, but for providers since some illnesses can be prevented and people do not need to be returning for the manifestations of imbalance in their lives produced through physical illness (Subramanian and Pisupati, 2010:182). This is not to say that all illness can be prevented, since health is not always predictable and therein lies the complexity of each individual.

In reference to prevention for ADOD, risks need to be contextualized within, “a framework that addresses the larger social and structural barriers that inhibit individuals from changing their health behaviours, even if they are aware of the potential benefits of doing so” (Pace et al., 2019: 89). Indigenous individuals and families need to have the support programs, manpower and self-determination in community to be able to offer prevention services and education. Dementia always needs to be situated within the lived experiences of Indigenous peoples that health is connected to the impact of colonialism that determine our access to health services. But a shift towards communities determining their own health journeys with their community members is a way to reclaim power over our health that includes a balanced approach to well-being as a life-long journey.

## 6.7 Importance of Connection

By viewing a person based on bias and knowledge construction on behalf of the provider, it creates a relationship where the person's life is evaluated as though it's a cross section, disconnected from their own past and future. For Indigenous populations, people are not alone and their ties to family, community and nation contribute to their health. But this is often missed in non-Indigenous approaches to healthcare focused on the individual and their specific illness. Ties to one's community positively contribute to one's cultural and social health, knowledge of their history and connection to the land which embodies the past, present and future where the nation, “...came first, not in an abstract sense, but in the concrete: the aged and children and those to come—all the people” (Johnston, 1982:50). The focus on the individual in mainstream services misses that Indigenous clients do not view themselves only as individuals, and that their ties to their community and nation or lack thereof is a social determinant of health (Ross,

2014:25). The recognition is that the well-being of a community can positively foster well-being for families because, "...family relationships... maintain health holistically—mind, body and spirit. Supporting one another was chosen rather than 'help seeking' based on our growing awareness of the disconnect between the vision of the health care system and that of the community" (Hulko et al., 2010:332). Annette provided an example of supporting community members when someone passed:

*Traditionally when there is a passing, this is how I was raised, I was fortunate to be raised in Métis culture, before anyone knew what the word meant. It was a blessing. When someone passes in the community, you drop everything. You bring food, whatever food you have right, you bring it. It doesn't matter what you're in the middle of, you go, and you pack an overnight bag because if you need to stay there for that person to cry on you, it doesn't matter how many days, you just do it. Anyways, that's how I was raised.*

The importance of supporting one another in times of need has intergenerational impacts where the health of one generation is tied to their ancestors and for those to come (Ellerby, 2005:10). It is the understanding of the importance of connection within families and community and you drop everything to be there for them. But there still needs to be a paradigm shift for non-Indigenous healthcare services to contextualize health and understand that being in your community and having support of this kind is integral to well-being.

## 6.8 Indigenous Led Approaches to Dementia

A common theme within literature about changing health services, policies and programs for Indigenous populations is through decolonization. Decolonization, "...brings about the repatriation of Indigenous land and life; it is not a metaphor. In the fields of child welfare and health services, decolonization entails devolving responsibility to Indigenous communities, thereby promoting their self-determination. Decolonization is best achieved by working in collaboration, and settlers are integral to the process" (Hulko, Balestrery and Wilson, 2019:5). For healthcare, decolonization is a shift where change is collaborative and a bottom up approach where the needs of the community are

determined by those who are accessing care (Stuart, Arboleda-Flórez and Sartorius, 2012:42). The importance of communities having control over their healthcare, policies and programs, is that it is based on the community's context instead of external decisions for funding and policies. This is still the existing issue where *Indigenous and Northern Affairs Canada* determines funding and thus what programming and how long it can be offered. This attests to larger structural issues because the, "...lack of a deeper understanding of the Indigenous connections to ceremony, protocols, spiritual teachings, community, stories, the impact of history, they will repeat the cycle of assimilation and colonization" (Steinhauer and Lamouche, 2015:153). Communities that are in control of their healthcare are founded on holism where physical, mental, emotional and spiritual well-being are not only provided for clients but are reflective of the culture of the specific community. But the importance of the community needs is not only health based but are definitely tied to, "land claims and reserve economic development" (Belanger, 2014:333). The economic and connections to traditional territory are paramount to health and if Indigenous communities are in control, these are factored into healthcare.

For Indigenous families affected by ADOD or ARD, they need to be a part of the healthcare programs in order to develop meaningful supportive services and help caregivers. Richard discussed that trust building is needed to offer dementia support services:

*Yeah it is very difficult because of that mistrust outside of the community right? And I don't want to delve, I don't know if you want me to delve into that, the negative sides of these things. I think that's very prominent when you try to work with them to accept help from the outside. Some of the comments I got was 'it's just another white man telling us what to do'. So, I don't do that. I go in and first I get to know them. They're very welcoming but very guarded with what they say and how they work with you.*

Trust takes time because of negative experiences in the healthcare system. If those impacted and their loved ones are a part of the development through the implementation and evaluation of services, their experiences can offer critical insight to changes that are needed (Stuart, Arboleda-Flórez and Sartorius, 2012:47). Social supports are minimal



financially for non-Indigenous caregivers (Lock, 2013:40) and are almost non-existent for Indigenous caregivers. For caregivers, their needs are not often addressed and the clinical aspects of ADOD are predominantly focused on. The most difficult aspect for caregivers is dealing with the behavioural symptoms (Leibing and Cohen, 2006:44). But there are minimal supports for caregivers and since financial supports do not currently exist, the stress and management is solely placed on them. Caregivers have a higher risk of depression and illness as they try to manage their shifted roles and identities for caring for a loved one (Matè, 2003:176; Leibing and Cohen, 2006:45; Lipton and Marshall, 2013:61) especially since most who take on the role are women (Hughes, Louw and Sabat, 2012:5). Changes to supporting caregivers as well as their loved ones can be a form of relationship centred care that is beneficial to all populations. This is an existing gap in service for families affected by ADOD and the importance of the health of caregivers connected to the wellbeing of their loved ones. Jason discussed the difficulties faced by caregivers for alcohol-related dementia:

*D: I was going to ask you too because you mentioned with caregivers, since I focus on caregivers, what are some of the impacts you're seeing for those coming in with a connection between drinking and dementia and the impact on the caregivers?*

*J: It's very hard at any age. Figuring out what works for the caregiver and how much you're putting the caregiver into the role, the person that's regulating the amount of alcohol intake for the person that is demented who often is unaware and they're often fearful because they've often tried to challenge the alcoholic on their alcohol intake and they've been rebuked. That's not a surprising source of friction between them and being able to suggest alternative ways over time, they're often very leery because they've tried and nothing works. Then when the person is more cognitively impaired that it will work now. But convincing them is not easy. For some people going to day programs is a way to keep them from drinking for the day...and the caregiver gets a break from their drinking. They're not drinking the 6-8 hours that they're at the day program and then they're coming home again and it's harder for them to catch up and it's a less draining day on that basis. Trying to substitute lowering alcohol, watering down alcohol, going to near beer, etc. because they got so upset. But that was two years ago and it might work*

*now and a fairly good chance that it might work now, but you have to try it, and have to feel supported enough to try it and often times people who are living alone with alcohol, the preferred route is that we will continue to let them do this until they've hurt themselves or others. Literally they will let them keep doing this until they break their hip or something and then, and only then will we move them to a place where we can control their drinking.*

This is a snippet of the physical and mental diminishment; the stress of caregiving increases as the health of their loved ones deteriorates especially for aging loved ones with regular substance use. Caregivers' stories are completely missed from the interactions with healthcare providers (Kenyon, Clark and de Vries, 2001:253). This connects to the need for a holistic approach where the patient is not the only person whose well-being needs to be addressed.

## 6.9 Treating People like Kin

Not only is focusing on a family and not just the individual beneficial for caregivers of a loved one with ADOD but is beneficial for the health system and all patients. A way to transform the interactions with healthcare providers can be an ideological shift to treat people like kin. It is a change to view people as extended family members (Nelson, 2008:263) and that relationships are important with everyone and not just based on your immediate family or ties. It is also a way to move away from, "the false conception of humans as simply bodies, or minds, or even minds and bodies interacting, rather than as persons, is positively harmful in its effects on how we see people and therefore how we treat them" (Hughes, Louw and Sabat, 2012:55). Applying a kincentric approach to health is holistic where treating people as though they are extended family members and not within the biological sense of family, but that everything and everyone is connected (Salmón, 2012:21; McCall, 2011:120-121; Nelson, 2008:263; Leibing and Cohen, 2006:61). Based on an ecosystem of connections, it can change the dynamics where people are not reduced to their bodies, but there is a level of responsibility if someone is viewed as kin and to move away from perceived incompetence of the individual and examine systemic flaws (Smith, 2005:221). Treating people like kin also includes

emotions and feelings because, “relation centred on emotional connections, not cerebral ones, and everyone’s duty is to focus on helping all relatives brings the best they can into each and every relationship, whether with trees, rocks, bugs, or other people” (Ross, 2014:63-64). Viewing and treating people like kin moves towards a relationship of partnership and support.

Treating people like kin instead of based on their illness or influenced by biases and stereotypes that impacts access to care, another issue for Indigenous populations is jurisdictional barriers. I think a way to address this to improve healthcare is that the concept of *Jordan’s Principle* needs to be applied to everyone. *Jordan’s Principle*, “stipulates governments of first contact must pay for vital life-saving services and seek reimbursement later” (Lett, 2008 in Walker and Behn-Smith, 2015:245). Indigenous populations are limited geographically and have to travel extensively to access services. Not having transportation and or financial support to cover the cost if longer stays are required and there is no support for more than one companion. This means that people who are unable to access services have higher risks of preventable illnesses (Dew and Matheson, 2008:44). A way to contend with the geographical barriers is that there needs to be policy changes that health rights are mobile as people are. Another way to contend with jurisdictional barriers is by bringing programming into communities and not people having to go out to get help. This applies to changes in funding responsibilities from the federal and provincial government since, “Health Canada will assist with the provision of health services for Aboriginal peoples within Canadian reserve jurisdictions. This assistance will follow a band member who is referred for specialist services off reserve; it does not follow a band member who purposely moves outside the jurisdiction” (Kirmayer and Valaskakis, 2009:384). Leaving your community whether by choice or not, should not determine if someone has access to health services.

## 6.10 Changes to Funding

Since change is slow and usually dependent on the government to provide funding, there are long term benefits of mobile health rights and bringing programming and services into the community (Ellerby, 2006). The application of mobile services or bringing

services to the community has sustainable benefits connected to health because of the opportunities for education, careers and culturally safe care determined by the community. Different funding models for Indigenous peoples is that the cost is based on population and not need, “which would enable an increase in the number of personal support workers to aid the community’s elderly population” (Habjan et al., 2012:219). Shifting funding to be focused on home care supports for Indigenous families impacted by dementia would mean a reduction or delaying of people having to move to long term care outside of their communities. The variance for Indigenous communities that are based on geography are critical to funding for dementia programming and research needs to be at the forefront since the needs of each community will be unique as discussed by a healthcare provider:

*I guess it’s really up to all of us to keep the torch going and to not say we’ve got this great momentum and now we’re maybe getting this great data, and now what do we do with it? And where is the need in the community because each community is going to be different. Like people across the country, they might have different needs in different communities and different models that are going to work. So, where Southern Ontario is a little bit more urban...needs are going to be a bit different than somewhere in northern Ontario. So, we have to understand that difference. You can’t find a model and then just stick it into every other community and think it’s going to work. (Amanda)*

Within Northern and rural communities, access to homecare is fragmented and based on availability of service in community which is affected by funding. Findings from a National conference focused on dementia in Canada found that,

participants reported that people in different parts of the country experience inconsistent access to dementia care, services and supports, especially in rural, remote and Northern communities. Information and services tend to be designed to meet the needs of the dominant culture; as such, they do not reflect the diversity of needs and may exclude Indigenous populations and other linguistic and cultural groups (Public Health Agency of Canada, 2018:18).

For supporting Indigenous families impacted by dementia, it needs to be community focused and led with the insight and experiences of Indigenous families to meet their needs. Ultimately, self-determination for funding at the community level should be based

on need as opposed to what funding is allotted. Currently, services are based on the top down model from the federal government.

But self-determination will not happen overnight, and collaboration has benefits working with non-Indigenous community agencies, academia and other communities. Research can be a tool in order to show that self-determination for health within Indigenous communities has long term benefits where community based research can change policy in Indigenous contexts as long as the entire research approach is determined by the community and their methodologies (Richmond, 2015:59; Kovack, 2009:13; Belanger, 2014:352). As stated by Amanda, she has seen a positive shift within knowledge about dementia in the Indigenous communities her organizations serve:

*In nine years doing this, once upon a time I didn't see, there was no data looking at dementia in Indigenous communities across Canada that I was ever aware of. I know we look for it and I know that can be a barrier because how do we support and provide information for a number we don't know? Like we see it anecdotally, but we don't have a way of measuring it. So, I think that it's great that there are a number of different researchers and champions who are making the case, you know where some of these research dollars can be directed to get this work going to build that foundation for future research.*

Community based research produces meaningful research when the question, methodologies and those conducting the research are determined by the community to ensure that the process and information produced is not only relevant, but beneficial (Lambert, 2014:64; Dew and Matheson, 2008; Etmanski, Hall and Dawson, 2014). Community based research can also be used to make visible structural barriers (Smith, 2005:198; Smith 1999:227). It is important to be able to critique and combat racism and stereotypes where the blame is placed on the person distinct from their context and the impacts of structural violence and oppression as a result of colonialism. Self-determination means engaging, "...in Indigenous processes, since according to our traditions, the processes of engagement highly influence the outcome of the engagement

itself' (Simpson, 2011:17). Through self-determination and having healthy communities and services based on the needs of their members and context of community,

Indigenous thought can only be learned through the personal. This is because our greatest influence is on ourselves, and because living in a good way is an incredible disruption of the colonial metanarrative in and of itself. In a system requiring presence, the only way to learn is to live and demonstrate those teachings through a personal embodiment of *mino bimaadiziwin* [living the good life] (Doerfler, Sinclair and Stark, 2013:288).

*Mino bimaadiziwin* needs to apply to research to improve health in order to focus on the strengths of the community. Instead of analyzing negative community issues that have been researched repeatedly, research should look at, "how we kept our children alive, kept our stories, kept our knowledge about how to live on the land, kept our ceremonies, kept our fires burning with hope for generations yet to come" (Strega and Brown, 2015:5).

Richard discussed that more knowledge is needed about experiences of dementia in Indigenous communities:

*It's hard for outsiders I think speaking for myself to come in and do research. I think as a younger person I would try that, I really would because I think it's amazing the stories and stuff. It's just absolutely amazing what we could learn. As one people that we can learn from them and how they do things and again we could help. But we need that research and there's just not enough people doing it in North America or Canada anyway. The States is a whole different ball game because there is huge disparity between the two.*

Richard brought up the issue of disparities in the United States in connection to dementia. There is non-existent data because, "the Indian Health Service has traditionally not collected statistical data on dementia. One unfortunate reason for this is that AI/AN (American Indians/Alaskan Native) elders did not survive to the age of greater risk. At this time, statistical data concerning dementia prevalence and mortality are not available from the Indian Health Service's Department of Program Statistics" (Carson, Henderson and King, 2019:188). The importance of research is the knowledge of the number of

people impacted and how healthcare needs to shift. In the United States, there is minimal information on AI/AN experiences of having dementia or caring for a loved one with dementia. A shift in research is needed where Indigenous communities are in control of their health, connected to self-governance, environment and social capacity in the community. Health is not just one thing, it is many parts of a community that need to change, but only if decided by community members of what will work for them.

There are excellent community-based projects or even health research being conducted where implementation for improving healthcare access are put into place but are not sustainable. Research conducted in systemic reviews have found that less than 10% of implemented strategies change practice on behalf of healthcare providers because their behaviours are often neglected (Hoffman, Bennett and Del Mar, 2013:383) or they are not systemically supported to implement the changes (Straus, Tetroe and Graham, 2009:90). The other issue is that social scientists are doing work to improve healthcare access or services, but their findings are not shared in a user friendly, accessible and culturally safe way, so they are not applied by healthcare professionals (Banister, Leadbeater and Marshall, 2011:19). This creates gaps in knowledge and practice if there is a schism between researchers, healthcare providers and community members including those who share their experiences for accessing services. To mitigate this knowledge gap, there needs to be collaboration where research is practical and, “where knowledge in itself is not seen as the ultimate goal, rather the goal is the change that this knowledge may help to bring about” (Wilson, 2008:37).

Removing the fragmentation of services can improve comprehensive, appropriate and timely care for Indigenous clients and Indigenous communities. One example of a service provider in Montreal at a centralized location where all health and social services are provided to Indigenous people regardless of nation or whether they are status or not (Kirmayer and Valaskakis, 2009:389; Wendt and Gone, 2012). More barriers exist for people accessing services for regular substance use and dementia because of stigma and social ostracism. Alcohol-related dementia and being Indigenous thus comes with a complexity of intersecting stigmas and barriers to face. This deters or stops people from accessing services where prevention of the progression of ARD is possible, but usually

people only seek help if there is an emergency. It also means going to many different specialists for dealing with different aspects of yourself. This put stress on the individual and their caregivers who may have to contend with a lack of social and financial resources to access services in the first place. There needs to be centralized services and where a person's life is treated holistically including bringing together all providers to reduce travel time and foster collaboration amongst providers and the person seeking help. A centralized location within the community where all services are amalgamated under one roof is a way to remove geographical barriers that can be applied for non-Indigenous communities, especially in rural settings. Providing health and social services to meet someone's needs based on Indigenous approaches, treatment and by and with community members has applications for other communities since context of the community would determine the context of the hub of services. There is a shift towards healthcare providers being more culturally safe through education and practice, but there is still a gap for sustainable change if there is not sufficient funding and communities are not partners in the process. Collaborations not only needs to extend to community members, but individuals and families who are accessing care.

## 6.11 Discussions on End of Life Care

Indigenous understanding and approaches to end of life are missed within the healthcare experiences for families when their loved one with dementia is going to pass. This connects to the lack of understanding of varying ideas of death and dying and the importance of being surrounded by family and support. Annie was not notified when her Dad was going to pass and found out when she arrived to visit him. It is difficult to convey the emotion that accompanies Annie retelling this story. It brought me to tears and made me sad and angry as the listener that the staff did not call to let her know. Below is a small part of Annie of sharing such a terrible memory and can provide insight of exactly what needs to change and what should never be done by healthcare providers. She recounted the last day of her Dad's life:

*But I needed my nights rest. But the time he died is the time I didn't like. They had my cell, I had a cell, they had my brother's number, they had my home number, they had all the numbers OK of how they could reach me, at least on my cell. I got there, I said I'm*



*going to take a Friday night in bed, I am going to sleep, I'm not going to wake up for him. I'm going to have a good night's rest and tomorrow night I will go there and stay up all night with him. I know he'll have me running around but I'll stay with him. I did not doubt anything because I called him Thursday. So I called him up and I told him 'on Saturday I'm going to come sleep there and stay with you'. He said 'OK good show', he loved it. So Saturday morning my uncle, he was quite an Elder and his daughter and his son, his son-in-law, my cousins came to visit and they said, I had breakfast with them and they said 'we haven't seen him for a long time so will go visit him'.*

*To my shock, my Dad had a big patch on his heart of morphine, his eyes were glassy and he was like on and off. He was not with us and I ran out and I grab the nurse. I grab a nurse by the arm and I said 'what is on his chest?'*

*'Oh he's dying'.*

*I said 'what do you mean he's dying?, I said I called Thursday and he was OK. What do you mean he's dying?'*

*'He's dying'.*

*So I said 'why didn't you notify me?'*

*'He was going'.*

*She didn't answer, she took off. I wanted to see the doctor and the doctor never showed, the doctor who ordered the patch. I wanted to know my Dad's condition. I know he was old. I know he wasn't able to walk. But Dad didn't want to die like that, unnatural death. He didn't want to die by putting him to sleep. I had no choice than to watch my Dad die with me being alone, my husband was [away]. I had no family members around, I couldn't find my brothers until later. I had friends that all of a sudden started to sing his song in the mall, they said we haven't seen [him] in a long time. 'Let's go see him', and they found him dying. They said 'we didn't know he was dying'. They said 'we didn't know he was dying'. So, they took care of me, these two girls. They took me out for lunch because I was all over the place. I didn't know if I was coming or going. I was expecting*

*it, you expect at that age but you don't expect. I was kind of in a shock because nobody told me, because if he told me three or four days I could've prepared to be with him. I was with him. But to be with him. They didn't tell me what would've happened if I didn't go. They would've called me at 7 o'clock and said your father is going, he's dying and I wouldn't have been able to go up and be with him on his last breath. But I caught them off guard. I got them. I said 'you're killing my dad'. I really just came out and said 'you're killing my Dad. You didn't notify me, that's death, that's killing. I signed in for him and you're killing him' and they all took off and I didn't hear nothing. I rocked him to sleep literally.*

Not notifying Annie that her father was passing took away her ability to bring family to be with him in his last moments. She was not able to prepare for his passing and to have family and friends there with her to say goodbye and provide much needed support. This experience shows that this long term care home did not give Annie and her father the respect to notify family so that he would not pass alone. Annie shared her fears that if she did not go to visit, that they never would have told her, and he would have passed without her being there.

Annie shared that she was in shock and confusion when he passed. She said she knew her Dad was old and frail, but she wanted him to die in dignity:

*With my Dad, I went to the morgue with him which is strange and unusual. It was the morgue at the hospital that I covered him with a blanket. But one of my brother's was there and my two cousins, and they stood with me until 4 in the morning. A doctor, a kind doctor who I think worked in the morgue, said 'he's gone. Go home and rest'. He stayed with me for 4 hours, the gentleness of that doctor who stayed with me. The others said I had to come back the next day to clean his room in an hour. They had somebody else moving in. It was so cold.*

A lot of education, training and support is needed for Indigenous families to have the space, time and presence of extended family, friends and community when a loved one is passing. Annie remembers the kind doctor who stayed with her to provide support which shows the long-lasting impact of compassionate care. The staff at the long term care who

told her she had to return the following day to pack up his room is described by Annie as “treating people like a business”. She still does not know to this day who ordered the morphine patch for her Dad, if he asked for it or why he needed it. Annie’s experience is common for a lot of Indigenous families, those with dementia and those with a loved one in hospital settings. Research focused on changing Intensive Care Unit to be more culturally safe found that nurses, doctors and staff,

must understand that trauma and the worry that goes with family members who have to deal with a loved one laying on that bed in intensive care. And then you have some nurse tell you that you can’t be there or whatever because we’re very busy. The last thing that family person wants to hear is how busy a person is and we need their understanding, compassion, whatever it takes to make that person, that family member as comfortable as possible. It only takes one or two exceptions to make it even more difficult for family members (Hampton et al., 2009:8).

With Annie, the doctor at the long term care did not come to see her as the caregiver to let her know what was happening with her Dad before he passed. Nursing staff was not there to offer comfort and support when her Dad was passing. It exemplifies the Western approach to death where it is private and alone, but families deserve truth, honesty and support from staff.

Kathleen discussed end of life for her husband before he passed and the understanding that he was returning to the early stages of life:

*K: You know, the one thing that I, maybe two weeks before he died, he sat up and I know he knew who I was, and you know how they go back to being a baby eh?*

*D: Yeah.*

*K: They baby talk. He sat up and he was very, very serious and he was talking and I was scared to say yes or I was scared to say no because I didn’t want to upset him. So what I said to him is oh really? And then he kept on talking and I would say yeah? Really? And um but I truly believe, I surely believe that he told me that... to look after myself and umm and take care of myself and that he was getting ready to go. That’s what I truly believe.*

*D: Yeah.*

*K: That was about 2 weeks before he passed away.*

A lot of literature discusses the concepts of aging within Indigenous communities view it as returning to the first stages of life before they pass. It is discussed that memory loss is a part of aging. It is explained within interviews with Elders on aging in British Columbia of seniors as being described as returning to babies and,

this likening of an Elder to a baby may strike the reader as problematic, perhaps as an example of infantilizing older people (see Hockey and James 1993). Persons with dementia have been likened to babies due to their need for assistance with personal care and the process of progressively losing the ability to care for oneself is referred to as ‘retrogenesis’ (see Reisberg 1984; Reisberg et al. 1999). Being considered a baby does not have the same meaning in First Nations communities as it does in the field of aging and dementia care, however. Babies are highly valued in First Nation cultures, as they are not seen as empty vessels, rather they are viewed as closest to the Creator. The Elder is thought to be moving back towards the Creator and the spiritual realm (Hulko et al., 2010:330).

This cultural and spiritual understanding of dementia and aging needs to be explored in Indigenous programming and outreach for Indigenous families because it is founded on respect for seniors and that aging is returning to the Creator, being close to the spirit world. Returning to the baby stage was also discussed within a Grandmother’s Advisory Council and that memory loss was a natural part of the aging process and caregiving was needed for the ‘second childhood’ (Lanting, 2011:45). Concepts about aging and memory need to be discussed with caregivers and communities in order to create programming that is tailored to their needs and understandings of aging. It also allows a discussion about symptoms and what is the difference between aging and memory loss that is because of ADOD.

## 6.12 Parallels with Newcomer Populations and the Importance of Patient Navigators

The ramifications of an approach that is family centred and accommodate for death and ceremony is that it is beneficial to everyone. For cultural safety within healthcare settings including long term care, there are similarities for newcomer populations affected by ADOD. Relationship centred care and being linguistically and culturally compassionate

is needed for minority populations because their needs are being unmet. From research at the Wellesley Institute, “ethno-specific long term care facilities have far greater waiting lists compared to mainstream long term care facilities; those waiting for ethno-specific long term care homes wait on average six months longer than those waiting for mainstream long term care homes, and many people wait for several years to get into their preferred ethno-specific long term care home in the Greater Toronto Area (GTA)” (Laher, 2017: 4). Seniors waiting many years to be able to move into a long term care home where it feels safe, where they are able to speak their language, practice their traditions, eat foods that they have always had and be with people of the same ethnic background, shows that existing long term care homes are not meeting needs. The positive ramifications for culturally safe care for Indigenous clients is the learning of its value and importance to the health journey of seniors and families with dementia and that one model based on Euro-Canadian ideas of home does not apply to everyone. Minority populations are also facing similar barriers of not accessing mainstream services for care and relying on informal caregivers in the home as opposed to using external services such as nursing and PSW support (Laher, 2017: 5). Therefore, their need for support at home are not being met because they do not access services because the care providers are not knowledgeable about their culture, speak their language or understand their histories. Amanda shared a great example for a newcomer family coming to access services for the first time:

*Yeah we had a situation not too long ago. We had a new person come for one of our programs and the woman did not speak English or if she did she was not speaking it currently and we knew she was coming so we arrange for one of our volunteers we knew spoke the same language to make sure that she was going to be here for that day. So when she came, it was horribly raining. It was just an awful day. A couple of us went out to help her daughter to get her out of the car, to keep her as dry as possible and the volunteer was there with a big smile on her face and welcomed her in her own language and the daughter, she just broke down. She was so appreciative and gave the volunteer a hug and thanked her for just welcoming her mom and that was really meaningful. I was just thinking about it and it took some work behind the scenes to make sure that we had that volunteer here and gave that woman a really great experience her first time here and*

*her Mom is in a safe place and that she was going to be OK. You're going to get a bit of respite time and she was able to meet with one of the social workers for what was going on in her life and what we could do to support her.*

This shows a positive experience for a family and a caregiver who is trying to access care and the importance of the preparation to have someone available who speaks their language to make them feel safe. For Indigenous seniors and their caregivers, when accessing services, their languages are not promoted anywhere, especially health settings. Hospitals and long term care homes do not have Indigenous speakers unless they are an Indigenous run long term care home. This is a huge barrier where a change can be made to work with Indigenous communities to have services offered where Indigenous speakers are paid for their time and support in long term care and hospital settings to make it a safer environment. It can also be the creation of Indigenous patient navigators whose role is to be an advocate for families, to liaise with workers, doctors and health professionals and to be a support. The benefits of having an Indigenous patient navigator to provide support to families affected by ADOD would mean they can provide the resources and referrals to external agencies and ensure good care throughout the process. Research has found that patient navigating or a case manager,

...could act as advocate, provide on-going guidance and support, and enhance continuity of care from the community to the nursing home. Although more research on care transitions and coordination of care in rural areas are needed (Magilvy, 1996), Krout (1997) argued that case management for the rural elderly can prevent hospital and nursing home stays, increase awareness of and access to in-home services, improve service coordination, provide support for family members, and improve quality of life (Morgan et al., 2002:1140).

The economic benefits would outweigh the cost of patient navigating since they can keep people in their homes much longer with support services for the families including caregivers. Since many Indigenous families have to relocate to hospitals or long term care homes away from their community, patient navigators can be a support when they are there to have social interaction, speak their language and engage in their traditions if they want. The most important piece is giving people options instead of only having access to services that can be institutionally racist and discriminatory. It also reduces admissions to hospitals if preventative care is provided. In the *Peter Ballantyne Cree Nation (PBCN)*

*Health Services*, they have home care nurse assessors who are the link for families in community who have to access services in urban centres. They have the knowledge, expertise and work with families providing care that is compassionate and based on relationships (Beatty and Weber-Beeds, 2013:120). *The Alzheimer's Societies* in Ontario launched a navigator program last year:

*We have a new position, it's a new position throughout all the Alzheimer's Society's that might help is a navigator role to work with primary care and others in the community...and it's a very new role for all of these societies and its funding coming from the dementia strategy so I know some of their working groups are looking at how to do more outreach to primary care, to other people who might be early referral sources to let people know what we offer and to provide some education support. (Amanda)*

The creation of this role is a bridge for families impacted by dementia to be able to access someone who is aware of what services exist and can connect people, so families do not have the additional task of having to research services and coordinate them. Indigenous patient navigators specific to dementia care does not currently exist but could be paramount to increasing support to families and should be considered within the healthcare system. Richard shared that he would often accompany Indigenous families to medical appointments in the past:

*I've gone in and I've gone to doctors' appointments with them... and I advocate with them for services. But they are very afraid of hospitals and they're very angry about going to hospitals or seeking medical help outside because it's always been a bad experience and continues to be a bad experience to this day for them.*

Richard accompanying to be there as an advocate, understood the importance of this role since Indigenous families have had negative experiences in the past and deter them from seeking medical intervention or support. Patient navigators can be a solution until systemic changes are made to be culturally safe for Indigenous families.

## 6.13 Concluding Remarks

Systemic changes for improving care and support programs for Indigenous caregivers are needed with cultural safety as the foundation. Cultural safety means that healthcare providers and institutions work from an approach of respect, understanding, collaboration and ensuring that the care recipients feel safe in their interactions. In order for this change to be implemented, education needs to begin as soon as possible for all non-Indigenous peoples, especially healthcare providers. Change is possible if support programs are developed with, by and for caregivers, their loved ones and with communities. It translates to developing programming that is created with the needs of Indigenous peoples from a bottom up approach and the inclusion of decolonization founded on culture, history and healthy aging. Most importantly, holistic healthcare is needed for systemic change where a person is not defined by their disease, but the context of who they are, their history and their connections to family and community. Holistic approaches also mean a shift to self-determination for communities to have the financial resources to offer services in their community so people can remain there and do not have to travel extensive distances for specialists. Since jurisdictional boundaries created by the Canadian government stops self-determination for healthcare in communities, changes within institutions is to bring services into community. It can be small changes within long term care to include Indigenous culture and access to land, language and food and flexibility in care to be compassionate and accommodating for families.

## 6.14 Key Findings

- Cultural safety needs to be institutionalized into healthcare practices to remove systemic barriers of racism, discrimination and underutilization of services
- Holistic health and removing siloed healthcare is not only beneficial for Indigenous families impacted by dementia, but newcomers to Canada and rural populations



- Bring services, resources and training into communities so aging loved ones can remain at home which contributes to intergenerational well-being and aging well
- Work with Indigenous communities to develop programming and support where uptake is based on their specific culture, history, language, connection to land and concepts of aging
- Change can be educational training in healthcare institutions, bringing Indigenous programming into long term care and hospitals, treating people like kin and creating dementia patient navigators

## 7 Conclusion and Resources

### 7.1 National Dementia Strategy

As of June 17, 2019, the *National Dementia Strategy* was released, which is the first of its kind rather than being provincially focused. It provides an overview of the current situation and aspirations for change to improve research, resources, public outreach and most importantly, support for families. The strategy is amazing because it is focused on lived experiences of those with dementia and their caregivers. My research focused on the stories of Indigenous female caregivers and care providers is pertinent because dementia rates are rising as the population ages and the current healthcare system is not meeting the needs of families, especially First Nations, Inuit and Métis communities. My research is also focused on the lived experiences of caregivers, which the dementia strategy states needs to be centralized to developing resources, conducting research and support programs.

While reading the dementia strategy, it is parallel to my own research findings that the experience of caregiving is gendered since, “the majority of these caregivers are female, most commonly female intimate partners and daughters. Caregivers spend 20 hours a week caring for and supporting a person living with dementia” (Canada Public Health Agency, 2019:2). The gendered caregiving role needs to be examined to create financial supports and programs that contextualize that women are predominantly the caregivers for loved ones with ADOD and this is applicable in Indigenous communities where women are providing care with minimal to no resources. Caregivers’ experiences have been excluded from a lot of existing literature on dementia and the strategy and a shift in research trends is moving towards lived experience. This is also applicable to the

experiences of healthcare providers for families affected by dementia, that their stories are missing from research practice as well. The experiences of healthcare providers are instrumental for what is working well in their practice and what they need to continue or improve culturally safe care for Indigenous clients. My research contributes to bridge the knowledge gap by including the lived experiences of caregivers as well as healthcare providers since both are instrumental to healthcare needs of loved ones with dementia.

The dementia strategy is reflective of the changes that are needed based on the lived experiences and input of those who need or are accessing services along with the inclusion of training healthcare providers to have the knowledge, skills and expertise to provide excellent care to those affected by dementia. The strategy includes a focus on Indigenous peoples in Canada and,

the Government of Canada recognizes that Indigenous communities and individuals have distinct dementia experiences and distinct needs. Engagement with Indigenous organizations, communities and governments will continue as the strategy is implemented to better understand these needs and facilitate Indigenous-led efforts to improve the quality of life for people living with dementia and caregivers in those communities (Public Health Agency of Canada, 2019:4).

This is a shift of recognition that Indigenous peoples have a distinct culturally, linguistic and land-based approach to health and well-being and that Indigenous peoples including individuals affected, caregivers and communities need to be the stakeholders for change in collaboration with sustainable funding and resources. Throughout my research, I focus on the importance of culturally safe care and that in order for uptake in Indigenous communities, it needs to be collaborative and specific to the nation since a pan-Indigenous approach never works. Culturally safety is also prioritized in the national dementia strategy where, “work is also needed to design interventions that are culturally safe and culturally appropriate to increase the adoption of healthy behaviours.

Interventions need to be adapted in ways that best address the unique needs of individuals, particularly within higher risk populations and for those facing barriers to care” (Public Health Agency of Canada, 2019:13). Culturally safe care is shifting to be placing the responsibility on care providers, but it needs to be institutionally based. If care providers are given the training and knowledge such as the online culturally safety

program, there needs to be systemic changes for them to practice what they learn in an environment that is supportive of culturally safe care and reflected in policy, accountability and longevity.

The strategy has a social determinants of health approach to dementia where,

Dementia prevention efforts include sharing knowledge about the links between the design of our environments and dementia risk factors. The social environment is the space in which we engage in social activity within our communities, including recreation and education. The built environment refers to the physical environment around us, including buildings, roads, green spaces and public transit— the places where we live, learn, work and play. The natural environment, from plants and animals to water and air, also plays an important role in our lives, particularly for those who live in rural and remote communities across Canada. In these communities, geography may amplify both positive and negative impacts of the social and built environment on healthy living (Canada Public Health Agency, 2019:11).

The strategy is a shift in discourse where prevention is not focused solely on the individual to be responsible for their health, but the contextual understanding of the impact of their social and physical environment to be able to be physically active outside, if there is infrastructure in community such as programs or a space to meet and socialize and to remain in community as long as possible. As discussed with caregivers, their loved ones all moved to the closest city or town for placement in long term care because there was not one in their community. This is reflected in the dementia strategy because, “health and social supports are typically more sparse in rural and remote regions compared with urban communities, which can result in people living with dementia having to leave their communities or travel long distances for care and supports” (Canada Public Health Agency, 2019:53). The inclusion of environmental factors for prevention and reduction of dementia is integral to Indigenous health since our physical and spiritual connection to land is intertwined with our overall well-being and healthy aging. The ways in which culture, ceremony, speaking your language and the familial and community connections should be included during interaction with Indigenous clients. Indigenous concepts of personhood can be understood as, “...relational or communalistic as well as ecocentric (connected to the land, animals and the

environment) and cosmocentric (connecting the person to an ancestral lineage or to the spirit world)” (Kirmayer and Valaskakis, 2009:22). Spirituality is often perceived in biomedicine and healthcare as only a religious affiliation, but the concept of spirit is not limited to a monotheistic entity, but, “dispersed throughout the cosmos or embodied in an inclusive, cosmo-sanctifying divine being” (Knudston and Suzuki, 1992:13). Spirituality included in healthcare as only institutional based religion segments the individual and the, “recognition of the interconnectedness and interdependence of all living things-a holistic and balanced view of the world. All things are bound together and connect” (Nelson, 2008:34). Indigenous spirituality is not limited to your connection to a divine being or denomination, but the recognition that you are, “a part of a vast, multilayered, cosmic whorl of life cycles; the natural world emerges as an unbroken continuum between humans, animals and the spirit world” (Knudston and Suzuki, 1992:153). Within health, it is expanding to be more inclusive of well-being, but needs to extend further. If a person is being treated for dementia, it needs to be connected to their community physically and conceptually to include their connection to the land, their responsibilities to it and animals and how ties to the spirit world can help someone.

The national dementia strategy inspires hope for change, grounded in lived experiences of those impacted whether they are the person diagnosed, their family members, health care providers or the general public; since everyone knows someone affected by ADOD. The strong Indigenous women I spoke to and the amazing healthcare providers who already work from a holistic approach to health, all of their stories are grounded in hope. Their stories show what changes are needed to improve access and care and the importance of intergenerational caregiving, connection to family, nation and community. All the caregivers are astounding women who honoured the lives of their loved ones through their dedication, love, compassion and kindness. I am humbled by their resilience and strength and hope their stories can enact change through the power they hold in being shared. I am grateful to learn from the women who opened their hearts and shared their memories of their loved ones with me. As a caregiver, I understand the

struggles of coping while balancing many aspects of busy lives as women. So, I hope our stories can influence change so that caregivers are not alone in their journey.

All of the caregivers including myself are advocates and many of us enact change through sharing our stories. Michelle shares her stories and memories of her grandfather to educate about ADOD. Her courage inspired me to share my story as a young Indigenous caregiver at several community and academic venues in hopes of reducing stigma of alcohol-related dementia in the last year alone. Speaking from the heart and sharing the beautiful and challenging aspects of caregiving, I hear from healthcare providers that my story had an impact and I hope it stays with them to inform their practice. Kathleen showed me that love keeps us going as caregivers and that needs to be foundational for healthcare providers to understand the resiliency and strength of female, Indigenous caregivers. Annette has taught me that laughter is so important, even through difficult times. Annie has taught me so much about our stories, our culture and language. I want to end with resonating wisdom from Annie that,

*Respect is easy to say, but harder to do. If Canada wants to be a leader, the Anishanaabe have the 7 Grandfather teachings that are the mental, physical, emotional and spiritual.*

The 7 Grandfather teachings, “is a gift the Anishinaabeg carry, a potential tool for living a good life. Our understanding is that as we use these gifts, our experience of living improves. Using these gifts in our lives is an ongoing challenge for each of us, requiring attention, discipline and perseverance.

1. **Minwaadendamowin** – Respect: Place others before yourself in your life and do not look down on anyone.
2. **Zaagidiwin** – Love: It is my turn; I have to love myself before I can love anyone else.
3. **Debwewin** – Truth: You have to look at yourself before you judge another’s way of walking.

4. **Aakodewewin** – Bravery: Hold firm in your thoughts and stand strong even when you do not know what will happen.
5. **Nibwaakawin** – Wisdom: Wisdom allows me to eloquently and correctly interpret others' ideas.
6. **Miigwe'aadiziwin** – Generosity: Standing together, transferring and responding to needs.
7. **Dibaadendiziwin** – Humility: Humble yourself to your fellow human in the way you walk with him or her." (Eshkakogan, 2019)

Non-Indigenous healthcare providers can learn so much from our teachings that are founded in respecting our seniors and living a good life so we can use our gifts to help others.

## 7.2 Memory Loss Resources in London and Surrounding Area

Since I currently reside and am familiar with existing resources in Southwestern Ontario through research and experience as a healthcare provider, I have compiled a list of resources that are beneficial for caregivers and care providers. The importance is that if care providers are aware of existing services, they can share their knowledge with the families they are trying to support on their journey. Navigating the Canadian healthcare system as Indigenous families is difficult as discussed throughout. Thus, sharing my knowledge of supports might be helpful. The resource guide is included in the appendix.

I also recognize the importance of peer support since speaking with all of the caregivers was wonderful to be able to relate to other women who understand how you feel and to reminisce about those we love whether they are still here or in the spirit world. Through partnership with the local *Alzheimer's Society* in London, we are offering a workshop to support Indigenous caregivers to share what resources they offer as an organization while educating about self-care with the support of an Elder. We hope to create a space where caregivers can meet to foster relationships to support one another. The *Alzheimer's Society* in London is phenomenal and next year, in collaboration with another Indigenous caregiver, we are organizing an art exhibit for anyone who has been affected by ADOD including individuals, their family members and healthcare providers. It is an opportunity to showcase the artistry of those affected by ADOD and using a creative outlet for public

outreach and education. As an Indigenous caregiver and an academic, I recognize the importance of public education using storytelling to inform change for non-Indigenous healthcare providers. Thus, I hope to use my knowledge to continue to educate and to provide support and care for caregivers.



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## Appendices

### London INDIGENOUS Resource Guide



**Figure 2 London Indigenous Guide**

*Support provided by the Alzheimer's Society Research Program*

## What Will I Find?

This resource guide is based on services that are offered in London and surrounding area with a focus on Indigenous specific organizations and supports for families affected by memory loss including dementia.

Dementia is, “an umbrella term for a variety of brain disorders. Symptoms include loss of memory, judgment and reasoning, and changes in mood and behaviour. Brain function is affected enough to interfere with a person’s ability to function at work, in relationships and in everyday activities” (Alzheimer's Society, 2019).

### **Memory Loss Ten Signs to Look for:**

- Misplacing things**
- Changes in personality**
- Loss of initiative**
- Changes in mood or behaviour**
- Memory loss that affects day-to-day function**
- Difficulty performing familiar tasks**
- Problems with language**
- Disorientation of time and place**
- Poor or decreased judgment**
- Problems with abstract thinking**

(Alzheimer Canada, 2003)

Included are resources for care providers as well to improve support for families as they navigate the health care system. Each section is organized based on type of service and provides a short description and their contact information.

Most importantly is the inclusion of Indigenous services because they provide a holistic approach to health that focuses on the emotional, spiritual, mental and physical well-being of the clients they serve.

## Memory Support Services

### **Alzheimer Society London Middlesex**

Services include counselling, drop in support groups including a young caregiver support group and an adult child support group. They also have a *First Link Care* navigator to assist with services and supports. Services are



geared for those with dementia and their care partners including recreational activities, day programs and the *Enhancing Care program*, which provides therapeutic skills training to family or other care partners who provide care to individuals living with dementia.

M-F: 8:30am-4:30pm  
435 Windermere Road  
London, Ontario N5X 2T1  
1.888.495.5855

<https://alzheimerslondon.ca>

### **McCormick Day Program**

“Living with dementia does not mean that quality of life no longer matters. Our day program provides a diverse and stimulating range of activities based on the personal needs and backgrounds of our clients. In addition, our program benefits caregivers by giving them a sense of reassurance that their loved one is well taken care of so that they can have some often much-needed time for themselves. Our clients are involved in small and large group programs based on their interests and abilities, where the goal is always to have clients succeed in whatever activity they choose to participate.

Each client’s social-recreational history is obtained upon admission and is used to guide the staff in developing a person-centred, individualized program.

#### Day Program Schedule:

- Morning Program-Monday-Friday: 9:30am-3:00pm (65 clients)
- Afternoon Program-Monday to Friday: 2:30pm-8:00pm (15 clients)
- Extended Hours Program (optional)-Monday-Friday: 9:30am-6:30pm
- Weekend Program-Saturday and Sunday: 9:30am-6:30pm (15 clients)

On weekends, we also offer our Overnight Respite program for up to five clients to stay overnight or for the entire weekend to provide an enhanced caregiver respite opportunity” (McCormick,2019).

M-F: 8:30am-4:30pm  
2022 Kains Road, London, Ontario N6K 0A8  
Tel: 519.439.9336

<http://www.mccormickcaregroup.ca/>

## **Aging Brain and Memory Clinic**

Referral to the clinic is needed from a doctor. At the clinic, they provide:

- Outpatient assessments and diagnosis for persons with impaired memory and cognition
- Management of the symptoms of dementia with education, medication(s) and counseling
- A resource for health care professionals, community service providers such as the LHIN and families in Southwestern Ontario
- Typed report to referring physician and involved health professionals and services
- Opportunities for people with memory impairment and their caregivers to be involved in clinical research studies

M-F: 8am-4pm  
Parkwood Institute, Main Building  
550 Wellington Road, London, Ontario N6C 0A7  
Tel: 519.685.4000 Ext. 42270  
Referrals: 519.685.4046 or  
Fax: 519.685.4020

## **Behavioural Supports Ontario (BSO)**

“The Behavioural Supports Ontario Program’s target population includes older adults presenting with or at risk for responsive behaviours that may be associated with dementia, complex mental health, regular substance use and/or other neurological conditions and their care partners” (2019). BSO has a family centred approach and is team based to partner with many service providers including the *Alzheimer’s Society* and *London Health Sciences Centre*. They also provide crisis support and respond in under 72 hours. Listed below are the contact numbers based on region including their crisis response teams.

BSO Mobile Teams have been established at local hospitals across the South West Local Health Integrated Network including:

***Huron Perth Health Care Alliance- Seniors Mental Health and Regular substance uses Response Team***

M-F: 8:30am to 8:30pm  
Tel: 519.527.8421 ext.4818

Fax: 519.527.8420

After hours support from Huron Perth Helpline and Crisis Response Team:  
1.888.631.2180

***Grey Bruce Health Services- Geriatric Behavioural Response Team***

7 days/week: 8:00am-8:00pm

Tel: 519.376.2121 ext. 2436

Fax: 519.372.3968

***London Health Sciences Centre- Behavioural Response Team***

M-F: 8:00am to 4:00pm

Tel: 519.667.6865 ext. 2745 OR ext. 2746

Fax: 519.667.6559

Crisis response line: 519.433.2023

***Woodstock General Hospital- BSO Geriatric Outreach Team***

M-F: 8:00am to 4:00pm

Tel: 519.421.4223 ext. 2342

Fax: 519.533.6972

After hours crisis support from CMHA: 519.539.8342

***St. Thomas Elgin General Hospital-BSO Mobile Team***

M-F: 8:00 am to 4:00 pm

Tel: 519.631.2020 ext. 2745 OR ext. 2746

Fax: 519.631.6497

After hours crisis support from Canadian Mental Health Association:  
1.888.829.7484

<http://southwest.behaviouralsupportsontario.ca>

## **Telehealth**

Call to speak to a specially trained nurse for dementia support, advice and referrals.

Tel: 1.866.797.0000

## **GeriMedRisk**

“GeriMedRisk is an interdisciplinary telemedicine consultation and education service for doctors, nurse practitioners and pharmacists in Ontario. Using telephone and eConsult, clinicians receive a coordinated response to questions regarding optimizing medications, mental health and comorbidities in older adult patients from a team of geriatric specialists and pharmacists. GeriMedRisk is a not-for-profit service for clinicians. Clinicians can access GeriMedRisk by toll-free phone or through eConsult” (GeriMedRisk, 2019).

M-F: 9:00am-5:00pm  
Tel: 1.855.261.0508

<https://www.gerimedrisk.com/>

## **Indigenous Health and Social Services**

### **Southwest Ontario Aboriginal Health Access Centre**

An Aboriginal Health Access Centre (AHAC) that has services that span the Southwest of Ontario. SOAHAC provides holistic health services from primary care, traditional healing, mental health counselling for First Nations, Inuit and Métis peoples. For families impacted by dementia, there is program called “Supporting Aboriginal Seniors at Home” (SASH). SASH provides social and medical support for seniors over the age of 55 to access culturally safe care and navigation support. There is also an Aboriginal Patient Navigator who provides support to families and individuals in hospitals in London, St. Thomas and Strathroy.

M-F: 8:00am-5:00pm  
Evening clinics available at all sites; please call for information

<https://soahac.on.ca/>

#### ***London***

425-427 William Street, London, Ontario N6B 3E1  
Tel: 519.672.4079  
Fax: 519.672.6945  
Toll Free: 1.877.454.0753

#### ***Windsor***

1405 Tecumseh Rd West, Unit 2, Windsor, Ontario N9B 1T7  
Tel: 519.916.1755

Fax: 519.253.6567  
Toll Free: 1-877-452-5114

***Chippewas of the Thames***  
77 Anishinaabeg Drive  
Muncey, Ontario N0L 1Y0  
(If using GPS/Google Maps:  
6609 Switzer Drive, Melbourne, ON)  
Tel: 519.289.0352  
Fax: 519.289.0355  
Toll Free: 1.877.289.0381

***SOAHAC Pharmacy-Pharmasave***  
Tel: 519.289.3500

***Owen Sound***  
733 9th Avenue East, Owen Sound, Ontario N4K 3E6  
Tel: 519.376.5508  
Toll Free: 1.844.737.0725  
Fax: 519.376.1845

***Delaware Nation Health  
Centre (Moraviantown)***  
Tel: 226-494-1787

## **Oneida Health Centre**

“The Community Health Program in Oneida provides a range of public health programs and services that evolves around health promotion, illness and injury prevention, and health maintenance. The Community Health Program is delivered by Registered Nurses with certification in Community Health Nursing, and Community Health Representatives, who hold a diploma in Native Community Care with Counseling and Program Development.” (Oneida of the Thames, 2016)

Support services are for all ages and for seniors specifically, there is an ‘Aging at Home’ program to maintain independence and remain at home, provides non-emergency medical transportation and has a long term care home in community. The long term care home called “Tsi’Nu:Yoyantle’Na’Tuhuwatisni” where community members from Oneida are prioritized as well as other First Nations seniors requiring long term care. They are unique from other long term care homes because culture is foundational to the home and provide single room accommodations.

Oneida Health Centre  
2213 Elm Avenue  
Southwold, Ontario, N0L 2G0

Tel: 519.652.0500  
Fax: 519.652.0504

<https://oneida.on.ca/homepage/healthservices/>

### **Chippewa of the Thames First Nation**

Chippewa of the Thames First Nations has a home and community care program, provides advocacy for navigating Non-Insured Health Benefits (NIHB) and provides home visit support if needed. They also have a loan cupboard of medical equipment and supplies for community members to access for those who live on reserve and non-emergency medical transportation support.

320 Chippewa Road  
Muncey, Ontario N0L1Y0  
Tel: 519.289.5555  
Fax: 519.289.2230  
Toll Free: 1-866-550-5539

<http://www.cottfn.com/health-department/>

### **Munsee Delaware First Nation**

Munsee Delaware First Nation provides a seniors' program and home visits and can accompany individuals and their families to medical appointments to provide additional support if needed. They also provide a home and community care program to keep seniors in their homes and maintain independence.

RR #1, Muncey, Ontario N0L1Y0  
Tel: 519.289.5396

### **Non-Insured Health Benefits (NIHB)**

“NIHB provides coverage for dental services, medical services and equipment, drug and pharmacy products, vision care, medical transportation and mental health counselling for status First Nations peoples and Inuk

recognized by an Inuit land claim organization including children whose parent has their status card until the age of 18” (2019). NIHB is integral to providing medical support to Indigenous peoples, especially seniors. Navigating NIHB can be difficult but knowing what is covered is important. There is a list of services and products that are covered.

Any provider can submit a claim to NIHB and not all services are paid upfront, so not all service providers work with NIHB. The information needed for all claims include the individuals’ name, date of birth, status card number and what community they belong to. Some medical equipment and supplies require a prescription and there are restrictions on how often things can be provided such as a walker is only eligible every 5 years. Prior approval is needed for some items including wheelchairs and walkers; **thus, the process needs to be started as soon as possible since processing can take up to 8 weeks.**

Being familiar with the website is key to providing excellent care since navigating NIHB can be daunting, so service providers should become more comfortable with it. NIHB also has a toll-free line to inquire if a service is covered or to answer questions. There are locations in every province and based on the region where the persons’ Indigenous community is: <https://www.canada.ca/en/indigenous-services-canada/corporate/contact-us-first-nations-inuit-health/non-insured-health-benefits.html#a4>.

If a loved one is in hospital, they are eligible for financial support for meals, accommodations and travel if they need support. This process is started by calling NIHB to explain the situation and to start the paperwork since documentation from a medical doctor, social worker or service provider is necessary. **This process needs to be started immediately with clients in hospital to get support especially since their office is closed on the weekends.**

M-F: 8:00am-4:00pm  
Toll-free: 1.800.640.0642  
Fax: 613.952.7054

## **Drugs Exemption Centre**

If a pharmacy needs prior approval or if a certain medication or product is prescribed and is not covered by NIHB, the pharmacy can contact the Drugs Exemption Centre for approval at:

Telephone (toll-free): 1.800.580.0950 (English)  
Telephone (toll-free): 1.800.281.5027 (French)

## **NIHB Patient Navigators**

Sometimes NIHB will deny a claim and support is needed, there are two navigators through the *Chiefs of Ontario* who know their policies, regulations and navigation support to social workers, support workers or families. There is a Northern region navigator and a Southern region navigator.

### **South West Cancer Aboriginal Patient Navigator**

In London (and surrounding area) and in Windsor (and surrounding area), there are Indigenous patient navigators for cancer care through *Southwest Regional Cancer Care Program* working with First Nations, Inuit and Métis clients to navigate the healthcare system on their cancer journey and provide medical, social and cultural support.

### **N’Amerind Friendship Centre**

“The N’Amerind Friendship Centre is a non-profit organization committed to the promotion of physical, intellectual, emotional and spiritual well-being of native people and in particular, urban native people.

The commitment is realized through the implementation of culturally relevant programs aimed at social recreational and educational needs; at developing leadership, at increasing awareness levels of native heritage, establishing resources for community development and in promoting the development of urban aboriginal self-governing institutions.” (2019)

N’Amerind provides cultural and social programming shared on their *Facebook* page and website. For seniors, they provide a ‘Life Long Care Program’ that is culturally and socially supporting Indigenous seniors to remain independent at home. They assist by connecting to other medical and social services in London and surrounding area, friendly visiting and wellness checks, social outings and dinners along with transportation and navigating.

M-F: 8:30am-5:00pm  
260 Colborne St, London, Ontario N6B 2S6  
Tel: 519.672.0131

<http://www.namerind.on.ca>



## **Atlohsa Family Healing Services**

“Atlohsa means ‘Friends’ in the Onyota’a:ka language. The name was chosen to reflect the desire to provide support, understanding, education, intervention and prevention to victims of family violence” (2019). Atlohsa provides social and cultural program shared through their *Facebook* and website.

### ***Status Cards***

Atlohsa and SOAHAC have teamed up to provide monthly transportation support to *Indigenous Services Canada* in Brantford. It will be the last Tuesday of every month leaving Atlohsa at 8:30am based on first come, first serve. One piece of photo identification is needed along with 2 passport photos. More information can be provided via email at [admin@atlohsa.com](mailto:admin@atlohsa.com) or by calling 519.438.0070 or 519.438.0068.

M-F: 9:00am-5:00pm  
343 Richmond St.  
London, Ontario N6A 3C2  
Tel: 519.438.0068

<https://atlohsa.com/>

## **Talk 4 Healing**

A culturally grounded, fully confidential helpline for Indigenous women available in 14 languages all across Ontario providing:

- Culturally sensitive crisis counselling
- Advice and support
- Personalized information and referrals
- Acceptance of Aboriginal women's issues in a non-judgemental way
- Help to find the path to personal healing
- Scheduled telephone counselling sessions

Tel: 1.855.554.HEAL

## **Support Organizations**

### **Southwest Local Health Integrated Network (LHIN)**

“If you, or someone you care about, needs health care services at home, at school or in the community, or if you are considering supported living

programs or long term care options, home and community care at the South West Local Health Integration Network (LHIN) can help.

South West LHIN works with people of all ages to ensure they can make informed choices about their care, when and where they need it. We also have useful information about local community support service agencies and can link people to these providers to arrange services” (2014).

The South West LHIN starts with a home visit from a care coordinator and they review medical and social history. They make referrals for in home supports including nursing, Personal Support Workers (PSW), occupational therapy and physiotherapy. There is an Indigenous care coordinator providing care for complex clients in London and surrounding area.

Tel: 1.800.811.5146

<http://www.southwestlhin.on.ca/>

### **London Consistory Club**

This is a great resource of donated medical equipment that is available to borrow at no cost for as long as it is needed. The only request is to return after use or donate to someone else. They provide equipment including wheelchairs, walkers, crutches, shower chairs, canes and so on. They also repair equipment, so they accept equipment that they will fix and provide for borrowing.

Tuesday and Thursdays: 9:00am-12:00pm  
243 Wellington Rd S., London, Ontario N6A 4V3  
Tel: 519.438.5443

### **Life Spin**

“Life Spin is a grassroots organization that has led programming in London for over 25 years. These programs are all geared to enhancing the lives of low-income families through education, advocacy, and community-building. Front-line services include social benefits mediation, publication of public legal educational resources, housing, environmental education workshops, nutrition programs, financial literacy, Income Tax preparation clinic, children & senior’s programs, a Free Store, and homelessness prevention supports” (2010).

LifeSpin is another excellent resource because they can assist with filling out forms for housing, *Ontario Disability Support Program*, *Ontario Works* and

advocacy for supports for utilities such as Hydro or gas. They also offer support for completing income tax at no cost but need to be contacted early since there is high demand.

Monday: 9:30am-noon & 1:00pm-4:30pm  
Tuesday: 9:30am-noon & 1:00pm-4:30pm  
Wednesday: 9:30am-noon & 1:00pm-4:30pm

***Free Store***

Monday: 10:00am-2:00pm  
Tuesday: 3:00pm-7:00pm  
Wednesday: 10:00am-2:00pm

866A Dundas Street, PO Box 2801, London, Ontario N6A 4H4  
Tel: 519.438.8676  
life@execulink.com

<http://www.lifespın.org>

## **Housing Stability Bank**

“The housing stability bank offers financial support to low income Londoners to obtain and retain their housing and offer financial assistance to those at risk of homelessness to remain housed”. (March 2018)

### ***Rental Assistance***

The Housing Stability Bank provides interest free loans to assist with Rental Arrears, First Month’s Rent (ODSP recipients only) and/or Last Month’s Rent.

### ***Emergency Utility Assistance***

The Housing Stability Bank provides grants (until grant funds are exhausted annually) or interest free loans to assist with utility arrears pertaining to gas, electricity or water.

### ***Ontario Electricity Support Program***

The Housing Stability Bank assists with completion of Applications to the Ontario Electricity Support Program.

### ***Connections and Referrals to Community Resources***

The Housing Stability Bank will provide relevant connections to community services.

Law Students from Pro Bono Students Canada are on-site on a weekly basis (September to April) to provide legal referrals, information and resources.

Contact the Housing Stability Bank for the current day and time.

Applications are completed by appointment only. Appointments can be scheduled at a location close to you, including:

- The Salvation Army Centre of Hope- 273 and 281 Wellington St.
- Jalna Branch Library-1119 Jalna Blvd.
- Westmount Branch Library-3200 Wonderland Rd. S.
- Pond Mills Branch Library-1166 Commissioners Rd. E.
- East London Branch Library-2016 Dundas St.
- Beacock Branch Library-1280 Huron St.

Tel: 519.964.3663 ext. 300  
Fax: 519.661.0500  
housing@centrefhope.ca

<https://centrefhope.ca/services/housing>

## **City of London Recreation**

“The City of London’s *Play Your Way Fund* offers financial support to low income Londoners who want to access recreation programs and activities offered by the City of London. Once approved, funding can be accessed for the next 12 months, up to a maximum of \$300 per person. Program credits are not transferrable between family members or between years. The Play Your Way Fund does not apply to facility rentals or birthday parties” (2019).

To be eligible for *Play Your Way Program*, applicants must be:

- 18 years of age or older
- City of London residents
- Have a family income that falls within the ranges below, based on Statistics Canada’s 2016 After-Tax Low-Income Cut-Offs (LICOs)

M-F: 8:30am-4:30pm  
Tel: 519.661.5575  
recreation@london.ca

[www.london.ca](http://www.london.ca)

## **London Food Bank**

“If you find yourself in an emergency situation and require food, we are here to help. A household may visit either our main location or a satellite depot at most once every 30 days. Food hampers include perishable (milk, eggs, and

bread) and non-perishable (canned and dry goods) items. When available or in season, we also provide fresh produce or frozen meat. Food quantities and varieties are based on donations and are subject to change frequently.

What you need to bring: 1 piece of identification for each family member - required every visit and proof of income, if any (e.g. paystub, OW/ODSP statement)” (2019).

926 Leathorne Street  
London, Ontario N5Z 3M5  
M-F: 9:00am-4:00pm (except holidays)  
Tel: 519.659.4045

<https://www.londonfoodbank.ca>

## **Meals on Wheels**

“Meals on Wheels London provides service to adults with disabilities and seniors (55+) in need of nutritional support. We assist those who need short term (caregiver relief, recuperation, seasonal) or long term assistance and no long term contract necessary” (2019).

Meals on Wheels also offers transportation support for a round trip cost of \$22. Subsidies are available within London for medical appointments and family or friends can accompany at no additional cost.

M-F: 8:30am-4:30pm  
356 Queens Ave., London, Ontario N6B 1X6  
Tel: 519.660.1430

## **Transportation Supports**

### **Victoria Order of Nurses (VON)**

Volunteers provide seniors and adults with disabilities transportation to medical appointments, grocery shopping, adult day programs, and other appointments. Wheelchair and ambulatory transportation are available in Strathroy-Caradoc, Thames Centre, Alymer, East Elgin, St. Thomas and Central Elgin.

Suite 100 - 1151 Florence Street, London, Ontario N5W 2M7  
Toll-Free: 1.866.865.6711  
Tel: 519.659.2273

Fax: 519.659.6191

274 Head St N., Strathroy, Ontario N7G 4L7

Toll-Free: 1.800.265.7058

Tel: 519.245.3170

Fax: 519.245.3164

175 South Edgeware Road, St Thomas, Ontario N5P 4C4

Toll-Free: 1.800.201.0909

Tel: 519.637.6408

Fax: 519.631.4798

### **Paratransit**

“A shared ride, door to door service for passengers that require a lift-equipped vehicle for travel. Trips are not guaranteed, and the service is operated in accordance with policy and procedures as reviewed and amended from time to time. The cost is the same as public transit for adults and seniors. You can call the London Community Transportation Brokerage (519.451.1340 ext. 381) and leave your name and address and a registration form will be mailed out to you or pick up a form. The application can also be downloaded, and a portion needs to be completed by your medical providers” (2019).

150 Dundas Street (near Richmond St.) or 450 Highbury Avenue N (at  
Brydges St.).

M-F: 7:30am-7:00pm, Saturday:8:30am-6:00pm

519.451.1347

ltc@londontransit.ca

[www.londontransit.ca](http://www.londontransit.ca)

# Curriculum Vitae

**Name:** Danielle Alcock

**Post-secondary Education and Degrees:** York University  
Toronto, Ontario, Canada  
2006-2011, Honours B.A. Anthropology and a minor in History,  
Graduated with distinction

Western University  
London, Ontario, Canada  
2012-2014, M.A. Socio-cultural Anthropology

Western University  
London, Ontario, Canada  
2015-2019, Ph.D. Socio-cultural Anthropology

**Honours and Awards:** Province of Ontario Graduate Scholarship  
2016-2019

Alzheimer's Society Research Program Scholarship  
2016-2019

Western Graduate Research Scholarship  
2015-2019

2017 Highly Commended Award for the paper "Transforming First Nations Health Governance in British Columbia"

Indspire Scholarship  
2015-2016

Regna Darnell Award for Fieldwork in Sociocultural Anthropology  
2012

**Related Work Experience:** Teaching Assistant  
Western University  
2012-2014, 2015-2019

Research Assistant  
Western University

2014-2016

Research Assistant  
Simon Fraser University  
2014-2016

Transitional Case Manager  
Southwest Ontario Aboriginal Health Access Centre  
2019-current

Aboriginal Patient Navigator  
Southwest Ontario Aboriginal Health Access Centre  
2018-2019

Seniors' Health Advocate  
Southwest Ontario Aboriginal Health Access Centre  
2016-2018

**Publications:**

Alcock, Danielle. *Write My Story Before I Forget: An Auto-Ethnography of Aboriginal Alcohol Dementia*, MA thesis, Western University, August 2014.

O'Neil et al. "Transforming First Nations' Health Governance in British Columbia". *International Journal of Health Governance* (21)4 (2016): 229 – 244.

Alcock, Danielle et al. "Developing Ethical Research Practices Between Institutional and Community Partners: A Look at the Current Base of Literature Surrounding Memorandums of Understanding in Canada". *International Indigenous Policy Journal* (8)4 (2017).